Living well with Functional Neurological Disorder

Jessica Hughes

Doctorate in Clinical Psychology Thesis

May 2023

Word count statements

Section	Text	Appendixes, references, and tables	Total
Thesis Abstract	198	0	198
1. Literature Review	7,527	9,938	17,465
2. Empirical Paper	7,959	8,999	16,958
3. Critical Appraisal	3,843	416	4,259
4. Ethical Proposal	4,076	5,401	9,477
Total	23,603	24,754	48,367

Total wordcount in thesis excluding appendixes, references, tables and figures is 23,603.

Total wordcount in thesis including appendixes, references, tables and figures is 48,367.

Declaration

This thesis was undertaken for the Doctorate in Clinical Psychology at Lancaster University, within the Division of Health Research. The work presented here is the author’s own, except where due reference is made. The work has not been submitted for the award of a degree elsewhere. The author has no competing interests to report.

Acknowledgement

I am eternally grateful for all the participants who volunteered to share their experiences as part of this research study, thank you for trusting me with your stories.

Thank you to Fiona and Will for supporting me throughout the development of the thesis, both of you have been so generous with your time, advice, and support. Thank you for all the hard work you do.

A special thank you to Rosa, Katie, Emily, and Molly. Your support throughout the course has been invaluable. Thank for the car shares, role plays and laughter. I wouldn’t have wanted to share this experience with anybody else.

Finally, thank you to Chris. You have been my rock throughout the course, and before. Thank you for doing all the life admin whilst I dedicated myself to this thesis, for believing in me, and for bringing me coffee and ice cream every time I felt overwhelmed. I love you, always.

Abstract

Overview: This thesis explored concepts related to the experiences of living with Functional Neurological Disorder (FND). FND is known as a heterogeneous presentation of neurological symptoms that cannot be explained through known disease pathologies.

Systematic Literature Review: The systematic literature review explored the experiences of health care professionals engaging individuals with functional seizures, in healthcare interactions. The review identified that healthcare professionals described engagement as successful when they; acknowledged the challenges and systemic difficulties with the condition; adapted for the individual, both being flexible in-service provision and in strategies used by the professional, and when the individual's social network were consistent with their understanding and support.

Empirical Paper: The empirical paper explored how individuals with Functional Neurological Disorder 'lived well' with the condition. The results were divided into four themes (1) Knowing and prioritising your values; (2) Having control of the narrative; (3) Navigating personal and therapeutic relationships and (4) Developing personal coping strategies. The results of this paper suggested that 'living well' with FND, was different for each individual based on their values, beliefs, and social environment.

Critical Appraisal: The critical appraisal discusses further strengths and limitations of the research, reflections of the researcher and clinical implications.

Contents

Chapter 1: Systematic Literature Review

What are the experiences of healthcare professionals engaging clients experiencing functional seizures in a therapeutic intervention: a systematic review.

Jessica Hughes

Doctorate in Clinical Psychology

Lancaster University

Formatted for submission to the Epilepsy & Behaviour

(For Author guidelines see Appendix 2-C)

Word count (including abstract but excluding references, appendices, figures and tables):

7,527/8,000 words

Correspondence should be addressed to:

Jessica Hughes

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Health Innovation One

Sir John Fisher Drive,

Lancaster University

Lancaster, LA1 4AT

Email: J.hughes17@lancaster.ac.uk

Abstract

Background: Functional neurological disorders (FNDs) are defined as a presentation of neurological symptoms that cannot be explained through known disease pathologies. Amongst these symptoms, functional seizures are among the most common symptoms associated with FND. Individuals who experience functional seizures often report dissatisfaction with healthcare intervention and negative experiences, which can lead to discontinuation in services. Successful engagement is a crucial stage of treatment for individuals with functional seizures. However, there is little research that explicitly explores the experiences of healthcare professionals engaging those with functional seizures in healthcare intervention, and thus this review of qualitative studies explored this area.

Method: Nine papers were included in the review. Papers were synthesised using a meta ethnography approach.

Results: A meta-ethnographic synthesis produced three themes; (1) Acknowledgement; (2) Adaptation; and (3) Consistency.

Conclusions: It was important for professionals to acknowledge the wider challenges for individuals with functional seizures and to consider ways healthcare providers can be flexible and make their services and interventions accessible. Consistent, and predictable interactions from healthcare professionals enabled the development of the therapeutic alliance and offered opportunities for collaboration between the client and the healthcare professional.

Keywords: Functional neurological disorder, functional seizures, engagement, healthcare professionals.

1.1 Introduction

Functional Neurological Disorder (FND) refers to a range of heterogenous neurological symptoms that known organic disease pathologies cannot explain. Symptoms can include limb weakness, tremors, sensory disturbances, or seizures, among others. FND symptoms are common reasons for referrals to neurology clinics [1]. Amongst these symptoms, functional seizures are among the most common symptoms associated with FND [2], with an estimated prevalence of 4.90/100,000 in the UK [3]. Functional seizures can present as a sudden and involuntary loss of control with abnormal movements that resemble an epileptic attack. However, these symptoms are not caused by abnormal electrical activity in the brain as shown by an electroencephalogram (EEG) [4].

Traditional models have theorised that functional seizures are a result of psychological distress being converted into physical symptoms [5]. Whilst it has been demonstrated that psychological distress and trauma are common in those who experience functional seizures, [6], there are many cases that do not report experiences of trauma, or report stressful life events [7]. For those who do report such experiences, research would suggest that correlation between these factors is not established as causal, nor does the experience of psychological distress provide a full explanation of symptoms [8]. Alternatively, there is a growing understanding of neurobiological perspectives aiming to understand the development of functional seizures in the context of abnormal brain function [9]. However, the evidence and knowledge of this is still emerging. To bridge these gaps in understanding, Brown & Reuber [10] proposed an integrative model of functional seizures that combines psychological and neurobiological perspectives. According to this model, functional seizures are a combination of psychological and neurobiological factors, including the experience of difficult life experiences that may change the way the brain processes information.

Despite efforts to develop a cohesive understanding of the condition, there are debates about the terminology for functional seizures. Research suggests that those who experience the condition find terms such as “pseudo seizures” suggesting that the name implies that the individual is malingering or feigning symptoms [11]. Goffman defined stigma as a social construct whereby people are seen by others as discredited due to possessing an undesired attribute and thus part of an individual’s identity impacts their acceptance in their social and cultural environment [12, 13]. Researchers have debated the strengths and limitations of alternative ways to name functional seizures [14, 15]; however, inconsistent terminology can impact how individuals with functional seizures, their families, and professionals understand the condition [16]. For this review, the term “functional seizures” will be used to define the experience where an individual will experience a seizure-like activity with no known organic underlying cause. This term was selected based on a recent systematic review that found the term “functional seizures” was an acceptable term to name the condition from the perspective of those who live with the condition [14].

Furthermore, functional seizures can have a debilitating effect on an individual’s quality of life and social functioning. [17-19]. The presence of seizures often has consequences on an individual’s ability to drive, their employment, and their relationships [17]. More so, individuals with functional seizures are likely to experience low mood [20] and are often faced with stigma, and negative stereotypes from others which can impact the care they receive [21].

Providing an informative and validating diagnosis can aid the individual’s ability to accept and understand the condition [22] and clinical guidelines have been developed to support neurologists in delivering a clear understanding. However, a lack of clear pathways within the UK for FND [23] or functional seizures [24] can result in those who experience functional seizures being seen by emergency departments, neurology, psychiatry, and mental health teams [2]. More so, whilst it’s recommended that individuals with functional seizures are supported by a range of professionals within a multidisciplinary team [10, 25], following diagnosis, psychological therapy is often the treatment chosen by referring practitioners [24].

Individuals with functional seizures often report feeling judged and stigmatised by healthcare professionals. Often, individuals report their symptoms are not taken seriously and state that they are commonly questioned about the legitimacy of their symptoms and illness [26]. Studies on healthcare professionals' attitudes towards individuals with functional seizures align with the experiences reported by those with the condition. Rawlings and Reuber [27] conducted a systematic review exploring the views and experiences of healthcare professionals working with functional seizures. Across the thirty studies included in their review, the researchers found that healthcare professionals often reported a lack of training and reported feeling uncertain about intervention, or how to offer support. More so, professionals also queried who was best placed to provide intervention. Participants viewed working with individuals with functional seizures as a challenge and reported often finding interactions frustrating.

Baslet et al. [23] highlighted that professionals often found it challenging to retain individuals with functional seizures in mental health treatment. Further studies have demonstrated that dissatisfaction with healthcare intervention and negative experiences may prevent individuals with functional seizures from returning to subsequent appointments and may lead to discontinuation in services [21, 25, 26]. Successful engagement is a crucial stage of treatment for individuals with functional seizures [23], with research stating that further attention needs to be given to the engagement of individuals with functional seizures throughout healthcare interactions [24].

Further studies have explored the use of therapeutic techniques to promote engagement and motivation to treatment, such as therapists' use of motivational interviewing techniques. However research indicates that the most important contributor to good outcomes is the relationship between the individual with functional seizures, and the healthcare professional [28]. Findings suggest that when therapeutic relationships are reported as negative, this can impact the outcomes for the individual, and decrease the likelihood of the individual seeking future support from healthcare professionals [29]. However, it is unclear from the research what interactions benefit the therapeutic relationship, nor if the therapeutic relationship directly impacts engagement in healthcare interactions. More so, current research highlights the need to understand the individual dynamics that strengthen the therapeutic relationship and benefit treatment intervention [30].

Consequently, the aim of this review is to understand the experiences of healthcare professionals successfully engaging individuals with functional seizures in a therapeutic interaction. As the research suggests, individuals with functional seizures are often seen by multiple members of a multidisciplinary team, this review aims to capture common themes across different professional roles to understand what therapeutic techniques promote engagement in the services offered and support the development of the therapeutic relationship. For the purpose of this review, "therapeutic interaction" describes a health care appointment between a health care professional and an individual with functional seizures. "Successful engagement" was determined by the opinion of the health care professional within the papers reviewed and is defined here as an activity or interaction that was deemed to improve communication or an activity that subsequently improved the outcome of the appointment.

1.2 Method

In developing the search terms for this review, the researcher consulted the faculty librarian on two occasions. Five major databases were searched: Psycnfo, CINAHL, Medline, AMED, and Scopus. The databases were advised by the faculty librarian and were chosen for their focus on healthcare professionals and health sciences research. Terms were searched using free text terms and subject headings where relevant. The search strategy included a combination of three concepts (qualitative research, healthcare professionals and functional seizures). A variety of terms have been used to describe functional seizures within the literature, and the terms used within this review are based on previously published literature [27, 31]. Free text searches were conducted to search for terms specified in the title OR the abstract. The three concepts were searched together with an 'AND' operator. The full search strategy can be seen in Appendix 1-C.

1.2.1 Inclusion/Exclusion criteria

Papers were included if they were published in peer reviewed journals and used qualitative methodology. Within this review only qualitative papers were used to answer the research question as qualitative research provides a deep understanding of individuals' thoughts, motivations, and experiences. Included papers were required to focus on the perspective of a healthcare professional, particularly their direct comments on their experience of working with individuals with a diagnosis of functional seizures. Papers had to be available in English. The included papers were required to have reported a theme or similar portion of included text to describe their experience of engaging with individuals with functional seizures. Extracts were taken from the papers that directly commented on an interaction between a health care professional and an individual experiencing functional seizures.

Papers were excluded if they aimed to explore only the professionals' views and attitudes of working with functional seizures. Papers that referenced 'medically unexplained symptoms' were excluded from the results due to the ambiguity around the meaning of the language. Papers that focused on intervention efficacy measured by a reduction of symptoms were also excluded, as the review focused on how therapeutic interactions benefitted engagement, rather than the impact on seizure frequency.

The final search was carried out on March 29th, 2023. A total of 4,719 papers were identified from the databases searched. Duplicates were removed adhering to the guided step-by-step deduplication method [32]. After duplicates were removed, 3,284 papers remained. The title and abstract of these papers were screened for relevance, and this process removed 3,163 papers. 121 papers remained and were further assessed for their suitability. At this stage, 112 papers were removed, and 9 papers remained. The researcher conducted forwards and backward reference searching at this stage, but this did not add any additional papers. See Figure 1 for a PRISMA diagram of the screening process. Table-1 outlines the study characteristics of the papers included in the final review.

[Insert Figure 1 here]

1.2.2 Quality rating system

The quality rating system used in this review was the Critical Appraisal Skills Program (CASP) qualitative research checklist [33]. The CASP is designed to screen the quality of published research papers and evaluate their trustworthiness by helping the researcher consider the study's validity, the reliability of the methodology and to consider the clinical implications of the paper. The ratings of the CASP tool did not determine if the papers were to be included or excluded in the review, but instead enabled the researcher to consider the quality of the themes developed. The use of the checklist ensured a theme was not dependant on papers that scored lower on the CASP checklist.

The rating system consists of ten questions; the first two questions are used as tools to screen out papers quickly and the remaining eight assess the quality of the review. As the CASP tool does not provide a scoring system, the researcher followed the three-point rating system advised by Duggleby et al [34]. Answers scored on a three-point system; a weak score (1 point) if they offered no evidence or justification; a moderate score (2 points) when little evidence was offered, but not elaborated in the review and a strong score (3 points) that provided an argument of justification and adequate evidence. Only the latter eight questions were scored using this structure. See Appendix 1-A for full list of CASP questions. The papers were rated by two people, the lead researcher, and a peer, to improve reliability of the scores. The two raters reached the same score on the CASP 73% of the time. The scores were discussed after each person had reviewed them independently, and any disagreements in scoring were discussed until an agreement was reached. See Table-4 for CASP scores.

1.2.3 Meta-ethnography approach

A meta-ethnography approach was used within this review. The meta ethnography approach is suitable when researchers are interested to gain a deeper understanding of a particular concept [35] therefore this approach was used to understand the ways healthcare professionals successfully engage individuals with functional seizures in therapeutic engagement. Meta-ethnography was used over alternative methods of synthesis as it is suited for the development of theories and hypothesis in health care research [35].It also aims to go beyond the original papers and develop new interpretations, unlike meta-aggregation which explicitly summarises and reports the original authors' findings [36].

The meta ethnography approach following the revised step-by-step method developed by Sattar et al. [35] based on Noblit and Hare's seven-step method [37]. The revised method is broken down into seven stages. The first three stages include (1) getting started; (2) Defining a focus of the synthesis; (2b) Locating relevant studies; (2c) The decision to include studies; (2d) Quality appraisal and (3) Reading the studies. These stages have been detailed in the method section. The fourth stage involved determining how the studies were related. In this stage the researcher developed a list of themes from each paper and then grouped common concepts together, alongside the first and second order constructs noted within the research paper, an example the translations table which can be seen in Appendix 1-B.

The fifth stage involved 'translating the studies into one another'. In this stage the researcher ordered the papers chronologically, led by year of publication and summarised the themes and concepts from each paper, noting any consistent or contrasting themes in the papers, whilst also noting new information being presented. This method is used to see how the studies inform one another and to see how the literature has developed over time. In addition, it informed the researcher that the studies should be synthesised using a reciprocal approach. Finally, the themes were brought together in a line of argument synthesis. The final stage involves expressing the synthesis. The synthesis was expressed through the writing of this paper.

1.2.4 Conceptualisation

The name assigned to the experience of functional seizures has been debated within the literature and often has multiple synonyms, even within the titles of the papers included in this review. For this paper, the researcher will refer to "functional seizures" to describe a condition to which an individual will experience a seizure-like activity with no known organic underlying cause. This descriptor was selected based on a recent systematic review that found the term "functional seizures" was an acceptable term to name the condition, from the perspective of those who live with the condition [18].

Within the results the term 'clinician' is used as a generalised term for the variety of professional roles within the papers reviewed. See Table-2 for a list of professions included in the review.

1.2.5 Reflexivity

The researcher approached the review as a female, working class, trainee clinical psychologist living in the north of England. The researcher had worked alongside individuals with functional seizures prior to the commencement of their current training on the Doctorate of Clinical Psychology (DclinPsy) and interviewed individuals with functional seizures for the purpose of their empirical paper. Whilst these experiences provided inspiration and enthusiasm for the review, it is noted that the researcher's preconstructed views and beliefs could have influenced their view of the and thus how the data were coded and interpreted. To hold these views and beliefs in mind, the researcher kept a reflective diary throughout the analysis and write up of the paper and regularly discussed themes and views with their research and field supervisors.

1.3 Results

1.3.1 Study Selection

This review incorporated nine qualitative papers. Two papers used within the analysis [38, 39] are developed from the same data sample. A further two studies [40, 41] were published from a large-scale research study known as the CODES trial (COgnitive behavioural therapy vs standardised medical care for adults with Dissociative non-Epileptic Seizures**)** [42] as additional arms to the randomised control trial.

1.3.2 Sample Characteristics

There were 154 participants in total across the nine studies in the synthesis. Geographically, participants were recruited from five different countries: the United Kingdom [40, 41, 43, 44], Namibia [45], South Africa [46], Australia [38, 39] and the United States [47]. Participants were all professionals working with individuals with functional seizures, and their occupations varied across 14 professional roles, as seen in Table-2.

The review identified three themes: (1) Acknowledgement and (2) Adaptation, and (3) Collaboration. These themes will be expressed through the results of the synthesis. The distribution of themes across the papers within the review can be seen in Table-3.

[Insert Table-2 here]

[insert Table-3 here]

1.3.3 Theme one: Acknowledgment: “Society knows nothing about these, which is the huge problem”.

This theme relates to the clinicians’ awareness of the potential for challenging experiences and healthcare inequalities that can arise, for those who experience functional seizures. Prior to the start of a piece of therapeutic work it was beneficial to have a good awareness of the condition. This knowledge enabled clinicians to understand how to start developing a therapeutic relationship that validated the experiences and offered an opportunity to provide a different therapeutic interaction.

Acknowledging the obstacles that those with functional seizures may have previously faced, allowed individuals with functional seizures to express their anger and frustration about their experiences. In the accounts provided in three studies [39, 41, 44] participants noted it was beneficial for the therapeutic relationship if the clinician could tolerate difficult emotions directed at the healthcare system and its previous failures, in addition to acknowledging and validating their client's experiences. In the descriptions provided by the clinicians interviewed, participants experienced a *"range of emotions from the patients"* [44][Page 3]. Holding this knowledge of the individual's previous experience, clinicians were then able to offer a compassionate understanding to their current emotions. In particular, this enabled practitioners to be validating of the individuals' feelings and emphasise the possibility of good outcomes, to give individuals with functional seizures a "a sense of control." [47][Page 279].

Similarly, it was valuable for clinicians to understand how the individual's social context may view the condition, including the stigma attributed to functional seizures. Participants considered the views of individuals' cultural and social beliefs, in order to understand how functional seizures may be considered within their wider social system. This theme was present despite the range of geographical locations of the studies within this review. In one study developed in South Africa, a participant shared: *"Society knows nothing about these, which is the huge problem, and automatically people are assumed to be malingering ... and so it's critical to inform the patient that this is truly beyond their control."* [46][Page 5].

Participants also noted the difficulty individuals could have in developing a compassionate understanding of their condition within healthcare systems that did not hold a cohesive understanding of functional seizures. Particularly, noting that it was difficult for society to understand the link between the mind and the body, commonly used to describe the aetiology of the condition; *"I think it's really important that we view people as a whole rather than as the body doing one thing and the mind doing something else. There's more acceptance of people's physical ill health than there is of their mental health. And I think, you know, there's very good reasons why people end up having physical difficulties rather than then expressing it more emotionally".* [44][Page 3]. Participants highlighted that the public understandings of mental health conditions are still developing and stated the benefit in understanding and acknowledging that others may hold alternate illness beliefs, to those that are understood in mental health services.

Understanding common perceptions of functional seizures enabled clinicians to consider the possibility that individuals with functional seizures may have internalised stigmatised views of their experiences. Awareness of the systemic narratives of the condition encouraged the clinician to consider asking about the client's own understanding of their condition. If needed, clinicians then offered the opportunity to acknowledge previous narratives but offer something different; *"The first thing I would say is that their symptoms are absolutely real and we're not doubting them at all"* [46], page 5]. Clinicians returned to this narrative throughout the initial sessions to ensure that the individual understood their experiences were acknowledged and believed before beginning any therapeutic work *"keep saying that it's real; although sometimes you say all those things and they just don't hear you, which is why it has to be done often*" [46][Page 5].

Alongside acknowledging the difficulties associated with the condition, clinicians considered how they could enable the client to feel safe within therapeutic interactions. Some participants reflected on their ability to offer something different to other healthcare professionals due to the time available to spend with clients or in the context of their service.

"It's relationship building, and we have the luxury of that because we have an hour with the patient. We're not a neurologist who has 15 minutes or a GP with five or whatever" [44][Page 3]. Clinicians recognised the importance of the therapeutic relationship to validate the patient's experiences, acknowledging that this may be the first opportunity individuals will have had to spend a prolonged period of time with a healthcare professional.

More so, the results suggest that it was beneficial for professionals to also acknowledge and communicate the limits of what therapeutic intervention they can offer, such as outlining the boundaries of the therapeutic work and to develop goals to work towards. One paper outlined *the "importance of setting expectations at the beginning of therapy"* [44], page 5] so the client and therapist both know what they are working towards and develop a clear goal. Moreover, it was important to be transparent with the limitations of the service provision, and state the possibility of their service also not meeting the expectations that individual may hold, and being clear about this from the start; *"…they understood what the remit of the treatment was and how many sessions it was going to be… we had discussed what the treatment covered, but also what it hasn't been able to cover"* [41][Page 6]. This enabled clinicians to develop a trusting relationship with the individual that prioritised honestly and acknowledgement of systemic difficulties that still may be out of the clinician's control.

1.3.4 Theme two: Adaptation: "You're not doing a cookie cutter intervention".

This theme related to the importance of clinicians being flexible within their services to accommodate the individual needs of the client. By working flexibly, the clinician was able to improve the accessibility of services and provide person-centred intervention in a condition that is heterogeneous. For the clinician to offer an accessible service, they might adapt the way the service offered their provision and also adapt their individual working practices to provide the most useful therapeutic interaction.

In the papers reviewed, mental health professionals referred to the ways in which they would draw upon their experience and expertise, which offered them the opportunity to provide a more tailored and flexible intervention; *"I think you have to understand the population. And I think you do need to have experience of complexity because you are not doing a cookie-cutter intervention at all."* [41][Page 5]. Experience-based knowledge enabled co-workers and clients to have more confidence in the clinician's decision making and the individual's confidence in adapting the treatment; *"I think it's one of those conditions where seeing people who know what it is, know what to do with it even if they can't promise to get it better it reduces everybody's anxiety levels about it".*[40][Page 4].

Moreover, it was important to be flexible to support and maximise the therapeutic relationship, among a range of interventions included in the review. In a review of cognitive behavioural therapy (CBT), therapists' experiences of working with functional seizures, the authors reported, *"It was considered important to have space for reordering and placing specific emphasis on the features of the intervention when encountering the diversity and complexity of the patients*"[41][Page 6]. Examples of flexibility across the papers reviewed included the use of different therapeutic modalities and techniques to discover what may work for each individual client. In one study, clinicians described that they use a variety of therapeutic tools from different therapeutic modalities to tailor the intervention to the person; "*I've always thought that the work with people with non-epileptic seizures has been challenging because you can't apply a single model that tells you exactly how to do it. So, it's quite interesting, exciting, challenging because you have to use every bit, you know, of your toolkit that help*s somebody." [44][Page 5]. This approach enabled the clinician to offer person-centred intervention, and work together using a therapeutic intervention that was beneficial for the individual with functional seizures.

Being flexible in approach also extended to non-mental health professionals. In one paper, researchers explored the experiences of physiologists completing an EEG with individuals with functional seizures. Participants reflected on the challenge they faced within their professional role, navigating the dilemma of what they would like to do and how they would like to help, alongside the constraints of their service and their role. One participant reflected on their need to be responsive to an individual's emotional distress and develop a different therapeutic interaction to the ones they would typically hold; *"I had a patient who again was sort of disclosing some things to me. Really upsetting, and normally I am sat, you know, quite a way away, […] I just needed to go and sit with her and hold her hand"* [43][Page 12]. Adapting the manner in which the participant interacted with the individual during the appointment, offered an intervention that was adapted based on the individual's needs.

Furthermore, collaboration was also stated as an important tool for engagement. In some papers that discuss psychotherapeutic interactions [38, 39] participants stated that it was beneficial for the therapy to be led by the client to enable them to bring up what was important to them, rather than be led by the therapist. However, other papers stated the benefit of providing structure to support the conversation and provide a framework around what the time might be spend doing/discussing [41]. Overall, the synthesis demonstrated that individuals with functional seizures did not all consider one style to be mutually beneficial, further highlighting the benefit of adaptation. The papers did however consistently report the importance of offering unconditional positive regard within their interactions; professionals recognized that *"genuine mutual regard was necessary"* [39][Page 692].

