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DOCTORAL THESIS

Women’s perspectives on the experience and sense-making of Functional Seizures
an interpretative phenomenological analysis

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Women’s perspectives on the experience and sense-making of Functional Seizures: an interpretative phenomenological analysis

by

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A thesis submitted in partial fulfilment of the requirements for the degree of PsychD

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Abstract

Background:

Functional seizures (FS) are episodic disturbances that resemble epilepsy but which, unlike epilepsy, have no electrical or epileptic activity in the brain. While they are viewed as psychological in aetiology, they are often embedded treatment-wise within a medical model and disproportionately affect women. The role of trauma and stress as risk factors or diagnostic features in its aetiology remains contested among Psychologists, Psychiatrists and Neurologists.

Despite the wealth of literature on Functional Seizures, there is a dearth of qualitative studies exploring the sense-making and attributions of people with FS in relation to their seizures. This explorative study investigated women's perceptions and sense-making of these seizures.

Aim:

To explore and gain an in-depth understanding and sense-making of the Functional Seizures and the meanings attributed to them from the perspectives of women.

Methods:

Eight women who had recently received a diagnosis of Functional Seizures were asked to share their experiences, understanding and attributions of the seizures in semi-structured interviews. Transcriptions were analysed using Interpretative Phenomenological Analysis (IPA). The positioning of the researcher within these narratives was also explored.

Results:

Three themes emerged from the analysis: In a State of Siege; Connecting and Disconnecting to the Diagnosis and A Disrupted Self. Overall, the findings conveyed a complex, heterogenous understanding and experience of the seizures. Participants largely struggled to connect to any association with trauma.

Conclusions:

The findings show a wide divergence in sense-making and explanatory models among women. This raises implications for health professionals working in treatment pathways for FS. Firstly, the need to collaboratively establish with people with FS their individual understanding of the seizures and for Psychologists to take a lead in validating these attributions. Further research is warranted within a Counselling Psychology framework. Limitations, implications and directions for future research are discussed.

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Acknowledgments:

Firstly, I would like thank the eight women who gave up their time and energy to taking part in my study and who were so courageous in sharing their often very difficult stories. I hope I have given their narratives the importance they deserve. I would also like to thank the numerous other women who contacted me hoping to take part but were ineligible. My introduction to all these women would not have materialised without the invaluable help of the national charity FND Action.

Thank you to my external supervisor Rosie Rizq - originally my Director of Studies - whose guidance and wisdom I have clung to throughout. Also, huge gratitude to James Davies, my Director of Studies, who offered wonderful guidance along the way and to Desmond King, my therapist, who was already an expert in reassurance.

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GLOSSARY:

AED – Anti-Epileptic Drugs

CP – Counselling Psychologist

DS – Dissociative Seizures

FS – Functional Seizures

GET – Group Experiential Theme

IPA – Interpretative Phenomenological Analysis

NEAD – Non-epileptic Attack Disorder

PNES – Psychogenic Non Epileptic Seizures

TA- Thematic Analysis

(V) EEG – (Video) electroencephalogram

1.Introduction

1.1 Chapter overview

This chapter will provide a personal and theoretical background to the present doctoral thesis, making an argument for the importance of a greater understanding of women's sense making and individual attributions in relation to the phenomenon of Functional Seizures. I will do this by first introducing the evolving theoretical frameworks surrounding Functional Seizures, the complexity of the diagnostic process and the burden for those who experience them. I will elaborate on the problematic roles and relationships between trauma and stress in relation to FS nosology and will explore different psychodynamic and contemporary cognitive models underpinning the seizures. Finally, I will describe my own reflexivity in relation to these seizures, which have the potential to devastate people's lives, and why I was so curious and impatient to do this particular study.

1.2 The phenomenon of Functional Seizures

Functional Seizures (FS), also known as Dissociative Seizures (DS), Psychogenic Non-Epileptics Seizures (PNES), Non-epileptic attack disorder (NEAD) or historically "*pseudoseizures*" - resemble epileptic seizures or fainting (Goldstein, 2020); they are, however, *not* a result of epilepsy or any other medical condition, so as such, are conceptualised as a medically unexplained symptom. They involve a sudden, involuntary attack of symptoms and are broadly understood as psychological episodes that arise via dissociative mechanisms (Pick, 2017).

As a disorder, they sit at the interface between Neurology and Psychiatry/ Neuropsychology. Functional Seizures are currently classified as Conversion (Functional Neurological Symptom) Disorder (American Psychiatric Association, 2013) (APA) and a

Dissociative Neurological Symptom Disorder (ICD-11, World Health Organisation) (WHO). As such, they present a conundrum both for health professionals working with patients in Neurology, Psychiatry and Psychology and, by extension, even greater difficulties for people who experience them to access treatment.

Due to the superficial resemblance to epilepsy, most people with these seizures are initially seen in Neurology clinics and are treated with strong anticonvulsant/antiepileptic drugs (AEDs), sometimes for many years (Reuber, 2002). Up to 40% of patients are maintained on an inappropriate and potentially harmful course of AED treatment even after a diagnosis of FS, further complicating the understanding and acceptance of it. Studies have shown how people with FS find it difficult to understand how a physical problem such as a seizure, could be caused by psychological processes. Consequently, many feel misunderstood, ashamed and rejected when they are presented with a psychological model of their disorder. They may even reject the idea of the FS diagnosis due to the very physical nature of the seizure, combined with a mind/body dualistic understanding of their condition (Rawlings and Reuber, 2016).

Problems over diagnosis and the communication of the diagnosis are still very present despite the emergence of video-electroencephalographic (VEEG) recording in the 1970s which revolutionised the diagnostic and research landscape and sparked a renaissance of inquiry into FS aetiology and treatment. The ability of VEEG to distinguish between those who have electric activity leading to a diagnosis of epilepsy and those who do not and who are diagnosed with FS, has led to this being the current gold standard for a diagnosis. The studies mentioned in this study will only use participants diagnosed via VEEG.

In this study, I have used the term Functional Seizures throughout because the word ‘functional’ reduces stigma, does not imply a specific aetiology and also fits with the existing nosology of other functional movement disorders (Goleva et al., 2020). It also fits in line with recent research concluding that the term "Functional seizures" was one of the more preferred and acceptable among patients (Loewenberger et al., 2021).

1.3 Prevalence and incidence of FS

Both gender and age play a role in the aetiology of FS, as women represent approximately 75% of reported cases (Goldstein, 2019). Although FS can occur in both the old and young (Alper, 1994, Benbadis, 2000), a more recent study (the largest study of adults with FS to date) showed a median age of 28 and an overall modal age of 19 (Goldstein, 2019). The prevalence of FS is estimated as 4.9/100,000/year (Duncan et al., 2011). It is thought that around 12-20% of patients presenting at epilepsy clinics may have FS and among patients presenting with convulsive seizures to emergency services, FS are recognised in 11% of cases (Dickson et al., 2017). This type of seizure is also the most common functional ('medically unexplained') symptom presenting to neurologists.

In terms of race and ethnicity, FS is recognised around the world but differences in access to health centres and expertise mean that there is no reliable epidemiological evidence allowing prevalence comparisons between different countries. In the UK, Goldstein (2019) found that of the 368 people recruited into the largest CBT treatment trial for people with FS, 89.7% were white and 10.3% were Black, Asian, mixed or other.

1.4 Quality of life and mortality rates in people with FS:

Difficulties over diagnosis and a lack of general understanding of their aetiology and treatment have led to estimates suggesting that there is an average of 7 years from onset of FS to diagnosis (Reuber, 2002). When people with FS have been followed up in out-patient clinics, over half were found to be in either a poor or very poor state due to a combination of physical, psychological and social issues (Reuber & Elger, 2003). This same study suggested that around half of patients were receiving or dependent on disability/state benefits during follow up. One study reported that although 69% of patients were in employment when the seizures were initially experienced, by the time they had received the correct diagnosis, this had reduced to just 20% (Quigg et al., 2002). In terms of psychiatric comorbidity, Goldstein (2019) found that 187 of the 368 participants, (51%), had two or more current diagnoses, most commonly anxiety disorders as well as PTSD and depression. Furthermore, a more recent paper highlighted the heightened risks of mortality compared with the general population, illustrating the need for quick and accurate diagnosis (Nightscales et al., 2020).

1.5 Theoretical underpinnings of FS

1.5.1 A Psychodynamic theoretical framework

Early theories on the aetiology of FS are rooted within the psychodynamic literature and conceptualised as the conscious expression of underlying distress and conflict (Freud, 1966). The two major psychogenic models of FS in use today – dissociation and conversion – were developed in the nineteenth century by Janet and Freud respectively (Kanaan & Craig, 2019). Reports of childhood sexual abuse in late nineteenth-century descriptions of FS created controversies, but pioneering French psychologist and philosopher Pierre Janet’s theory that FS is rooted in dissociated trauma has gained currency over the past century. In line with these theories, childhood sexual abuse has been identified as a common precipitant to the development of FS and people with them commonly have co-morbid Post Traumatic Stress Disorder (PTSD) (Bowman & Markand, 1996). Since then, the idea that FS may serve the individual in some way (as a way of escaping emotion) has been broadened to include a wide range of systemic or interpersonal functions.

From a psychoanalytical perspective, FS represent the emotional expression of significant trauma (often sexual abuse). Traumatic experiences are repressed by the individual or the person dissociates during the experience in order to cope. Repressed feelings later convert to ‘hysterical’ symptoms such as seizures. These seizures act as a defensive ‘conversion’ process to cope with emotions associated with traumatic experiences and stress more generally, thus enabling painful feelings to remain in the unconscious (Goldstein et al, 2000).

1.5.2 Contemporary cognitive models:

While keeping the psychological aspects of Janet’s theory, contemporary cognitive models suggest that FS are altered states of consciousness similar to panic attacks, in which the subjective fear component is dissociated from awareness, leading to a so-called “panic without panic” theoretical model, or a “fear-escape avoidance” model (Chalder, 1996). New hypotheses that the cognitive system is organised hierarchically have brought new light to a cognitive model of FS in which perceptual and behavioural processing is held to occur automatically and outside of awareness (Carlson et al., 2012). So, symptoms could emerge as a consequence of psychological processes at these lower levels of processing, and not involving conscious systems at all. While psychotherapy is deemed the first-line treatment intervention for FS (NICE, 2012) and randomised controlled trials looking at the treatment effectiveness of CBT are beginning to take place, in the largest randomised controlled trial to date, there was no significant difference between 12 sessions of manualised CBT plus Psychiatry compared with a few sessions with a Psychiatrist in terms of the primary outcome of seizure reduction (Goldstein, 2020).

Reuber and Brown’s more recent proposal of an Integrative Cognitive Model (ICM) takes into account current research on experiential, psychological and biological risk factors for the development of FS, but due to the wide heterogeneity of presentations, it is questionable whether a universal model can capture the full range of FS manifestations (Brown & Reuber, 2016)

1.5.3 The problematic roles of trauma and stress in relation to FS nosology:

The word “trauma”, from the Greek *traumatikos*, means wound. The current DSM-5 definition of trauma requires “actual or threatened death, serious injury, or sexual violence” (APA, 2013), so stressful events or psychosocial stressors such as divorce or job loss that do not involve an immediate threat to life or physical injury, are not considered trauma in this definition. This nosology becomes complicated when events such as bereavement are considered; the latter not conceptualised as trauma *per se* while the more complex grief reactions such as prolonged grief disorder have a separate nosology in DSM-5 and ICD 11. Complicating matters further, the diagnosis of PTSD was removed from the Anxiety Disorders in DSM-5 and added to a new, more focused, diagnostic category entitled “Trauma and Stressor-related Disorders”, indicating a common focus of the disorders within as relating to adverse events (Pai, 2017).

While the incidence and prevalence of FS appear to be widely accepted in the literature, the role of trauma, stress and its association to conversion disorders in general has become increasingly contested among researchers and health professionals investigating and treating FS, chiefly because the traumatic events could not be seen and were not deemed to be always objectively traumatic. The debate prompted one well-cited FS researcher to comment that “the trauma history has become perhaps the critical issue in the field” (Kanaan, 2016). One of the reasons behind this was that the presence of a causal relationship was unclear. To illustrate the point, Kanaan & Craig described a case in which a woman suffered her first seizure upon hearing her partner say that he was abandoning her. The authors believed that the time factor in this case illustrated that a relationship of some kind was beyond doubt even if the *nature* of the causal relationship remained obscure (Kanaan & Craig, 2019). While they preferred the idea of FS being conceptualised as a "post-stressor disorder" rather than an objective trauma, cases where there is such a temporal proximity such as this are rare. To illustrate their point further, they asked how trauma or stress could be elucidated from people with FS when, by hypothesis, they are "downplaying them, repressing them or dissociating from them?" (Kanaan & Craig, 2019, p.1586). Following this debate, the name "Psychogenic Seizures" has been removed from the DSM-5 (APA, 2013), "psychogenic" meaning 'preceding trauma that explains the illness". The diagnostic manual emphasised instead the need to find "positive clinical features such as a sudden prolonged motionless unresponsive episode with eyes closed in dissociative seizure" (Ludwig et al., 2018). This shift was not however reflected in the International Classification of Disease (ICD)-11 (WHO, 2018) which includes FS in its dissociative disorders group and requires the symptoms to occur within the context of trauma, unsolvable problems and/or relationship disturbance.