Cultural adaptations were important to consider in both the diagnosis of the condition and also intervention. One study, conducted in Namibia, described the benefits to being flexible, and being culturally sensitive to meet the client's belief's; *"I would apply different approaches to different cultures. And of course, depending on certain cultures some people* *feel like talking about their inner self is not an issue and they avoid that. And they are coming from a background of doctor patient of tell me what I should do. Which of course is not at all like cognitive behavioural. They want advice".* [45][Page 48]. To be flexible and adapt to the clients' needs in a meaningful way, clinicians needed an understanding of the clients' values, beliefs, and cultural norms. A culturally sensitive understanding ensured healthcare professionals met the clients cultural, psychological, and medical needs.

1.3.5 Theme three: Consistency: "A bit more like integrative and joined-up care".

This theme outlines the importance of working collaboratively with other professionals within the individual's healthcare systems and working with families. Working together, fostered a consistent understanding of how the condition is understood, and explained. More so, collaboration supported a shared approach of how to support an individual with functional seizures. Through the analysis, the papers outlined the importance of developing a collaborative understanding between the clinician and the client, where they both invested and co-developed a understanding of predisposing and perpetuating factors, which was further benefitted by sharing this understanding and education with family members.

The use of transparent and straightforward language, specifically tailored to the individual with functional seizures, was demonstrated to benefit the professional's communication and supported the person to understand their condition. For the professional, this could mean the terminology used to describe mental health vulnerabilities in lay language such as "stress", or using visual aids to communicate complex neurological concepts, such as the body and brain connection. Developing a meaningful understanding between a client and a healthcare professional enabled the client to form a sense of control and autonomy over their condition. In some cases, the therapist, and the client codeveloped new language that would explain their experiences in a way that was more comfortable for the individual with functional seizures, rather than using medical terminology; *"'So actually, we could call it blue, and they'd be quite happy. And equally I would be too.*"[44][Page 3]. By assigning a new name to the condition, it enabled individuals with functional seizures to develop a new understanding and sense of control over their symptoms, which seemed to facilitate empowerment and coping.

In one study, the authors described that the therapeutic intervention was difficult if there was no understanding of how and why functional seizures were present in the client's life; *"Therapists shared the opinion that, although these PNES [Psychogenic non-epileptic seizures] shared some features, it was important for effective treatment that the therapist understand the function that PNES performed. Therapists realized that these functions varied across seizures within a client"* [38][Page 114]. As a result, a shared understanding between the individual with functional seizures and the clinician can support effective treatment, helping the person better understand their experiences and feel more in control.

Additionally, papers within the analysis also highlighted the benefit of consistency among different professionals. For example, "*therapists commented that they and their patients had benefitted from close working relationships with medical colleagues (i.e., neurologists and/ or psychiatrists) during the trial"* [41][Page 7]. In a qualitative study exploring the views of CBT therapists working within the CODES trail, participants highlighted the benefit of close working relationships, and the impact this had on the care therapists were able to provide. Close working relationships and a consistent approach benefitted how the client felt during the trial; *"They suggested that this cohesiveness served to mitigate any sense that patients may have had of being abandoned by medical colleagues after being referred for psychological therapy"* [41][Page 7]. This suggests that having close working relationships with multiple members of the MDT, provides consistency and makes communication and understandings of the condition more transparent.

Consistency and collaboration were also important outside of the therapeutic interaction. Three papers [41, 45, 46] described it as beneficial to work with the individual's family members in addition to working with the individual alone. Working in this way, enabled family members to understand the condition. A shared understanding provided a consistent message and response to the presence of symptoms, or any anxiety associated with the condition; "*It is important to involve the family in the treatment of the PNES patient. Participants explained that incorrect perceptions can be addressed by providing information to the family in order to facilitate adequate support and understanding*."[45][Page 49]. More so, a shared understanding within a family unit was important to reduce stigma and shame commonly associated with the condition and helped *"facilitate adequate support and understanding"[45][Page 49].* Additionally, family members' accounts were helpful for the professional to build a rounded understanding of the client, which could help support the professional's intervention. One paper stated involving family *"was an opportunity to gather an observer's account of the seizures"* and had the potential to *"enhance patient engagement by offering them control over which family members they would invite and when".* [41][page 4].

1.3.6 Line by argument synthesis

The findings suggest that it was important for professionals to acknowledge the wider challenges for individuals with functional seizures. In acknowledging that individuals may have experienced lack of support, long waiting lists and possible stigmatised interactions with healthcare professionals it allowed professionals to consider ways in which healthcare providers can be flexible and make their services and interventions accessible. In doing so, professionals could ensure that part of their intervention included supporting the understanding of professionals and family supporting the individual to provide a consistent and collaborative approach, that was empowering, and contributed to the individual's sense of control. Healthcare professionals reported that successful engagement was supported by consistent, and predictable interactions from healthcare professionals as this strengthened the therapeutic alliance and offered opportunities for collaboration between the individual with functional seizures and the healthcare professional.

1.4 Discussion

The aim of this review was to understand professionals' experiences of working with individuals with functional seizures, and their knowledge of what promotes therapeutic engagement. The analysis generated three themes; (1) Acknowledgement; (2) Adaptation; and (3) Consistency. Previous research has highlighted that individuals with functional seizures are likely to experience stigma from healthcare professionals [48] which can affect individuals' engagement in therapy. This study contributes to the understanding of this, by suggesting that acknowledgment of the experience of stigma and societal inequalities faced by those with the condition, can promote engagement.

In the first theme, 'Acknowledgment' the results suggest that healthcare professionals should acknowledge systemic inequalities and normalise feelings of anger and frustration. Previous research has highlighted that individuals with FND and functional seizures are often upset and angry with the healthcare they receive, including how professionals understand, and communicate the condition [49, 50]. Studies have highlighted the systemic inequalities that those with the condition face, and despite further research and awareness of the condition, many individuals meet with professionals who have not heard of the condition or hold onto outdated views of how the condition is understood [51]. Research exploring healthcare professionals' views of working with individuals with functional seizures also reflects these themes, suggesting that negative healthcare interactions can result in individuals being stereotyped, discriminated and judged, which can have a long term impact on individuals wellbeing, and future care [21]. Such interactions can damage the therapeutic alliance, and thus affect long-term adherence to healthcare intervention, including psychological and psychiatric support [52, 53]. Due to the prevalence of stigma associated with the condition, the papers included in this review suggest that it is likely that individuals with functional seizures may require professionals to present consistent and repeated feedback that the individuals experiences are believed, and that the professional does not view this as malingering. Professionals who were aware of the systemic difficulties, and were able to acknowledge them, could then reflect on the ways in which they could make changes and offer adaptations to ensure the service provision was accessible and individualised.

Studies have found that diagnosis alone may reduce seizure frequency [22]. This change in symptom frequency has been attributed to individuals learning about the relationship between psychosocial stressors and their seizures [54]. Individuals with functional seizures, often benefit from further education about their condition [55]. Additionally, the use of transparent and straightforward language supported the individuals understanding, which enabled individuals to challenge internalised illness perceptions. This finding is consistent with previous literature in chronic health conditions, that proposes that individuals are driven and respond to health threats in accordance to their own understanding of the condition[56]. Illness perceptions are noted to be key in an individual’s ability to develop adjustment and acceptance of treatment [57]. Thus, by understanding that individuals may not yet understand their condition, clinicians could acknowledge the importance of providing further information, delivered in an accessible format.

In the second theme, ‘Adaptation’, the results highlighted the benefits of adapting therapeutic interventions based on the individual's needs, which can lead to better outcomes for the patient. This is supported by previous research that suggests that different modalities of intervention have been identified to have a beneficial effect on quality-of-life measures [42, 58-60], thus, suggesting that different intervention can benefit different people. Furthermore, social environment, and an individual's cultural beliefs can affect individuals' ability and motivation to seek treatment [61]. The results suggested that cultural and religious beliefs can affect both the individuals' and their communities' understanding of the condition.

How others understood the condition also impacted how they were able to offer support and then how they are subsequently treated. Two of the papers within the review [39, 45], noted the challenges of completing assessment and treatment for functional seizures both due to availability of appropriate healthcare professionals and equipment, but also the cultural underpinnings of how healthcare is positioned and interpreted within the cultural context. This impacted the way in which health professionals would engage and communicate with the individual when they worked together in a therapeutic context. Professionals spoke about how they adapted their approach, for example with the use of directive statements.

More so, whilst this was only highlighted in two of the papers within the review, it highlights the importance of adapting clinical assessment and intervention to the appropriate context for the individual. Previous research has highlighted the variation in explanatory models for functional seizures, and how cultural and religious understandings of the condition affect the treatment individuals seek [61]. Further research has highlighted that the study of functional seizures often portrays a western medical understanding of the condition, and often fails to consider cultural understandings of the condition [62]. Canna & Seligman [63], further state how more research into cultural understandings of functional seizures would be beneficial professionals to further understand individuals' illness models. Thus, it could be an important consideration for professionals working within this area to think about the clients' views, values and cultural beliefs and incorporate them into any intervention provided.

In the final theme, 'Consistency', the results suggested that it was important for engagement in a therapeutic interaction, for professionals to support a new understanding of the condition, and for this to be shared with others, including family and other professionals. The findings of this review suggest that it was beneficial to have a consistent understanding throughout an individual's social network, including joined up care provided by professionals, but also a shared understanding and social support from family members or friends. This finding is consistent with previous research that suggests family members can benefit individuals' adjustment and improve coping, by offering support and encouragement [51]. Individuals with functional seizures have described ongoing support from family and friends as extremely important [50]. However, research suggests that individuals with functional seizures often report reduced social functioning due to the doubt and uncertainly related to others' perceptions, or fears related to their ability to risk manage their symptoms [31, 64]. Thus, having a consistent and collaborative approach from friends, family and professionals may have helped to reduce perceived stigma by supporting the development and maintenance of social support.

The review identified that there are three common steps in promoting engagement between healthcare professionals and individuals with functional seizures, that begins with understanding and acknowledging the challenges faced with the condition, in order to offer a different approach. Recent studies in the broader literature of FND, has demonstrated that education can inform and support professionals' understanding of the condition, and can have a positive impact on their view and attitudes [52]. It is well documented that individuals with functional seizures often have difficult interactions with healthcare professionals and are negatively affected by experiences of stigma [13]. Therefore, this would suggest that there is an additional need for professionals to receive training and education on functional seizures, in order to reduce stigma individuals with functional seizures receive, and to offer professionals a way to engage with individuals with the condition, through acknowledgment and then change.

More so, the review identified the benefit of joined up care and a collaborative approach. The results within this review highlight the need for clear service pathways and a consistent understanding of functional seizures throughout the treatment provision. Participants within the review reported long waiting lists, and inconsistent support form services, and thus clear information about service pathways and referrals criteria would enable individuals with functional seizures to have a broader understanding of their treatment options.

Finally, the research highlights that individuals with functional seizures often seek support from family members and friends, with broader research suggesting 69% of individuals seeing a family member once per week [65]. Therefore, this would suggest that there is an addition need for individuals to consider family psychoeducation in treatment delivery, where appropriate.

1.4.1 Limitations

There are a number of limitations to this review. Firstly, whilst the papers included in the review incorporate a professional's perspectives from 5 different countries (UK, USA, Australia, Namibia and South Africa), 78% of the papers were conducted in western countries, and represent the views of a westernised health system. The review does not appropriately represent a range of cultural viewpoints, and therefore likely does not represent the views of health professionals in non-western countries. More so, the majority of the papers included in the review did not state the ethnicity of their participants; therefore, it is unclear whether the review has represented views from different cultural groups within the review.

Moreover, the research hoped to capture the experiences of different healthcare professionals within the synthesis, however this was not the product of the systematic search, and instead the majority of the data portrayed the experiences of healthcare professionals within mental health services. It’s possible that this demonstrates that individuals with FND are more likely to be seen by mental health services, despite the recommendations discussed in the introduction.

Furthermore, there is little research that highlights healthcare professionals’ experiences of working with individuals with functional seizures, that directly reports on what interventions, and interactions support therapeutic engagement. Using meta ethnography as a means of analysis enables the researcher to synthesise qualitative studies, whilst also including author interpretations of the data. Thus, limited participant data is available to be synthesised, and themes are developed largely due the interpretation of the authors within the studies.

Finally, the results of this review may have been influenced by prior work. Originally, the aim of the meta-ethnography was to synthesise all the papers on staff working with people with functional neurological disorder. However, following an initial screening, the papers retrieved did not represent the broad spectrum of symptom presentations within the condition. A large proportion of the papers described experiences of health care professionals working with functional seizures and therefore the review findings would have been highly biased towards the experiences of this group. As a result, the decision was made to focus solely on the experiences of healthcare staff working with people functional seizures and new searches were carried out with this aim. Whilst steps were taken to minimise any bias within the data, by use of reflective journals, and ongoing supervision, it’s likely that the themes developed within this review will have been influenced by the authors’ (and supervisors’) preconceptions and cultural backgrounds.

1.4.2 Recommended future research

Functional neurological disorders are heterogenous in their presentation. The experience of inequality and poor prognosis is associated with other presentations of functional neurological disorders, beyond the presentation of functional seizures. There is a developing number of studies that aim to understand the experience of engaging individuals with functional neurological disorders in therapeutic interactions [43, 48], but there is currently little research exploring professionals accounts of helpful interactions during psychological intervention. It would be beneficial to further understand what interventions improve engagement and adherence to psychological interventions for those with functional seizures, and also for those with other symptoms of FND.

More so, the ability of the clinician to adapt therapeutic intervention has been a key theme within the findings of this study. It would be beneficial to explore the ways healthcare interactions could be adapted to meet different religious and cultural needs, outside of a westernised understanding of FND, and how healthcare professionals can understand adapt to different cultural understandings and illness beliefs within a westernised healthcare service.

Finally, the findings in this literature review predominantly outline the experiences of professionals within mental health services and their experience of engagement. One recommendation would be to explore how other professionals within physical health, and rehabilitation settings also provide engage individuals in therapeutic interventions.

1.4.3 Conclusion

The literature review highlighted that healthcare professionals reported that engagement was successful if they were able to acknowledge the systemic difficulties through understanding the condition, use this knowledge to adapt their intervention, and if the individual with functional seizures had consistent support from their social support system, and professionals. The findings also suggest that the development of a therapeutic alliance is beneficial for engagement in treatment, therefore implementing the findings within this review, could support engagement.

1.5 References

1. Stone, J., et al., *Who is referred to neurology clinics?—the diagnoses made in 3781 new patients.* Clinical neurology and neurosurgery, 2010. **112**(9): p. 747-751.
2. Aybek, S. and D.L. Perez, *Diagnosis and management of functional neurological disorder.* bmj, 2022. **376**.
3. Duncan, R., S. Razvi, and S. Mulhern, *Newly presenting psychogenic nonepileptic seizures: incidence, population characteristics, and early outcome from a prospective audit of a first seizure clinic.* Epilepsy & Behavior, 2011. **20**(2): p. 308-311.
4. LaFrance, W.C. and S.R. Benbadis, *Differentiating frontal lobe epilepsy from psychogenic nonepileptic seizures.* Neurologic clinics, 2011. **29**(1): p. 149-162.
5. Raynor, G. and G. Baslet, *A historical review of functional neurological disorder and comparison to contemporary models.* Epilepsy & Behavior Reports, 2021. **16**: p. 100489.
6. Stone, J. and A. Carson, *Functional neurologic symptoms: assessment and management.* Neurologic clinics, 2011. **29**(1): p. 1-18.
7. Ludwig, L., et al., *Stressful life events and maltreatment in conversion (functional neurological) disorder: systematic review and meta-analysis of case-control studies.* The Lancet Psychiatry, 2018. **5**(4): p. 307-320.
8. Espay, A.J., et al., *Current concepts in diagnosis and treatment of functional neurological disorders.* JAMA neurology, 2018. **75**(9): p. 1132-1141.
9. Allendorfer, J.B., et al., *FMRI response to acute psychological stress differentiates patients with psychogenic non-epileptic seizures from healthy controls–A biochemical and neuroimaging biomarker study.* NeuroImage: Clinical, 2019. **24**: p. 101967.
10. Brown, R.J. and M. Reuber, *Towards an integrative theory of psychogenic non-epileptic seizures (PNES).* Clinical psychology review, 2016. **47**: p. 55-70.
11. Stone, J., et al., *What should we call pseudoseizures?* Seizure, 2003. **12**(8): p. 568-572.

12. Goffman, E., *Stigma and social identity*, in *Understanding Deviance*. 2014, Routledge. p. 256-265.

13. Foley, C., A. Kirkby, and F.J. Eccles, *A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder.* Disability and Rehabilitation, 2023: p. 1-12.

14. Asadi-Pooya, A.A., et al., *Terminology for psychogenic nonepileptic seizures: Making the case for "functional seizures".* Epilepsy Behav, 2020. **104**(Pt A): p. 106895.

15. Kerr, W.T. and J.M. Stern, *We need a functioning name for PNES: consider dissociative seizures.* Epilepsy & Behavior, 2020. **105**.

16. Tolchin, B., et al., *What's in a name?* Epilepsy & Behavior, 2020. **112**.

17. Jones, B., M. Reuber, and P. Norman, *Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: a systematic review.* Epilepsia, 2016. **57**(2): p. 171-181.

18. Asadi-Pooya, A.A., et al., *Social aspects of life in patients with functional seizures: Closing the gap in the biopsychosocial formulation.* Epilepsy & Behavior, 2021. **117**: p. 107903.

19. Reuber, M., et al., *Measuring outcome in psychogenic nonepileptic seizures: how relevant is seizure remission?* Epilepsia, 2005. **46**(11): p. 1788-1795.

20. LaFrance, W.C. and S. Syc, *Depression and symptoms affect quality of life in psychogenic nonepileptic seizures.* Neurology, 2009. **73**(5): p. 366-371.

21. Robson, C. and O.S. Lian, *" Blaming, shaming, humiliation": Stigmatising medical interactions among people with non-epileptic seizures.* Wellcome Open Res, 2017. **2**: p. 55.

22. Stone, J., A. Carson, and M. Hallett, *Explanation as treatment for functional neurologic disorders.* Handbook of clinical neurology, 2016. **139**: p. 543-553.

23. O'Connell, N., *Functional neurological disorder in acute stroke and mental health services: A mixed methods assessment of experiences, prevalence, associated clinical factors, and treatment*. 2018, King's College London.

24. Mayor, R., P.E. Smith, and M. Reuber, *Management of patients with nonepileptic attack disorder in the United Kingdom: a survey of health care professionals.* Epilepsy & Behavior, 2011. **21**(4): p. 402-406.

25. Gilmour, G.S., et al., *Management of functional neurological disorder.* Journal of Neurology, 2020. **267**: p. 2164-2172.

26. Fairclough, G., et al., *Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures.* Epilepsy & Behavior, 2014. **31**: p. 295-303.

27. Rawlings, G.H. and M. Reuber, *Health care practitioners' perceptions of psychogenic nonepileptic seizures: a systematic review of qualitative and quantitative studies.* Epilepsia, 2018. **59**(6): p. 1109-1123.

28. Dworetzky, B., *Perceptions in PNES: A Bidirectional Problem.* Epilepsy Currents, 2019. **19**(1): p. 31-32.

29. Bertakis, K.D. and R. Azari, *Patient-centered care is associated with decreased health care utilization.* The Journal of the American Board of Family Medicine, 2011. **24**(3): p. 229-239.

30. Baslet, G., et al., *Mindfulness-based therapy for psychogenic nonepileptic seizures.* Epilepsy & Behavior, 2020. **103**: p. 106534.

31. Rawlings, G.H. and M. Reuber, *What patients say about living with psychogenic nonepileptic seizures: a systematic synthesis of qualitative studies.* Seizure, 2016. **41**: p. 100-111.

32. Bramer, W.M., et al., *De-duplication of database search results for systematic reviews in EndNote.* Journal of the Medical Library Association: JMLA, 2016. **104**(3): p. 240.

33. Checklist, C. and C. How, *Critical appraisal skills programme. 2018.* URL: https://casp-uk. net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018. pdf [accessed 2021-05-04], 2022.

34. Duggleby, W., et al., *Metasynthesis of the hope experience of family caregivers of persons with chronic illness.* Qualitative Health Research, 2010. **20**(2): p. 148-158.

35. Sattar, R., et al., *Meta-ethnography in healthcare research: a guide to using a meta-ethnographic approach for literature synthesis.* BMC Health Serv Res, 2021. **21**(1): p. 50.

36. Lockwood, C., Z. Munn, and K. Porritt, *Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation.* JBI Evidence Implementation, 2015. **13**(3): p. 179-187.

37. Noblit, G.W., R.D. Hare, and R.D. Hare, *Meta-ethnography: Synthesizing qualitative studies*. Vol. 11. 1988: sage.

38. Quinn, M.C., M.J. Schofield, and W. Middleton, *Permission to speak: therapists' understandings of psychogenic nonepileptic seizures and their treatment.* J Trauma Dissociation, 2010. **11**(1): p. 108-23.

39. Quinn, M.C., M.J. Schofield, and W. Middleton, *Successful psychotherapy for psychogenic seizures in men.* Psychother Res, 2012. **22**(6): p. 682-98.

40. Jordan, H., et al., *Exploring psychiatrists' perspectives of working with patients with dissociative seizures in the UK healthcare system as part of the CODES trial: a qualitative study.* BMJ Open, 2019. **9**(5): p. e026493.

41. Wilkinson, M., et al., *The experiences of therapists providing cognitive behavioral therapy (CBT) for dissociative seizures in the CODES randomized controlled trial: A qualitative study.* Epilepsy Behav, 2020. **105**: p. 106943.

42. Goldstein, L.H., et al., *Cognitive behavioural therapy for adults with dissociative seizures (CODES): a pragmatic, multicentre, randomised controlled trial.* The Lancet Psychiatry, 2020. **7**(6): p. 491-505.

43. McNicholas, O. and H. Pryce, *Clinical physiologists' experiences of working with people with nonepileptic attack disorder: A qualitative study.* Epilepsy & Behavior, 2022. **127**: p. 108501.

44. O'Connor, P.J. and M. Reuber, *'It's both challenging and probably the most rewarding work' - A qualitative study of psychological therapy provider's experiences of working with people with dissociative seizures.* Epilepsy Behav, 2021. **122**: p. 108156.

45. du Toit, A. and C. Pretorius, *Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations.* Seizure, 2017. **50**: p. 43-52.

46. Hartwig, L. and C. Pretorius, *Psychogenic nonepileptic seizures: Comparing what South African healthcare providers communicate to patients at the point of diagnosis against international guidelines.* Epilepsy & Behavior, 2019. **101**.

47. McMillan, K.K., et al., *Providers' perspectives on treating psychogenic nonepileptic seizures: frustration and hope.* Epilepsy Behav, 2014. **37**: p. 276-81.

48. Barnett, C., et al., *The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder.* Disability and Rehabilitation, 2022. **44**(10): p. 1802-1811.

49. Wyatt, C., A. Laraway, and S. Weatherhead, *The experience of adjusting to a diagnosis of non-epileptic attack disorder (NEAD) and the subsequent process of psychological therapy.* Seizure, 2014. **23**(9): p. 799-807.

50. Pretorius, C. and M. Sparrow, *Life after being diagnosed with psychogenic non-epileptic seizures (PNES): A South African perspective.* Seizure, 2015. **30**: p. 32-41.

51. Reuber, M., et al., *Non-Epileptic Seizures and Other Functional Neurological Symptoms: Predisposing, Precipitating, and Perpetuating Factors.* Psychosomatics, 2007. **48**(3): p. 230-238.

52. Tolchin, B., B.A. Dworetzky, and G. Baslet, *Long-term adherence with psychiatric treatment among patients with psychogenic nonepileptic seizures.* Epilepsia, 2018. **59**(1): p. e18-e22.

53. Tolchin, B., et al., *Adherence with psychotherapy and treatment outcomes for psychogenic nonepileptic seizures.* Neurology, 2019. **92**(7): p. e675-e679.

54. Baslet, G., et al., *Treatment of psychogenic nonepileptic seizures: updated review and findings from a mindfulness-based intervention case series.* Clinical EEG and neuroscience, 2015. **46**(1): p. 54-64.

55. Wiseman, H., et al., *A multicenter evaluation of a brief manualized psychoeducation intervention for psychogenic nonepileptic seizures delivered by health professionals with limited experience in psychological treatment.* Epilepsy & Behavior, 2016. **63**: p. 50-56.

56. Leventhal, H., L.A. Phillips, and E. Burns, *The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management.* Journal of Behavioral Medicine, 2016. **39**(6): p. 935-946.

57. Baxter, S., et al., *Understanding patient perceptions following a psycho-educational intervention for psychogenic non-epileptic seizures.* Epilepsy & Behavior, 2012. **23**(4): p. 487-493.

58. Mayor, R., et al., *Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: Seizure control and health care utilization.* Epilepsia, 2010. **51**(7): p. 1169-1176.
59. Howlett, S., et al., *Engagement in psychological treatment for functional neurological symptoms--Barriers and solutions.* Psychotherapy: Theory, Research, Practice, Training, 2007. **44**(3): p. 354.
60. LaFrance, W.C., et al., *Cognitive behavioral therapy for psychogenic nonepileptic seizures.* Epilepsy & Behavior, 2009. **14**(4): p. 591-596.
61. Sarudiansky, M., et al., *What patients think about psychogenic nonepileptic seizures in Buenos Aires, Argentina: a qualitative approach.* Seizure, 2017. **51**: p. 14-21.
62. Martínez-Taboas, A., et al., *Cultural aspects of psychogenic nonepileptic seizures.* Gates and Rowan's nonepileptic seizures, 2010: p. 121-130.
63. Canna, M. and R. Seligman, *Dealing with the unknown. Functional neurological disorder (FND) and the conversion of cultural meaning.* Social Science & Medicine, 2020. **246**: p. 112725.
64. Thompson, R., et al., *What is it like to receive a diagnosis of nonepileptic seizures?* Epilepsy & Behavior, 2009. **14**(3): p. 508-515.
65. Vaidya-Mathur, U., et al., *Socialization characteristics in patients with psychogenic nonepileptic seizures (PNES).* Epilepsy & Behavior, 2016. **56**: p. 59-65.

1.6 Tables

1.6.1 Table 1 Characteristics of study

Author	Year	country	Participant			Data collection	Method	Aims	Findings	CASP Rating
			No.	Age	Gender					
Claire, Schofield and Middleton	2010	Melbourne, Australia	8	27 - 50	5 Females 2 Males	Semi-structured interviews	Grounded theory	The researchers explored therapists' views about successful treatments of PNES.	For some participants, PNES was conceptualised as a form of nonverbal communication behaviours and could be treated with interventions focused on verbal expression. Others were successfully treated by a sensitive delivery of the diagnosis and brief cognitive interventions	21
Quinn, Schofield and Middleton	2012	Melbourne, Australia	2	27 - 50	2 Males	Semi-structured interviews	Interpretive Phenomenological Analysis	The researchers sought to understand the contributing factors to PNES and their resolution in psychotherapy in a small sample of civilian men.	Successful treatments occurred in long-term therapeutic relationships focused on expressing strong emotion verbally.	20
McMillan, Hamid and Pugh	2014	Texas, Austin, United States	74	Not stated	Not stated	Semi-structured interviews	Grounded Theory	This study aimed to describe providers' perceptions of PNES care and the impact of intervention	The results revealed variation in care and two emergent domain themes of frustration and hope.	22

Toit and Pretorius	2017	South Africa	15	Not stated	Not stated	Semi-structured interviews	Thematic Analysis	This study investigating the perceptions and frustrations of healthcare providers (HCPs) in Namibia working with Functional seizures	HCPs' perceptions and frustrations were often related to the lack of knowledge and lack of access to specialised services	23
Jordan, Feehan, Perdue, Murray and Goldstein	2018	London, United Kingdom	10	31 - 60	5 Males 5 Females	Semi-structured interviews	Thematic Analysis	The objective of this study was to gain an understanding of UK-based psychiatrists' experiences of the Dissociative Seizure patient group.	The key themes identified were other HCPs' attitudes to Dissociative Seizures and the challenges of the DS patient group.	20
Hartwig and Pretorius	2019	South Africa	11	Not stated	4 Males 7 Females	Semi-structured interviews	Thematic Analysis	To compare South African HCPs' communication of diagnosis to national guidelines.	There was close alignment between the guidelines and HCPs' communication. Describing that condition was real, how difficult the condition was, possible causes and maintaining factors; that effectiveness of and appropriate treatment options.	22

Wilkinson, Day, Purnell, Pilecka, Perdue, Murray, Hunter and Goldstein	2019	London and Scotland, United Kingdom	12	31 - 50	10 Female 2 Male	Semi-structured interviews	Thematic Framework Analysis	This study set out to explore therapists' experiences of delivering DS-specific, manualized cognitive behavioural therapy (CBT) to adults with DS within the context of a randomized control trial.	The results found that therapists considered some parts of intervention to be helpful, the significance of formulation and the limitations and challenges of working within a protocol.	24
McNicholas and Pryce	2020	London/ Birmingham, United Kingdom	12	23-67	10 Females 2 Males	Semi-structured interviews	Grounded Theory	The study aimed to understand physiologists' experiences of working with patients with NEAD	Participants described the experience of working with people with NEAD as anxiety provoking and unpredictable.	21
O'Connor and Reuber	2021	Leeds and Sheffield, United Kingdom	12	31 - 70	7 males 5 females	Semi-structured interviews	Thematic Analysis	The objective of this study was to gain an understanding of Psychology therapy providers working with people with dissociative seizures (DS)	The study demonstrated that unclear diagnosis and long waiting times negatively impacted patients at the starting point of therapy. People with DS were perceived as a heterogeneous group whose treatment needed to be individualized.	19

1.6.2 Table 2: Participants' professional titles across the studies

	Total number	Across how many studies?
Clinical psychologist	18	5
Educational psychologist	1	1
Counselling psychologist	2	1
CBT therapist	1	1
Psychotherapist	6	2
Clinical physiologist	12	1
Nurse	15	2
Physiotherapist	1	1
Occupational therapist	1	1
Psychiatrist	23	4
EEG technologist	6	1
Neurologist	54	3
General practitioner	6	1
Other	7	1

1.6.3 Table 3: Themes across papers

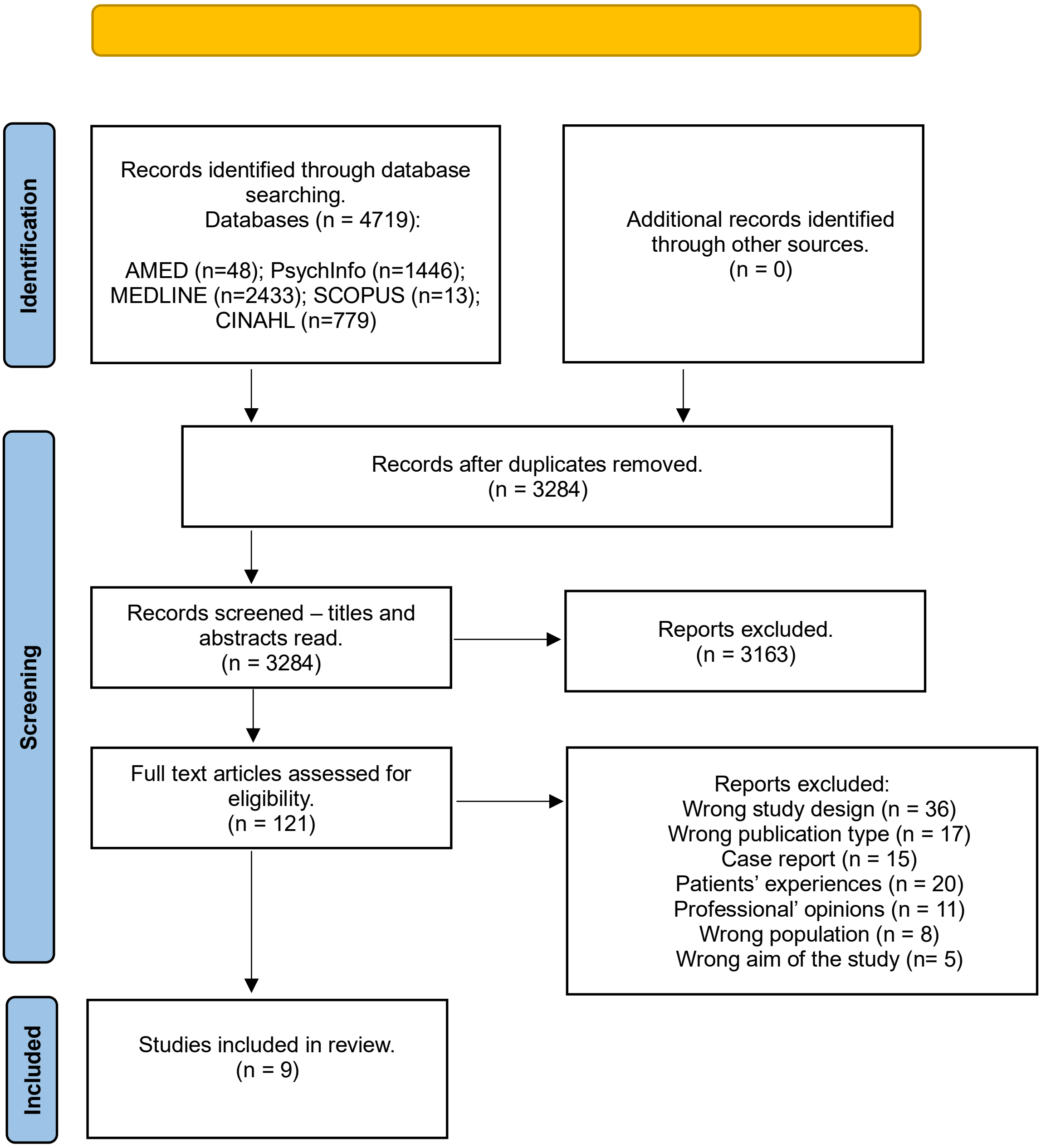
Paper	Acknowledgment	Adaptation	Consistency
Wilkinson, Day, Purnell, Pilecka, Perdue, Murray and Monika (2019) [41]	X	X	X
Du Toit and Pretorius (2017) [45]	X	X	X
Hartwig and Pretorius (2019) [46]	X	X	X
McMillan, Hamid and Pugh (2014) [47]	X	X	
McNicholas and Pryce (2020) [43]	X	X	
Quinn, Schofield, and Middleton (2010) [38]	X	X	
Jordan, Feehan, Perdue, Murray and Goldstein (2018) [40]		X	X
Quinn, Schofield, and Middleton (2012) [39]	X	X	
O’Connor and Reuber (2021) [44]	X	X	X

1.6.4 Table 4: CASP Scores

Paper	Research design	Sampling	Data collection	Reflexivity	Ethical issues	Data Analysis	Findings	Value of the research	Total Score
Wilkinson, Day, Purnell, Pilecka, Perdue, Murray and Monika (2019) [41]	3	3	3	3	3	3	3	3	24
Du Toit and Pretorius (2017) [45]	3	3	3	2	3	3	3	3	23
Hartwig and Pretorius (2019) [46]	2	3	3	3	3	2	3	3	22
McMillan, Hamid and Pugh (2014) [47]	3	3	3	3	1	3	3	3	22
McNicholas and Pryce (2020) [43]	3	3	3	1	2	3	3	3	21
Quinn, Schofield, and Middleton (2010) [38]	3	3	3	1	3	2	3	3	21
Jordan, Feehan, Perdue, Murray and Goldstein (2018) [40]	3	3	3	1	2	2	3	3	20
Quinn, Schofield, and Middleton (2012) [39]	3	3	3	1	2	3	3	2	20
O’Connor and Reuber (2021) [44]	3	2	3	1	2	2	3	3	19

1.7 Figures

Figure 1: PRISMA Flow diagram



1.8 Appendix

1.8.1 Appendix 1-A: CASP Questions

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

1.8.2 Appendix 1-B: Example Translations Table

1st order	2nd order data	Descriptors	Authors
They’ve wanted help for usually a very long time. And, and that anger, you know, often the therapist is the first person they’ve met who had more than 15 minutes of time for them’ (page 3)	“Nine of the participants described how the length of time between diagnosis and treatment had a damaging effect on patients, with a wait of up to six years for psychological input (in addition to the ‘several’ years for a correct diagnosis of DS’). Participants experienced a range of emotions from patients, including anger at them and the system.” (Page 3)	Acknowledging systemic failures and being able to sit with the client whilst they communicate how they feel.	Jane, O’Connor and Reuber (2021)
We have often talked about ‘Wouldn't it be nice if we had a psychologist that we paid part of his/her salary?’ Or, even if we hired somebody who had an interest in conversion disorders who we could send all the patients to? (Page 279)	“Cross disciplinary team working” theme (page 279)	Acknowledging failures and gaps within the service.	McMillan, Hamid, and Pugh (2014)
We sometimes lose these people …. Sometimes, they feel neglected. We have some problems getting the communications across. In ideal circumstances, I would manage patients with PNES on some regular interval. (Page 279)	“Managing the patient in neurology” theme (Page 279)	Acknowledging failures and gaps within the service.	McMillan, Hamid, and Pugh (2014)
He took the approach of ‘‘starting where the client is at.’’ He believed the goal of therapy was, ‘‘... more than knowledge, it’s a sense of self awareness.” (Page 688)	“Breaking this silence entailed reappraisal of John’s masculinity. The development of interpersonal skills became possible in this relationship with an accepting male”. (Page 688)	Acknowledging current difficulties.	Quinn, Schofield, and Middleton (2012)

"it's never nice, ummm… but it's quite useful because then you can talk about it afterwards and you've got kind of a nice example right in front of you so you can kind of formulate it afterwards if they are able to sit with you and talk a bit about it." (Page 4)	"One of these therapists indicated that seizure occurrence could be useful in developing seizure control techniques" (Page 4)	Sitting with difficult things within the session and talking about them / working with them.	Wilkinson, Day, Purnell, Pileka, Perdue, Murray, and Monika (2019)
"…they understood what the remit of the treatment was and how many sessions it was going to be… we had discussed what the treatment covered, but also what it hasn't been able to cover" (Page 6)	"Overall, participants agreed that the structure gave clarity to the scope and capacity of the intervention" (Page 6)	Having clarity about the therapeutic input and acknowledging failings or difficulties.	Wilkinson, Day, Purnell, Pileka, Perdue, Murray, and Monika (2019)

1.8.3 Appendix 1-C: Table of full search strategy

		Healthcare professionals	Functional seizures	Qualitative
PSYCHINFO	Free text	Counsel* OR therap* OR psychother* OR "general practitioner*" OR GP* Or Nurse* OR physiother* OR psychol* OR Psychiatrist OR Neurologist OR Doctor OR practitioner	FND OR FMD OR NES OR PNES OR NEAD OR non-epileptic OR “non epileptic” OR non-epileptic OR ((functional OR psychogen* OR Pseudo*) N3 (neurological* OR disord* OR convulsion OR seizure OR attack)) OR “conversion disorder” OR “dissociative seizure”	interview* OR discussion* OR questionnaire* OR qualitativ* OR views OR experience* OR engag* OR perspective* OR qualitative OR phenomenological OR "lived experience" OR "grounded theory" OR "life experiences" OR "focus groups" OR thematic OR Narrative
	Subject	DE "Health Personnel" OR DE "Allied Health Personnel" OR DE "Caregivers" OR DE "Medical Personnel" OR DE "Mental Health Personnel"	(DE "Conversion Disorder" OR DE "Functional Paralysis" OR DE "Functional Visual Symptoms" OR DE "Pseudocyesis" OR DE "Pseudodementia")	DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis"

CINAHL	Free text	Counsel* OR therap* OR psychother* OR "general practitioner*" OR GP* Or Nurse* OR physiother* OR psychol* OR Psychiatrist OR Neurologist OR Doctor OR practitioner	FND OR FMD OR NES OR PNES OR NEAD OR non-epileptic OR “non epileptic” OR non-epileptic OR ((functional OR psychogen* OR Pseudo*) N3 (neurological* OR disord* OR convulsion OR seizure OR attack)) OR “conversion disorder” OR “dissociative seizure	interview* OR discussion* OR questionnaire* OR qualitativ* OR views OR experience* OR engag* OR perspective* OR qualitative OR phenomenological OR "lived experience" OR "grounded theory" OR "life experiences" OR "focus groups" OR thematic OR Narrative
	Subject	(MH "Allied Health Personnel+")	(MH "Psychogenic Nonepileptic Seizures")	(MH "Qualitative Studies+")
MEDLINE	Free text	Counsel* OR therap* OR psychother* OR "general practitioner*" OR GP* Or Nurse* OR physiother* OR psychol* OR Psychiatrist OR Neurologist OR Doctor OR practitioner	FND OR FMD OR NES OR PNES OR NEAD OR non-epileptic OR “non epileptic” OR non-epileptic OR ((functional OR psychogen* OR Pseudo*) N3 (neurological* OR disord* OR convulsion OR seizure OR attack)) OR “conversion disorder” OR “dissociative seizure”	interview* OR discussion* OR questionnaire* OR qualitativ* OR views OR experience* OR engag* OR perspective* OR qualitative OR phenomenological OR "lived experience" OR "grounded theory" OR "life experiences" OR "focus groups" OR thematic OR Narrative
	Subject	(MH "Allied Health Personnel") OR (MH "Health Personnel") OR (MH "Physicians") OR (MH "Medical Staff") OR (MH "Health Facility Administrators")	(MH "Psychogenic Nonepileptic Seizures")	DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured

				Interview" OR DE "Thematic Analysis"
Scopus	Free text	Counsel* OR therap* OR psychother* OR "general practitioner*" OR GP* Or Nurse* OR physiother* OR psychol* OR Psychiatrist OR Neurologist OR Doctor OR practitioner	fnd OR fmd OR nes OR pnes OR nead OR "non epileptic" OR {functional seizure} OR "psychogenic seizure" OR {Psychogenic nonepileptic seizure} OR "pseudo seizure" OR {conversion disorder}OR {dissociative seizure} OR {nonepileptic attack}	interview* OR discussion* OR questionnaire* OR qualitativ* OR views OR experience* OR engag* OR perspective* OR qualitative OR phenomenological OR "lived experience" OR "grounded theory" OR "life experiences" OR "focus groups" OR thematic OR Narrative
AHMED	Fee text	Counsel* OR therap* OR psychother* OR "general practitioner*" OR GP* Or Nurse* OR physiother* OR psychol* OR Psychiatrist OR Neurologist OR Doctor OR practitioner	FND OR FMD OR NES OR PNES OR NEAD OR non-epileptic OR “non epileptic” OR non-epileptic OR ((functional OR psychogen* OR Pseudo*) N3 (neurological* OR disord* OR convulsion OR seizure OR attack)) OR “conversion disorder” OR “dissociative seizure”	interview* OR discussion* OR questionnaire* OR qualitativ* OR views OR experience* OR engag* OR perspective* OR qualitative OR phenomenological OR "lived experience" OR "grounded theory" OR "life experiences" OR "focus groups" OR thematic OR Narrative

Chapter 2: Empirical Paper

The Experiences of 'living well' with Functional Neurological Disorder: A Qualitative Account.

Jessica Hughes

Doctorate in Clinical Psychology

Lancaster University

Formatted for submission to Epilepsy and Behaviour Journal

(For Author guidelines see Appendix 2-C)

Word count (including abstract but excluding references, appendices, figures and tables):

7,959/8,000 words

Correspondence should be addressed to:

Jessica Hughes

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Health Innovation One

Sir John Fisher Drive,

Lancaster University

Lancaster, LA1 4AT

Email: J.hughes17@lancaster.ac.uk

2.1 Abstract

Background: Functional neurological disorders (FNDs) are defined as a presentation of neurological symptoms that cannot be explained through known disease pathologies. Those with the condition often experience a poor prognosis and experience persistent and disabling symptoms, with poor access to health services. Despite these challenges, some individuals learn to ‘live well’ with the condition. This research aimed to explore the experiences of individuals with FND who identify as ‘living well’ with the condition, focusing on what has been helpful for them and how they have navigated difficult circumstances and experiences.

Method: Eleven participants diagnosed with FND participated in individual semi-structured interviews over Microsoft teams. These interviews were analysed using reflexive thematic analysis.

Results: A thematic analysis produced four themes (1) Knowing and prioritising your values, (2) Navigating personal and therapeutic relationships, (3) Developing personal coping strategies, (4) Taking control of the narrative.

Conclusions: These results highlighted that it was important for participants to be able to personalise strategies and interventions that fit with their social, emotional, and financial situations. It would benefit healthcare professionals working with this population to develop a shared and collaborative understanding of the condition with their client and consider interventions that would fit for them.

Keywords: Functional neurological disorder, values, living well.

2.2 Introduction

Functional Neurological Disorder (FND) is a condition that affects the functioning of the nervous system. How the condition presents can be heterogeneous. Symptoms can appear in isolation, or as a combination of symptoms. The mechanisms underlining FND, cannot be explained through current understanding of known disease pathologies. Current understandings of FND theorises an interlink of biological, social, and psychological vulnerabilities which disrupt the way the brain and body communicate [1, 2]. In recent years there have been considerable modifications in the classification and treatment recommendations for FND [3, 4], mainly, concerning diagnosis; whilst a history of adverse life events are present for many, they are not present for all [5], and experiences of trauma or abuse are now not necessary for a diagnosis of FND [6].

Research suggests that those with the condition often experience persistent and disabling symptoms, with 39% experiencing an increase or worsening in their symptoms over time [7]. Those with the condition are likely to experience periods of disability, and as a result, periods of health related unemployment [8], more so than other neurological conditions [9].

Further difficulties associated with the condition include how individuals are supported and treated within the healthcare system. Some literature suggests that healthcare professionals may hold negative attitudes towards individuals with the condition, which may be explained partly due to limited knowledge on the condition and how best to provide support and intervention [10]. A recent review highlighted that healthcare professionals perceived FND to be an illegitimate condition [11]. Clinical guidelines have been developed for health professionals such as Neurologists [12, 13], Occupational therapists [14] and Physiotherapists [15]. However, despite the condition being a common presentation in services [16] there is still yet to be a clear pathway developed within the United Kingdom. The lack of clarity means that those experiencing symptoms of FND can be passed between services [17] and are frequently seen by emergency departments.

Studies exploring the experiences of those living with the condition report that the condition negatively impacts their quality of life, affecting their mental health and social functioning [18]. Individuals with FND often report stigmatising interactions with healthcare professionals where their symptoms are misunderstood or not believed [19]. As a result, individuals with FND symptoms at times report feeling abandoned by healthcare professionals [20]. Many people disengage from services and find ways to navigate their condition outside statutory provision [20-22].

Research has sought to understand how individuals navigate other complex long-term health conditions, which may share some neurobiological commonalities with FND [23]. Qualitative research exploring individuals' experiences of 'living well' with such conditions gives a unique insight into individuals' ability to navigate challenging circumstances and highlights the ways in which healthcare services can change and adapt in order to support individuals to 'live well' with FND. For example, studies examining the effects of a particular psychological intervention, suggested that one contributing factor in enabling individuals with the condition learn to 'live well', was to accept how the condition presented, and how they could live with the symptoms [24, 25].

Similarly, psychological interventions targeted for chronic health conditions often aim to support acceptance of the condition in relation to the individual's identity. A study using Acceptance and Commitment Therapy (ACT) for individuals with FND benefitted individuals due to a lack of focus on the mental health, or attention to symptoms, but rather that the model allowed individuals to understand how to 'live well' within their context [26].

It is important to explore individuals' perspectives of 'living well' with a diagnosis of FND, as understanding of individuals' needs and experiences will inform research and clinical practice. Previous qualitative studies have studied the experiences of those living with specific symptoms, such as functional seizures [27] and functional movement disorders [18, 20, 28]. However, these studies focus on one symptom of FND. There has been little research on the experiences of a heterogeneous sample of FND and the experiences of navigating multiple symptoms. Furthermore, these aforementioned studies have highlighted the challenge individuals face when living with the condition. However, there has been no research to the authors knowledge, that invites those who identify as 'living well' with the condition to share their experiences.

Consequently, this paper aims to understand the experiences of individuals with multiple and persistent symptoms. It aims to understand the experience of 'living well' with functional neurological disorder, and to understand experiences of navigating the condition.

2.3 Method

2.3.1 Design

The study aimed to understand the experiences of individuals 'living well' with FND. In using the term "living well", the authors conceptualised people living as best they could with the condition, perhaps reaching some sort of equilibrium where the condition was still present, but life was able to continue in some way, without a very high level of distress. However, each potential participant decided for themselves whether they felt they were "living well", and thus self-defined whether they met this inclusion criterion for the study. A qualitative study design was chosen to allow for an in-depth understanding of participants' experiences. A semi-structured interview design was used, and data was analysed using Braun & Clarke's [29] recent revised approach of Reflexive Thematic Analysis (RTA).

The researcher aimed to recruit between 10–18 participants for the study. The number of participants was not fixed prior to interviews. Instead, the researcher decision to stop recruitment was informed by the richness of the data, or conceptual depth [30, 31]. Although the notion of data saturation is debated within the research [32], recruitment was terminated when the researcher had sufficient data.