1.5.4. Dissociation:

The term "dissociation" is hard to describe but integral to the phenomenon of FS. The ICD-10 dissociative disorders category describes it as a "…*partial or complete loss of the normal integration between memories of the past, awareness of identity and immediate sensations and control of bodily movements*" (ICD-10, 1992, p 151). There is huge empirical evidence for a dissociative account of FS (Pick et al., 2017). Traumatic life events, including but not limited to childhood abuse and neglect, are known risk factors for dissociative symptoms and the development of dissociative disorders. However, while dissociation may account for the mechanism of FS, it doesn't necessarily account for the aetiology.

1.5.5. Brain Network Disorder:

In an attempt to identify biomarkers for diagnosis, treatment response, and prognosis of FS, in the past decade there has been a sharp increase in neuroimaging studies which have highlighted structural brain differences in people with FS. A study by Perez et al (2015) compared cortical thickness in patients with functional seizures with those in a control group who experienced syncope (fainting or passing out). While the study did not find between-group differences, individual differences in illness duration negatively correlated with cortical thickness in anterior and posterior cortical midline structures. Findings such as these, together with recent functional brain imaging literature, contribute to the implication of sensorimotor, limbic, salience, and default mode networks in the pathophysiology of functional seizures (Bègue et al., 2019). These studies however have small sample sizes and the results are often contradictory. They may also tell us nothing about aetiology given that structural changes could result from the seizures.

In summary, the above theoretical debates have highlighted the complexity in diagnosis FS and the potential role of trauma and stress in its aetiology. The following reflexivity will trace my own personal relationship with these seizures and my reasons for wanting to conduct this study.

1.6 Reflexivity:

Between 2015 and 2019, I worked as a Researcher on a randomised controlled treatment trial investigating the effectiveness of Cognitive Behaviour Therapy (CBT) for people who had been diagnosed with FS. I had no idea what these seizures were at the beginning of the study and recall having to Google them before my job interview. My own personal ignorance about these seizures was, I later realised, far more generalised, and included GPs and other health professionals, and by consequence those who suffer with them.

As the trial continued, I became aware just how valuable receiving a diagnosis was to participants, while simultaneously becoming (as a psychology researcher and now trainee psychologist practitioner) far more critical of psychology's medically-driven diagnostic process. For the majority of the participants who were initially referred to Neurology clinics, once epilepsy was discounted, they were often left in a treatment vacuum. I became the focal point of contact in the trial to 70 participants which entailed contacting them every fortnight to ask how many seizures they had noted in their seizure diaries. I became a sort of confidante or "witness" to their suffering and at times it felt more relational than the usual participant-researcher relationship. Many of them voiced their disenfranchisement from the treatment process, while also dealing with losing employment, driving licences, support networks and quality of life.

The trial was followed by a qualitative study in which I interviewed 30 participants about their experience of the seizures, their participation in a research trial and the psychological and psychiatric treatment they received. My paper was published in the Neurology journal *Epilepsia & Behavior* and my own intense personal research experience in which I had strived to be as congruent as possible to participants' inner worlds, was now in the public domain. By this point, I had become privy to many distressing narratives of childhood and adulthood trauma - not just trauma in its narrow definition but broader life stressors such as bereavement, family dysfunction, interpersonal relationships gone awry. These events had emerged to varying degree in most of the interviews, even if they were not always conceptualised within the confines of *trauma* or even stress. But there was a minority for whom there was no apparent trauma or perceived stress and it became incredibly stressful for them when health professionals questioned them, in particular in relation to past trauma.

On an intersubjective level, during the three-year trial and the interviews, I experienced strong feelings of discomfort at both not being able to have answers as to why they, as individuals, had developed these seizures, and at sharing this uncertainty. Part of my discomfort was due to being part of a research team that (I felt) was perceived by participants as a team in a position of power which held some objective knowledge or absolute truth, and who might have answers to their many questions. I certainly brought this interpersonal discomfort to the construct of the current research question in an attempt to find answers. I reflected on how that discomfort continued to play out in the following literature review – a constant tension of trying to uncover some objective truth about any association of trauma and seizures while also attempting to keep a more critical realist epistemological stance.

The following critical literature review will examine how the debates outlined in the Introduction have remained in the world of medicine and to a lesser extent psychiatry and psychology. The review will trace the theme of trauma and stress within the currently published literature.

2. Critical Literature Review:

2.1 Chapter overview

The following narrative review synthesised the abundant literature to identify potential links between trauma, stress and FS. The literature search was conducted in a systematic way but is written as a narrative review. As the literature review largely yielded quantitative studies, synthesising them with the few qualitative studies was methodologically problematic as the two approaches are developed from different ontological, epistemological and methodological perspectives. As such, a narrative approach was felt to be appropriate (Baumeister, 2013).

2.2 Literature review

To create a comprehensive review of the literature pertaining to trauma, stress and FS, a systematic literature search of Pubmed and Psychinfo databases was conducted using the string search “Functional Seizure*”, “Dissociative Seizure *” or “Non epileptic attack disorder” or “Pseudoseizure*” or “NEAD*” or “PNES” or “Psychogenic seizure*” or “Psychogenic non epileptic seizure*” and “trauma*” or “stress*”. The same terms were searched in both databases in title, abstract or as keywords.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses framework (PRISMA; Moher et al, 2009) was used to guide and illustrate the process. The search resulted in a combined total of 1056 records when the date of publication was limited to between the years of 1975 and 2021 in line with the advent of VEEG. Using the RefWorks options Exact Duplicates and Close Duplicates, a total of 848 records were removed and the remaining 208 records’ titles and abstracts were accessed in full text, at which point a further 198 were eliminated for being replicates in methodology or not relevant. Additionally, a snowball search was performed using references in eligible articles which resulted in a further 2 papers. In line with the overall methodology, this is a narrative literature review. Five cross-sectional/case control studies (of which three focused on trauma and two which broadened the research focus to include stress), three within group comparison studies, one qualitative study and three literature reviews were evaluated as suitable for the literature review. Due to the difficulties of synthesising studies with widely different methodologies, the following review studies have been grouped by methodology as far as possible and, within the quantitative literature section, by research focus.

2.3 Positivist research

2.3.1 Case control studies focusing on trauma:

Much of the focus of quantitative literature investigating the role of trauma in FS aetiology has been the psychological profiles of people with FS and compared them with people diagnosed with epilepsy, those with both epilepsy and FS or those with other types of conversion disorder and/or healthy controls. The rationale behind these types of study design was due, in part, to the myriad problems surrounding the superficial resemblance of FS to epilepsy and the need to investigate the *psychological* differences between the groups to improve diagnostic accuracy and prevent unnecessary medication. Given Janet's more than century-old theory of the association between these seizures and child abuse and Freud's formulations on childhood sexual trauma and hysterical symptoms, once Neurologists could be more certain of an accurate FS diagnosis, initial more contemporary studies (since 1975) focused on the links between childhood trauma and FS.

In one of the largest and earliest prospective controlled studies, Alper compared 71 consecutive outpatients with a FS diagnosis, 14 with a diagnosis of both FS *and* epilepsy against a matched (demographic) group of 140 complex or partial epilepsy. Gathering data through clinical interviews and trauma/abuse histories, the study found higher rates of childhood sexual *and* physical abuse in the FS outpatients compared with the epilepsy group and a clear trend of a closer relationship of the perpetrator of sexual abuse to the victim among the FS group than in the epilepsy group. The authors concluded that the elevated rate of childhood physical abuse in the FS group indicated that the antecedent trauma need not be sexual in nature. They also concluded that a history of abuse could not preclude an epilepsy diagnosis as authors found childhood abuse in 8.6% of patients with epilepsy (Alper et al., 1993).

These findings were replicated by Turkish researchers who found significantly more childhood sexual and physical abuse and physical neglect reported by outpatients with FS compared with demographically matched healthy controls (Ozcetin et al., 2009). The study used the Childhood Trauma Questionnaire, a tool that has been used in various studies of FS and childhood trauma - to compare rates of emotional abuse, neglect, physical and sexual abuse between 56 female patients in a psychiatric outpatient clinic against a matched group of 59 controls. Rates of dissociative experiences between the two groups were also explored using the Dissociation Questionnaire (DIS-Q). Study outcomes found the strongest correlations between emotional abuse and neglect scores and conversion. Three quarters of the outpatients also showed dissociation liability. The study concluded that seizures were far better explained by a *multifactorial stress model* rather than a unifactorial one of trauma, thus building on Alper's evidence. In a more recent study comparing people with FS with healthy controls, Pick found higher rates of trauma, in particular sexual and physical abuse (Pick, 2017). The study, comparing 40 people with FS to 40 healthy controls, also found higher rates of emotional abuse and neglect when compared with controls. Further regression analysis concluded that a self-reported history of sexual abuse was solely predictive of FS diagnosis and that sexual abuse increased three-fold the chances of someone receiving a diagnosis of FS. The study used a questionnaire that had up until that point never been used with people with FS – the Multiscale Dissociation Inventory (MDI) (Briere, 2002, as cited in Pick, 2017), which is a major strength of the study. The authors reported that scores on all the MDI subscales were significant predictors of being in the FS study cohort.

Building on the work that came after World War 1 which investigated the links between functional paralysis and shell shock, Salinsky's research has shone a light on the links between the trauma of war and FS. Veterans with FS were compared with those with epilepsy in terms of diagnostic comorbidity (Salinsky, 2012). Using medical records, researchers found that veterans with FS had a median of three Axis 1 diagnoses prior to admission whereas those with epilepsy had a median of one. PTSD was the most common Axis I diagnosis in veterans with FS, documented in 58% of veterans compared with 13.5%

in those with epilepsy. Rates of major depressions followed in a similar vein with a rate of 46% to 29.7%. Like many of the studies looking at PTSD diagnoses, this study is flawed by the fact that not everyone who has experienced a trauma will continue to develop PTSD.

2.3.2 Broadening the positivist focus to psychosocial stressors

From 1980 onwards, researchers in FS began realising that childhood sexual abuse alone could not be predictive of the seizures and started broadening research to focus on the links between stress and FS. Given that life events form the basis of psychological formulation, incorporating adverse life events would appear to be an important step forward in the diagnosis and treatment of people with FS. Studies by Bowman were among the first to consider broadening out the relationship between FS and trauma to encompass stressful life events (Bowman & Markand, 1999). In a unique mixed methods study design, they used a narrative, psychodynamic interview style for data gathering to ascertain whether participants with FS had experienced traumatic events or life stressors either “recently”, “contextually” or “remotely” (occurring more than a year before) the onset or recurrence of seizures and what these events were. The researchers rated remote events on whether there was an emotional response, conversion symptom or whether the participant spontaneously said that the event was significant in relation to seizure onset. They found that women (63%) reported far high levels of childhood and adulthood physical or sexual abuse than men, while men with FS reported more relationship or family problems or status change (such as a job losses). Importantly, the authors noted that it was the traumatic act itself rather than its timing that was key in the association with FS. Significantly, they also found that where there was no specific trauma, participants spoke of personal or familial avoidance of discussion of conflict or expression of affect or emotion.

Similarly motivated to broaden the research to explore other life stressors other than childhood trauma, to include perception of stressful events, somatic symptoms, illness worry and bodily awareness and alexithymia, a controlled study by Tojek (2000) found elevated rates of all these variables among the group with FS as compared with the group with epilepsy. Using an adapted version of the Lifetime Events Checklist among other measures, Tojek found significantly higher rates of adult physical abuse in the FS group than the epilepsy group, more stressful life events and a perceived greater impact of these events. However, the authors also noted that sexual abuse as an adult, separation/divorce and alcohol/drug problems were marginally statistically significant in the FS compared with the epilepsy group. They concluded that while childhood trauma was a possible determining factor for some people, adult stressors were just as likely to be part of the aetiology and as such, should be investigated as part of any research focus.

2.3.3 Within group studies:

Investigating the hypothesis that the presence (or not) of trauma may indicate two *distinct* trauma psychological profiles for people with FS, a prospective study by Hingray separated a group of 25 people with FS into those with a history of trauma, based on the presence of self-reported trauma, and those without. They used questionnaires such as the Childhood Trauma Questionnaire (CTQ) and clinical interviews to ascertain past trauma and found that those with trauma (*n*=19) had other psychological comorbidities and dissociation while those in the smaller group of no trauma (*n*=6), there were no comorbidities (Hingray et al., 2011). The study found that 5 in the trauma group had not experienced childhood abuse but had experienced a traumatic event just before the development of the seizures, for example, been told of a family member's terminal illness or witnessed a violent death. In the trauma group, everyone had experienced several traumas (median =3). They also found that 9 in the trauma group had mood disorders and a history of suicide attempts (Hingray et al., 2011). Results showed a high level of psychiatric comorbidity and a strong dissociative mechanism linked to the presence of trauma. In the no trauma group, there was no comorbidity and only a weak link to dissociative experiences, although there were precipitating and perpetuating factors present. The study concluded that the presence of a psychiatric comorbidity in addition to FS should strengthen the possibility of a trauma, but it was hard to generalise from this study as the sample was small and there was an overrepresentation of men in the no trauma group. It did however suggest there were two distinct FS psychological profiles - one with trauma, one without - which remains significant for treatment purposes. Elevated levels of childhood sexual abuse were also found in a previous study by Selkirk et al., (2008) who separated 176 consecutive patients with FS attending an outpatient clinic into those who reported this abuse and those who did not. A total of 45% of women and 11% of men reported abuse. Between group difference analyses led the researchers to conclude that those with previous abuse histories had earlier onset of FS (28 versus 33 years old), greater delay from onset to diagnosis and were less often in cohabiting relationships (*p*=0.0006). They also had poorer mental health on a range of measures and their seizures were characterised by being more severe, more "convulsive" in nature and resembling epilepsy. They reported more nocturnal seizures, as well as incontinence and injury during seizures (Selkirk, 2008).