Semi structured interviews were used within the research interview. The researcher developed a topic guide, influenced by previous research aimed to understand how individuals manage with difficult and chronic conditions [33]. The interview questions were also guided by Solution Focused (SFT) approaches to therapy, which enable participants to take the position of expert, and enables participants to consider ways they have used their own skills, or strategies to overcome difficulties [34]. Solution focused questions were used to gain more knowledge of how FND has affected their life, and how they have navigated their condition. Other questions within the topic guide, were aimed at understanding how the condition presented for the participants and their experience thus far, and also to understand how they would define ‘living well’ in their context.

It was important that the questions within the interview were designed to be appropriate and considerate to the participants recruited, exploring their experiences of ‘living well’ with the condition, whilst not minimising the difficulties associated with the condition. Therefore, the interview design, and poster, and interview questions, were discussed with an expert by experience who held a diagnosis of FND, to check their suitability (See section 4 for participant information, consent and debrief sheets).

2.3.2 Ethical Approval

This research study was formally approved by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). REF: FHMREC21041.

2.3.3 Participants and recruitment

Participants were eligible to take part in the study if they were over the age of 18 years and had a diagnosis of FND. Participants were required to live in the United Kingdom, to enable participants to comment on similar healthcare provisions. Participants were required to have more than one symptom of FND and not self-identify their leading symptom being functional seizures, though people who experienced seizures alongside other FND symptoms were included. This was because a large proportion of the literature already focused on living with functional seizures [1, 35-37] and this research focused on the experiences of having broader set of FND symptoms.

Participants were recruited through FND Hope, a national charity for the condition. An advertisement for the study was shared on their social media channels and advertised on the researcher's professional Twitter page. Interested participants were asked to email the researcher to request more information on the study. Due to the large amount of interest, recruitment was paused after 5 days. All participants were sent an acknowledgment of interest email. The researcher contacted five interested participants at a time, allowing one week for them to respond, before contacting the next batch of participants, until sufficient participants had been recruited. Participants who registered their interest but could not be recruited in the study were informed by email.

Interested participants contacted the researcher via the university email provided, and an initial meeting was arranged on Microsoft Teams (video calling software). This meeting lasted between 10-15 minutes, and enabled participants to hear about the research study, and what the interview would involve. This also provided participants an opportunity to use the Microsoft Teams program and troubleshoot any problems. The research interview was arranged during this meeting, if participants wanted to proceed, or in a follow up email.

Verbal consent was obtained at the start of the interview by reading aloud the consent form to participants, and offeried opportunities to ask questions before the interview began.

Interviews were recorded, and Microsoft Teams developed an automatic transcript of the interview, which was anonymised and saved. Due to the varying nature of the condition, participants who experienced symptoms that affected their verbal communication, were given the option to type their responses into the Microsoft Teams chat if they preferred. No participants chose this option.

A total of 11 interviews were conducted for this study lasting between, 37 and 67 minutes (Mean = 57 minutes). Participants age ranged from 22-47 years of age (Mean = 33.6 years of age). Participant identified as Male = 1, non-Binary = 1. Female = 9. Pseudonyms were given to all participants. Participant characteristics are outlined in Table-1.

[Insert Table-1 here]

2.3.4 Data Analysis

The transcripts were analysed using reflexive thematic analysis [38]. This model of thematic analysis highlights the role of the researcher and encourages the researcher to be reflexive throughout the research process, to highlight their biases and influences, and how this could impact the data collection and analysis.

At the beginning stage of analysis, the researcher familiarised themselves with the data by first going through each automated transcript and reading the text, removing any time stamps or obvious inaccuracies. The researcher then re-watched the recorded interviews, working through the transcript line by line. Following this, first impressions were noted in a document. Codes were written in the right-hand margins of the text, see appendix 2-A, and then all codes were extracted into one document. Each code was colour coded to participant, printed out and then hand sorted into separate categories for the initial coding stage.

Emerging themes were then condensed, until five themes were developed, see appendix 2-A. Through discussions with supervisors, five themes were narrowed into four themes. After further consideration, the fifth theme, “Maintaining a positive outlook”, was separated into the remaining themes due to overlap e.g. participants described using personalised coping strategies to attend to positive things within their day or navigating relationships to maintain a positive outlook. Data transcripts were then revisited to check the code assigned to the text and if it fit within the theme developed.

2.3.5 Reflexivity

To maintain validity and reliability within qualitative research, methods of reflexivity are encouraged to enable researchers to understand how their preconceived views and beliefs, may shape the data analysis and write up. In the development of this research paper, the researcher kept a written, and voice recorded reflective diary over the two years, from developing the research question, to completion of the write up.

Braun & Clake [38] state that reflexivity not only involves noting how the data feels, but also developing an awareness of how personal positionings (class, culture, sex, race, ability) overlap with the research topic and data. The researcher identified as a white, working-class cis female with no lived experience of a chronic health condition. The choice to commence this research project, was influenced by the researchers professional and personal experiences with FND, Chronic Fatigue, and Medically Unexplained Symptoms. Thus, these prior experiences have been an inspiration for the topic of the thesis. With the aim to make meaningful contribution to the research literature, by empowering others to share their stories, in hope of informing and educating future professionals.

Furthermore, the researcher considered the principles of good quality research that were outlined in Yardley’s paper [39]. The paper proposes that there are four essential qualities that contribute to good research including (1) sensitivity, (2) commitment to rigour, (3) transparency and coherence and (4) impact and importance. The researcher considered sensitivity by working with an expert by experience to the development of the research materials and working with a field supervisor who worked clinically with the population to consider the research materials and to check the themes. Commitment and rigour were considered to improve the reliability of qualitative research, for example, an electronic paper trail for each theme was developed on OneNote and shared with the research supervisor. The author considered transparency and coherence, by outlining examples of theme development within the paper, see table-2. Finally, the researcher considered the impact and importance of the paper within the clinical implications and will discuss methods of dissemination with the expert by experience, and national charity for the condition, FND Hope.

[Insert Table-2 here]

2.4 Results

Four themes were generated from the RTA: (1) Knowing and prioritising your values; (2) Having control of the narrative; (3) Navigating personal and therapeutic relationships and (4) Developing personal coping strategies.

2.4.1 Theme one: Knowing and prioritising your values.

Within this theme, participants shared their experiences of navigating their condition, and what it meant for their sense of identity, and what was important to them. Participants considered a shift in how they viewed themselves in society, as their focus shifted to the values that enabled them to ‘live well’ within their context, rather than the expectations society held for them.

Participants reflected on the societal and cultural expectations that had previously narrated their sense of identity. In particular, participants reflected on the way others would perpetuate the idea that they should always be doing something or striving towards something better. These narratives were held mainly by the females within the study who highlighted the pressures they were under, that were often reinforced by social media influences.

> *"Social media is the worst for it, but you've got to be amazing at everything and got to be perfect, your kids have got to be perfect, house has got to be perfect, your jobs got to be amazing you've got to be earning loads of money and I just think sometimes the amount of pressure that people put themselves under" (Grace).*

Participants implied that working towards what others might expect of them, resulted in participants sacrificing the things that were important to them, and affected their wellbeing. One participant reflected the problematic standard that she held her self to, in line with her gender.

> *"Being brought up in a home and a school where I was told as a was a woman [...] I could do anything and everything, and it's like, actually, you know what? Maybe I can, but maybe I shouldn't" (Iris).*

To 'live well' with the condition, participants instead needed to understand what was important to them, and connect with their own values, rather than the implicit standards that society held. It was believed by participants that in order to 'live well' with the condition, they first needed to prioritise their own needs, and participants described an intentional shift towards prioritising their well-being in a way they had not, prior to their diagnosis.

> "*[Your wellbeing is] the most important thing you can spend your time and energy and money on [...] if you don't have your health [you have nothing]" (Iris)*

Participants stated that they would often feel emotions such as guilt and shame, when they were unable to meet the expectations that they held for themselves. To navigate this, individuals shared their experiences of working towards a new way of looking at things.

> *“Whether you've got mental health issues or not, I think you need to have a mindset to deal with [FND] properly… so it won't overwhelm you or ruin your life” (Iris).*

To cultivate a mindset to ‘live well’ with the condition, all participants noted that this involved a process of change.

> “I*t just makes you re-evaluate things a lot and kind of just think do you really need to do that today. Do you need to be putting that pressure on yourself today? […] [can I] cut it down? […] Is it manageable? Yes, it is, so why you're not doing that anyway?” (Hannah).*

Connecting with their values and what was important to them for their own wellbeing allowed participants to engage in activities that they wanted to spend their time on. To ‘live well’ with the condition, participants described how they often challenge themselves to do things, even in times when they felt worried about their own safety as a result of the unpredictability of symptoms or were worried about others’ perceptions of them. Rather, participants sought experiences that were in line with their values, and what was important to them, whilst being open to the possibility that to engage with the things they enjoy, they also had to tolerate and accept that their symptoms may be present.

To navigate this, participants would plan for the symptoms to be present, and the adjustments that they would need to make to complete an activity. Participants spoke about adjustments they might make to complete activities such as swimming, yoga or hiking, and how they may connect with these activities in a way that enabled them to complete them e.g., with the support of a waking aid, or by joining groups remotely rather than in person.

One participant shared her experience of using adaptations that allowed her to attend live music with her friends.

> *"What if I can't stand all of that time? […] one option is I will come completely out of the arena and sit outside on the floor for a bit […], but we don't have to miss the whole thing" (Danielle).*

Participants noted that they often still felt worried when completing a new task, but preparation and support from others made it more tolerable.

Furthermore, issues of identity were common in the research interviews, particularly participants talked about their role as a parent, and what it meant to be a good parent. How this was defined was different for each participant, but included making home cooked meals, ensuring their children always had clean clothes, or ensuring they had the energy to be fun with their children.

One participant in particular reflected on the things they wanted to achieve as a father and how holding this in mind helped him 'live well' with the condition.

> "We'll take the girls for example, knowing that one day they gotta grow up, they're gonna get married. They're gonna want either a first dance or walking down the aisle" (Ben).

Overall, understanding what was important for the participant guided how they spent their time and energy, and helped participants to develop their own rules for living.

2.4.2 Theme Two: Having control of the narrative.

Within this theme, participants described how important it was for them to have a personalised understanding of the condition, which helped them understand why this had happened, and how they could manage it. Participants talked about how they navigated disclosure of the condition. When they discussed their condition, and others agreed with this explanation, it helped participants feel heard, validated and more in control of their FND.

For some participants, having a personalised understanding of their FND helped participants feel more in control of the condition and impacted how they navigated coping day to day. Participants hoped to understand why they developed FND symptoms and when these might change or fluctuate. One participant described how their symptoms fluctuated with their menstrual cycle whilst other examples included linking symptom presentation to fatigue, anxiety or physical injury.

Some participants sought a more specific diagnostic label that articulated what they experienced in more detail, rather than under the broader umbrella diagnostic label or FND. Having a more defined diagnosis helped them communicate the condition more efficiently rather than explaining how it was presented each time.

> *"So now they have, as you know, all the different subtypes. Then they've given, you know, sort of specific names. So, I can actually say to people I have [...] functional neurological disorder paralysis type" (Iris)*

For some participants, it was more meaningful describe their symptoms and experiences by using different ways of communicating, such as using art, images, poetry, or music. Metaphors were commonly used to describe how the condition feels to live with rather than the neurological mechanisms behind the condition. Participants also shared how art had enabled them to understand how they feel about the condition.

> *"There's a Florence and the Machine song, I think it might be called Free. I can't quite remember, but she uses Bill Nighy in the video, and he's, her brain. So that's what I kind of separate my brain. So, when I can't do something, I imagine my brain to be Bill Nye [...] he's pulling her back. So that's I think, for me, that visualisation really works as well." (Caitlin)*

Controlling the narrative also involved navigating disclosing the condition to others. For most participants, controlling what information was shared about them in their communities, workplaces, and families was helpful. Disclosure was affected by fears of stigmatized understandings of the condition, and the fear that others would negatively judge them due to their misunderstanding of the condition.

> *"They don't need to know the finite details of what happened and what medication I'm on. They just need to know that I went through an experience… a health event… and I'm still recovering, and I'm okay. (Fiza)*

Participants were conscious of the narratives widely associated with the condition and the stigma. Without being able to signpost individuals to trustworthy information about the condition or be able to explain it in more detail, participants shared that they might avoid telling some people for fear of how it might change how those people would think of them and the narrative they might hold about them moving forward.

> *"I guess I don't really want all the parents to know I've got a neurological condition 'cause I… it's difficult to explain it because then they might start to panic and think 'ohh is she… she ok in front of the kids, or you know, is she capable'?" (Danielle)*

Likewise, if professionals held rigidly onto an understanding of FND that participants did not align with, this led to ruptures in the relationship and affected how much they believed and valued their intervention in future appointments.

> *"So, I Googled it, and I was like, what the hell, you like cause all these things? Like conversion disorder? and it's… it's made up? And hysteria? and all that came up, and I was like I want to chase this man down and give him a good bloody, thumping cause that's not what like who I am, and it's not made-up." (Jade)*

Some participants sought opportunities to provide feedback to the services and actively contributed to changing the narrative of the condition by educating services or by educating others on social media.

> *"The next day I, I was very angry. And as angry about the care that I'd received or the lack of care that I'd received, should we say? So, I did. I put it, I put it on Twitter. I detailed exactly what happened, and I put all on Twitter and I tagged the local MP and the hospital and the director." (Ben)*

2.4.3 Theme Three: Navigating personal and therapeutic relationships.

This theme describes how participants navigated relationships with others. In this theme participants consider how their relationships have changed, and how they made and sustained relationships with friends, family, and professionals.

All participants spoke of how others had supported them in their journey to 'living well' with the condition. It was important for participants to identify as part of a community and have relationships with friends, family, and professionals.

> *"Having a community that's another important thing is having like… often with disabled people we get isolated from our communities and finding a way to get back into a community was really important, whatever that community may be for you, ukulele playing or whatever, anything just to have some kind of human contact" (Iris).*

A participant's sense of community could be developed from their family, social groups or by strong relationships with professionals. The commonality between participants was that the relationships added value to the participants lives, and provided a relationship that felt safe, and validating.

In personal relationships and friendships, participants often referred to times in which others had enabled them to complete an activity by adjusting it or their communication in a way that held their needs in mind. One participant noted the ways in which her friends could adapt to what she needed in the moment, to provide care and safety, but then later offer humour and camaraderie, which enabled the participant to sustain different parts of her relationships.

> *"They knew at that time that's what I needed like later on, rip the shit out of me. Absolutely fine. But at that time, when I was vulnerable and wobbly, they […] helped me, got me back up to the van and then bought my chips" (Caitlin).*

Likewise, participants noted that in the initial stages of the condition, they accessed online support groups to gain information, feel less isolated, and have others normalise their experiences. Online groups provided a space in which individuals felt less alone with the condition and could compare their experiences to learn from one another.

> *"I think the online stuff that helped me was probably other people's experiences […] when you did hear from other people about kind of what was going on and what had helped them, it gave you ideas about what to try" (Hannah).*

It was equally crucial for participants to incorporate their personalities and values into the treatment they received. Whilst all participants valued when healthcare professionals were understanding and skilled, participants reported stronger therapeutic relationships with clinicians who tried to personalise sessions by what was meaningful for the participants. One participant shared why she valued her relationship with her physiotherapist, describing the clinician using her language and humour to motivate her within sessions.

> *"She also knows how I work. And I won't say this on the recording, but I said a very, very rude word. But she's like, what are you thinking right now? And, like, my brain is an absolute beep and she laughed […] then when I was talking on Friday, I was like,*

> *why can't I do it? She was like cause your brains are absolute beep and said it back to me and it kind of... it kind of took me out of my sad grump, made me laugh […] You're coming at me on my level. You're understanding the way I work, the way I disassociate my brain" (Caitlin)*

When participants felt like the clinician spent the time to know them and understand what would be significant and relevant, it improved the professional relationship and let them feel more in control of the treatment they received.

On the contrary, when the intervention felt generic and standardised, participants felt like the clinician didn't 'get them' and disengaged from the work and the relationship to find their way of navigating through the problem.

One participant spoke about a time when she received input from the speech and language therapist and didn't feel like the intervention was delivered in a way that met her needs.

> *"It would have benefited being done a different way […] So, I didn't develop that relationship with him, and I think I only saw them twice because, you know, I had in a way better support at home and from parents than what I did from them, which is sad" (Kathryn).*

For Kathryn, being able to step away from relationships that she didn't feel contributed to what she needed, enabled her to choose different ways to support herself, which allowed her to find a way to 'live well' with her condition.

Other participants reflected that their needs may also change throughout time, as their relationship with the condition changed. In particular, participants reflected that the use of social media for support could change. One participant spoke about stepping away from the online spaces and reconnecting with their own needs. She reflected that It was useful being part of an online community but at some point she had to distance herself from this so that she could find her own way to ‘live well’ with the condition.

> *“I did kind of distance myself from that after a while because it was becoming more unhelpful than helpful. And actually, I think I just did need to kind of focus on my own journey ‘cause it was different.” (Hannah)*

Participants spoke about friendships lost over time and feeling isolated from their friendship groups due to not being able to partake in as many social events as they would like, particularly if they required long travel or late nights. Some participants shared how they had implemented boundaries with some friends and family to reduce the effect it had on how they thought and felt.

> *“I do have that boundary of stopping conversations before they get uncomfortable, keeping people out of the house, [otherwise] I would be more depressed, I would be more negative” (Fiza).*

Most participants shared how, within their relationships, they had developed a way to focus on things that brought them joy, or helped them feel proud, accomplished, and loved. Some participants coped using humour and found it helpful for others to laugh with them when they experienced symptoms.

> *“I take everything with humour as well, so erm when we’ve had tremors […] my husband will go “that you dancing again?” I’m like, ‘yeah, you want to join in?’ […] it's just that kind of thing is just my makeup, so I think because I’m that kind of person, it's helped me get through all” (Emma)*

Ultimately, participants prioritised how they felt within interactions with others. It was important for participants to feel seen and heard and for professionals to understand how to meet their needs.

> “One thing I find with her that I don't find with the GPs is that she listens, and she's got time to be able to almost like listen to your, your moans and groans and you know” (Jade).

2.4.4 Theme Four: Developing personal coping strategies and managing your energy levels.

This theme outlines the unique ways that participants navigated their condition and used coping strategies that were personal to them. How participants lived with the condition was conditional on their lifestyle, family life, employment, values and how the condition presented for them.

In the early stages of their condition participants reflected that they valued options and choice when taking on new skills or interventions to try and live alongside the condition. In particular, participants recounted the benefit of being able to have the choice of support that most aligned with their understanding of the condition and their values. Often, professionals provided different descriptions of the condition and a variety of suggestions for how best to manage the condition. Whilst some participants outlined that this was frustrating and confusing, in retrospect this enabled individuals to pick and choose the information that felt the most relevant to them.

> *“You won't get all the information from one source, so the more people… you can see it almost like build up your picture using lots of different pieces” (Kathryn)*

Some participants were still searching for how best to manage their condition. For these individuals, it was helpful for participants to understand that FND would present differently in others. This knowledge enabled participants to find their own way of coping with the condition.

> *"No two FND people are the same… so no one can have the same sort of symptoms. Somebody else… might have similar symptoms, but the duration or the angle of these symptoms may be different between person to person" (Ben)*

Knowing that others had different ways of managing with the condition, offered an opportunity for individuals to find their own way of coping. Holding in mind that strategies had not worked for them, because they needed something different, not because they were ineffective.

Participants valued having their own way of dealing with symptoms and had individual techniques that they had learnt from others or had developed themselves.

> *"It was hard to know what to do. Listening to their advice helped and I think just finding things for myself" (Fiza)*

Participants first needed to feel safe in order to feel safe taking risks. Participants described how they could begin to take risks and spend time doing things they enjoyed when they felt safe to fail, in addition to feeling safe with their symptoms. For one participant, feeling safe with her symptoms enabled her to approach her symptoms in a different way.

> *"Quite often, because of the time of day, I just fall asleep during them because I'm not finding them as scary anymore. You know, initially, obviously like I didn't know what they were and but actually, I just sort of relaxed into them and accept that they were happening. And quite often I just fall asleep and then wake up the next morning, and I'm fine" (Hannah)*

Participants spoke about the importance of having a positive outlook daily, enabling them to 'live well' with the condition. To maintain this, participants used strategies to actively reframe their thoughts throughout the day. One participant shared an activity she completed to help focus her attention on the good things each day.

> *"We did this thing of three good things in a day so mental, social, physical, and I've got that on my kitchen wall." (Fiza)*

More so, to enable individuals to maintain a positive outlook that was beneficial to their mindset and wellbeing, some participants considered the effect that anger had on their ability to 'live well' with the condition. One participant talked about how she committed to stepping away from being angry, noticing the negative effect it would have on her well-being if she thought of how she or others had been treated due to the stigma she had experienced due to the conditions.

> *"It's very easy when you're disabled and ill to get caught in reruns […] of anger and frustration about how this person should have treated me […] [But I] don't get caught up in them because I stay more in the present moment and I'm not worrying about what the future holds and I'm not trapped in the past." (Iris)*

Instead, participants focused on practices that would enable them to be present in their life and approach tasks mindfully, which allowed them to reconnect with their bodies, in a way that worked for them. For example, participants spoke of taking a strategy offered by another person and adapting it for themselves.

> *"I meditate, and that doesn't necessarily look like sitting on a cushion; it can be listening to music while I walk the dog, or it can be, umm, even listening to a book […] it's an integral part of my day, but that doesn't mean I'm like a little Buddha sitting on a cushion because I don't ever do that really. But it's that mindfulness and meditation, all through my day" (Iris)*

For most participants, it was essential to consider how to navigate energy levels and how fatigue might impact them if they had too many things in one day. Participants focused on the positive aspects of their lives, that they maintained through regular use of coping strategies that enabled them to attend to the things that were important for them. Practical strategies were also used to maintain their energy expenditure across the week, and included planning for days when they might not be able to participate in activities, they need to do due to symptoms.

For participants who were still developing the ways in which they were living with the condition, knowledge of what was helpful or not helpful was developed as a result of learning from repeated negative experiences. One participant shared how she would reflect on her week if she was experiencing an increase in symptoms and then make changes or plan better for the week following.

> *"If it's very obviously too stressful, then I would take a step back, or I think perhaps I won't do this again, but other times I might try and manage the symptoms in the moment if it's a bit milder. (Anna)*

To 'live well' with the condition individuals needed to understand the strategies that enabled them to feel in control, and maintain a positive mindset, but also consider how they might actively reduce factors that they considered to negatively affect them.

2.5 Discussion

The present study aimed to explore the experiences of adults who self-identified as 'living well' with FND. A thematic analysis of the data produced four themes: (1) Knowing and prioritising your values; (2) Having control of the narrative; (3) Navigating personal and therapeutic relationships and (4) Developing personal coping strategies.

In the first theme, participants spoke of a transition from a way of living before FND, to now, stating that this transition involved a period of change and adaptation. This finding is supported by previous research that theorises that chronic illness brings a biographical disruption [40] that invites individuals to view themselves differently, due to illness and the changes this may have on their lives. This theme suggested that participants within the study focused on their own wellbeing more so than before their FND to enable them to 'live well' with the condition. This was achieved through developing a new way of living that prioritised their personal goals and was led by what was important for them within their context. The results suggest that individuals responded to this disruption in stages, first, accepting the diagnosis, before making a conscious choice to adjust, which then enabled them to 'live well' with the condition. More so, in the fourth theme 'developing personalised coping strategies', participants stated how they tailored intervention to their own context which enabled participants to cope with their condition. This finding is consistent with previous research in FND, that highlighted the benefit personalising interventions had on engagement, and the individuals' skill and autonomy [5].

In the theme, 'taking control of the narrative', participants described experiences of navigating the assumptions and stigma associated with the condition. Participants described ways that they would understand the condition, the benefit of others' understanding their experiences and their strive to contribute to a more accurate and consistent public understanding of the condition. There were mixed understandings of the predisposing factors for the condition, with some participants aligning with psychological explanations, others refuting them. Rawlings and Reuber [37] found psychological explanations of the condition were often rejected. Instead, the explanation of FND should be relevant and understandable to the individual for it to be accepted, and be further supported with a collaborative treatment plan [41, 42].

Furthermore, within this theme, most participants discussed their experience of strategic disclosure, which involved a cost-benefit analysis of whether to disclose their diagnosis to another. The use of strategic disclosure is documented in other long term conditions, suggesting that participants may opt for more widely understood and publicly accepted conditions, such as a stroke or brain injury, to communicate their symptoms easily [43]. Avoiding the stigma associated with the condition was another reason participants made strategic disclosures within the study, which is supported by previous literature exploring the experiences of those with functional movement disorders [20]. Research into the experiences of stigma and shame, in individuals with FND, suggest that the experiences of perceived stigma from others, can lead to isolation [44]. Multiple studies have highlighted the stigma associated with the condition, and many individuals have reported experiences of being mistrusted, or accused of feigning their symptoms, with many individuals with FND facing queries into the legitimacy of their symptoms across multiple domains in their life [18, 44]. Within the results of the study, participants disclosed their condition to trusted family and friends, or to understanding colleagues, with the intent of improving others understanding of their symptoms and enabling others to provide support if needed.