2.3.4 Reviews:

A much cited critical review of quantitative literature by Fiszman - which analysed 17 studies between 1993 and 2004 comparing the prevalence of traumatic events and PTSD symptoms in people with FS with control groups - found very high levels of trauma (44-100%) and PTSD symptoms in the FS group (Fiszman et al., 2004). The review concluded that there were rates of between 23-77% of either physical or sexual abuse in the FS population. The study found that 82.6% of FS patients across seven studies reported "general traumatic events” other than abuse, compared to 62% in epilepsy patients across three studies. Fiszman suggested that in some cases, FS might represent a manifestation of the dissociative type of PTSD. However, there were limitations with the individual studies making any comparison of results between them methodologically spurious and the authors cautioned against generalisations. There was a lack of standardised instruments detecting traumatic experiences and abuse; the one study which used a specific questionnaire (Trauma History Questionnaire) found the highest rate of reported trauma (100%), which may have meant that other studies were failing to pick this up.

An association between trauma (as defined by a diagnosis of PTSD) and FS was further supported by a meta-analysis of 32 quantitative studies by Diprose investigating rates of psychiatric comorbidity between people with FS and those with epilepsy and the general population. The meta-analysis was an attempt to build on Fiszman’s work but to include other psychiatric comorbidities, not just PTSD. Despite the widely varying methodologies of the studies reviewed – the studies were not all case controlled and widely varied in their detail of reporting in relation to the DSM classifications - the analysis revealed rates of between 53% and 100% in the FS population, with elevated levels of PTSD, anxiety disorders (in particular panic disorder), personality disorders and depression (Diprose, 2016). The elevated levels of psychiatric comorbidities led the authors to highlight the possibility that FS may in fact be a clinical expression of several disorders rather than one discrete nosology, and queried whether treatment of the other disorders may in turn reduce seizure frequency.

In the only synthesis of qualitative studies to date exploring the subjective lived experience of FS, Rawlings and Reuber combined a total of 220 participants from 21 studies who were interviewed in relation to different aspects of FS. The 5 overarching themes that emerged were seizure events, diagnosis, treatment and management, emotional events and impact on daily life (Rawlings & Reuber, 2016). The subtheme 'emotions and trauma' emerged as part of the superordinate theme "emotional events". Many participants discussed traumas, such as emotional, physical and sexual abuse, but crucially they also spoke about a wide range of psychosocial issues such as relationship problems, domestic abuse and conflict. In many cases, participants associated feelings of anxiety, panic and highly stressful events with the initial onset of the seizures, while a few also described happy occasions around the time of the initial seizure (Rawlings & Reuber, 2016). However, there were wide variations in methods of data collection, ranging from open ended interviews to structured clinical interviews and an even more diverse range of research methodologies (content analysis, linguistic analysis, conversation analysis, IPA to name a few).

2.4 Qualitative studies:

While quantitative techniques are crucial in understanding the separate psychological profiles of those with FS compared with epilepsy, qualitative techniques can be used to explore a far richer understanding of people's experiences and for the purposes of this paper, the unique attributions those with FS may have about their seizures and links or hypotheses to previous life experiences. The process and understanding of the diagnosis or of a changed diagnosis (Karterud, 2009; Reuber, 2019) or the burdensome experience of living with the seizures (Rawlings et al., 2016) have all been explored in qualitative literature. Pick conducted semi-structured interviews with 14 people with FS to explore their experience and sense-making of emotion (Pick, 2016). Interpretative Phenomenological Analysis (IPA) was used in the analysis in which the onset of FS as linked to trauma and stress emerged as a superordinate theme. Participants often described stressful circumstances or elevated stress levels as having occurred at onset of the disorder, or immediately preceding this. Some patients described multiple life stressors occurring prior to FS onset. The study concluded that almost all participants had experienced traumatic (interpersonal abuse) or stressful life events, often in childhood. Participants reported that while they had often locked these traumas away, they also attributed them to the onset of FS and often formulated FS as a consequence of unprocessed negative affect, allowing them a release or a shutting-off from the ensuing emotional experience (Pick, 2016). The study's main limitation was that once study participants had received a diagnosis, they had then been directed to Functional Neurological Disorder websites from which they may have gleaned psychoeducation on the trauma-seizure theoretical associations, which in turn may have biased the data.

2.5 Conclusions:

The weight of the evidence of the studies reviewed supports the thesis that both trauma and stress, jointly and separately, have a role to play in the onset of FS, but problems remain with perception and interpretation. The literature reflects the gradual realisation that the initial narrow focus on childhood trauma was to the detriment of looking at adult life stressors or even the possibility of both. Hingray's study is of note in the research canon as she used her research findings to question the need for a traumatic history and her development of two distinct trauma-related and non-trauma related groups linked to FS remains significant. However, we could also hypothesise that the *precipitating and perpetuating factors* in Hingray's non-trauma group could be conceptualised at the very least as stressful events for other researchers in the field.

The positivist reliance on diagnostic criteria, questionnaires and measures - however well validated in the empirical sense - are nonetheless constructions which fail to provide the whole, subjective story and risk diminishing participants to physical units rather than human beings with life stories to explore and consider. Further limitations of quantitative studies - noted in the systematic reviews by Fiszman (2004) and Diprose (2016) - were that the majority of quantitative research has been characterised by small sample sizes and retrospective data, thus hampering the possibility of confirming hypotheses. Furthermore, the individual controlled and cross-sectional studies reviewed here cannot (and should not) provide causation, only association. Given the far higher rates of sexual assault and violence reported by women than men, FS studies that did not control for gender are vulnerable to reporting falsely elevated rates of abuse associated with FS (Bowman, 2018). In short, the research methodologies that have investigated FS in psychiatry and cognitive psychology from a quantitative approach appear to fall short of appreciating the full subjectivity and heterogeneity of the experience of living with Functional Seizures and this should be a priority for future research.

Conversely, researchers specifically focusing on the associations between childhood trauma and FS have justifiably questioned the ethics of asking people to talk in depth about their childhood experience and relied on questionnaires instead (Ozcetin, 2009). What remains significant however is when studies have used a clinical interview with a psychotherapist in a confidential setting, they have found overall lifetime trauma to be between in 84% to 90% of people with FS while studies using self-report or non-systematic assessment report lower rates (Bowman & Markand, 1996). These clinical interviews however are also subject to their own limitations, being non-standardised and possibly subject to interviewer bias when not blind to participant group.

In conclusion, the evidence from the literature regarding trauma and stress has at times been mixed, prompting researchers to increasingly caution against looking for trauma *per se*. A broader sense of stress and stressful life events, with or without a childhood trauma, appears from the evidence to be a greater indicator of FS and methodologically valid. The literature suggests that a more helpful conceptual framework for health professionals involved in therapeutic treatments for people with FS is that exposure to potentially traumatising events is *not* present in everyone with these seizures, and that trauma is *neither* a necessary nor sufficient condition for symptom development. The literature suggests that a more comprehensive account of FS must be able to accommodate these indications without relying on them to explain the seizures. Yet, while attributing a specific cause to FS is conceptually and clinically contentious, there seems to be agreement that FS represent a *physical* expression of *psychological* distress.

Descriptive, qualitative work such as that by Pick (2017), exploring at greater length the specific themes of trauma and associated factors, has lagged far behind quantitative studies. Within the qualitative literature synthesis (Rawlings & Reuber, 2016), only one study sought to explicitly ask participants about their understanding of why they had seizures while the others focused on the experience of the diagnosis. This should be a focus of further research.

What the literature did reveal is that as a psychological phenomenon, FS sit uncomfortably and unhelpfully in a liminal space between the medical world of neurology and the world of psychology or, more typically, psychiatry. It seems apparent that the phenomenon of FS, due to its physical resemblance to a medical condition, is hampered by its very essence, and often investigated through the lens of a medical, diagnostic model let alone a psychological or even phenomenological one. One effect of this reliance on the medical model, from the broader aspects of the literature review, is that the majority of the published research into FS was found in Epilepsy journals such as ‘Epilepsy and Behaviour’, ‘Seizure’ and ‘Neurology’, and as such, conducted by Neurologists, rather than Psychologists. Counselling Psychologists need to conduct separate research in this area. Their involvement in the FS debate would increase the chances of finding better treatments.

2.6 Limitations:

This review condensed and contrasted an important body of literature concerning the role of trauma and stress in the aetiology of FS and asked whether the voice of those with FS was heard in the literature. There are several limitations. The studies were not systematically evaluated against any methodological research quality or appraisal, although these were considered in defining the inclusion criteria. There were no papers on FS published in the developing world included here which limits the transferability of any conclusions beyond the ‘global north’, making them culture specific and not necessarily reflecting the research and views of health professionals or clinical populations in non-Western, non-English speaking countries.

2.7 Rationale for this study:

The current understanding of the links between FS and trauma and stress has largely been held up as an objective truth but has nonetheless been garnered via blunt tools such as questionnaires. The unique voice of those with lived experience of it needs a far greater presence in the research canon. The importance of understanding the perceptions of those with lived experience of this condition is crucial as it can impact adjustment and acceptance of FS. For most people it is important to know how to categorise an illness and to know its causes. This narrative review highlighted the striking paucity in the literature to date of the subjective voice, so doing this would be an attempt to redress the balance while providing greater insight into the inner world of people with FS. Given that women suffer from these seizures at a ratio of 4:1 in comparison to men, this study proposes a more phenomenological approach to the lived, subjective experience and sense making of women living with FS. My research proposal aims to:

- Explore women’s sense-making of the seizures and whether and how their seizures relate (or not) to experiences of trauma and stress.

- Explore whether notions of trauma and stress are helpful or unhelpful in the sense-making of the seizures.

The rationale is that some salient understandings could be generated to further inform therapists, health professionals and researchers in terms of psychological interventions. This could have a particular importance for the field of Counselling Psychology as the research would fit with Counselling Psychology’s emphasis on prioritising the client's subjective and unique experience (Cooper, 2009).

2.8 Reflexivity:

I began this research assuming that I would recruit men and women into the study. However, after discussions with my Director of Studies, we agreed that the study should focus on women only. This was largely due to the fact that research has shown that women are four times more likely to report these seizures than men. Also, men tend to report these seizures at a much later age than women and are more likely to follow health related issues. As such, we hypothesised that their attributions for seizures might be quite diverse from those of women and as a result, not in keeping with Interpretative Phenomenological Analysis (IPA) requirement for homogeneity.

A central ethos of Counselling Psychology is the appreciation of (inter-)subjectivity (Cooper, 2009). By choosing IPA for my study methodology, I was able to practice regular reflexivity in how my research topic was influenced by my own personal experiences and values, as well as how these affected the subsequent research process. IPA allowed me to appreciate the subjective sense-making of FS as well as how these meanings were inevitably co-constructed between me and the participant – the double hermeneutic - in the context of the research interview. Conducting this study has enabled me to gain a greater sensitivity towards inter-subjective processes in research and illustrated the importance of reflexivity when conducting psychological studies.

3. Methods

3.1 Chapter overview:

This chapter will provide a rationale for employing a qualitative approach for my research, explore conceptual underpinnings and address the epistemological and ontological considerations. The methodology will be outlined, followed by the research design, procedure, analysis and ethical considerations. I will begin critically outlining my choice of epistemology and ontology, followed by a discussion and justification of the chosen method of Interpretative Phenomenological Analysis (IPA) (Smith, 2003).

3.2 Research methods in existing literature:

Research into Functional Seizures continues to be dominated by a positivist or "natural science" framework. To date, quantitative studies have focused on symptoms, psychiatric diagnoses and checklists of traumatic events in order to differentiate the clinical presentations between people with FS, those with epilepsy and healthy controls. While the rationale for such studies can be understood to shed light on the diagnostic problems faced by clinicians, in particular Neurologists, and the decision making around care pathways and treatment, it does not contribute towards a greater understanding of how individuals with FS make sense of this very difficult condition. From a Counselling Psychology, critical realist perspective, this reductionist, cause-effect relationship perspective has left a gap in the literature which this research aims to fill with the subjective lived experiences and unique voices of women with FS. These voices need to be respected and understood in their own terms.

3.3 Rationale for adopting a qualitative approach:

To bridge the gap, this current study question demands a qualitative rather than quantitative approach and aims to complement existing literature, as well as add to the growth of new knowledge in this area. A qualitative approach is also consistent with the critical realist position of this study which considers reality to exist, with meanings and experiences of this reality to be fluid and subjective, as they depend upon people's individual beliefs and expectations (Bhaskar, 2008; Finlay, 2006).

In the past 30 years, there has been a greater recognition and appreciation of the benefits of qualitative research methods in psychological research (Ponterotto, 2005), with Counselling Psychologists arguably being some of the strongest proponents of such methods within the field (Morrow, 2007). Counselling Psychology's foundational and strong appreciation of subjectivity and intersubjectivity as well as an understanding of the impact of social contexts on psychological research and practice, lends itself to qualitative research (Cooper, 2009; Morrow, 2007). Applying such a congruent method to this research therefore can allow for a richer, deeper exploration and understanding of the interplay between external and internal experiences, phenomena and realities.

3.4 Rationale for adopting IPA:

As a methodology, IPA is particularly suited to exploratory and reflexive research and encourages the researcher to explicitly integrate aspects of their identity within the data. The phenomenological foundation of IPA will allow for the subjective, idiographic sense-making and lived experience of people with FS to emerge. Specifically, it supports the notion of individuals holding different perceptual realities and reflects the fact that this research is concerned with how people see the world and further assumes that individuals' accounts suggest 'something' about their thoughts and feelings.

In attempting to understand the sense making and idiosyncratic experience of Functional Seizures, the research prioritises the individual, subjective perspective. IPA's focus is on the person - the personal experience of an individual and their views and understanding - rather than on the phenomenon itself (Finlay, 2009). IPA's inductive approach allows for the use of flexible techniques which can lead to the emergence of unanticipated themes during analysis. In line with this approach, IPA researchers do not attempt to verify or negate specific hypotheses established on the basis of extant literature; instead, they construct broader research questions which lead to the collection of expansive data (Smith et al., 2009). IPA's inductive approach is apposite for this study which aims to explore women's experiences and personal meanings of Functional Seizures, in order to contribute to richer, new and enhanced understandings in this field.

To further understand the approach adopted for this research, it is first helpful to consider IPA's three main influences, phenomenology, hermeneutics and idiography, under the broader philosophical themes of epistemology and ontology.

3.5 Epistemological and Ontological Position:

In reflecting on the epistemological stance underlining this research, three issues needed to be considered, as proposed by Willig (2013). What kind of knowledge do I aim to produce? What are the assumptions I make about the world and lastly, how do I conceptualise the role of the researcher in the research process?

This research aims to give a narrative, a story (or body) of knowledge that would reflect something of the subjective experience of Functional Seizures and the attributed meanings ascribed to them by women participants. This understanding emerges through dialogue and interpretation between myself and the participants and therefore is intersubjective in nature and not purely individual. The philosophical underpinning of this current study is one of phenomenology, one of the three foundations of IPA. The analysis aims to represent the women's sense making and experience of Functional Seizures yet remains dependent on my own standpoint, resulting in a reflective approach. In assuming that as researchers, we cannot separate ourselves from what is known, the area of exploration and myself are connected. It is believed that who we are and how we understand the world is therefore integral to how we understand ourselves, other peoples' experiences and the worlds (Fosha, 2002). Furthermore, an interpretative paradigm suggests that my own values are inherent in all phases of the research.

3.5.1 Phenomenology

Husserl (1973) is recognised as one of the earliest influential figures in phenomenology and introduced the significance of '*life worlds*' or '*lived experience*' as the foundation for understanding, rather than empirical science. This position is understood to prioritise *experience* as the most basic knowledge, and recognises the value in using individuals' understanding of experience in discovering the world. Husserl advocated for a focus on ‘the things themselves’, the experiential content of consciousness (Smith, Flowers & Larkin, 2009). He believed that it is only in consciousness that something can materialise, and only by reflecting upon the way something appears without bias can it be possible to comprehend what it is to know something. The notion of intentionality of consciousness and the related notion of intentional content is considered as the crux of Husserl’s philosophical investigation.

From a phenomenological perspective however, his research also assumes that there are multiple subjectivities and realities and that the same event – even a seizure - could be interpreted and experienced in varying ways, supporting the assumption that there is no simple reality. Rather, it is argued that there are only interpretations of the world, as the world in this respect does not exist independently of our knowledge of it. This relativist position questions the outer world and ultimately forgoes the belief of a single truth and fixed meaning, as truth is considered dependent upon perspective (Willig, 2013). This current research aligns most closely with Willig’s (2013) assertion that reality as we know it is formed intersubjectively through meaning and understanding shaped independently, experientially and socially.

3.5.2 Hermeneutic Phenomenology:

Phenomenology is often considered to have two significant orientations, the transcendental and the hermeneutic (Larkin & Thompson, 2011). Hermeneutics is the theory of interpretation, and within a research paradigm, involves the researcher interpreting the participant’s interpretation, a double hermeneutic. The interpretative researcher therefore is able to offer a perspective on the participant’s text which the participant themself is not. However, as Smith cautions, from an IPA perspective, this does not mean that we as IPA researchers believe that our claims are truer or more valid than those of our participants, but the methodology does perhaps allow for our analyses to “offer meaningful insights which exceed and subsume the explicit claims of our participants” (Smith, 2022). As Smith suggests, some of this researcher insight is a result of a systematic, detailed reading of all the transcripts, and also from some link with psychological or an/other theory.

For the German philosopher Heidegger however, phenomenology is a discipline which concerns itself with comprehending the thing as it emerges or is “brought to light” (Smith, 2022) and he advanced the theory of a hermeneutic or interpretative phenomenology. Heidegger’s belief that appearance has a dual quality – both visible and invisible or concealed meanings – is a useful lens through which we can study FS. There is the participant’s understanding of the *appearance* of the seizures but this current study also concerns itself with exploring what is hidden from view, what is concerned with participants’ ideas and sense-making. In that way, the IPA analysis will aim to deliver participants’ embodied and existential understanding of the seizures. Further triangulation will also allow readers to make links between the findings of an IPA study, their own personal and professional experience, and their understanding of the extant literature.

For Heidegger, his notion of ‘being-in-the-world’ views humans as always being in context, and he places emphasis on our engagement with the world. As such, Interpretative Phenomenology assumes that we are embedded in a pre-existing world of language, history, culture and social relationships and human experience cannot be meaningfully detached from these. This position postulates that we are entangled with the world and in relation to others. It speaks to the notion of inter-subjectivity, to the shared, overlapping and relational nature of our engagement in this world. It also holds that while we attempt to make sense of the world, we also attempt to understand ourselves.

Hermeneutic thinking suggests that when interpreting phenomena, the interpreter (researcher) inevitably brings their fore-conceptions (prior experiences, assumptions, preconceptions) to the encounter and that these influence the interpretation (Heidegger, 1962/1927). Hermeneutics highlights however that priority should be given to the new phenomena, rather than to one's own preconceptions (Heidegger, 1962; Spinelli, 1989; Smith et al., 2009). Similarly, IPA recognises that access to experience is always dependent on what participants say about that experience, and that the researcher then needs to interpret that account from the participant in order to understand their experience – the aforementioned double hermeneutic (Smith et al., 2009). In keeping with hermeneutic phenomenological thinking, IPA acknowledges that in advance of an interview reading, a researcher may not necessarily be aware of all of their pre-conceptions that might influence the analysis, and so recognises that reflective practices are required (Smith et al., 2009). This study acknowledges my role as researcher in the exploration of these seizures. Its more interpretative philosophy means that I cannot preclude my own influences and pre-conceptions about the topic under research. This study is therefore not concerned with accurately identifying and measuring an independently existing singular reality, or determining whether participants' accounts may be 'true' or 'false', but will focus on providing a rich and comprehensive description and interpretation of experience and sense-making. For the German theorist Gadamer, hermeneutics involves "the interpreter's own thoughts …have gone into re-awakening the text's meaning." (Gadamer, 1989), generating what Gadamer understands as an integrating "conversation" or a "fusion of horizons" (*Horizontverschmelzung*) (*Truth and Method*, 1989: p. 370), allowing something to "emerge" which henceforth exists. For Gadamer, it is the integration of the text and the interpreter's response which is akin to a "a real conversation” in which “the common subject matter is what binds the two partners, the text and the interpreter, to each other” (Ibid. p. 389).

3.5.3 Ontology

Much of the literature surrounding Functional seizures is grounded within a positivist, empirical framework. My rationale for this study is that the subjective voice of those with FS has often been overlooked, leading to a detrimental negation of those who suffer with them. My own ontological position in relation to this thesis is one of critical realism. Several realist assumptions underpin the study focus: that participants are active agents who can access their experience, and that I can to some extent capture the participants’ thoughts and feelings as they exist in the world (Willig, 2013). As such, critical realist ontology allows for the recognition of the existence of realities outside of language such as embodiment, subjectivity and unconscious, sub-symbolic processes.

3.5.4 Limitations of IPA

IPA is a relatively new methodology (it was developed in the 1990s) and so it continues to evolve and mature. As such, an arguable limitation may be that researchers are still grappling with how to show its transparency and validity. IPA’s requisite of small sample sizes mean that it cannot be usefully used to achieve generalisations. However, gathering rich, transparent and adequately related literature can assist in the findings’ transferability (Smith et al., 2009). Moreover, IPA does not aim to achieve generalisations or be representative through populations; its intention is to enrich or reveal in-depth aspects of unique understandings of FS that can be sufficiently attained in small samples.

3.6 Other Methodologies and Summary

Given IPA's original development as a tool for qualitative research in the psychology of health and illness (Willig, 2008), it was the most appropriate analytic tool for this study. It allows for an exploration of the unique meanings that people assign to a certain experience, in this case Functional Seizures. IPA is concerned with the individual as opposed to the nomothetic and is particularly useful if the phenomena is emotionally laden (Smith & Osborn, 2014). As a methodology, it allows for the exploration of specific experiences and understanding without seeking to establish generalisations at a group level on the basis of large datasets (Larkin, Watts & Clifton, 2006; Eatough & Smith, 2008). The aim of this study is not a transferability of results as each participant will be viewed as an individual case study with a unique experience and understanding of the aetiology of their seizures. It will then be up to the researcher to interpret this sense-making in a process of double or triple hermeneutic interpretation (Smith, 2009) - the latter meaning that the participant came to the interview with me already in a process of interpreting the Neurologist's own understanding and communication of the diagnosis.

Other qualitative approaches such as Thematic Analysis (TA) or even Thematic Framework Analysis could be potential methodological alternatives to IPA (given the heterogenous nature of the seizures), but the more experiential or phenomenological aspect of the study might be lost. As mentioned above, the aim of this study is to generate in-depth descriptive accounts of how participants understand their seizures, rather than explanatory, theoretical accounts, as might be expected from a methodology such as Grounded Theory. IPA is the optimum methodology for this as it remains self-reflective and focussed on the subjective human experience communicated in its own terms. It aims to capture complexity, process and novelty, appealing to the present research area (Smith & Osborn, 2003).

3.7 Study Design:

The research used an inductive, qualitative paradigm to analyse in-depth semi-structured interviews. The decision to use qualitative rather than quantitative methodology was grounded in the fact that the research question lent itself to a more in-depth, focused approach. The research topic demanded a strong gaze on participants' subjective understanding rather than looking for patterns in large datasets. A further strength of conducting interviews was that conversation was more likely to be natural, leading to the production of richer and more realistic data than using questionnaires. It could also promote the establishment of a rapport between interviewee and Researcher which is not always possible when using quantitative methods (Coolican, 2001). My epistemological approach is one of critical realism in which I am not seeking some positivist, objective truth but rather a subjective exploration of women's sense-making of FS.

3.7.1 Sampling and Participants

Purposive sampling was used to recruit eight women over the age of 18 who had received a FS diagnosis via EEG or Video EEG, who continued to experience seizures (at least one in the past 3 months), and who had *not* received psychological treatment. The rationale for participants *not* to have received any psychological treatment was that therapy, irrespective of approach, would introduce a potential bias in their responses to questions about how they understand FS. Potential participants were included if they have additional diagnoses such as PTSD, bipolar disorder or Borderline Personality Disorder, all of which are relatively common in this group. However, comorbid diagnoses of either epilepsy or psychosis were an exclusion criteria.

Online recruitment took place via the website of a national charity - FND Action - that supports people with a wide range of functional neurological disorders such as Functional Seizures and who support a wide range of research. The charity advertised the poster on their website and on their Facebook page. The advertising of the study was linked to an information sheet detailing what the study would involve for participants and the Researcher’s contact details.

3.7.2 Procedure

Eight women participants aged between 19 and 62 (mean = 35) were recruited to the study, in line with the above inclusion and exclusion criteria (Table 1). Prior to approval of participation, an initial telephone screening was conducted to verify the suitability of the participants and to ensure that they fitted the inclusion criteria. The study was explained in full and any questions that potential participants had were answered.

Consent was sought from participants and a suitable day and time was agreed for the interview. Participants were offered a face-to face-interview if they preferred but all participants preferred the online option. Participants were sent a Microsoft Teams link to their email and a reminder text on the day of the interview. Before the semi-structured interview, each participant was asked a set of demographic questions which included whether they had any comorbidities (Table 2). Confidential, open-ended semi-structured interviews took place online lasting no more than 90 minutes.