Finally, in the theme navigating personal and professional relationships, participants spoke about the impact of others on their ability to ‘live well’ with the condition. Participants highlighted experiences of positive interactions with healthcare professionals and recalled instances when they felt valued, heard, and respected. The experiences of individuals with FND suggest that they often report poor and stigmatizing interactions with healthcare professionals and are often dissatisfied with the support they receive [20, 27, 45]. Despite individuals reporting poor experiences with professionals, further research in functional seizures suggested that when individuals did find professional support that they valued, this positively impacted the individuals’ sense of resilience, and their ability to cope with the condition [46]. Most importantly, therapeutic relationships were strengthened when the intervention and approaches were tailored to the individual [47].

Across all the themes, participants shared their experiences of relinquishing control of FND, and instead learning to live with the condition and the symptoms. It was beneficial for individuals to be prepared for potential difficulties, but not to let these stop, or hinder their activities. Living with a condition, rather than trying to control it requires psychological flexibility [48] .Psychological flexibility is a core component of Acceptance and Commitment Therapy (ACT), a psychological intervention used widely within chronic health conditions [49, 50] with an emerging evidence base in FND [26, 51]. ACT is currently recommended in the UK guidelines from the National Institute for Health and Care Excellence (NICE) for chronic pain, [52]. The benefit of therapeutic approaches that engender values-based goals, such as ACT, is that this approach encourages individuals to work towards actions in line with their personal values, meaning that individuals develop goals based on reasons that align with what define them as a person. In this study participants were guided by values, such as being a good parent, which enabled them to work towards outcomes even when difficulties or challenges arose.

2.5.1 Clinical implications

It has previously been proposed that due to the condition's heterogeneity, multi-disciplinary intervention needs to be tailored uniquely to the individual with the condition [5, 53]. The results of this study propose that intervention and support are unique to each person and propose tailoring personal and professional ways of coping with the condition to the client's own circumstance, which can be understood through the biological, psychological and social needs of the person [54]. When offering ways for clients to support themselves, it is essential to welcome tailoring, or personalisation of strategies, to encourage ownership, control, and belief in the intervention. It would benefit healthcare professionals to enable clients to contribute to a collaborative formulation and a shared understanding of the condition and its perpetuating and predisposing factors, in line with a biopsychosocial understanding for FND [1]. The barriers to this recommendation are however well documented, such as long waiting lists for neurology, lack of specialist pathways and poor understanding and training provision for healthcare professionals [54].

The findings from the study suggest that therapies that engender a process of psychological flexibility would be helpful to enable individuals to work towards a valued way of living alongside the condition, in contrast to symptom reduction. Acceptance and Commitment Therapy (ACT) aims to engender the process of psychological flexibility and offers a practical framework for integrating multidisciplinary (MDT) approaches in line with the recommended treatment for FND.

2.5.2 Limitations

There are a number of limitations within the study. Firstly, all participants were recruited from a poster shared by a national charity, on their social media pages. Those who do not engage with charity or social media will likely not have had the opportunity to register their interest in the study. More so, the researcher received a large number of participant interest in the five days following the information poster being shared and closed recruitment after this point. After discussion with the research supervisor, maintaining a first come, first served approach to recruitment remained the most unbiased way of recruiting; however, it would mean that those recruited were likely individuals who were able to register their interest on a weekday, meaning those who work full time, or may not be accessing social media within that time, were less likely to be recruited to the study.

Furthermore, the researcher's profession as a trainee clinical psychologist may have influenced those who volunteered to participate in the research study and consented to be interviewed, as this may have attracted those who were more likely to consider a psychological understanding for their symptoms. Therefore, the interviews may not have captured the experiences of those who rejected a psychological understanding of their condition. More so, nearly all the participants identified as female, and thus the results may portray a female perspective on ‘living well’ with FND.

2.5.3 Further research

Whilst there may be ongoing research to suggest the best ways to cope with the condition of FND, the uptake of clinical support and motivation to engage in future sessions or treatment is determined by how the session feels and the therapeutic relationship. It was important for participants to feel valued, heard and respected in professional relationships and find their own sense of community through online support groups or within their social circle. This suggests that it would be beneficial to understand more the experiences of those with FND, in good and valued interactions with healthcare professionals.

A further consideration for future research is to explore the concept of “living well” further amongst individuals who live with the condition. “Living well” is determined in this paper as a social construct, that participants aligned with prior to registering interest in the study. Due to the individuality of what “living well” would mean to each participant, it would be beneficial to further explore this concept, due to the limited research that is currently published on this topic.

2.5.4 Conclusion

The results of this paper suggested that ‘living well’ with FND, was different for each individual based on their values, beliefs, and social environment. It was important for participants to be able to personalise strategies and interventions that fit with their social, emotional, and financial situations. Therapies that enable participants to engender psychological flexibility, and goals-based living would be beneficial.

2.6 References

1. Asadi-Pooya, A.A., et al., *Social aspects of life in patients with functional seizures: Closing the gap in the biopsychosocial formulation.* Epilepsy & Behavior, 2021. **117**: p. 107903.
2. Pick, S., et al., *Emotional processing in functional neurological disorder: a review, biopsychosocial model and research agenda.* Journal of Neurology, Neurosurgery & Psychiatry, 2019. **90**(6): p. 704-711.
3. Stone, J., et al., *Conversion disorder: current problems and potential solutions for DSM-5.* Journal of psychosomatic research, 2011. **71**(6): p. 369-376.
4. Stone, J., et al., *Functional disorders in the Neurology section of ICD-11: a landmark opportunity.* Neurology, 2014. **83**(24): p. 2299-2301.
5. Lidstone, S.C., et al., *Functional movement disorder gender, age and phenotype study: a systematic review and individual patient meta-analysis of 4905 cases.* Journal of Neurology, Neurosurgery & Psychiatry, 2022. **93**(6): p. 609-616.
6. Espay, A.J., et al., *Current concepts in diagnosis and treatment of functional neurological disorders.* JAMA neurology, 2018. **75**(9): p. 1132-1141.
7. Gelauff, J., et al., *The prognosis of functional (psychogenic) motor symptoms: a systematic review.* Journal of Neurology, Neurosurgery & Psychiatry, 2014. **85**(2): p. 220-226.
8. Carson, A., et al., *Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'.* Journal of Neurology, Neurosurgery & Psychiatry, 2011. **82**(7): p. 810-813.
9. Vroegop, S., M.G. Dijkgraaf, and M. Vermeulen, *Impact of symptoms in patients with functional neurological symptoms on activities of daily living and health related quality of life.* Journal of Neurology, Neurosurgery & Psychiatry, 2013. **84**(6): p. 707-708.
10. Barnett, C., et al., *The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder.* Disability and Rehabilitation, 2022. **44**(10): p. 1802-1811.

11. Begley, R., et al., *Clinicians' implicit and explicit attitudes about the legitimacy of functional neurological disorders correlate with referral decisions.* British Journal of Health Psychology, 2023.

12. Stone, J. and M. Edwards, *Trick or treat?: Showing patients with functional (psychogenic) motor symptoms their physical signs.* Neurology, 2012. **79**(3): p. 282-284.

13. Carson, A., et al., *Explaining functional disorders in the neurology clinic: a photo story.* Practical neurology, 2016. **16**(1): p. 56-61.

14. Nicholson, C., et al., *Occupational therapy consensus recommendations for functional neurological disorder.* Journal of Neurology, Neurosurgery & Psychiatry, 2020. **91**(10): p. 1037-1045.

15. Nielsen, G., et al., *Physiotherapy for functional motor disorders: a consensus recommendation.* Journal of Neurology, Neurosurgery & Psychiatry, 2015. **86**(10): p. 1113-1119.

16. Stone, J. and A. Carson, *Functional neurologic symptoms: assessment and management.* Neurologic clinics, 2011. **29**(1): p. 1-18.

17. McMillan, K.K., et al., *Providers' perspectives on treating psychogenic nonepileptic seizures: frustration and hope.* Epilepsy Behav, 2014. **37**: p. 276-81.

18. Dosanjh, M., et al., *What is it like to live with a functional movement disorder? An interpretative phenomenological analysis of illness experiences from symptom onset to post-diagnosis.* British Journal of Health Psychology, 2021. **26**(2): p. 325-342.

19. Rawlings, G.H. and M. Reuber, *Health care practitioners' perceptions of psychogenic nonepileptic seizures: a systematic review of qualitative and quantitative studies.* Epilepsia, 2018. **59**(6): p. 1109-1123.

20. Bazydlo, S. and F.J. Eccles, *Living with functional movement disorders: a tale of three battles. An interpretative phenomenological analysis.* Psychology & Health, 2022: p. 1-18.

21. O'Keeffe, S., et al., *A service evaluation of the experiences of patients with functional neurological disorders within the NHS.* Frontiers in Neurology, 2021: p. 888.

22. Stone, L., *Blame, shame and hopelessness: medically unexplained symptoms and the'heartsink'experience.* Australian Family Physician, 2014. **43**(4): p. 191-195.

23. Wilson, L., L. Whitehead, and B. Burrell, *Learning to live well with chronic fatigue: the personal perspective.* Journal of Advanced Nursing, 2011. **67**(10): p. 2161-2169.

24. Feliu-Soler, A., et al., *Current status of acceptance and commitment therapy for chronic pain: a narrative review.* Journal of pain research, 2018: p. 2145-2159.

25. Roche, L., et al., *An Acceptance and Commitment Therapy (ACT) intervention for Chronic Fatigue Syndrome (CFS): a case series approach.* Journal of Contextual Behavioral Science, 2017. **6**(2): p. 178-186.

26. Graham, C.D., D.J. O'Hara, and S. Kemp, *A case series of Acceptance and Commitment Therapy (ACT) for reducing symptom interference in functional neurological disorders.* Clinical psychology & psychotherapy, 2018. **25**(3): p. 489-496.

27. Rawlings, G.H., et al., *Written accounts of living with psychogenic nonepileptic seizures: a thematic analysis.* Seizure, 2017. **50**: p. 83-91.

28. Nielsen, G., et al., *A qualitative study of the experiences and perceptions of patients with functional motor disorder.* Disability and Rehabilitation, 2020. **42**(14): p. 2043-2048.

29. Braun, V. and V. Clarke, *Is thematic analysis used well in health psychology? A critical review of published research, with recommendations for quality practice and reporting.* Health Psychology Review, 2023: p. 1-24.

30. Nelson, J., *Using conceptual depth criteria: addressing the challenge of reaching saturation in qualitative research.* Qualitative research, 2017. **17**(5): p. 554-570.

31. Malterud, K., V.D. Siersma, and A.D. Guassora, *Sample size in qualitative interview studies: guided by information power.* Qualitative health research, 2016. **26**(13): p. 1753-1760.

32. Braun, V. and V. Clarke, *To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales.* Qualitative research in sport, exercise and health, 2021. **13**(2): p. 201-216.

33. Bhaloo, T., M. Juma, and C. Criscuolo-Higgins, *A solution-focused approach to understanding patient motivation in diabetes self-management: Gender differences and implications for primary care.* Chronic Illness, 2018. **14**(4): p. 243-255.

34. Bannink, F., *1001 solution-focused questions: Handbook for solution-focused interviewing*. 2010: WW Norton & Company.

35. Thompson, R., et al., *What is it like to receive a diagnosis of nonepileptic seizures?* Epilepsy & Behavior, 2009. **14**(3): p. 508-515.

36. Fairclough, G., et al., *Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures.* Epilepsy & Behavior, 2014. **31**: p. 295-303.

37. Rawlings, G.H. and M. Reuber, *What patients say about living with psychogenic nonepileptic seizures: a systematic synthesis of qualitative studies.* Seizure, 2016. **41**: p. 100-111.

38. Clarke, V. and V. Braun, *Thematic analysis: a practical guide.* Thematic Analysis, 2021: p. 1-100.

39. Yardley, L., *Dilemmas in qualitative health research.* Psychology and health, 2000. **15**(2): p. 215-228.

40. Bury, M., *Chronic illness as biographical disruption.* Sociology of health & illness, 1982. **4**(2): p. 167-182.

41. Stone, J. and I. Hoeritzauer, *How do I explain the diagnosis of functional movement disorder to a patient?* Movement Disorders Clinical Practice, 2019. **6**(5): p. 419-419.

42. Rommelfanger, K.S., et al., *Disentangling stigma from functional neurological disorders: conference report and roadmap for the future.* Frontiers in neurology, 2017. **8**: p. 106.

43. Corrigan, P.W., *The stigma effect: Unintended consequences of mental health campaigns*. 2018: Columbia University Press.

44. Foley, C., A. Kirkby, and F.J. Eccles, *A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder.* Disability and Rehabilitation, 2023: p. 1-12.

45. Canna, M. and R. Seligman, *Dealing with the unknown. Functional neurological disorder (FND) and the conversion of cultural meaning.* Social Science & Medicine, 2020. **246**: p. 112725.

46. Pretorius, C. and M. Sparrow, *Life after being diagnosed with psychogenic non-epileptic seizures (PNES): A South African perspective.* Seizure, 2015. **30**: p. 32-41.

47. O'Connor, P.J. and M. Reuber, *'It's both challenging and probably the most rewarding work' - A qualitative study of psychological therapy provider's experiences of working with people with dissociative seizures.* Epilepsy Behav, 2021. **122**: p. 108156.

48. Kashdan, T.B. and J. Rottenberg, *Psychological flexibility as a fundamental aspect of health.* Clinical psychology review, 2010. **30**(7): p. 865-878.

49. Hann, K.E. and L.M. McCracken, *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, 2014. **3**(4): p. 217-227.

50. A-tjak, J.G., et al., *A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems.* Psychotherapy and Psychosomatics, 2015. **84**(1): p. 30-36.

51. Cope, S.R., N. Poole, and N. Agrawal, *Treating functional non-epileptic attacks–Should we consider acceptance and commitment therapy?* Epilepsy & Behavior, 2017. **73**: p. 197-203.

52. guideline NG193, N., *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain.* Methods, 2021.

53. Gilmour, G.S., et al., *Management of functional neurological disorder.* Journal of Neurology, 2020. **267**: p. 2164-2172.

54. Reuber, M., *The etiology of psychogenic non-epileptic seizures: toward a biopsychosocial model.* Neurologic clinics, 2009. **27**(4): p. 909-924.

2.7 Tables

2.7.1 Table 1: Participants Characteristics

Participant Pseudonym	Gender	Age	Ethnicity	Symptoms of FND
Anna	Non-binary	22	White British	Dystonia, tics and fatigue
Ben	Male	31	White British	Left sided weakness and functional speech difficulties
Caitlin	Female	39	White British	Dystonia, pain, muscle weakness
Danielle	Female	41	White British	Leg weakness and abdominal pain
Emma	Female	43	White Scottish	Tremor, speech difficulties and dystonia
Fiza	Female	46	Pakistani	Speech difficulties, fatigue, tremor, and functional seizures
Grace	Female	34	White British	Functional stroke
Hannah	Female	24	White Scottish	Fatigue, weakness, and functional seizures
Iris	Female	47	White British	Body Paralysis and fatigue
Jade	Female	43	White British	Weakness, speech difficulties, bladder retention, fatigue and functional seizures
Kathryn	Female	34	White British	Speech difficulties, leg weakness, fatigue and pain

2.7.2 Table 2: Worked example of theme development.

Navigating personal and professional relationships	
Subthemes	Example quotes for the subtheme
How the session feels rather than the skill of the clinician	“She changed the way she's worked with me, and it's made a massive difference having that diagnosis and knowing what it is rather than kind of just working in a general way. It's helped loads with her, but it’s still like my walking’s got much worse” (Caitlin) “I was also seeing a psychologist so, but then again but one meeting was in the actual practice and she was late for it, to if it was anybody with hang high anxiety, that would have been could have been a contributing factor for them to like get more stressed” (Emma) “I think more than anything, they probably I felt like they understood where I was emotionally ok and obviously what a massive impact it had on me personally” (Georgina) “It can happen to anyone, you know, these things are are not pleasant and they're very real symptoms, but they're not gonna do any harm. So, I was quite happy with his explanation of it.” (Iris) “I really took them at their word for that. I did let them know as soon as things can weren't going so well and they're really receptive to that. And it was really a partnership the whole way through” (Iris) “At the time I appreciated it, you know that it kind of talked to me on my level, rather than trying to be incredibly medical, which is what I tended to find anyway and explain things to me to try and help me understand it… it doesn't really, it's just a lot to get your head around.” (Kathryn)
Feeling seen and heard	“Just gave me massive hug afterwards. And I said like… was that prescribed on the NHS? And she was like God, no. But you need one, don't you? I was like, yeah, a little bit” (Caitlin) “I think she too she knows she knows me well enough that we probably had about seven or eight appointments in the year, and she knows me well enough how to push me and how I work.” (Caitlin)

	"All of my friends have been really supportive. And yeah, they've been really supportive of just coming and entertaining the children and just coming in and just getting things done for me or just being there for me emotionally." (Fiza) "But I would say that those people, in particular, they stand out because of how understanding that they were, and they took the time to basically to try and help me understand and explain what was happening to me." (Georgina) "And he was like, well, that would make perfect sense because, you know, they are almost like a reset for you and that's why your body sort of doing that and ideally you probably wouldn't want to have them at all. But this seems to be the way that you're hoping." (Hannah) "The most important thing in any of the therapies, I had was learning that people didn't judge me. I was a I was able to be with medical professionals who didn't judge me who didn't think I was making it up. They treated me as if I was believed erm and therefore I could believe it and I could move from there." (Iris) "But my GP was brilliant and she kind of just went with what the consultant had sent over to her" (Kathryn)
Finding your community	"My wife and my bother in-law. They're my two primary carers say look after me. A lot of the time to them to really sort of understand the condition and understand what it means and what to say to the right, you know, to the people." (Ben) "She so she met me. She walked into the pub with me, so I didn't have to walk him on myself and. and then she went. She went to the bar to order the drinks like … they know, like, stuff like that. Like they would never go or go and get the drinks. So, I'll give him my card. But they know me well enough, after that, that's not gonna end well, like me coming up. Two glasses. Give me no wine. Laughed and then she ordered chips." (Caitlin) "So yeah, they're pretty good at it, sort of accommodating me without making it really obvious that they're doing it. You know, because I would hate people to change their plans all the time, but I've got a friend that just comes down from a movie night every week and you know, we just have a kind of quiet evening and that that seems to not have a big impact on the next day" (Hannah)

	“Having a community that's another important thing is having like… often with disabled people we get isolated from our communities and finding a way to get back into a community was really important, whatever that community maybe for you, ukulele playing or whatever anything just to have some kind of human contact.” (Iris) “I've kept in contact with who were very like-minded, and we've supported each other” (Jade) “I tend to more sort of focus on the there's like FND support groups on social media which I tend to go to more so because you can find comfort in other people who are suffering like you are.” (Kathryn)
Boundaries	“I don’t talk to my mum as much, I don’t talk to my mother-in-law much, not because I don’t want to but because they remind me of what I’ve lost.” (Fiza) “I did sort of distance myself from the peer support group because I found there was a lot of kind of negativity in that and a lot of people experience a lot worse symptoms than I was. So, when I was just trying to kind of get through my own life” (Hannah)
Believing in the intervention	“So, I think after my first appointment, I told my whole family. And this is what you need to do. This is what you don't need to do, and it let's just see what happens if it doesn't make a difference, then you know professionals have different advice and some might work. Some might not. But I did find that. Just normalizing it. If I'm having tremors, just don't. Don't look at it. Don't you know? Don't do things for me. Don't look all worried because it does pass.” (Anna) “So, we've done there walking normally, and she's filmed me and then she's filmed me walking with the bean bag on my head and I'm much better with the bean bag on my head because I'm concentrating on not letting it drop rather than walking. So, I think visibly seeing that really helped me see the difference.” (Caitlin) “I’ve had CBT with more recently with somebody in [removed], but she's not an FND specialist whereas at the [Removed]… the guy that I worked with, he understood the condition and it really made a difference.” (Danielle)

	“Because the occupational therapist would always say “oh concentrate on your breathing” but I had no idea how to… how to do that. Because for some of the sessions they were done on the phone anyway she couldn't see what I was doing so it” (Fiza) “Erm because they got prescribed different medication in relation to my Migraines believing and different medication tended to help and with some of my symptoms now, I don't know whether that was sort of placebo effect or not, but whether it is or not, I’m taking it cause yeah, it works.” (Georgina) “I probably took it more on board from him because he was so renowned in the fields, and he was so knowledgeable, and it was really an area of passion and interest for him.” (Hannah)

2.8 Appendix

2.8.1 Appendix 2-A: Initial coding

my walking's got much worse. I kind of struggle to do more than 100 metres about having to stop a hold on and have some sort of support, but I am still kind of getting out and about and doing stuff. I've learned to adapt. So I love swimming but now go swimming pools that are easy to get into or if I get in the sea, I had to have someone come with me to get in and out. But for a while I was a bit like I just avoided this task, whereas now I'm like, it doesn't really matter if I struggled to get in if I think yeah, it's learning to not worry about others people conceptions which take me long time to to kind of get my head round. So that's kind of where I am at the moment. So I'm currently on reduced hours. But going back up to full time at the end of the month to just to try to give me some time to rest and I'm not... I'm a single parent right, I work full time, rest if not my Forte and so when the physio signed me off I kind of asked for a physio regime as like in the afternoons. Give me something could be doing and she was like absolutely not and what you do fuck all, like it's like if you want to swim, swim. If you want to go for a walk, walk. But actually, if you need a 3 hour nap or you need to sit under a blanket and watch the telly or I want you to do that more than ever. So I've I've used that time to sleep a lot if I'm honest but

I've tried to adapt the way I do things or wasn't feel like I have to do exercise so my my right hand significantly worse they think because I spent so much time trying to do exercise. My brain then sent the message that create the neuropathways saying you don't work. So, my hands kind of shut down. so I've started doing pottery and some crafts so that I'm using it in a different way without my chimp going "ooh your hand isn't working" so yeah kind of taken that opportunity to... because I've had that extra time to kind of explore it which is working well at the moment? How that's gonna work in winter? My potter's wheel is in my shed. It's gonna light. Is not gonna be fun in in December, but I'm. Yeah, it's kind of adapt and kind of learn new ways of doing things without. Is that is, you're constantly trying to trick your own brain. It's a weirdest way to be and then I feel that it was showing up with him the other day and she said about I want to count back from 100, but in threes. And I said to her, I've heard, like, people counting backwards from 100 before, but never in threes. And she's a bit like, you're too intelligent... Your brain knows what you're doing. And if I ask you to count, it won't work. You need to really concentrate on something else. So kind of. Yeah, that was quite so. I'm trying to. Adapt that into my everyday existence like really, really. Do you know the song alphabet aerobics? So, I'm trying to learn the lyrics of that and I was like that as I walk, which is really, really random, but it's a really hard song to learn. I've only got up to G, but that's kind of. So what other than when I'm walking? What I think about anything else? I'm saying in alphabetic aerobics my head and sometimes that loud and Asda, but I'm like, well, people might give me a wide birth that would be fine. So yeah, it's kind of learning those adapt and that might be singing terrible rap songs was walking in the supermarket. Sorry I just went on a little bit of a rant then

Commented [HJ(R13]: Can't think of how to code this but a thinking point would something to do with the emotional/relational impact of the session seems to be valued higher than the physical gains

Commented [HJ(R14R13]: How the session feels is more important than what the session does

Commented [HJ(R15]: The learning process

Commented [HJ(R16R15]: Making changes to your life in light of the condition

Commented [HJ(R17]: Using adaptations

Commented [HJ(R18]: Avoidance is unhelpful

Commented [HJ(R19R18]: Psychological understanding of the condition

Commented [HJ(R20]: Having hope/striving for more/seeking change

Commented [HJ(R21R20]: Energy management / planning / hope for the future

Commented [HJ(R22]: Feeling seen / heard / valued by professionals / your relationship with your body

Commented [HJ(R23]: Understanding the brain

Commented [HJ(R24]: Having a strategy, and a plan that you believe in

Commented [HJ(R25]: Unsure how to code this at this stage - something about having a reason for why you're doing something. Tasks having a meaning or purpose behind them which fit with your understanding of the condition

Commented [HJ(R26R25]: Relationship with the body

Commented [HJ(R27R25]: Believing in the intervention

Commented [HJ(R28]: Positive regard from professionals/respect/being seen/

Commented [HJ(R29]: Learning new strategies

Commented [HJ(R30R29]: Believing in the intervention

Commented [HJ(R31]: Others views or assumptions

Commented [HJ(R32R31]: How life has changed

2.8.2 Appendix 2-B: Development of codes and themes

Image 1: Initial coding process

Image 2: Constructing emerging themes from coded data

Image 3: Constructing themes

2.8.3 Appendix 2-C: Author guidelines for Epilepsy and Behaviour

EPILEPSY & BEHAVIOR

AUTHOR INFORMATION PACK

GUIDE FOR AUTHORS

.

Submission checklist

You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:
- E-mail address
- Full postal address

All necessary files have been uploaded:
Manuscript:
- Include keywords
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any

figures in print *Graphical Abstracts / Highlights files*
(where applicable) *Supplemental files* (where
applicable)

Further considerations
- Manuscript has been 'spell checked' and 'grammar checked'
- All references mentioned in the Reference List are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)

- A competing interests statement is provided, even if the authors have no competing interests to declare

- Journal policies detailed in this guide have been reviewed
- Referee suggestions and contact details provided, based on journal requirements

For further information, visit our Support Center.

BEFORE YOU BEGIN

Ethics in publishing

Please see our information on Ethics in publishing.

Studies in humans and animals

If the work involves the use of human subjects, the author should ensure that the work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. The manuscript should be in line with the Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals and aim for the inclusion of representative human populations (sex, age and ethnicity) as per those recommendations. The terms sex and gender should be used correctly.

Authors should include a statement in the manuscript that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects must always be observed.

All animal experiments should comply with the ARRIVE guidelines and should be carried out in accordance with the U.K. Animals (Scientific Procedures) Act, 1986 and associated guidelines, EU Directive 2010/63/EU for animal experiments, or the National Research Council's Guide for the Care and Use of Laboratory Animals and the authors should clearly indicate in the manuscript that such guidelines have been followed. The sex of animals must be indicated, and where appropriate, the influence (or association) of sex on the results of the study.

Declaration of interest

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work. Examples of potential competing interests include employment, consultancies, stock ownership, honoraria, paid expert testimony, patent applications/registrations, and grants or other funding. Authors must disclose any interests in two places: 1. A summary declaration of interest statement in the title page file (if double anonymized) or the manuscript file (if single anonymized). If there are no interests to declare then please state this: 'Declarations of interest: none'. 2. Detailed disclosures as part of a separate Declaration of Interest form, which forms part of the journal's official records. It is important for potential interests to be declared in both places and that the information matches. More information.

Declaration of generative AI in scientific writing

The below guidance only refers to the writing process, and not to the use of AI tools to analyse and draw insights from data as part of the research process.

Where authors use generative artificial intelligence (AI) and AI-assisted technologies in the writing process, authors should only use these technologies to improve readability and language. Applying the technology should be done with human oversight and control, and authors should carefully review and edit the result, as AI can generate authoritative-sounding output that can be incorrect, incomplete or biased. AI and AI-assisted technologies should not be listed as an author or co-author, or be cited as an author. Authorship implies responsibilities and tasks that can only be attributed to and performed by humans, as outlined in Elsevier's AI policy for authors.

Authors should disclose in their manuscript the use of AI and AI-assisted technologies in the writing process by following the instructions below. A statement will appear in the published work. Please note that authors are ultimately responsible and accountable for the contents of the work.

Disclosure instructions

Authors must disclose the use of generative AI and AI-assisted technologies in the writing process by adding a statement at the end of their manuscript in the core manuscript file, before the References list. The statement should be placed in a new section entitled 'Declaration of Generative AI and AI-assisted technologies in the writing process'.

Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the publication.

This declaration does not apply to the use of basic tools for checking grammar, spelling, references etc. If there is nothing to disclose, there is no need to add a statement.

Submission declaration and verification

Submission of an article implies that the work described has not been published previously (except in the form of an abstract, a published lecture or academic thesis, see 'Multiple, redundant or concurrent publication' for more information), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, including electronically without the written consent of the copyright-holder. To verify compliance, your article may be checked by Crossref Similarity Check and other originality or duplicate checking software.

Preprints
Please note that preprints can be shared anywhere at any time, in line with Elsevier's sharing policy. Sharing your preprints e.g. on a preprint server will not count as prior publication (see 'Multiple, redundant or concurrent publication' for more information).

Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Content should make no assumptions about the beliefs or commitments of any reader; contain nothing which might imply that one individual is superior to another on the grounds of age, gender, race, ethnicity, culture, sexual orientation, disability or health condition; and use inclusive language throughout. Authors should ensure that writing is free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions. We advise to seek gender neutrality by using plural nouns ("clinicians, patients/clients") as default/wherever possible to avoid using "he, she," or "he/she." We recommend avoiding the use of descriptors that refer to personal attributes such as age, gender, race, ethnicity, culture, sexual orientation, disability or health condition unless they are relevant and valid. When coding terminology is used, we recommend to avoid offensive or exclusionary terms such as "master", "slave", "blacklist" and "whitelist". We suggest using alternatives that are more appropriate and (self-) explanatory such as "primary", "secondary", "blocklist" and "allowlist". These guidelines are meant as a point of reference to help identify appropriate language but are by no means exhaustive or definitive.

Reporting sex- and gender-based analyses

Reporting guidance

For research involving or pertaining to humans, animals or eukaryotic cells, investigators should integrate sex and gender-based analyses (SGBA) into their research design according to funder/ sponsor requirements and best practices within a field. Authors should address the sex and/or gender dimensions of their research in their article. In cases where they cannot, they should discuss this as a limitation to their research's generalizability. Importantly, authors should explicitly state what definitions of sex and/or gender they are applying to enhance the precision, rigor and reproducibility of their research and to avoid ambiguity or conflation of terms and the constructs to which they refer (see Definitions section below). Authors can refer to the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER guidelines checklist. These offer systematic approaches to the use and editorial review of sex and gender information in study design, data analysis, outcome reporting and research interpretation - however, please note there is no single, universally agreed-upon set of guidelines for defining sex and gender.

Definitions

Sex generally refers to a set of biological attributes that are associated with physical and physiological features (e.g., chromosomal genotype, hormonal levels, internal and external anatomy). A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth"), most often based solely on the visible external anatomy of a newborn. Gender generally refers to socially constructed roles, behaviors, and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society. Sex and gender are often incorrectly portrayed as binary (female/male or woman/man) and unchanging whereas these constructs actually exist along a spectrum and include additional sex categorizations and gender identities such as people who are intersex/have differences of sex development (DSD) or identify as non-binary. Moreover, the terms "sex" and "gender" can be ambiguous—thus it is important for authors to define the manner in which they are used. In addition to this definition guidance and the SAGER guidelines, the resources on this page offer further insight around sex and gender in research studies.

Changes to authorship

Authors are expected to consider carefully the list and order of authors **before** submitting their manuscript and provide the definitive list of authors at the time of the original submission. Any addition, deletion or rearrangement of author names in the authorship list should be made only **before** the manuscript has been accepted and only if approved by the journal Editor. To request such a change, the Editor must receive the following from the **corresponding author**: (a) the reason for the change in author list and (b) written confirmation (e-mail, letter) from all authors that they agree with the addition, removal or rearrangement. In the case of addition or removal of authors, this includes confirmation from the author being added or removed.

Only in exceptional circumstances will the Editor consider the addition, deletion or rearrangement of authors **after** the manuscript has been accepted. While the Editor considers the request, publication of the manuscript will be suspended. If the manuscript has already been published in an online issue, any requests approved by the Editor will result in a corrigendum.

Article transfer service

This journal uses the Elsevier Article Transfer Service to find the best home for your manuscript. This means that if an editor feels your manuscript is more suitable for an alternative journal, you might be asked to consider transferring the manuscript to such a journal. The recommendation might be provided by a Journal Editor, a dedicated Scientific Managing Editor, a tool assisted recommendation, or a combination. If you agree, your manuscript will be transferred, though you will have the opportunity to make changes to the manuscript before the submission is complete. Please note that your manuscript will be independently reviewed by the new journal. More information.

Copyright

Upon acceptance of an article, authors will be asked to complete a 'Journal Publishing Agreement' (see more information on this). An e-mail will be sent to the corresponding author confirming receipt of the manuscript together with a 'Journal Publishing Agreement' form or a link to the online version of this agreement.

Subscribers may reproduce tables of contents or prepare lists of articles including abstracts for internal circulation within their institutions. Permission of the Publisher is required for resale or distribution outside the institution and for all other derivative works, including compilations and translations. If excerpts from other copyrighted works are included, the author(s) must obtain written permission from the copyright owners and credit the source(s) in the article. Elsevier has preprinted forms for use by authors in these cases.

For gold open access articles: Upon acceptance of an article, authors will be asked to complete a 'License Agreement' (more information). Permitted third party reuse of gold open access articles is determined by the author's choice of user license.

Author rights

As an author you (or your employer or institution) have certain rights to reuse your work. More information.

Elsevier supports responsible sharing

Find out how you can share your research published in Elsevier journals.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement, it is recommended to state this.

Open access

Please visit our Open Access page for more information.

Elsevier Researcher Academy

Researcher Academy is a free e-learning platform designed to support early and mid-career researchers throughout their research journey. The "Learn" environment at Researcher Academy offers several interactive modules, webinars, downloadable guides and resources to guide you through the process of writing for research and going through peer review. Feel free to use these free resources to improve your submission and navigate the publication process with ease.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's Author Services.

Submission

Our online submission system guides you stepwise through the process of entering your article details and uploading your files. The system converts your article files to a single PDF file used in the peer-review process. Editable files (e.g., Word, LaTeX) are required to typeset your article for final publication. All correspondence, including notification of the Editor's decision and requests for revision, is sent by e-mail.

Submit your article

Please submit your article via https://www.editorialmanager.com/eb/default.aspx.

PREPARATION

Queries

For questions about the editorial process (including the status of manuscripts under review) or for technical support on submissions, please visit our Support Center.

Statistical analysis

The authors should carefully consider proper statistical analysis, and are encouraged to consult with a biostatistician when they are not certain which statistical methods are to be used. The following components should be explicitly addressed in the Methods and applied to the data analysis.

Power analysis, to justify sample size. Test for normality, as well as an explanation as to whether the data are continuous or categorical, to justify the choice between parametric and non-parametric tests. Multivariate ANOVA when multiple dependent variables are involved Mixed models analysis of longitudinal data (unless repeated measures ANOVA is well justified)

If statistical methods are found to be inappropriate, the manuscript will be rejected with a possibility to resubmit once the corrections are made.

Peer review

This journal operates a single anonymized review process. All contributions will be initially assessed by the editor for suitability for the journal. Papers deemed suitable are then typically sent to a minimum of one independent expert reviewer to assess the scientific quality of the paper. The Editor is responsible for the final decision regarding acceptance or rejection of articles. The Editor's decision is final. Editors are not involved in decisions about papers which they have written themselves or have been written by family members or colleagues or which relate to products or services in which the editor has an interest. Any such submission is subject to all of the journal's usual procedures, with peer review handled independently of the relevant editor and their research groups. More information on types of peer review.

Use of word processing software

It is important that the file be saved in the native format of the word processor used. The text should be in single-column format. Keep the layout of the text as simple as possible. Most formatting codes will be removed and replaced on processing the article. In particular, do not use the word processor's options to justify text or to hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. When preparing tables, if you are using a table grid, use only one grid for each individual table and not a grid for each row. If no grid is used, use tabs, not spaces, to align columns. The electronic text should be prepared in a way very similar to that of conventional manuscripts (see also the Guide to Publishing with Elsevier). Note that source files of figures, tables and text graphics will be required whether or not you embed your figures in the text. See also the section on Electronic artwork.

To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods
Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Results
Results should be clear and concise.

Discussion
The **Discussion** section should explore the significance of the results of the work, not repeat them. **Results** and **Discussion** should be separate and may be organized into subheadings. Avoid extensive citations and discussion of published literature.

Conclusions
The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Essential title page information

- ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

- ***Author names and affiliations.*** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

- ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**

- ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Please note that proprietary names for drugs should *not* be used in the article title.

Highlights

Highlights are optional yet highly encouraged for this journal, as they increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the examples here: example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Highlights are mandatory for Original Reports and Reviews only. They are optional but encouraged for all other article types.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using American spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Units
Follow internationally accepted rules and conventions: use the international system of units (SI). If other units are mentioned, please give their equivalent in SI.

Math formulae
Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

Footnotes
Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Artwork

Electronic artwork
General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.

- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.
- Ensure that color images are accessible to all, including those with impaired color vision.

A detailed guide on electronic artwork is available.
You are urged to visit this site; some excerpts from the detailed information are given here. *Formats*

If your electronic artwork is created in a Microsoft Office application (Word, PowerPoint, Excel) then please supply 'as is' in the native document format.

Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below): EPS (or PDF): Vector drawings, embed all used fonts.

TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.
TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of

500 dpi.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;

- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

Color artwork

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article**. Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

Color figures for exclusive use as **cover illustration** may be submitted by authors who are also submitting a manuscript for consideration. These figures should relate to the manuscript being submitted as well as the larger scope and focus of *Epilepsy & Behavior*.

Figure captions

Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

Data references

This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

Preprint references
Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

References in a special issue
Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software
Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley. Using citation plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes from different reference management software.

Reference style
Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.
Examples:
Reference to a journal publication:

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. J Sci Commun 2010;163:51–9. https://doi.org/10.1016/j.Sc.2010.00372.

Reference to a journal publication with an article number:
[2] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. Heliyon. 2018;19:e00205. https://doi.org/10.1016/j.heliyon.2018.e00205

Reference to a book:
[3] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.
Reference to a chapter in an edited book:

[4] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304. Reference to a website:

[5] Cancer Research UK. Cancer statistics reports for the UK, http://www.cancerresearchuk.org/ aboutcancer/statistics/cancerstatsreport/; 2003 [accessed 13 March 2003].

Reference to a dataset:
[dataset] [6] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015. https://doi.org/10.17632/ xwj98nb39r.1.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

Journal abbreviations source
Journal names should be abbreviated according to the List of Title Word Abbreviations.

Video

Elsevier accepts video material and animation sequences to support and enhance your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the file in one of our recommended file formats with a preferred maximum size of 150 MB per file, 1 GB in total. Video and animation files supplied will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect. Please supply 'stills' with your files: you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions please visit our video instruction pages. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

Data visualization

Include interactive data visualizations in your publication and let your readers interact and engage more closely with your research. Follow the instructions here to find out about available data visualization options and how to include them with your article.

Supplementary material

Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

Chapter 3: Critical Appraisal

Jessica Hughes

Doctorate in Clinical Psychology

Lancaster University

Formatted for submission to the Epilepsy & Behaviour

(For Author guidelines see Appendix 2-C)

Word count (including abstract but excluding references, appendices, figures and tables)

3,843/4,000 words

Correspondence should be addressed to:

Jessica Hughes

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Health Innovation One

Sir John Fisher Drive,

Lancaster University

Lancaster, LA1 4AT

Email: J.hughes17@lancaster.ac.uk

3.1 Introduction

The critical appraisal summarises the findings from the main empirical paper, and the systematic review, followed by a discussion of the strengths and limitations of each project. Following this, I will discuss my epistemological standpoint, and how this has influenced the thesis project and the subsequent analysis. Finally, I will discuss some personal reflections that I have noted throughout the development of the project before outlining some clinical implications.

3.2 Systematic Literature Review

This literature review aimed to understand professionals' views on building and sustaining therapeutic engagement, by systematically searching the literature to answer; what are the experiences of healthcare professionals engaging individuals with functional seizures in a therapeutic intervention.

Five major databases were searched including Psych Info, CINAHL, Medline, AMED, and Scopus. After screening 4,719 papers, 9 papers met the inclusion criteria. There were 154 participants in total across the nine studies in the synthesis from 14 different professionals' roles. The meta-ethnography generated the three following themes: (1) Acknowledgement; (2) Adaptation; (3) Consistency.

The review highlighted that it was necessary for professionals to understand and acknowledge the difficulties often associated with the condition e.g., Perceived stigma and lack of available and timely intervention. With this understanding, professionals were able to then acknowledge and make adaptations to support the individual's ability to engage in the service. Family involvement was noted to be supportive of therapeutic engagement, and the individual's ability to sustain new understandings of the condition. Consistency within services was stated to be beneficial, noting that when professionals were able to communicate a consistent rhetoric of the condition, it improved communication and eased anxiety.

3.3 Empirical Paper summary

The empirical paper explored the experiences of adults with functional neurological disorder (FND) who self-identified as ‘living well’ with the condition. Eleven participants were recruited from a national charity through their social media accounts and interviewed through semi structured interviews held on Microsoft Teams. The participants’ data was analysed using Braun & Clake Reflexive Thematic Analysis (RTA) (Clarke & Braun, 2021). The results were developed into four themes; (1) Knowing your values; (2) Taking control of the narrative; (3) Navigating relationships; and (4) Developing personal coping strategies.

The results of this paper suggested that ‘living well’ with FND, was different for each individual based on their values, beliefs and social environment. Individuals benefitted from taking control of how the condition was described to others and benefitted from having a personalised understanding of their symptoms, that others also aligned with. In addition, participants benefitted from supportive relationships with others. When working with professionals, individuals valued the therapeutic relationship, and trust in the relationship over the skill the healthcare professional offered and valued the ability to contribute to their recovery by personalising coping strategies.

3.4 Linking the two papers together

The two papers explore the experiences of living with FND, from the perspective of those with multiple symptoms, and those who experienced functional seizures. Whilst the two papers explore different aspects of the condition, the similarities and differences were important to note.

The themes in the empirical paper highlighted that ongoing motivation for engagement with professionals is determined by how the session feels and the strength of the therapeutic relationship, rather than the skills provided by the clinician. Whereas in the literature review, healthcare professionals suggested that engagement in healthcare interactions, was based on the professional having the skill and expertise to draw on pre-existing knowledge of the condition, and from multiple therapeutic modalities to enable them to adapt treatment. On first reflection, the views from those with FND in the results of the empirical paper, lay partly in contrast to the views held by healthcare professionals within the literature review. However, both findings emphasise the importance of the therapeutic relationship and adapting to provide person centred care.

More so, across the two studies the themes highlight the heterogeneity of the condition and the treatment needed. In the empirical paper, participants reflected on their desire to choose from a selection of interventions offered, and to personalise strategies when they were provided by professionals, to develop a sense of control and ownership over their recovery. Likewise, in the literature review, healthcare professionals reflected on their experiences of pulling strategies from different therapeutic modalities to tailor interventions to each person. The common narrative between the two papers further highlights the heterogeneity of the condition, and a need for professionals to be able to personalise interventions based on each individual.

3.5 Strengths

To the author's knowledge, the empirical research paper, is the first qualitative analysis to explore the experiences of "living well" for individuals with FND. A strength of the research is that it offers a new contribution to the research literature. Qualitative literature allows the researcher to gain a richer understanding of individuals' experiences, which can be valuable when trying to understand concepts and experiences that has not already been explored. The current literature focusing on the experiences of individuals living with FND, understandably emphasises the difficulties associated with the condition (Bazydlo & Eccles, 2022; Foley et al., 2023; Rawlings et al., 2017). However, until now there has not been a study that has offered insights into how individuals navigate the condition in a way that enables them to "live well" with FND.

3.6 Limitations

There are, of course, many limitations within the research, a few of which have been outlined in the individual sections of the thesis. This section aims to link the limitations of the studies in combination with current research, and my own reflections.

Accessibility of the study was a main limitation of the research. In keeping with the themes that emerged from the literature review, it is difficult to consider the ways in which to adapt without understanding the needs, and context. In particular, I had failed to consider necessary adaptations for those who experienced functional symptoms that affected their ability to verbally communicate. During recruitment, an individual registered their interest in participating, requesting to write their responses either live, or write some answers prior to the interview, and then respond to any other questions live in the interview. This was a consideration I should have reflected on earlier in the ethical approval process. To include the participant in the interview, I resubmitted an amendment to the ethics committee. However, once approved the participant was no longer interested in taking part in the study. In future research development, I would ensure that I was informed of the ways in which data collection methods could be adapted to meet the participants' needs.

Lack of consideration for the heterogeneity of the condition and the symptomology therefore provided a barrier for some people who may have been eligible for the study. In attempts to minimise mistakes being made in hindsight, an expert by experience provided advice in the setup of the thesis. Communication with the expert by experience was conducted through email, and they were sent the information to read through. Given the length of the information sent, it may have been useful to instead have discussed this with them in person, rather than through email, to allow further thinking around the set up of the interviews.

Moreover, most participants recruited for the study asked to receive a copy of a rough topic guide prior to the research interview. This allowed participants to take some time prior to the main research interview to consider their answers, and key points they wanted to communicate. Most participants stated that the experience of FND had impacted heir processing speed and reflected often experiencing symptoms of fatigue and cognitive fog, which they described being a barrier to conversation. Research into the cognitive symptoms of FND are understudied within the literature. Emerging research compares the cognitive abnormalities of functional neurological disorder to the experiences of those with fibromyalgia and chronic fatigue syndrome (Teodoro et al., 2018), advising protocols such as psychoeducation and pacing. To account for the difficulties participants might experience during an hour-long interview, participants were asked prior to the interview how they wished to plan the interview, and when to consider breaks. Despite this, in the eleven interviews conducted only one participant took a break. In hindsight, it may have been difficult for participants to request break time during the interview, and despite prompting all participants half way through, it may have been useful to set up the meeting in smaller time frames, rather than expect the participant to state when they needed a break.

A further limitation of the research is that the study recruited a predominantly white, female demographic. In the eleven participants recruited, one participant identified as male, and another identified as non-binary. Thus, over 80% of participants identified as female. A disproportional representation of women within the dataset reflects the current understanding of the gender demographic of FND. According to the data, women are disproportionally affected by FND (Lidstone et al., 2022). Some researchers argue that the over representation of women in the literature for FND, is not due to the increased risk of FND in females, but is instead an issue concerning gender and feminism, in how women are viewed within medical healthcare systems in comparison to men (McLoughlin et al., 2023). The original understandings of FND are rooted in the notions of women communicating distress through experiences of 'hysteria'. This understanding of psychological symptoms manifesting as physical symptoms continues to influence how some professionals understand FND. It has been suggested by some, that the under representation of men within the research is instead a reflection of how gender stereotypes continue to affect care seeking and influence medical professionals' diagnostic views. An alternative view would propose that males are less likely to receive a diagnosis of FND, and instead receive an alternate medical diagnosis for various factors (Edwards & Aybek, 2020). Ultimately, the views represented in this analysis may align more with the experiences of being a female with a diagnosis of FND, rather than the experiences of a male, or non-binary individual with the diagnosis.

3.7 Recruitment

During the recruitment and analysis of the data, knowing when to stop recruitment was particularly difficult. Many people registered their interest in the research study over a short period of time, some detailing arguments as to why they would be a good choice of participant. It felt uncomfortable to reject participants, knowing they had likely experienced negative experiences with healthcare professionals previously (Rawlings & Reuber, 2016). Braun and Clarke's model of reflexive thematic analysis (Clarke & Braun, 2021) refutes the concept of data saturation within their revised model. Due to the heterogeneity of the condition, it is likely further interviews will have offered new insights into how individuals lived well with the condition. Instead, my supervisor and I continued to discuss the data throughout the process of conducting interviews and were able to make a joint decision on when to stop participant recruitment, led by theories of information power (Malterud et al., 2016).

3.8 Epistemological position

Critical realism is positioned as an alternative epistemological stance to constructivism and positivism. The main difference is that critical realism believes that we can only ever understand a portion of reality. Critical realism understands that there is a truth to be understood, but we cannot access it, as our sense making of that truth is impacted by our beliefs, experiences, and use of language, and also through how individuals communicates it to another (Fletcher, 2017). As a researcher with this epistemological stance, my understanding is that qualitative research enables us to interpret experiences of participants which have been filtered through both their interpretation of events, and my own interpretation of their shared experiences. I hope to explain how my understanding of critical realism, and the lense in which I've interpreted the data. To consider how my epistemological stance has impacted the data collection and analysis.

Firstly, as a female, working class, qualitative researcher, and trainee clinical psychologist, I recognise that my understanding of the world, will be shaped by my individual experiences, perceptions, and beliefs. The ability for me to understand the experiences of the participants is limited by my subjective experiences, but also by the underlying structures and mechanisms that shape who I am as a professional, and as a person beyond my professional role. In this, I do, and have played a role in individuals' experiences of 'living well' with FND and have worked as a healthcare professional engaging others in therapeutic interactions. Thus, in this paper I am trying to understand a concept that I also contribute to and cannot remove this lens when interpreting the data. The social realities of the participants within the research study are also shaped by historical, cultural, and structural factors. In turn, the way the researcher then understands the information shared is impacted by these same factors. My belief is that the data does not provide a clear and direct reflection of reality, but instead a mediated version of that reality, as explained by Braun and Clake (Clarke & Braun, 2021) and it is not possible to know the 'truth'.