Table 1. Study Inclusion and Exclusion criteria	
Inclusion Criteria	Exclusion Criteria
Women participants aged 18 or over with a VEEG or EEG diagnosis of FS	Women with a diagnosis of FS with co-morbid epilepsy
Participants have experienced a seizure in the past 3 months	Women with FS who have co-morbid psychosis

Participants have not received any psychological or talking therapy for their seizures	Not able to read or speak English
Participants can communicate in English	

Table 2:

Socio-demographics table of participants

Pseudonym	**Age**	**Ethnicity**	**Work Status**	**Psychiatric Diagnoses**	**Comorbidities**	**Length of time of FS**	**Time between onset and diagnosis**	**Carers/ use of wheelchair**
Tara	23	White British	Student	None	Deafness, hypermobile, Irritable Bowel Syndrome (IBS)	3 months	4 days	No
Becky	43	White British	Unable to work	PTSD symptoms prior to seizures	Functional Neurological Disorder / coeliac disease	20 months	1 day	Yes (34 hours/week) Use of wheelchair
Pearl	32	White British	Part time nurse (previously patient facing)	Anxiety and Depression	None	6 months	5 months	No
Annie	36	White British	Sick leave	Anxiety and Depression/ ADHD with autistic traits/Cyclothymia/ Anxious Personality Disorder/Dependent Borderline Disorder/	Migraines/Fibromyalgia/ Functional Neurological Disorder	8 months	2 weeks	Yes (husband) Use of wheelchair outside
Georgina	62	White British	Retired	None	None	7 years	7 years	No
Bridget	32	White British	On maternity leave	None	Fibromyalgia, Endometriosis, Chronic asthma	5 months	7 weeks	No

Jane	37	White British	Sick leave	Anxiety	Chronic back pain/Migraines	2 months	4 weeks	No
Lucy	19	White British	Student	None	Hiatus hernia	8 months	6 months	No

3.7.3 Materials

Materials included:

- A Participant Information Sheet (outlining the purposes of the study, why participants have been invited to take part, and what it involves). Confidentiality was outlined as well as the right to withdraw at any time (Appendix 2).
- Consent form(s) ensuring participants understood the information sheet and agreed for research data to be gathered and analysed and published. Each participant was asked to sign two, allowing for both participant and researcher to keep a copy (Appendix 3 and 4).
- A demographic questionnaire covering sex, age, ethnicity, employment status, whether participants had carers, the length of time participants had experienced FS and the length of time between the onset of seizures and a FS diagnosis (Appendix 5).
- An encrypted audio recorder to record the semi-structured interviews.
- Interview schedule (Appendix 6)
- A debrief sheet with the contact details of the university and the researcher in case the participant had any follow-up questions following the interview and details of signposting to helplines/services (Appendix 7).

3.7.4 Data Collection

Consenting participants were contacted and interview data was collected between October 2022 and January 2023. To provide an adequate amount of time for the questions and subsequent follow-up questions, interviews lasted between 45 and 90 minutes. All interviews were recorded using an encrypted dictaphone and transcribed verbatim on to a password protected computer. Participants were given both an ID number and a pseudonym (within the transcriptions).

3.7.5 Data Analysis

I transcribed each interview once it had been completed and followed a set of seven steps:- 1) reading and re-reading; 2) initial noting, descriptive; linguistic and conceptual comments; 3) constructing experiential statements and developing emergent themes; 4) looking for connections across statements; 5) naming the Personal Experiential Themes (PETS) and organising them into a table; 6) moving to the next case and lastly 7) working with PETS to develop Group Experiential Themes (GETS) across cases (Smith et al, 2022). This process, as mentioned above, is described by Smith as a double hermeneutic during which the researcher tries to make sense of (interpret) the participant who is also trying to make sense of (interpret) their experience. Goldspink (2019) has recently suggested a reflexive adjunct to step 3 in which the researcher, as they reach the juncture between observation and interpretation, takes a pause to "attend to the echoes" of the data. This not only resonates with Heidegger's idea of space and time (past, present and future) but allows a space to start the process of seeing what the descriptive data means for the research and the researcher within their own "historicity and temporality".

3.8 Ethics

3.8.1 Ethical approval

Ethical approval was granted by Roehampton University Ethics Committee (PSYC 22/435) on 28th September 2022. During recruitment, measures were taken to ensure that potential participants did not feel any pressure to take part in the study. All advertising stated that there was no obligation to take part in the study. I reminded participants during the interview of the following:- that they could terminate the interview at any time; that following the interview they could ask for it to be withdrawn; that the interviews were being recorded and that the data will be kept and stored in accordance with the Data Protections Act (2018) and GDPR guidelines.

3.8.2 Risk:

I ensured that if a current participant had a seizure during the interview, I would respond sensitively and empathically to this. Prior to all interviews, the participant and I discussed a plan of action that I could follow in such an event. Strategies were put in place ahead of the interview such as knowing if there was a family member in a different room that I could call. If participants became fatigued or distressed, I responded sensitively, asking if the participant would like to move on to another question, suspend or postpone the interview, or withdraw from the process. Given the potentially distressing nature of the interview themes, a full debrief (Appendix 7) took place afterwards and relevant services signposted such as helplines such as the Samaritans. As a researcher, I was mindful that these women are potentially very vulnerable participants with whom a very sensitive one-to-one research engagement is required.

3.9 Methodological reflexivity:

I used a diary to record my reflections on the progress of these interviews. It can be understood as the “personal tale of what went on in the backstage of doing research” (Ellis & Bochner, 2000, p. 741). Using a reflective diary is a useful way of locating the researcher within the research or a way of ‘owning one’s perspective’ which is crucial in maintaining reflexivity (Elliott, Fischer & Rennie, 1999). This is important in terms of bias as the researcher is seen as a fundamental part of the construction of the research. While I would like to think I could bracket this knowledge off in a Husserlian way, it proved challenging.

While IPA has been described as a “hermeneutics of empathy” (Ricoeur 1970, cited in Langdridge, 2007) as the researcher attempts to understand the lived experience of the interviewee, my main concern for my participants was that the interview had the potential to take them to a place of isolation which might be difficult to return from. I worried ahead that they might feel abandoned, exposed even, after sharing their stories with me. My prior research experience of talking to people with FS was that they often felt quite confused by their own narratives. I harboured concerns that they would be left feeling an even greater sense of confusion than before the interview and that having given up their time thinking that they were helping research, might be left feeling alone and unattended to by the end. I tried to mitigate all this by spending time on a debrief and asking how they felt after the interview.

4. Findings

The following section outlines the three themes that emerged from an IPA analysis of participants' accounts about their sense making and experience of Functional Seizures; A State of Siege, Connection and Disconnection with the Diagnosis and lastly, A Disrupted Sense of Self. The Group Experiential Themes (GETs) and contributing subordinate themes are summarised below in Table 2.

Table 2

Group Experiential Themes and Subordinate Themes

GROUP EXPERIENTIAL THEMES (GETs)	**SUBORDINATE THEMES**	**EXAMPLE QUOTES**
A state of siege	A perfect storm of stress and burn out	"I just put it completely down to stress" *(Lucy, p.2 66-67)*
	A body of pain	"I felt really out of control, I felt like my pain is still not managed as well as it could *(Annie, p.3 138-139)*
	Feeling altered by illness	"So, I also question whether Covid triggered an underlying thing that connected malaria and those two things combined…because I have deteriorated to the point where I need carers 34 and three quarter hours a week" *(Becky, p.5 187-189)*
	External Threats	"I'm mainly not good with flashing lights and by fast-moving images. That's generally my trigger. So, driving at night-time well I can't drive any more. So, in the car at night time and pretty much anything on TV sets me off" *(Pearl, p.6 213-216)*
Connecting and Disconnecting with the Diagnosis	Looking for patterns and predictability - a lost cause?	"What they tell me doesn't fit my experience anymore" *(Becky, p.5 169)*

	Unable to identify with trauma narratives	"I don't think I'm hiding some kind of thing, that you know, I can't face up to. I feel completely fine" (*Georgina, p.6 230-232)*
	A therapeutic cure?	"And she said alright then you don't have any signs of anxiety. You're not stressed and you don't have any depression. She said then what can we do for you? And I said I don't know, I'm just here because I was told to." *(Tara, p.7 249-252)*
A Disrupted Sense of Self	The Vanishing of the Trusted Self	Five months on I'm like still trying to figure that out? How do I do this, how do I be a Mum that's still functioning, that's still getting out every day, still trying to be as normal as possible?" *(Bridget, p.8 311-313)*
	Marooned and Lonely	"And you're left feeling very isolated because you don't know why this is happening to you" (*Pearl, p.4 142-143*)

The first overarching Group Experiential Theme "A state of siege" relates to participants' recollections of feeling embattled to a greater or lesser degree prior to the onset of seizures. Most participants described how the onset of seizures had been preceded by a period of stress or burn out which had left them feeling under siege. It also relates to the overwhelm of not knowing what to make of the seizures themselves. Their accounts of the first seizure – which for all had come out of the blue - were recalled as if they had been etched in their memories like unprocessed horror stories. Only two of the eight had ever heard of Functional seizures before, but the onset of the seizures had left all of them frightened, bewildered and disorientated, not just because of the unpredictable nature of the seizures, or how they themselves might appear if they had one in public, but the general lack of knowledge around them. The second Group Experiential Theme "Connection and Disconnection to the Diagnosis" reflects how the lack of knowledge and unpredictability of the seizures had a direct impact on how participants might or might not make sense of the diagnosis. It also relates to how the changing presentations of the seizures left them questioning their original explanatory models and the diagnosis. The third GET “A Disrupted Sense of Self” relates to participants’ sense of themselves disappearing and taking on a different self when experiencing a seizure. While reading and re-reading the transcripts, I was struck by how often they talked of warning signs such as an “*aura*”, a “*tightening of the chest*” and elements of control, tiny chinks of light that gave them something they could hang on to, allowing for some a breath or a pause to prepare themselves and get into a safe place.

Given the widespread lack of awareness and understanding of these seizures, it is important to emphasise that interviewees’ comments were often very much a response to and interpretation of what they had been told by Neurologists, health professionals and websites they had been directed to, so there is some inherent interpretative triangulation involved in the interpretations below. Irrespective of the diagnostic approach and how Neurologists communicated it, there were wide variations in participants' attributions of the causes of their seizures, both in terms of their onset and explanatory models of subsequent seizures. Participants often attributed more than one theory to account for seizures which led to very rich but often contradictory, overlapping narratives and at times, paradoxical processes of meaning making. The majority of interviewees described seizures that had the insidious habit of changing both in timing and/or presentation, or a perceived recovery followed by relapse, all of which often led to a parallel process of change in attribution or explanation. It felt incumbent on me to capture as many of these theories as possible and to honour the descriptions and explanations of why these theories changed or no longer made sense. It was also essential to pay attention to what participants foregrounded initially in terms of sense-making, especially as there were widely different lengths of time between onset and the diagnosis itself.

The words Functional and Dissociative are used synonymously throughout though as mentioned in the Introduction, I will use the term Functional.

4.1. Group Experiential Theme 1: A State of Siege

The first Group Experiential Theme that half of the participants reflected on was a definite recognition of themselves in an embattled state as they faced huge emotional or work stress, physical ill health and/or pain in the run up to the onset of the first seizure. This state of embattlement was recognised by half of the participants, even if for some, the seizures were experienced as a hugely disproportionate response to the stress itself or that it took time to recognise the stress. The first subtheme entitled ‘A perfect storm of stress and burn out’ refers to what half of the interviewees had come to realise encapsulated their embattled lives prior to the onset of seizures. The second subtheme “A body of pain” describes their accounts of the various types of chronic pain experienced by four of the interviewees on a fairly regular basis. The third subtheme “Feeling altered by illness” reflects participants’ foregrounding of accounts of various illnesses that had been contracted before the seizures that they believed had left them in a weakened and vulnerable state. The final subtheme “External threats” describes the external triggers that participants believed contributed to seizure onset and in particular the maintenance of them.

4.1.1 Subtheme 1: A perfect storm of stress and burn out

Becky’s initial frame of reference for her seizures was a profound sense of burn out in the context of her job during the pandemic lockdown. She described the job as “the most stressful job” even without a pandemic lockdown. She reflected on her increased work load and stress, and a build-up of responsibility in the run up to the onset of seizures. Her burn out was compounded by a sense of isolation as she suddenly became the most senior worker in the department. Around this time, she was diagnosed with the auto immune disease coeliac. When the first seizures happened, not only did the diagnosis of Functional seizures (following an initial but short-lived diagnosis of epilepsy) make sense to her as a response to stress but her reflections described a whole system of shutting down in the face of huge adversity and feeling unable to cope.

"So it felt like my body said and my brain said, that's it! I can't cope, something's got to give, it just shut down because it couldn't cope anymore" (*Becky p.2 64-65).*

Her use of the words "shut down" of both body and brain can be considered metaphorically to imply not just her personal sense of finality, a whole system overload that she described as a result of her work stress, but also the sense of collapse that reflected the experiences of the seizures themselves. "Shut down" also perhaps conveys her sense that she can no longer be seen or even of going on strike or no longer being able to cope with strong emotion. Her sense-making of the seizure as a response to saturation of both the "brain" and the "body" illustrates perhaps both her awareness and embodied felt sense of heading towards this collapse as she struggled through lockdown.

Similarly, Lucy made strong connections between emotional upset and her seizures at the outset. Her first experience of them was the night before an A'level exam when she suddenly felt very nauseous and overly hot. A few months later while at University, she experienced her second seizure upon realising that she has been excluded from a night out with her new friends. She recalled looking at pictures of them all on social media, whereupon she simultaneously had a seizure and vomited. Lucy's conceptualisation of stress as a trigger of seizures is related to her experiencing emotional distress and upset and initially, she connected certain situations such as exams, arguments with a boyfriend and friendship issues as triggers for a seizure.

In contrast, for Jane, a theory of stress as a possible cause of her seizures did not initially make sense to her and was experienced by her as a very gradual realisation. She reflected on how when she first heard of the link between stress and seizures, she did not relate this to herself. She said that she understood stress as something life-changing such as the "*death of a loved one*" or "*losing one's home"*. It was only after she was told by paramedics about the potential link between seizures and stress at which point her family and friends remind her of the accumulation of different stressors that she has had, that her understanding starts to change.