In asking participants to share their experiences of 'living well' with a complex and challenging condition, I am seeking their understanding on what enables them, within their context, to reach a point in which they define that they 'live well'. There are many interpretations of the research question, and this is in part what I was interested in exploring. To do this, I did not provide a definition of what 'living well' meant, but instead participants developed an understanding of this, and participated in the research study if they aligned themselves with such description.

Finally, Alvesson & Skoldberg (Alvesson & Sköldberg, 2017) emphasise that as a critical realist, it is important not just to explain the world, but also to change it. Therefore, my approach to this research has understood that whilst I may not capture the entirety of a person's experiences in qualitative interviews, I can use what I have understood, to try and install change, thinking about the clinical implications and the impact this acquired knowledge could have on future care and research.

3.9 The use of thematic analysis

Within Braun and Clarke's methodology (Clarke & Braun, 2021) the authors advise against researchers noting comparisons to other methodology as a means of justifying the use of RTA, which is not my intention. Rather, in considering the use of other methodology I am noting my reflections and decision making whilst developing my research question. My aim in the research was to explore the unique experiences of individuals with FND, which may lend itself to using a model of interpretive phenomenological analysis (IPA). After consideration, this methodology was not chosen as it requires a homogeneous sample and it felt important to recruit a heterogenous group of participants for the current study. Whilst the participants all experienced functional neurological disorder, each participant reported living with different symptoms including functional tremors, functional stroke, cognitive fog and functional seizures, among others. In the development of the project, it was important to for the participants recruited in the sample, to mirror individuals that I had worked with within my professional role. My experience was that individuals with complex presentations of FND were often underrepresented within the literature, and I wanted to support a meaningful contribution, that enabled these individuals to share their experiences. The method chosen for the qualitative analysis, was therefore reflexive thematic analysis (Clarke & Braun, 2021). This model offered an opportunity to find common themes within the data, to understand and infer meaning that would benefit other understandings of the condition.

Reflexive thematic analysis was applied using both indicative and deductive approaches. An inductive, or data led approach, encourages the researcher to consider the data as it is, rather than considering the information in the context of published literature, or theories. Fryer (Fryer, 2022) noted the benefit of this approach, is that it allows the researcher to learn from the data. Despite the intention of being data led, it could be argued that my clinical and personal experiences meant that I come with some understanding already, which may have hindered this. Danermark (Danermark, 2002) stated that all researchers have some knowledge of literature and theories that have been published. My understanding of previous research has been informed by previous assignments and teaching on the DCLINPSY. On the other hand, in the development of the themes it was not possible for some themes to develop without some understanding of the literature. For example, in the literature review, linking acknowledgment to engagement and validation, demonstrates my understanding of the systemic difficulties individuals with functional seizures face. For the final themes, both inductive and deductive approaches were used.

3.10 Further reflections

The goal of reflexivity in qualitative research is to validate the research findings by considering the researchers beliefs, sense making and biases (Berger, 2015). Braun and Clarke's model of reflexive thematic analysis (Clarke & Braun, 2021) proposes that rather than the researcher view this as a bias, instead, the researcher should accept this is unavoidable, and instead, seek to understand the ways in which their views and assumptions may influence the data (Braun & Clarke, 2023). To do this, I aimed to keep a reflexive diary throughout, to reflect on my own experiences throughout the research project. For ease, rather than a paper or typed diary, I found benefit in using recorded voice notes. These captured live thoughts, feelings, and reflections in recruitment, and the write up, but particularly when immersing myself within the research data and developing themes. I used voice notes to process and make note of my thoughts and then discussed any key themes with my clinical, research and field supervisor on the course.

The choice to commence a research project based on the experiences of individuals living with FND were influenced by both my professional background and personal experiences. Prior to starting the DCLINPSY, I worked within a professional role within both inpatient and community neuropsychology services. Within these services, I had the opportunity to support individuals who were managing FND, with all its complexities. Throughout our work together, I observed first-hand the challenges individuals with FND faced, including the stigma associated with the condition and the lack of knowledge among professionals, including myself. Despite these difficulties these women were able to navigate their condition and pursued their goals with determination. Working with these women has been an inspiration for the topic of my thesis. I hoped by completing this project I would make a meaningful contribution to the research literature, by empowering others to share their stories, in hope of informing and educating future professionals.

Personally, whilst undertaking this project I have witnessed a close family member navigate the challenge surrounding a diagnosis that was not easily explained through known disease pathologies. I have sat alongside them as they have navigated NHS systems, waiting lists, and medical jargon, and experience symptoms they, and medical professionals, don't seem to understand. Despite holding knowledge of medical systems, psychology, and neuroscience, I still have found it the process difficult to understand. Particularly, finding it challenging to attain clear answers and a meaningful diagnosis. These experiences have contributed to my own understanding of the systemic inequalities faced by those with conditions that are not easily explained and have undoubtedly influenced the lens in which I have viewed the data and the analysis.

Furthermore, whilst I approached the research question with some knowledge of how it felt to support another with FND, I do not have experience of what it is like to live with the condition myself. Berger (Berger, 2015) highlighted the benefit researching unfamiliar experiences. The benefit of approaching the research in this way, enabled me to listen and learn from the experiences of the participant. Empowering individuals with FND is important considering previous research states that individuals with FND are often dismissed and feel unheard by others (Foley et al., 2023; Rawlings et al., 2017). Thus, an interpretation of approaching the data in this way, suggests that this enables participants to hold a position of expertise, which can be empowering (Berger, 2015). In contrast, approaching the research without lived experience also presents challenges. As a researcher I cannot fully understand the experiences of the participants, instead I can only infer data provided through my own lens and my understanding of what has been shared in the context of an online research interview.

Finally, I have often reflected on my experiences of holding positions such as a researcher, or an academic. These are new aspects of my professional identity that I have carved out within the three years of the DClinPsy, particularly in the development and writing of this thesis project. Holding the position as a qualitative researcher in particular, felt incongruent at times with my desire to enable others to share their stories, rather than these experiences be interpreted by myself. When completing the data analysis, I noted the discomfort I felt interpreting participants' experiences through my own understanding of them. I felt indebted to their generosity of sharing their stories and contributing their time, and at times worried if I was accurately representing their views. Within thematic analysis, the themes should not 'emerge' from the data (Clarke & Braun, 2021), and the researcher instead should adopt a role of interpretation that considers both the semantic meaning of data, and the latent. Yet, to hold someone's experience and re-author it, has at times allowed me to adopt a position of power and privilege that feels incongruent with my beliefs and values. I noted that this dilemma influenced how I initially wrote my results section of the empirical paper, with a pull to use a larger proportion of quotes within the results rather than my interpretation of them. Ongoing use of a reflective diary, and conversations with my supervisor enabled me to feel more comfortable with this. Since, the results section has been edited to reflect the recommended guidance of a split balance between data and interpretation as suggested by Braun & Clarke (Clarke & Braun, 2021).

3.11 Clinical implications

There are a number of clinical implications that can be identified from the data in both the empirical paper, and the systemic literature review. Whilst the clinical implications of each are discussed in each paper, together the papers highlight a need for professionals to have the skills and confidence to understand and make adaptations when working with individuals with functional presentations. Both participants and professionals shared experiences where the therapeutic relationship had benefitted from tailoring interventions for the individual.

On a systemic level, its concerning that individuals with functional neurological disorders are consistently faced with difficult interactions with healthcare professionals, which have left them angry and scared. Whilst there is developing research into the experiences of individuals, there is still much to be done to convey these learnings to the public.

The themes within both the empirical paper and the systemic review suggest that it would be beneficial for healthcare professionals to understand the condition in more depth. Further education of the condition, which may in turn alter how professionals understand and communicate the condition and impact the interventions they provide.

3.12 References

Alvesson, M., & Sköldberg, K. (2017). *Reflexive methodology: New vistas for qualitative research*. sage.

Bazydlo, S., & Eccles, F. J. (2022). Living with functional movement disorders: a tale of three battles. An interpretative phenomenological analysis. *Psychology & Health*, 1-18.

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*, *15*(2), 219-234.

Braun, V., & Clarke, V. (2023). Is thematic analysis used well in health psychology? A critical review of published research, with recommendations for quality practice and reporting. *Health Psychology Review*, 1-24.

Clarke, V., & Braun, V. (2021). Thematic analysis: a practical guide. *Thematic Analysis*, 1-100.

Danermark, B. (2002). Interdisciplinary research and critical realism the example of disability research. *Alethia*, *5*(1), 56-64.

Edwards, M. J., & Aybek, S. (2020). Gender, Abuse, and Functional Movement Disorders: From His-story to the Future. *Movement disorders clinical practice*, *7*(2), 167.

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International journal of social research methodology*, *20*(2), 181-194.

Foley, C., Kirkby, A., & Eccles, F. J. (2023). A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder. *Disability and Rehabilitation*, 1-12.

Fryer, T. (2022). A critical realist approach to thematic analysis: producing causal explanations. *Journal of Critical Realism*, *21*(4), 365-384.

Lidstone, S. C., Costa-Parke, M., Robinson, E. J., Ercoli, T., & Stone, J. (2022). Functional movement disorder gender, age and phenotype study: a systematic review and individual patient meta-analysis of 4905 cases. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(6), 609-616.

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, *26*(13), 1753-1760.

McLoughlin, C., Hoeritzauer, I., Cabreira, V., Aybek, S., Adams, C., Alty, J., Ball, H. A., Baker, J., Bullock, K., & Burness, C. (2023). Functional neurological disorder is a feminist issue. *Journal of Neurology, Neurosurgery & Psychiatry*.

Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2017). Written accounts of living with psychogenic nonepileptic seizures: a thematic analysis. *Seizure*, *50*, 83-91.

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.

Teodoro, T., Edwards, M. J., & Isaacs, J. D. (2018). A unifying theory for cognitive abnormalities in functional neurological disorders, fibromyalgia and chronic fatigue syndrome: systematic review. *Journal of Neurology, Neurosurgery & Psychiatry*, *89*(12), 1308-1319.

Chapter 4: Ethical Approval

Jessica Hughes

Doctorate in Clinical Psychology

Lancaster University

Word count (including abstract but excluding references, appendices, figures and tables)

4,076/6,000

Correspondence should be addressed to:

Jessica Hughes
Doctorate in Clinical Psychology
Division of Health Research, Lancaster University
Health Innovation One
Sir John Fisher Drive,
Lancaster University
Lancaster, LA1 4AT
Email: J.hughes17@lancaster.ac.uk

4.1 Application for Ethical Approval for Research

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project: Living well with functional neurological disorder

Name of applicant/researcher: Jessica Hughes

ACP ID number (if applicable) *: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:
Email: J.Hughes17@lancaster.ac.uk
Telephone:(please give a number on which you can be contacted at short notice)
Address:

3. **Names and appointments of all members of the research team (including degree where applicable)**
Jessica Hughes, Trainee Clinical Psychologist
Dr Fiona Eccles, Research supervisor, Lancaster University
Dr Will Curvis, Field Supervisor, Lancaster University

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant: Dr Fiona Eccles, Dr Will Curvis.

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**:
Dr Fiona Eccles, Research supervisor, Lancaster University
Dr Will Curvis, Clinical Psychologist, Field supervisor, Lancaster university.

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and online 'chat-rooms' n o

4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? n o

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder
7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. How will the confidentiality and anonymity of participants who provided the original data be maintained?
Stored data, and documentation with be stored on a secure one drive, which will be password protected and encrypted. Participants names will be replaced with Pseudonyms following transcription of the interview.

9. What are the plans for dissemination of findings from the research?
The researcher will present the findings at the DclinPsy presentation day in 2023. The themes and codes derived from the data will be shared with the cohort members attending the talk. The findings will be written up into a thesis for the researchers' thesis qualification on the Doctorate Clinical Psychology at the University of Lancaster. The findings will be shared with the Functional Neurological Disorder Hope charity in a summarised report. They would be free to share on their social media platform or their website. The participants who state they would like to receive a copy of a summarised report after completing the research project. The researcher intends to publish the study in a peer reviewed journal.

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE
Complete this section if your project includes *direct* involvement by human subjects

Summary of research protocol in lay terms (indicative maximum length 150 words):

Functional Neurological Disorder (FND) is a problem with the functioning of the nervous system and how the brain and body send and receive signals. Physical and/or psychological risk factors can cause functional symptoms which include a variety of physical, sensory, and cognitive symptoms. There is no clear explanation of the condition's cause, making it confusing for individuals to navigate services and understand the condition. This study will examine what helps individuals cope when symptoms may still present among these confusing and challenging circumstances. I will interview a group of people with more than one symptom of FND, where the main symptom is not non-epileptic seizures. Participants will be recruited from a charity, FND Hope, and advertisement on a professional Twitter page. Participants will be interviewed about their experiences and given the opportunity to talk about the important things to them, rather than only answering questions that I have prepared. The information from all the participants will be sorted into common themes, aiming to capture the overall critical experiences of the people interviewed.

2. **Anticipated project dates (month and year only**)
Start date: February 2022 End date: May 2023

Data Collection and Management
For additional guidance on data management, please go to *Research Data Management* *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

I will aim to recruit 10-18 adult participants aged 18 and above.
Participants can identify as any gender.
Participants must be able to speak or write in fluent English due to the lack of funding availability for an interpreter.
Participants will be recruited in a staged recruitment process. At the start of the study, participants will be recruited if they reside within the UK at the time of the study. Recruiting participants from the UK will enable participants to reflect on similar healthcare systems and pathways that are present within the UK.
If the researcher cannot recruit sufficient participants in the UK, the researcher will broaden the inclusion criteria to English speaking countries outside of the UK.

Participants must have a diagnosis of FND, given by a medical professional.
Participants will have one or more symptoms of FND and will not self-identify as their leading symptom being functional seizures. However, the person may still experience these. A large proportion of the literature already focuses on what it is like to live with non-epileptic seizures (Rawlings et al., 2018; Rawlings et al., 2017; Thompson et al., 2009), and this research would focus on the experiences of an alternate, or broader set of symptoms.
Participants will be excluded if they have a concurrent medical condition that significantly impacts their lives daily. The research aims to capture the experiences of managing FND in all its complexity.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (e.g. adverts, flyers, posters).

I will be working with FND Hope, an international not-for-profit charity, when at the recruitment stage. FND Hope has agreed to publicise a recruitment poster on their website and social media channels like Facebook and Twitter. I will provide a link to the research study on my own professional Twitter page at the same time. Those who decide they would like to take part will need to contact me via email. I would then contact them to discuss the study further, and if they are happy to continue with the research and meet the inclusion and exclusion criteria, an interview would be arranged, which would take place on Microsoft Teams.

5. Briefly describe your data collection and analysis methods and the rationale for their use.

Data will be collected from participants using semi-structured interviews. This method will enable the researcher to present a topic for discussion while providing flexibility to allow participants to describe their thoughts, feelings, and beliefs around what enables them to live well with the condition. This interview style works well with thematic analysis. It allows the researcher to be led by the participant rather than the researcher's preconceived views or current information in the literature. Instead, semi-structured interviews enable new ideas to emerge, engrained in the individuals' experiences and how they have made sense of them (Fylan, 2005) The data will be analysed following the steps of Clarke and Braun's thematic analysis. A transcript of the interview will be autogenerated by Microsoft teams, and this will be checked for accuracy, making amendments where needed. Participants who have experience symptoms affecting their voice, may contribute by writing down their responses in the chat function. These responses will be added into the automatic transcript manually by the lead reviewer following the interview.

6. What plan is in place for storing, back-up, security, and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Interviews will be recorded on a video call using Microsoft Teams via Lancaster university account. Participants will be invited to participate in video interviews, rather than telephone interviews to maximise engagement, communication and to allow the researcher to acknowledge nonverbal cues in addition to verbal information communicated in the interviews. A recording will be collected on Microsoft teams, which will record both the sound and image of the interviews. However, prior to the interviews this will be discussed with participants. Should participants decline being recorded on video, the video will be switched off on the call, and an audio only recording will be taken. Verbal consent will be recorded using a video file. Transcripts will be downloaded and stored in the researcher's secure storage space on the Lancaster service for the duration of the study. All the transcripts, video and audio recordings will be anonymized and saved under a pseudonym or an assigned number.

When recruiting the participant for the study, the participant will be asked to provide an emergency contact number for a next of kin or friend whom the researcher may contact if the person becomes unwell, or in need of immediate support. The participant will be made aware that this is optional. This will be deleted as soon as the interview is completed.

Participants will be asked to provide the address from which they are conducting the interview. This is so that the researcher is able to direct emergency services to the correct location, should they display signs of immediate risk, or become medically unwell during the interview. This information will be stored in an encrypted, password protected document on the researcher's secure storage space and will be deleted as soon as the interview is completed. Participants will be provided with contact information for support services that may be appropriate.

Any information collated using personal information such as name and email address will be saved in a separate folder to protect anonymity. Once the project has been examined and a copy of the results has been sent to all participants, all personal contact information and video recordings will be deleted by the researcher. The audio/video recordings of the consent process and the written transcripts will be securely transferred to the research coordinator of the DclinPsy for storage, and these will be kept for 10 years. Fiona Eccles will act as data custodian and give permission for the research coordinator to delete the data and ensure this has been deleted after 10 years has lapsed.

7. Will audio or video recording take place? ☐ no ☒ audio ☒ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps to protect the data.

Interviews will be recorded using a video recording application on Microsoft Teams. Participants will be recorded giving verbal consent or may type their answer into the chat function box. This will be recorded as a separate recording to the research interview. Microsoft teams will provide an automated transcript after the interview, which will be downloaded and immediately transferred onto the researcher's secure storage space, which is encrypted and duo password protected. Transcripts and any other information will remain in this storage space for the duration of the study until the research study has been submitted. All the transcripts, video, and audio recordings will be anonymized and saved under a pseudonym and assigned number.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

The video/audio recordings of participants verbally giving consent will be encrypted, password-protected, stored under an assigned code or pseudonym and stored separately from any other information for the participant. For participants who provide their consent in the chat function box, the video recording of this will be saved. These recordings will be stored for 10 years by the Research Coordinator of the DclinPsy. Video/audio recordings of the interviews will be stored securely on OneDrive (or any similar university approved cloud storage) and deleted by the researcher once the research project has been examined.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder.

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

Once the project has been examined and a copy of the results has been sent to participants, all personal contact information and video/audio recordings will be deleted. The video/audio recordings of the consent process and the written transcripts will be securely transferred to the research coordinator of the DclinPsy for storage, and these will be kept for 10 years. Fiona Eccles will act as data custodian and give permissions for research coordinator to delete the data, and ensure this has been deleted oversee after 10 years has lapsed.

8b. Are there any restrictions on sharing your data?

Yes, there are restrictions on sharing the data. Raw data will not be shared availably. Raw data will only be made available to genuine researchers upon request. They will not be publicly accessible since the content of the information is likely to be identifiable due to the research method.

9. Consent
a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorized representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Once the participant has declared their interest in the study and had a subsequent follow-up call to screen the participant for their suitability, they will be sent an information sheet and consent form via email. The participant will be asked to read both before the arranged interview. On the interview day, I will go through the information sheet and consent form and read these aloud; I will ask the participant to confirm if they consent to the study. This will be audio or video recorded and saved separately from the interview recording.

10. What discomfort (including psychological e.g., distressing, or sensitive topics), inconvenience, or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

The participant will be asked to describe their experiences post-diagnosis of functional neurological disorder and how they have managed their condition. Therefore, there is the potential for the participants to become distressed while talking about these events. When seeking informed consent, the participant will be informed that they may decline to answer any question during the interview and they may also stop the interview at any point, should they become upset, distressed, or for any other reason.

In the information sheet, the participant will be made aware that there are limits to confidentiality within the study. Participants will be informed that any disclosed risk to themselves or others will need to be shared with my research supervisors, and an agreed course of action will be made to keep the participant or others safe.
The participant will also be informed they can stop the interview at any point. Participants may withdraw from the study at any point in the interview and up to two weeks following the interview. After this stage, due to the data analysis, it may not be possible to withdraw the participant's data.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

There will be no physical risks related to the research, as interviews will be taken in the researcher's home online. The researcher will seek support from supervisors if they require additional support.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There are no direct benefits for participants taking part in the study. However, using their data may inform future psychology provisions for other people diagnosed with functional neurological disorders.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Participants will not be given any incentive to participate in the research study.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

In the information sheet, limits of confidentiality will be outlined. Participants will be informed that any disclosed risk to themselves or others will need to be shared with my research supervisors. Together, we would agree on the following steps to take, which may involve contacting Social Care or the Police. Should immediate risk be apparent during the interviews, emergency services would be contacted to aid the participant. Prior to the interview, participants will be asked to provide the address from which they will be taking part in the interview so that the researcher can provide emergency services with their location should they display signs of immediate risk.

Microsoft teams will provide an automatic transcript of the interview, which will be downloaded and checked for accuracy. Corrections will be made if the information on the transcript has been recording inaccurately. The transcripts will be saved in an encrypted and a duo password-protected file on the university's secure server. Any identifying names will be removed from the transcripts and participants will be given a pseudonym in the write up of the results. All attempts will be made to not use quotes that could potentially identify the participants.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

An expert by experience from FND Hope has reviewed the information sheet, recruitment poster, Interview topic guide and the consent form, and no changes were made. If their schedule permits, they may also provide input into the data analysis, including reviewing the themes. An agreement will be made by email that FND Hope will not publicise any information about the study, themes or data from the interviews without the researchers' consent. FND Hope will advertise the study, but potential participants will contact the researcher to indicate interest, so they will not know who has taken part.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The researcher will present the findings of the study at the DClinPsy presentation day in 2023. The themes and codes will be shared with the cohort members attending the talk. The findings will be written up into a thesis for the researchers' thesis to complete their doctorate in clinical psychology. The findings will be shared with FND hope in a summarised report which they will be free to share on their social media platforms or their website. The participants who state they would like to receive a copy will be sent one after completing the research project. The researcher intends to publish the study in a peer-reviewed journal and may present at conferences and special interest groups.

17. What particular ethical considerations, not previously noted on this application do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?
No

References

Fylan, F. (2005). Semi-structured interviewing. *A handbook of research methods for clinical and health psychology*, *5*(2), 65-78.

SECTION FOUR: signature

Applicant electronic signature: Jessica hughes   Date 01/11/2021

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Fiona Eccles, Will Curvis. Date application discussed:1/11/21

Submission Guidance

1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    i. **FHMREC application form.** Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    ii. **Supporting materials.** Collate the following materials for your study, if relevant, into a single word document:
        a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
        b. Advertising materials (posters, emails)
        c. Letters/emails of invitation to participate
        d. Participant information sheets
        e. Consent forms
        f. Questionnaires, surveys, demographic sheets
        g. Interview schedules, interview question guides, focus group scripts
        h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
    ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:
        a. existing documents/data only;
        b. the evaluation of an existing project with no direct contact with human participants;
        c. service evaluations.
3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

4.2 Appendix

4.2.1 Appendix 4-A: Thesis Protocol

How do people live well with a functional neurological disorder?

Lead Researcher: Jessica Hughes, Trainee Clinical Psychologist at Lancaster University

Field Supervisor: Dr. Will Curvis, Clinical Neuropsychologist

Academic Supervisor: Dr. Fiona Eccles, Lecturer, Doctorate in Clinical Psychology, Lancaster University

Background

Formerly known as conversion disorder, functional neurological disorders (FND) describes a wide-ranging set of symptoms affecting an individual's sensory, motor, and cognitive function (Espay et al., 2018). This can include difficulties walking, problems with their bladder/bowels, seizure like experiences, and difficulties with speech or swallow, among others. Currently, there is not a defined medical or neurological explanation. Historically, FND has been explained as a conversion of psychological distress or psychological experiences such as trauma, anxiety, or stress. Current research posits this does not explain the diagnosis sufficiency. While psychological stressors are present before the onset of symptoms for many, the link between the two is not causal and indeed often individuals receive a diagnosis without the presence of psychological stressors (Lidstone, Araújo, Stone, & Bloem, 2020)

Despite research into the understanding of FND, there remains a lot to be explained. FND is a relatively under-researched field, given its prevalence as the second most common cause of neurological illness in the UK (Stone et al., 2010). Moreover, research has suggested that many health care professionals report feeling ill-informed and unconfident when providing care for people with FND (REF).

For individuals with FND, research suggests that many individuals feel disbelieved, misheard, and frustrated post-intervention with a healthcare professional (Rawlings, Brown, & Reuber, 2018). Often individuals experience lengthy delays to diagnosis and treatment and are passed between services, and are statistically more likely to experience poorer health outcomes (Barnett, Davis, Mitchell, & Tyson, 2020; Gelauff et al., 2014)

Clinical psychology can play an essential role within neurology teams, providing formulation, intervention, and consultation. Research indicates that psychology input is beneficial for FND rehabilitation (Gilmour et al., 2020), to promote understanding of the brain-body relationship (Nielsen et al., 2015), to complete neuropsychological testing (Pennington et al., 2015), and to support the interdisciplinary team. Moreover, given the poor prognosis and longevity of symptoms, it is likely, individuals may develop further difficulties such as stress, anxiety, or low mood, which may require psychological support (Moussavi et al., 2007).