"I didn't think at any point they (the seizures) were about anxiety and stress. They did say to me are you under any anxiety and stress and I said 'No' because my interpretation, what I thought stress at that kind of level is when you're really suffering, you know, you've lost a loved one, or you've had real financial distress and had your house taken away from you. But now obviously I've got a different perspective on it but at the time I didn't have a clue" (Jane, p.4 132-133)

Jane's acknowledged minimising of (and disconnection to) her own stress, and her sense of "*I didn't have a clue*" was enlightening. She reported that her seizures were usually followed by "*uncontrollable sobbing*". Her self-awareness was forced to undergo a shift after she accepted the diagnosis of Functional Seizures and was able to reflect that stress was something that could also be accumulated as opposed to one major life event. This sense of not knowing related to the other participants in their descriptions of grappling with the diagnosis and being left to reflect on what their triggers were and how to manage them. It was also significant to Jane that she experienced a huge amount of pain through migraines which had caused her to reduce her work load which in turn, had compounded her stress. There was a sense that she was unaware of the signs and potential links between psychological distress and this pain. She described the seizures as a sort of frightening wake-up call about her own stress and she described feeling a gradual shift in her understanding of how this unacknowledged stress could have left vulnerable to experiencing seizures. It transpired later in the interview that Jane had had panic attacks but had not foregrounded or contextualised them as a real sign of anxiety.

4.1.2 Subtheme 2: A body of pain

This subordinate theme of physical pain in the body and head was a recurring theme for half of the participants who disclosed suffering chronic pain either from migraine, fibromyalgia, joint pain, pregnancy pain or back pain. For some women, the pain was experienced as a trigger for a seizure, a response to the pain. For others however, there was a different understanding and explanatory model - the seizure was conceptualised as a way of shutting the body down to *avoid* the pain. This latter understanding is encapsulated in a comment by Annie when she says:

"*He [The Neurologist] actually had a theory that, as well because my fibromyalgia was a bit out of control with the pain….and his theory was that because the pain hadn't been managed that well, that that actually triggered the seizures and the functional symptoms. And that made sense to me as well……He said it's your brain's way of protecting you. It's dissociating you from that pain, which made complete sense. I felt really out of control, I felt like my pain is still not managed as well as it could be." (Annie, p.3 113-117)*

Annie told me she had experienced a lot of pain from fibromyalgia, migraine and chronic back pain, the latter being currently under investigation for being an additional functional symptom. She described the pain in her back as so bad that she was now forced to use a wheelchair when she was outside. She had had a diagnosis of Functional Neurological Disorder for over a decade following a head injury that had led to post-concussion syndrome, a functional byproduct of the initial injury. Pain seemed to have been a constant in her life ever since. There was a lightbulb moment in our interview when she realised that her seizures had reduced in frequency since she had increased her migraine medication and had had no migraines since. She had not realised this before and there was a palpable sense of excitement and relief in her voice when she made this connection. I interpreted this connection as meaningful for her as she described herself as someone who was "*interested in all Neuro stuff*" and unlike the other participants, was someone who used similar language and metaphors I had heard Neurologists use to explain functional symptoms. She also then made the connection that she had had her first seizure after a period of terrible migraines so the theory of pain as trigger but seizure as protector made complete sense to her as an explanatory model.

The sense making of having a seizure to protect oneself from pain was also a helpful explanatory model for Jane. While she gradually realised that she had accumulated a lot of stress, she believed that the explanation by a paramedic of seizures as a way of shutting the body down by way of protection, fitted with her understanding of what was happening and was helpful to her.

"She (the paramedic) was like.. they can be termed dissociative seizures and it's because you're coping with too much at that point in time so your mind and body take you away from it and it's almost as if you dissociate from what's happening to protect yourself. You don't have control over it."

Pain was also very much part of the symptomatology of pregnancy experienced by Bridget. Her pregnancy narrative was a harrowing story to hear and such a profound ordeal for her that it became *"the only logical thing I could put it down to*" when thinking what caused the seizures in the first place. From the outset, Bridget's pregnancy was complicated by hyperemesis, tachycardia and then Covid. Unable to tolerate any medication, she was temporarily hospitalised during lockdown, where she felt isolated and disconnected from the world. The unborn baby however lay transversely causing her indescribable pain. Six weeks before she went into labour, she experienced her first seizure while at home folding baby clothes. She described how when she later told Neurologists that it was her belief that pregnancy and pain were the cause of the seizures, their response was that neither were likely causes and asked her whether she had some deep-seated trauma instead. The following words illuminated the frustration she felt about her conviction that the pregnancy was at the root of the seizures.

> "*After the three (seizures) that week, at the time I said could this be that my body is just drained, that my body is done? You know I'm physically exhausted and mentally exhausted and spending most days just lying feeling sick and in pain. And they were like, erm, no, that would be weird, that would be unusual."(Bridget, p.2 62-63)*

Bridget's language here conveyed the ordeal of the pregnancy with her words "*drained*" (used 11 times in the interview) and "*done*", emphasising not just the physical exhaustion of the pregnancy but also the mental exhaustion of isolation while trying to keep both herself and the unborn baby safe. But conversely, her words "*could this be that my body*….?." struck a note of defiance because she conveyed both through tone and repetition in the transcript a certain tenacity at sticking to this explanation, in particular when she recalled how her "*logical*" thinking clashed with Neurology's trauma-linked model of seizures. She remained protective of her stance of this theory throughout her interview, and I noted a certain grit in her voice as she weaved this sense-making into her account of her pregnancy. Even when she recounted an astonishing number of additional stressors such as house moves, a sick mother, a step-daughter that needed a lot of care, she remained unmoveable in her explanatory model. Her use of the words “*weird*” and “*unusual*” which she reported as third person speech, could also be interpreted as a reflection of how totally misunderstood, weird and unusual she was made to feel in terms of her own attributions of the seizures, a feeling shared by a number of other participants in relation to conversations with health professionals.

4.1.3. Subtheme 3: Feeling altered by illness

Contributing to the state of being besieged, three participants also described the onset or worsening of seizures following a period of illness. For two of the participants, the onset of seizures was linked to, and in one case worsened, after contracting a mild bout of Covid. “*Though the Covid was mild, it sent my seizures crazy, to the point where I was having seizures every ten minutes” (Becky)*. For Pearl, the onset followed three months of a sequence of family illnesses which had left her so exhausted she felt unable to speak properly. In Pearl’s mind, the end of tonsillitis and scarlet fever marked the start of her experiencing what I interpreted as an altered state in which she realised that she has lost the ability to connect her speech with her thoughts. The following passage illuminated her reflection that having the illnesses and caring for her family too had left her diminished, altered and disconnected.

> *“Afterwards, I just felt that my brain was just not working [….] I would be talking and the wrong thing was coming out of my mouth which was just not what I felt[…]my mouth was saying something completely different. It was scaring me and I was forgetting everything. Pearl, p.1 35-39)*

Her recollection that she could no longer rely on her brain to deliver what she wanted to say, compounded by a loss of memory, left her feeling disorientated. These became fundamental time points for Pearl as illness was the explanation that she foregrounded in our interview as the precursor to the seizures. As a theory, it fitted with her wider sense-making that the seizures must have some organic cause. It did not make sense to her that they could be connected solely to her mental health as she recalled that she had experienced far worse periods of mental ill health in her life. Interestingly, her first thought when she had her first seizure was that she was having a stroke.

Tara, who is deaf, said she felt ignored by doctors despite her repeated trips to the GP since having Covid, which for her marked the beginning of a long period of feeling generally unwell. She still had no proper diagnosis that made sense to her and felt increasingly disillusioned with what she perceived as a medical establishment that was resolutely not listening to her understanding of her seizures. As her father had developed epilepsy as an adult, initially Tara could not decide whether she had epilepsy or whether she agreed with the diagnosis of Functional seizures. As the seizures became more frequent and changed in semiology, she reflected on how unwell she had been since having Covid months earlier. As a result, she could only conceptualise her seizures within the framework of what she believed was Postural Tachycardia Syndrome (POTS), an undiagnosed condition which (she believed) caused her heart to beat very quickly and very slowly and which she believed was a result of Covid. She had very frustrated at not having received a diagnosis of POTS despite her firm belief that this was what she had.

"Just from researching it (POTS) because again if I bring it up with a doctor, it kind of gets fobbed off. They say 'no no it's not possible'. But my heart beat can go really high and really low quite quickly. It's not very stable for a good period of time."(Tara, p.3 91-94)

4.1.4 Subtheme 4: External Threats

Unlike participants who focused on physical triggers, a minority of participants suspected that their seizures were caused by environmental triggers. These participants described a range of environmental cues as potential causes of seizures although they were expressed in a more peripheral way than stress or pain for example. These external attributions however seemed to complicate the acceptance by some participants of the diagnosis because they believed these factors such as lights and flashing images were more widely accepted and understood in the public domain as triggers of epileptic seizures.

For Becky, the seizures had now taken hold over her life in such a dramatic way that she now experienced a whole host of external sensations as triggers.

"*It went from a point where really there were only a few things would trigger a seizure, to now everything will trigger a seizure*. *It's lights, fatigue, concentration, overwhelming, …a multi-sensory overload. Pain, getting too hot, too cold. All those things now can trigger a seizure*." *(Becky, p.2 148-150)*

Becky's dramatic increase in seizures had left her feeling that almost any external or even internal change could set off a seizure Her use of "*overwhelming*" here is double-edged and could describe not just overwhelm that might be a trigger but a parallel sense that she too was completely overwhelmed by them.

Having made an association between seizures and emotional distress, Lucy quietly clung to her mother's own long-standing epilepsy as a source of hope that her own seizures were epileptic. She described how she had watched her mother successfully control her seizures with medication and, crucially for Lucy, able to keep the condition under wraps. But the coincidence of an environmental trigger and seizure at the point of her diagnosis of Functional Seizures, left her even more confused than before.

"*So, I found another trigger of mine is lights. And my mum gets quite confused about this because lights are typically associated with epilepsy, not necessarily you know the FND or whatever". (Lucy, p.2 43-45)*

Lucy seemed to have projected the confusion that she felt on to her mother who does have epilepsy. It hinted to a possible reluctance and fatigue of shouldering this diagnostic muddle, and a sense that at least with epilepsy, there was a common understanding of what the triggers might be, as opposed to the diagnostic "*whatever?*" that she expressed as the muddled descriptor of Functional seizures and the wider spectrum of Functional Neurological Disorders.

4.2 Group Experiential Theme 2: Connecting and Disconnecting with the Diagnosis

Participants expressed a variety of reactions in relation to receiving the diagnosis of Functional seizures. For the majority of the women, initial theories of sense-making around the seizures were understood as a result of a diagnosis by exclusion. Many described arriving at a partial understanding of FS only because epilepsy simply made "*no sense*", compounded by the idea that you could not counter a Video EEG (VEEG) that showed no sign of epileptic activity. There was a general acknowledgement across cases that Functional seizures only made sense because epilepsy did not. This was further complicated for two of the participants (Tara and Lucy) who had close family members with epilepsy and while initially Neurologists suggested that epilepsy was a possible cause for at least three other participants, this was later disproved.

4.2.1 Subtheme 1: Looking for patterns and predictability – a lost cause?

The evolving nature of the seizure presentation left initial theories and attributions forced to undergo paradigm shifts and change. Most of the participants described feeling disheartened and disappointed by how they had started to feel some small element of control by establishing a pattern in the seizures – a certain time of the evening, during or after feeling distressed, a bout of very bad pain - but having made these associations and links, the seizures would change, either in nature and form (from full body jerks to tics or absences for example) or timing or length. This had an understandable impact on how and whether they accepted the diagnosis as well as their own explanatory theories. The evolution of the various presentations of seizures experienced by Tara are evocatively described as she recalls the chronology of the seizures:

"While in hospital I had easily over 300. I had about 10 an hour, non-stop. And then when I left hospital, they kind of reduced and I was having about 15 minimum a day but they were just me staring into space and my eyes would sometimes flutter and roll back. And I might jerk. And then they progressed to I want to say about a month ago where I would just stare."(Tara, p.5 166-170)

This changing semiology of seizures and time points was baffling for Tara but there was a definite sense in how she conveyed these changes that she was determined not to be ruled by them. Similarly, for Georgina, there was no predictability to her seizures. She described how the first seizure coincided with feelings of huge relief and happiness at being granted a loan. The original request for the loan had turned into a stressful, lengthy battle but it was at the point when she was granted it and felt a huge sense of relief that she had her first seizure. This incongruence between feeling joy at the point of the initial seizure, contributed to her bewilderment and confusion over her understanding of them. Conversely, her subsequent seizures, though very far apart, related either to periods of stress or occurred randomly, although often when she was walking down the high street on her own. As the theory of relief initially made no sense to her, she now held two seemingly contradictory theories.

"*The second one makes more sense. My brain shuts down and I can't cope. So why should my brain shut down when I'm all excited and happy and I think it's going to be good?*

We will see as we go through them that this perplexity, you know, there seems to be no pattern at all" (*Georgina, p.2 50-52)*

One of the greatest challenges facing participants as they tried to acclimatise to the seizures was trying to recognise and pre-empt the ever-changing patterns of the seizures, both in form, nature and time. Across cases, there was a generalised sense among participants of feeling psychologically one step behind, almost playing catch-up with the changeable, unpredictable nature of the seizures. Participants characterised this by telling me how they would acclimatise to what they perceived to be a set of seizure rules, only for the goalposts to change again.

For Becky, the dramatic increase in the seizures was life-changing and as she perceived it, at times life-threatening. Her seizures were initially manageable and initially framed by her within the context of extreme work-related stress. She was quickly diagnosed in hospital with epilepsy but the EGG proved otherwise and she received the diagnosis of Functional seizures three days later. She uses a marked sense of time and sense making to describe the process of this acceptance of the diagnosis.

"At that point he (the Neurologist) termed it functional. We just felt that[….]functional non epileptic seizures at that point because it felt more accurate."….It made sense to me because it was the functions of the brain that were shutting down.."(Becky, p.2 43-44).

In this short sentence, Becky pointed to a time element which hinted that worse was to come when she said, "*at that point*", and then repeated it - a sense of foreboding that the narrative of sense-making was about to change and that initial accuracy of diagnosis would, like her brain functions, vanish. She was careful to emphasise to me that by doing everything that the health professionals had told her to do – relax and rest – she originally had the seizures under control and they happened in the evening when she was at home. When she started to consider returning to work, she caught Covid and although it was mild, she attributed the dramatic worsening of the seizures to Covid. But her worsening of seizures had in face been preceded by her starting to lose mobility to the point where she could only walk 90 metres or so at which point she was given a new diagnosis of Functional Neurological Disorder. At the time of our interview, she was in a wheelchair at home with carers because she kept collapsing and getting concussed from the falls. This profound change in seizure presentation and loss of mobility had left her searching for and identifying with a new set of answers.

"I think it's interesting that they (Neurologists) have now changed it and now deem FND and non-epileptic seizures to be a brain network disorder. And that there is …when they've done research and studies on the brain, they've realised that there is something different and there are changes. I would like to know how that progresses, to know how … Because I do feel that it is multi-disciplinary. We cannot…when we look at our bodies and our lives we can't say that things are only caused by this….we are all influenced by lots of things so I think there's probably something psychological but also something organic going on as well." (Becky, p.4 131-133)

I recalled feeling that I had stopped breathing properly when Becky described this sinister unfolding of events and change in functional presentation. When she says "*They have now changed it….*" I reflected on the parallels at play between the changing presentation of seizures she experienced and the change in Neurology's understanding of seizures being caused by a "brain network disorder". And maybe the dramatic way her seizures have changed, can only be understood with something more systemic, like a brain network disorder? This new paradigm of understanding was also shared by two other participants who reported finding some solace in this new research and MRI findings. Understandably, the idea of therapy as a "treatment" option became less meaningful for them, a sense that talking therapy might help in a superficial way, but certainly not as a treatment cure for seizures.

For Lucy, she had felt intense pressure to keep her medical colleagues as minimally informed as possible about her seizures, so when the seizures changed in form and time and now happened during the day rather than just at night, she started to wonder and hope again that they were epileptic in nature.

"But if I was a different person, if I was someone who was not in a medical environment, I'm not sure what I would have done because it left me feeling very confused because I'd just had a seizure because of light which is more typical of epilepsy. I didn't know then if my seizures were photosensitive and if I needed to be careful about lights and things. I found it really difficult because I wasn't given much support at the beginning." *(Lucy, p.6 221-225)*

This short passage conveyed the sense of hopelessness and confusion over how she could help herself. But there was an inherent note of determination and self-reliance in her comments, an acknowledgement that it *would* be her medical training and curiosity that just might save her given the paucity of anything else on offer. She never really answered her own question as to whether the seizures were triggered by light but it highlighted the state of simply not knowing that most of the participants alluded to.

4.2.2. Subtheme 2: Unable to identify with trauma narratives

It was often at the point of diagnosis that the notion of a past trauma (as opposed to stress) as a cause or risk factor of seizures became a battle of aetiology between some of the participants and their Neurologists. The accounts of half of the participants were replete with expressions of frustration and even defeat regarding their meetings with health professionals. Over half of the participants left these clinical rooms feeling even more confused and scared by the diagnostic experience – told to go and look at a website and/ or seek therapy. But participants said they experienced a similar perplexity by the lack of meaningful connection with the weighted focus on trauma narratives embedded within the extant literature surrounding seizure aetiology. The lack of help and lack of sense-making around traumatic experiences contributed to feelings of disconnection to the diagnosis. The idea that participants had some unspoken, pre-existing trauma that was the cause of their seizures, made no sense at all and served only to compound their anxiety.

"*I was actually quite angry for quite a long time because I felt that something serious was going on in my brain and they were just telling me it was in my head. And mentally I have been in much worse, darker places before. And I felt OK and I just felt my main issue was having these physical symptoms, not my mind. I didn't feel my mind was bad enough to have such physical overwhelming symptoms that have completely changed my life. And I still don't to be fair. I have had a lot worse go on."(Pearl, p.2 72-75)*

For Bridget, the insistence by the Neurology team that the onset of seizures could not be related to her pregnancy, left her feeling that she should be looking for some past trauma.

"*I kind of felt not believed because I didn't have a traumatic event that I was pushing to the back. I felt they were looking at me wanting an answer and I don't have that for them. And they were like 'try and think' and I said 'nothing more than anyone else'. Everyone has issues but nothing that I have been traumatised by. Nothing that would have kept me feeling a certain way day to day, so nothing, so it was a bit weird" (Bridget, p.8 342-347).*

4.2.3 Subtheme 3: A Therapeutic Cure?

For six of the eight participants, the conclusion from Neurologists that they should be referred to or, more likely, refer themselves to therapy, seemed troublesome, seemingly connected to their feelings of disconnection to a trauma aetiology. From their descriptions of trying to engage with the diagnosis, there was a felt sense that therapy would be just a waste of time. For Georgina and Bridget, there was a real anxiety in their voices when they considered what they would even discuss in therapy. There was no indication in their comments that they felt therapy was worth it, even if simply as a means of talking about the seizures.

Tara recalled being told to go to therapy to make "seizures stop", and Lucy was advised to seek the trauma-focused Eye Movement Desensitisation Reprocessing (EMDR) therapy privately, but again, felt that this was anomalous as she said she had not experienced trauma. Jane however felt that therapy was far preferable to medication. Her sense now was that medication would only mask the stress and felt that the seizure was the manifestation of this unverbalised stress.

"*I don't want to take any more prescription medication, and so having counselling to talk about my anxiety and CBT to change the way I think makes so much sense to me now when I think about it. Because I've struggled with things over the years and over the last year I've struggled a lot with anxiety." (Jane, p.7 307-310)*

It feels important to include here the subsequent "*joined up multi-disciplinary care*" experienced by Annie who is a lone voice in the group in terms of treatment pathway and acceptance. When Annie's seizures began, she returned to the Neuropsychiatric department in the same hospital where she had received her original FND diagnosis a decade earlier. Following the seizure diagnosis, she was sent to a ward where the Occupational Therapists and nurses – referred to as "*the experts*" – specialise in FND. She described what felt like a safe haven, a place where she could learn grounding techniques and receive physiotherapy and reach what she described as an acceptance of the seizure diagnosis. The nurses suggested group therapy in the future and Annie felt hopeful in this regard that this could be helpful for her.

"I think that's very important that there is follow-up because a lot of it for me felt like acceptance is what's helping me". (Annie, p.8 332-334)

4.3 Group Experiential Theme 3: A Disrupted Sense of Self

Participants' descriptions of the disabling physical and psychological impairment wrought by the seizures, combined with the widely varying semiology both between and within individuals, left many of the participants feeling out of control, alone and isolated. They experienced a perceived loss of control or agency not just in relation to the seemingly random nature of the seizures but also over their bodies and minds, leaving participants with fractured notions of themselves. This disrupted sense of self was as much about a change in their self-perception as how they imagined being perceived by others and there is a thread of shame in their reflections as they try and gauge how to relate the seizures to themselves and better understand them. This shame was also combined with a profound sense of loneliness and isolation due to not knowing how to explain this change of self to others.

4.3.1. Subtheme 1: The Vanishing of the Trusted Self

The misunderstood or hard to diagnose nature of the seizures themselves, their unpredictability both in form and timing, left participants with a sense that their very self-concept had undergone some metamorphosis – they were someone who now experienced unpredictable and inexplicable seizures. Certain accounts of the seizures themselves described what could be interpreted as a sort of disappearing act, a vanishing on the part of participants as the seizures took over and whole periods of time collapsed and left unremembered. They described how they could often only remember very hazy details of events surrounding a seizure and could not properly know *what* or *how* they appeared to others when having them. Elements of shifts in how participants conceived themselves were often inextricably bound up with feelings of being out of control. Some participants gave raw accounts of what it meant for them to think they were turning into someone else as the trusted sense of self disappeared.

Lucy's seizures had started just before university but at the time of interview she had become a medical student and was still trying to understand why she had them. She was terrified of having a seizure in public because her self-concept as a fairly measured and composed undergraduate was liable to suddenly turn into someone quite different. Her sense of identity as someone being trained to understand and explain others' medical problems was felt to be completely compromised by the seizures. The following passage sheds lights in this regard.

"*I felt like a liability. Anytime I was worried that I could be just walking down the street and all of a sudden I get my aura and then I'm going to have one in public. And that was frightening for me because I am someone who, I don't know, I get embarrassed quite easily and find things quite embarrassing. And having a seizure where - because my face contorts quite a lot and having a seizure where I am moving uncontrollably and I am making all these weird faces, it is embarrassing and so I was concerned that I was going to have it in front of all these new friends that I was making who I hadn't met before. So I was worried that I would have one in front of them and I can't explain it.*" *(Lucy, p.3 105-112)*

Mirroring in some ways the experience of other participants, Lucy reflected on how her self-concept has undergone a real shift with the onset of seizures. She described having no control over when her self-image as A-grade medical student might disappear from view, to be replaced by the "*liability*" - a word she deployed three times in fairly quick succession in the interview. In this new guise, she was now someone who could be just casually walking down the street and randomly start jerking limbs and pulling "*weird faces*". As she described this transformation, there was a palpable anxiety and fear in her voice as she lamented the possibility that this career that she had "*worked really, really hard for*" could be ruined. Or, worse still, that she really would turn into a "*liability*" which, as I understood it, meant compromise patient safety. Having previously described how she had had a seizure when she had realised that all her new friends had gone out without her, she was now faced with the idea of having a seizure in front of them, yet not even able to provide an explanation. Her description conveyed with it a sense of humiliation of being a trainee doctor who could not *even* explain the workings of her own body.

Unlike other participants, Georgina's seizures were very rare, in some cases occurring years apart. However, her major seizures had real consequences, as they were *always* in public and an ambulance would always be called. But the major issue for her was the humiliation of the loss of bodily control and functions when she was in the seizure:

> "*But it's the wetting myself and being out in public and being completely hopeless. I can hurt myself as well. I fell down the stairs and broke my shoulder in June. I feel unsafe outside." (Georgina, p.4 143-144)*

This short description conveyed such a mix of painful emotions - the deep sense of sadness, humiliation, fear and both emotional and physical hurt as she described this person who had to face the public in her most vulnerable state, something that was shared by other but not all participants. Georgina experienced this shift in public appearance wrought by a seizure as not just alien and disquieting, but the stable person that she knew herself to be turned into someone who could not be entrusted to keep herself safe or her body in control in public. As a way of grounding herself while outside, she described how she now walked down the stress chanting a mantra out loud to ward off the seizures and touching the velcro on her jacket. But what remained unfathomable for Georgina was the fact that the seizures had recently returned "*at the most peaceful time of my life*". She despaired at the lack of knowledge among health professionals that she had encountered, and had almost given up trying to work out which theory best fitted with the unpredictable nature of her seizures. She was the only participant who during the interviews asked me twice if I knew what these seizures meant.

For Tara, seizures were preceded by marked physical and behavioural shifts - changes that reflected almost an identity shift, a transformation to someone who, she said, was markedly different to the person she knew herself to be.

"*It's hard to describe how I feel but I can feel quite odd, quite nauseous. I act a bit drunk and a bit dizzy and silly, or I go very quiet and then I check and can feel I am going to have one*." (*Tara, p.10 337-338)*

Her initial awareness that physically something internal was not quite right was quickly followed by what I interpreted as an altered state in which, according to her account, she started to act like someone alien. It was as if she was looking at this new self from the viewpoint of her original self as the new emerging Tara began to act a bit silly and drunk or the opposite – neither of which she related to. This shifting perception of self is pertinent as it hints at a behavioural transformation to someone who bears no relation to her real self, a sense that she had been taken over by an/other.

4.3.2 Subtheme 2: Marooned and Lonely

For most of the participants, the humiliating, uncontrollable nature of the seizures, exacerbated by the lack of comprehension and treatment around them, left a marked sense of isolation and loneliness in connection to their seizure experience. There was also a sense that the experience of playing the role of detective in relation to understanding the cause of the seizures was as lonely as having the seizures themselves.

For Pearl, there was no theory as to why her seizures had started and she believed that there was something organically wrong with her, rather than any notion that the seizures were linked to her history of mental health issues. As a nurse, she was surrounded by doctors and health professionals, but she felt not just alone with this new diagnosis but not taken seriously by other health professionals to whom she was referred. She had been told by health professionals to simply look for more information on the website *neurosymptoms.org* to get further information and felt left high and dry, feeling bewildered at the lack of treatment plan, expertise and understanding.

"It's not helpful because you're left with more questions after doing so because it's an absolute minefield and the reason why they send you to the website is because they just don't know why this happens. And you're left feeling very isolated because you don't know why this is happening to you?"*….* "*but I also feel that I am being left with no treatment, no plan going forwards and a lot of unanswered questions". (Pearl, p.4 40-43)*

This passage almost completely encapsulated the experience for all but one of the participants. Pearl's phrase "absolute minefield" alluded to the complexity of the seizures and the health professionals' lack of knowledge about them. Her isolation was experienced within this vacuum of information and understanding. She was originally informed that the seizures were anxiety attacks which for her, was not the correct diagnosis. She felt compelled to return and tell her Neurologist that that she was experiencing tremors and that her family believed they were seizures, relying on witnesses as the experts rather than herself.