Some qualitative studies have explored the challenges of living with the condition (Dosanjh, Alty, Martin, Latchford, & Graham, 2020; Rawlings, Brown, Stone, & Reuber, 2017; Rawlings & Reuber, 2016). This research has highlighted how societal issues and systemic challenges within the NHS lead to poor outcomes for individuals diagnosed with FND. However, despite the challenges of living with the condition, some individuals learn to live with the condition and develop ways, individual to them, to cope. More research needs to be completed to explore how individuals learn to manage their condition in the current context of having a poorly understood condition and considerable systemic challenges. Qualitative research allows researchers to gain a deeper insight into individuals' thoughts, views, and feelings (Willig, 2019). Due to the complex nature of the diagnosis of FND, it would be beneficial to explore the psychological and social processes that become a part of learning to live well with the condition.

Psychological models such as Acceptance and Commitment Theory (ACT) have built a framework for helping individuals with physical and mental health conditions move away from reducing symptoms and focusing more on valued living (Hayes, Luoma, Bond, Masuda, and Lillis, 2006). For some individuals, symptoms of FND may continue to present or flare across their lifetime. I am interested in how these individuals move forward with their lives, allowing them to manage their new condition. Consequently, This research project will explore what helps someone manage the condition and enables them to live well with FND.

Method

Design

The research study will take a qualitative approach and follow the methodology of Braun and Clarke's reflexive thematic analysis (Braun and Clarke, 2006; Braun and Clarke, 2012) to explore the experiences of people with a diagnosis of FND. Qualitative literature enables researchers to gain a unique understanding of participants' experiences (Willig, 2019). Due to the complex nature of the diagnosis of FND, it would be beneficial to explore the psychological and social processes involved in living with and learning to manage FND.

Participants

I will aim to recruit 10-18 adult participants aged 18 and above.

Participants can identify as any gender.

Participants must be able to speak or type fluent English due to lack of funding availability for an interpreter.

Participants will be recruited in a staged recruitment process. At the start of the study, participants will be recruited if they reside within the UK at the time of the study. Recruiting participants from the UK will enable participants to reflect on similar healthcare systems and pathways that are present within the UK. If the researcher cannot recruit sufficient participants in the UK, the researcher will broaden the inclusion criteria to English speaking countries outside of the UK.

Participants must have a diagnosis of FND that has been given a medical professional.

Participants will have one or more symptoms of FND and will not self-identify as their leading symptom being functional seizures (one of many possible symptoms of FND). However, the person may still experience these. A large proportion of the literature already focuses on what it is like to live with non-epileptic seizures (Rawlings et al., 2018; Rawlings et al., 2017; Thompson et al., 2009), and this research will focus on the experiences of an alternate, or a broader set of symptoms.

Participants will be excluded if they have a concurrent medical condition that significantly impacts their lives daily. The research aims to capture the experiences of managing FND in all its complexity.

Data Collection

I will be working with FND Hope, an international not-for-profit charity, at the recruitment stage. FND Hope has agreed to publicise a recruitment poster on their website (see appendix 4-B) and social media channels such as Facebook and Twitter. I will also provide a link to the research study on my own professional Twitter page, at the same time. If the recruitment strategies outlined are not sufficient to attain enough participants, then I will continue to promote the study via my own professional twitter page and reach out to relevant professionals and experts by experience in the field to share the study on Twitter.

Those who decide they would like to take part will be invited to contact me via email. I would then contact them to discuss the study further, and if they are happy to continue with the research and meet the inclusion and exclusion criteria, an interview would be arranged. Participants will be forwarded an information sheet and consent form (see appendices B and C) via email before the interview. Participants will be asked to read the consent form before the interview. At the start of the interview the researcher will read aloud the statements from the consent form, and ask participants to verbally consent, or if speaking is difficult for them, to type their consent into the chat function box. Participants do not need to return a signed consent form. I will review the information sheet and consent form at the beginning of the interview and answer any questions before the recording for the interview. Verbal consent will be recorded as a video file and saved as a separate file, and written consent will be recorded as a video file, saved with the transcription, and saved separately to the recording for the interview.

Data will be collected using semi-structured interviews. Participants will be encouraged to discuss their thoughts, feelings, and beliefs around what enables them to live well with the condition either verbally or, if speaking is difficult, in written responses, using the chat function on Microsoft teams. Interview questions will be used as a guide (see appendix 4-E).

The researcher's responses and follow-up questions will be flexible and seek more information on what the participants believe is relevant to their experience.

Data Analysis

The data will be transcribed using the automated function in Microsoft Teams, which will then be checked for accuracy by the lead researcher. For participants who experience symptoms that affect their verbal communication, written responses from the interviewer's questions will be manually added into the automated transcript post interview by the lead researcher. The study will follow the steps for thematic analysis outlined by Braun and Clarke (2006). This involves transcribing the interviews and reviewing the transcripts to code the interview data and develop themes that best represent the data from the interviews. The flexibility of thematic analysis will capture participants' views, thoughts, and experiences taking an inductive approach.

Data Storage

Interviews will be conducted and recorded on Microsoft Teams. Verbal consent will be recorded in a separate video file at the start of the interview, which will be kept separate to the recorded interview and transcript. For participants with symptoms affecting their verbal communication, a video will be recorded whilst participants give consent so that the responses in the chat function can also be recorded. ~~The video will then be turned on for the interview if the participant is comfortable with this.~~ Participants can choose to have their video on or off throughout the research interview. At the end of the interview Microsoft teams will provide an automatic transcript that will be downloaded and stored in the researcher's secure storage space on the Lancaster service for the duration of the study.

All the transcripts and video recordings will be anonymized and saved under a pseudonym or an assigned number.

When recruiting participants for the study, the participant will be asked to provide an emergency contact number for the next of kin or friend whom the researcher may contact if the person becomes unwell, or in need of immediate support. The participant will be made aware that this is optional. This will be deleted as soon as the interview is completed.

Participants will be asked to provide the address from which they are conducting their interview. This is so that the researcher is able to direct emergency services to the correct location, should the participant display signs of immediate risk, or become medically unwell during the interview. This information will be stored in an encrypted, password-protected document on the researchers' secure storage space ~~and will be deleted following the completion of the interview~~. The participant will be made aware that this is optional. This will be deleted as soon as the interview is completed.

Any information collated using personal information such as name and address or email address will be saved in a separate folder to protect anonymity.

Once the project has been examined and a copy of the results has been sent to participants, all personal contact information and video/audio recordings will be deleted by the researcher. The recordings of the consent process, and the written transcripts will be securely transferred to the research coordinator of the DclinPsy for storage, and these will be kept for 10 years. Fiona Eccles will act as data custodian and give permissions for the research coordinator to delete the data, and ensure that this has been deleted by the research coordinator once the 10 years has lapsed.

Ethical considerations

Due to the nature of the research question and the study's aims, participants may talk about experiences that may cause them some distress. The participant will be asked to describe their experiences post diagnosis of functional neurological disorder, and how they have managed their condition. Therefore, there is the potential for the participants to become distressed whilst talking about these events. When seeking informed consent, the participant will be informed that they may decline to answer any question during the interview and they may also stop the interview at any point, should they become upset/distressed, or for any other reason. In a meeting before the interview, participants will be asked how they would best like to structure the interview, to encourage participants to ask for breaks or any other reasonable adjustments if needed. For participants who have symptoms associated with their condition that affects their ability to contribute to the study verbally, will be given the option to type responses into the chat.

In the information sheet, limits of confidentiality will be outlined. Participants will be informed that any disclosed risk to themselves or others will need to be shared with my research supervisors. Together, we would agree on the following steps to take which may involve contacting Social Care or the Police. Should immediate risk be apparent during the interviews, emergency services would be contacted to aid the participant.

In the information sheet, participants will be given several contact numbers and information sites to provide emotional support. The researcher will be mindful of the participants' well-being within the interviews and encourage the participant to take breaks if needed. Participants also have the option to postpone or rearrange their interviews. Participants can withdraw their data from the study up to two weeks following their interview. After this it may not be possible to remove the participants' data from the emergent themes.

To protect participant's confidentiality, individuals will be referenced under pseudonyms, and no identifiable quotes will be used within the research paper.

Dissemination

The researcher will present the findings of the study at the DClinPsy presentation day in 2023. The themes and codes will be shared with those attending the talk. The results will be written up into a thesis for the researcher's thesis to complete their doctorate in clinical psychology. The findings will be shared with FND Hope in a summarised report which they will be free to share on their social media platforms or their website. The participants who state they would like to receive a copy at the start of the study will be sent one on completion of the research project, with a summarised lay summary. The researcher intends to publish the study in a peer-reviewed journal and at conferences and special interest groups.

Service user involvement

An expert by experience from FND Hope has reviewed the information sheet, recruitment poster, interview topic guide, and consent form and made no changes. If their schedule permits, they may also provide input into the data analysis, including reviewing the themes. An agreement will be made by email that FND Hope will not publicise any information about the study without the researchers consent. FND Hope will advertise the study, but potential participants will contact the researcher to indicate interest, so they will not know who has taken part.

Timescale

November 2021	Submit to ethics
April – June 2022	Begin data collection and analysis
July – September 2022	Complete the data collection, review literature for systematic review
October – December 2022	Complete data analysis and draft the discussion of the empirical data, draft results, and discussion of systematic literature review
January – March 2023	Complete the draft of the critical appraisal, format, and submit the thesis
April – August 2023	Viva-voce examination and complete corrections as required.

References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2012). Thematic analysis.

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., Nielsen, G., Reuber, M., Voon, V., Stone, J., & Morgante, F. (2018). Current Concepts in Diagnosis and Treatment of Functional Neurological Disorders. *JAMA Neurol*, *75*(9), 1132-1141. https://doi.org/10.1001/jamaneurol.2018.1264

Gilmour, G. S., Nielsen, G., Teodoro, T., Yogarajah, M., Coebergh, J. A., Dilley, M. D., Martino, D., & Edwards, M. J. (2020). Management of functional neurological disorder. *J Neurol*, *267*(7), 2164-2172. https://doi.org/10.1007/s00415-020-09772-w

Moussavi, S. M. P. H., Chatterji, S. D., Verdes, E. P., Tandon, A. P., Patel, V. P., & Ustun, B. M. D. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *Lancet*, *370*(9590), 851-858. https://doi.org/10.1016/S0140-6736(07)61415-9

Pennington, C., Newson, M., Hayre, A., & Coulthard, E. (2015). Functional cognitive disorder: what is it and what to do about it? *Pract Neurol*, *15*(6), 436-444. https://doi.org/10.1136/practneurol-2015-001127

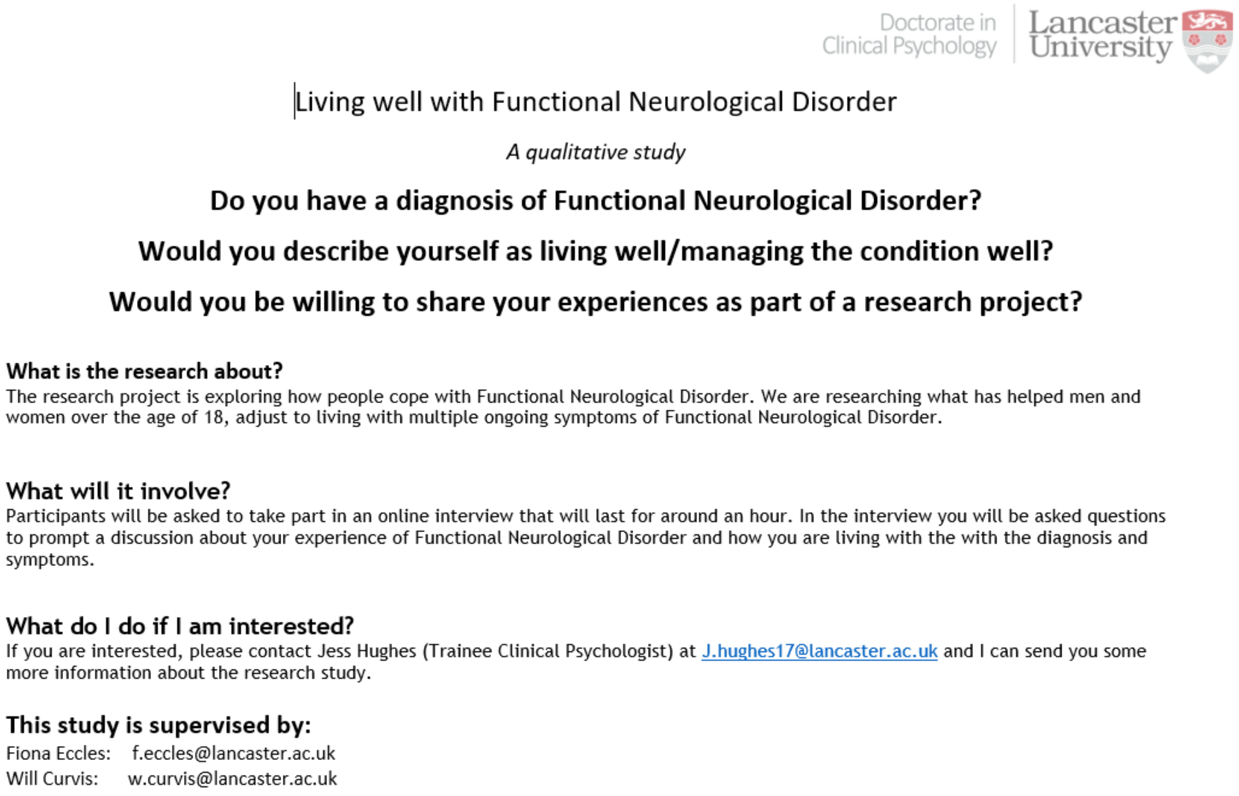
Rawlings, G. H., Brown, I., & Reuber, M. (2018). Narrative analysis of written accounts about living with epileptic or psychogenic nonepileptic seizures. *Seizure*, *62*, 59-65. https://doi.org/10.1016/j.seizure.2018.09.022

Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2017). Written accounts of living with psychogenic nonepileptic seizures: A thematic analysis. *Seizure*, *50*, 83-91. https://doi.org/10.1016/j.seizure.2017.06.006

Thompson, R., Isaac, C. L., Rowse, G., Tooth, C. L., & Reuber, M. (2009). What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy & Behavior*, *14*(3), 508-515. https://doi.org/https://doi.org/10.1016/j.yebeh.2008.12.014

Willig, C. (2019). What Can Qualitative Psychology Contribute to Psychological Knowledge? *Psychol Methods*, *24*(6), 796-804. https://doi.org/10.1037/met0000218

4.2.2 Appendix 4-B: Advertisement



Doctorate in Clinical Psychology
Lancaster University

Living well with Functional Neurological Disorder

A qualitative study

Do you have a diagnosis of Functional Neurological Disorder?

Would you describe yourself as living well/managing the condition well?

Would you be willing to share your experiences as part of a research project?

What is the research about?
The research project is exploring how people cope with Functional Neurological Disorder. We are researching what has helped men and women over the age of 18, adjust to living with multiple ongoing symptoms of Functional Neurological Disorder.

What will it involve?
Participants will be asked to take part in an online interview that will last for around an hour. In the interview you will be asked questions to prompt a discussion about your experience of Functional Neurological Disorder and how you are living with the with the diagnosis and symptoms.

What do I do if I am interested?
If you are interested, please contact Jess Hughes (Trainee Clinical Psychologist) at J.hughes17@lancaster.ac.uk and I can send you some more information about the research study.

This study is supervised by:
Fiona Eccles: f.eccles@lancaster.ac.uk
Will Curvis: w.curvis@lancaster.ac.uk

4.2.3 Appendix 4-C: Participant Information Sheet

'Living well' with a diagnosis of Functional neurological disorder?

For further information about how Lancaster University processes personal data for research purposes and your data rights, please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Jessica Hughes, and I am conducting this research as a student in the Clinical Psychology Doctoral programme at Lancaster University, Lancaster, United Kingdom.

Please take the time to read the following information carefully before deciding whether or not you would like to participate.

What is the study about?
The research project explores how people learn to live well with a diagnosis of Functional neurological disorder (FND). We know that living with FND can be very difficult, but that some people learn to manage and even 'live well' with the condition. We are researching what has helped people adjust to living with ongoing symptoms of FND and we would like to hear more from people who consider themselves to be managing the condition, to learn about what helps them cope.

Why have I been approached?
You will have requested to receive this information due to seeing the recruitment poster advertised on FND Hope or Twitter. This study aims to recruit participants who would like to share their personal experiences of their diagnosis of FND and how they manage the symptoms.

Do I have to take part?
No. Your participation is voluntary. It's entirely up to you to decide whether you take part.

What will I be asked to do if I take part?
If you decide you would like to take part, you will need to email j.hughes17@lancaster.ac.uk to let me know you are interested. I would then get in touch with you to talk about the project in more detail. At this point, we would have a conversation to check your suitability for the study, and it's here I will also answer any questions you may have about your participation. After this conversation, I will let you know whether you will be suitable for the study. If you are also happy to participate in the study, we will then arrange a time to conduct an interview.

Once we have arranged an interview, I will email you a consent form to read through before our interview. You do not need to return the consent form to me. At the start of the arranged interview, I will answer any questions you may have and then read through the statements on the consent form and check you agree. This conversation will be recorded and saved in an encrypted and password-protected file to protect your confidentiality.
The interview will be held or Microsoft Teams. On average an interview will last approximately one hour, but this can be adapted to meet individual circumstances e.g. Multiple shorter interviews, or longer interviews with multiple breaks.

Will my data be Identifiable?
The data collected for this study will be stored securely, and only the researchers conducting this study will have access to this data. The interview is recorded to allow me to write a transcription of the interview conversation. This transcription will allow me to develop themes that will summarise the key areas that collectively come out of all the participants' data.
Your data will be stored confidentially in the following ways:

- Audio or video recordings of the main interview will be destroyed and/or deleted once the project has been submitted for publication/examined.

- The files on the computer will be encrypted (that is, no one other than the researcher will be able to access them), and the computer itself password protected.
- Lancaster university will keep electronic copies of the transcripts and the video recordings of the consent process for 10 years.
- The typed version of your interview will be made anonymous by removing any identifying information such as your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to my research tutors about this. Where possible, I will talk this through with you beforehand.

What will happen to the results?
The results will be summarised and written up as a piece of work submitted as my thesis for the Lancaster Clinical Psychology Doctorate programme. The thesis may be submitted for publication in an academic or professional peer-reviewed journal, and shared at appropriate conferences or special interest groups. Participants can request a copy of the results.

Are there any risks?
There are no risks anticipated with participating in this study. However, if you experience any distress following participation, you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
Although there are no direct benefits to you taking part in the study, it is hoped that the study results will inform both care and research relating to functional neurological disorders and help other individuals diagnosed with Functional neurological disorder.

What if I change my mind after the interview?
Participants will have two weeks following the interview, to request to withdraw their data from the study.

Who has reviewed the project?
This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:

Jessica Hughes	Email: j.hughes17@lancaster.ac.uk

Or the project supervisors:

Fiona Eccles	Email:f.eccles@lancaster.ac.uk
Will Curvis	Email:w.curvis@lancaster.ac.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Ian Smith
Research Director (Lancaster University Doctorate in Clinical Psychology)
Lancaster
LA1 4YG

Email: i.smith@lancaster.ac.uk
Tel: 01524 592282

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin
Chair of FHM REC
Faculty of Health and Medicine (Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Email: l.machin@lancaster.ac.uk
Tel: +44 (0)1524 594973

Thank you for taking the time to read this information sheet.

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, the following resources may be of help.

FND Hope Support Groups via FND Hope Website: https://fndhope.org/
Mind: 03001233393
The Samaritans: 08457909090

4.2.4 Appendix 4-D: Consent form

Study Title: Living well with Functional neurological disorder

We are asking if you would like to take part in a research project to explore how people cope with functional neurological disorder. We are researching what has helped people adjust to living with ongoing symptoms of functional neurological disorder.

Before you consent to participate in the study, we ask that you read the information sheet and the statements below and familiarise yourself with the questions on this form.

You **do not need** to sign and complete this form. At the start of the scheduled interview, the researcher will go through both the information sheet, and ask you the statements below.

If you have any questions or queries about the consent form, please discuss these with the principal investigator, Jessica Hughes, before verbally consenting.

1. I confirm that I have read the information sheet and fully understand what isexpected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have themanswered. ☐
3. I understand that my interview will be video recorded and then made into an anonymised written transcript. ☐
4. I understand that audio and video recordings of the main interview will be kept until the research project hasbeen examined and then deleted. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at anytime without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, I have two weeks to withdraw my data, following the interview. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps willbe taken to protect the anonymity of the participants involved in this project. ☐
8. I consent to information and quotations from my interview being used in reports,conferences, and training events. ☐
9. I understand that the researcher will discuss data with their supervisors as needed. ☐
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor. ☐
11. I consent to Lancaster University keeping written transcriptions of the interview and this video recording of my consent for10 years after the study has finished. ☐
12. I consent to take part in the above study. ☐

4.2.5 Appendix 4-E: Interview schedule

This interview schedule will act as a topic guide to uncover the thoughts, feelings, views, and opinions of living with a functional neurological disorder (FND) and how participants manage their condition. Participants will be encouraged to share their personal experiences of what has been helpful to them and that there is no right or wrong answer. These questions will act as a guide only, and questions may be adapted depending on the participant's responses.

Topic Area 1:

The initial part of the interview will focus on collecting demographic information about the participants such as age, gender, ethnicity, partnership status, employment status.

Topic Area 2:

This part of the interview will allow participants to tell their story of FND, including how they first experienced their symptoms and their journey of being diagnosed. The questions will focus on how the process felt, their opinions of the condition, and learning more about their symptoms.

- How long have you had symptoms of FND?
- Can you tell me a bit about when you first experienced symptoms of functional neurological disorder?
- Who gave the diagnosis and what was that like?
- How would you describe your experience with FND?
- Did you know much about the condition before you were diagnosed? If so, what did you know?
- How did you feel about being diagnosed with the condition?
- How did the diagnosis affect your life when you were first diagnosed?

Topic Area 2:

The second part of the interview will focus on capturing how participants cope with the condition.

- What have you done to try and manage your symptoms? What have you learned, and how do you apply that knowledge now?
- What useful advice have you been told/read about?
- How does FND affect your life now?
- What is the focus on your life right now and how does living with FND affect that?
- Are there days when the symptoms feel less intense? What is happening on those days?
- What role did you play in making the symptoms feel less intense? How did you manage the situation?
- How did you develop the knowledge/skills in living well with FND?
- Have you managed the condition by yourself, or do others help? If so, how do they help?

Topic Area 3:

The third part of the interview will focus on how participants define living well with FND

- What does 'living well with FND' mean to you?
- How would you define a good day with FND?
- What guides how you want to live with your symptoms?
- What advice would you give to someone that has been newly diagnosed with the condition?

Topic Area 4:

The final part of the interview allows the participant to add any final comments or talk about something they think is important for the research question but have not had the opportunity to explore yet.

- Is there anything else that you feel is important to talk about?

4.2.6 Appendix 4-F: Ethics approval confirmation email

Approval of a new application
Subject: Ethics approval FHMREC ref: FHMREC21041

Dear Jess,

Thank you for submitting your research ethics application for the above project for review. The application has been reviewed by members of the FHM Research Ethics Committee and I can confirm that approval has been granted for this project.

Thank you for submitting your research ethics application for the above project for review. The application has been reviewed by members of the FHM Research Ethics Committee and I can confirm that approval has been granted for this project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer via this email address (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me on fhmresearchsupport@lancaster.ac.uk if you have any queries or require further information.

Best wishes,
Annie

Annie Beauchamp | Research Ethics Officer (FST/FHM)
Research and Enterprise Services | Lancaster University
Contact me on Microsoft Teams (for enquiries not related to REC applications)

I work flexibly so may send or respond to emails outside of standard office hours. There is no expectation for you to respond outside of your working hours.

Please note I do not work on Friday afternoons.

Pronouns: She/Her
Click here to hear my surname

4.2.7 Appendix 4-G: Ethics approval amendment confirmation email

This email originated outside the University. Check before clicking links or attachments.

FST-2022-2142-AmendPaper-2 Living well with Functional Neurological disorder

Dear Jess Hughes,

Thank you for submitting your ethics amendment application in REAMS, Lancaster University's online ethics review system for research. The amendments have been approved by the FHM REC.

Yours sincerely,

Faculty Research Ethics Officer on behalf of FHM