For Bridget, the isolation of being in hospital during lockdown, pregnant and ill was later exacerbated when no one felt that the pregnancy was at the root of the seizures.

"So, you're spending a lot of time alone in hospital because Covid as well was still going round at the time and so lots of hospitals had precautions in place. So a lot of that time I couldn't have anyone to see me and I spent a lot of time alone. You'd be lucky even to see the nurses. I had some amazing care but especially when I had covid, they'd leave the medication at the door and be like can you come and get this as we don't want to come in? A lot of time alone, you know. When I got the diagnosis, I just felt this would be enough, the isolation of it, you know and how much it drains you to be so physically drained, to be so mentally drained, you feel exhausted."(Bridget, p.3 122-126)

She used the word "*alone*" three times and also "*isolation*" in this short passage, but I interpreted her use of the term *"a lot of",* expressed five times, as conveying the sense of extended periods of time alone and almost being treated like a leper because she has covid. She herself felt that the experience of just being alone with this highly problematic pregnancy was traumatic for her. She talks about the "*amazing care*" but this is a little at odds with my own interpretation of her account, when read as a whole, that her isolation, compounded by no one believing her connection between the pregnancy and the seizures, often left her feeling completely uncared for.

Lucy's sense of loneliness was also acute and woven throughout her entire account. She was desperately trying to fit in to University and a new social life while remaining as inconspicuous as possible. Having received the diagnosis of FS, she could no longer identify even with her Mother with epilepsy.

"I just felt so isolated, I didn't know what to do. I didn't want to tell my friends because at that time none of them knew because I didn't know myself and I didn't want to tell

anyone else. All I could do is call my Mum who is hundreds of miles away and say well it's not epilepsy which you have that you could support me with. It's completely different. I don't know when it's going to end or how to control it. And I don't really know what it is because no one has told me and I've had to find it out myself."(Lucy, p.6 233-238)

This passage encapsulated Lucy's isolation which she experienced on a number of levels. Her sense of isolation was not just physical and psychological - there was not just the detachment from her mother who (she felt) could not support her as their seizures are different - but speaks to an even deeper, ontological deficit. How could she possibly express what she cannot describe, let alone understand or explain?

The sense of loneliness was also reflected in the need for others to validate the experience of seizures, a feeling shared by a few participants. For Becky, the challenge was how to make sense of her deterioration, someone who was "*completely healthy prior to the seizures and playing tennis and cycling to Paris"* to the wheelchair-bound person she was now who also relied on full-time carers and family. Like other participants, due to the context of dissociation or memory loss during the seizure, she described a sort of vanishing ("shutting down") as the seizure took over and was compelled to rely on the testimony of others to describe and explain. For Becky, the use of "*we*" 72 times in the interview, though she never clarified who she was referring to, was perhaps indicative of a need to feel understood or connected. It hinted at a possible emotional need for a/another to share this terrible ordeal, to feel less isolated, even just semantically. The "*we*" also spoke to another possible reality – the need for others to bear testimony and validate her experience of these seizures. Equally, it could have related to the presence of this other self that emerged in the seizures that others spoke of?

5. Discussion

5.1 Chapter overview:

The aim of this chapter is to critically synthesise and contrast the present findings with the current literature and explore their implications for research, theory and clinical practice, particularly within the field of Counselling Psychology. The chapter will draw on the available literature in relation to the three Group Experiential Themes that emerged through the analysis. I will then draw on the works of American feminist historian and writer Elaine Showalter (1985,1993), to provide an alternative feminist framework within which to contextualise some of the more unexpected findings. This will allow a discursive ‘zooming out’ away from the microcosm of the data to allow us to consider specifically the power dynamics experienced by these women in a more societal or structural way.

The strengths, limitations and implications of the present study will be addressed, followed by suggestions for future investigation and implications for Counselling Psychology. Finally, this chapter offers a concluding personal reflection in relation to the research process followed by a brief Conclusion.

5.2 Summary of Results:

This study sought to explore eight women’s unique experiences and sense making of functional seizures by employing interpretative phenomenological analysis. The analysis found three Group Experiential Themes: A State of Siege; Connecting and Disconnecting with the Diagnosis and A Disrupted Self. The main findings from this research are that most of these women experienced some sort of stress or burn out, illness or unmanageable pain in the run up to the seizures - more often than not they foregrounded this as a way of introducing their seizure narratives. Possibly due to the heterogenous nature of the seizures, participants shifted in their own explanatory models but did not relate or align themselves with a trauma-based understanding of FS. This made accepting the diagnosis difficult and confusing and participants expressed vacillating between connecting and disconnecting to the diagnosis. Lastly, participants expressed a sense of disconnect and a fragmented identity as a result of having the seizures.

5.3 Explanatory models:

This section will draw on the findings that emerged from the first Group Experiential Theme, A state of Siege. Participants' experiences of feeling mentally and physically under siege in the run up to the onset of seizures was a prominent cross-case finding and, as an explanatory model or risk factor, is well embedded in the literature (Carton et al., 2003; Tojek et al., 2000). Participants' rich accounts and narratives of their lives leading up to the first seizure revealed a wide variety of precipitating and perpetuating factors, attributions and responses to these factors, irrespective of whether interviewees felt these were causal or even connected to the seizures themselves (Green et al., 2004). Life stressors such as overwork, burn out, exams, relational upset and how they played out in their lives, were foregrounded in the accounts of half the participants.

The one participant who reported how she had minimised her anxiety and had to be reminded of her panic attacks, could be understood from a clinical point of view as being more alexithymic or avoidant of negative emotion. This is in line with a number of studies that have highlighted a strong association between FS and alexithymia (Bewley et al., 2005). For this participant, the seizure was usually followed by uncontrollable sobbing, a reaction which could be additional evidence to support literature which suggests that the seizure is a dissociative phenomenon, a manifestation of the saturation of stress, or even a symbolic form of that which *cannot* be expressed. It potentially adds to our theoretical and clinical understanding of how di/stress and emotion are embodied states. This emotional reaction to the seizures resonates with an IPA study by Pick et al (2016) which suggested that some people find a certain relief, an unburdening in having the seizure, as if some (emotional) expression has been uncontrollably released. A study by Novakova et al., (2015) observed far greater levels of self-reported suppressing of emotion in their sample of patients with Functional seizures, compared with controls.

Conversely, participants' accounts of having seizures when they felt happy, laughing, relaxed or unperturbed by worries, indicated the possible disconnect in a temporal relationship between the experience of stress and the occurrence of a seizure. It pointed to the possibility of stressors accumulating and occurring when (unconsciously perhaps?) participants felt they were in a safer place to have the seizure.

Pain as a trigger leading to a seizure was a prominent finding with that half of the women who suffered additionally with chronic comorbidities such as migraine, chronic back pain and fibromyalgia. The association of pain and seizures is well researched and reflected in the literature (Popkirov et al., 2019; Benbadis, 2005)). However, this study extended that in a more nuanced way in terms of perception of the role of the seizure. There was a divergence in how participants viewed the connection between pain and seizures. For some participants, pain was the trigger for a seizure whereas for others, pain was something from which they needed to protect themselves. In this latter case, seizures allowed them a form of escape from pain, even if this left them debilitated by the seizure itself. Viewing this latter explanatory model, seeing the seizure as having qualities of a "protector" might have allowed participants to arrive at a greater acceptance of them and this could be the subject of future research and clinical practice. The two participants who made links between a precursor of pain or emotion and the seizures, seemed to have reached a fuller acceptance of the diagnosis than the others. In the process of interpreting these accounts, the seizures seemed to represent some symbolic form of communication that participants were unable to ignore.

The idea of illness, and particularly a mild bout of Covid 19 as a precursor to the onset or worsening of seizures, was an unexpected finding but which is in line with new research from Iran and Brazil respectively (Asadi-Pooya & Farazdaghi, 2021; Valente et al., 2021). This latter paper found that people with a diagnosis of FS reported a worsening of their seizures during the pandemic, pointing to a stress diathesis explanatory model, and one that was exacerbated by anxiety and depression.

5.4 A problematic, "borderland" diagnosis:

Communicating the diagnosis of FS to patients has long been described as a fraught, difficult process. Numerous studies have attested to the inherent tensions in the diagnostic process, pinpointing a stigmatised and difficult terminology among other reasons (Stone, 2013, DOH, 2011, Karterud et al., 2009). In this study, participants were sometimes left even more baffled and confused after the diagnosis than before. This confusion arguably stemmed from the fact that irrespective of the length of time that participants had experienced the seizures, they had all had very recent diagnoses and appeared to be still in the process of interpreting these encounters. Furthermore, apart from one participant, they all reported a short space of time between onset and diagnosis, itself a very unexpected finding (Reuber et al., 2002) However, for leading researchers like LaFrance, the communication of the diagnosis by Neurologists is fraught because no one field "owns" FS. Unlike epilepsy, migraine or stroke which sit comfortably in Neurology and anxiety disorders and depression which sit in mental health, FS sits outside of all territories. For this reason, LaFrance has described it as a “borderland” diagnosis as it is so often perceived as a diagnosis of exclusion (LaFrance Jr & Devinsky, 2004) .

All of which compounds the lack of clarity and plausible explanation surrounding the aetiology of FS which in this study left almost all participants grappling with the phenomenon. Instead, they seemed to focus their energies on looking out for physical warning signs or predictions or ways of managing the seizures or ways of hiding them from others. What did emerge from this study and is not well reflected in other literature, is how initial attributions of the seizures became obsolete and new ones sought as a reflection of the way seizures changed in presentation or frequency or timing. This shift in theories, as described by some but not all the participants, may also be related to their very recent diagnosis of FS. Again, we might consider that these shifts contributed to ongoing processes of trying to work out what they could do to avoid a seizure? The shift in theories could also stem from a result of the frequently reported absence of a temporal relationship between experiencing stress and the occurrence of the seizure. This disconnect is further underlined by the detachment between their bodily experience of the seizures and any understanding of them. As the diagnosis itself seemed to often rest on a diagnosis of exclusion, it could be hypothesised that the lack of illness representation, explanation and understanding left this group of women in some sort of ‘ontological alienation’ - a sense of disconnect from the self, due to an uncertain identity (Heidegger, 1962, Cameron & Leventhal, 2003).

5.5 Not fitting the trauma narrative:

While participants’ responses to the diagnosis of FS were varied, they were almost unanimous in their lack of connection to a trauma aetiology of their seizures. The epidemiological link between trauma and Functional Seizures, well documented since the 19th century, is a central tenet in the literature. In this study, the trauma narratives that participants were confronted with, either in the available literature, research studies (Goleva et al., 2020) or questioned about during consultations with health professionals, did not reflect their experience. If anything, trauma narratives such as childhood treatment or sexual abuse, which for some was perceived as an event that they should try and remember, served only to alienate them further from the diagnosis, and appeared to cause greater confusion. Participants' accounts illustrated how the diagnostic process had been disempowering for them, and for some, a trauma aetiology made them feel as if this new condition was a case of it being 'all in your head'. Studies of FS have shown that an acceptance of the diagnosis (Ettinger et al, 1999) or relief (Carton et al, 2003) can be linked to a better prognosis. However, it would appear from these accounts that being asked to remember traumas ran counter to any furthering of an acceptance of the diagnosis. Furthermore, in line with Carton's (2003) study, an absence of trauma also meant for some participants that subsequent recommendations to seek therapy felt slightly absurd and pointless. As a theory of trauma did not make sense for participants, all they were often left with was a body that seemed to speak in a mysterious language. The only language that many of the participants were familiar with was one of pain and illness and life stress, a finding which is in line with the work of Bowman (1996, 1999, 2018). And while her work highlighted how people with Functional seizures reported higher prevalence of abuse, trauma and life stresses than patients with epilepsy, she concluded that the "most significant association" between functional seizures and trauma was a relational one, that it was the family environment that cultivated *attachment* trauma and led to tendencies towards somatisation.

5.6 A fractured self:

A prominent finding in this current study is the perception by some women that they experienced a shift in self-concept, a self that was changed with the advent of a seizure. There was the "I" that narrated the story and the alternate, other "I" which is being described during a seizure. This finding, which can be conceptualised as existing within a more existential framework, yields new information for Psychologists about what having seizures might mean for a person's relationship with their mind/body and even their place in the world. Participants descriptions illustrated a transition of being taken over by a different character, an untrustworthy, uncontrollable rebel who could wreak havoc. While these perceptions could be interpreted as being in line with previous studies which highlight states such as depersonalisation and derealisation as part of the seizure presentation, the qualitative findings in this study describe and illustrate perceptions of how seizures, which not only disrupt place and time, have the potential to disrupt the trusted self. Losing this trusted self as the different seizure-induced identity takes over, while transient in nature, could be understood as having the potential to distort self-identities, personal narratives and self-stories. These interpretations extend beyond the experiential significance of the seizure itself and shed new insights into how participants might view this other self who has seizures – perhaps a way of connecting with their new vulnerability? Woven throughout the narratives was a sense of shame (Reuber et al, 2022) and perhaps even revulsion that emerged in participants' tone of voice and expression when describing this usurper, who was simultaneously them and not them. This sense of embarrassment, stigma and shame is well documented in the literature. Studies have highlighted how people with FS experience a double stigma – that of a condition that is conceptualised as having its roots in psychological distress and that of having a seizure (Annandale et al., 2022).

Accounts of feeling isolated and alone were both directly stated or interpreted in the narratives, as participants sought to understand why they were experiencing these seizures.

This study shares similarity in findings with a systematic review investigating the links between loneliness and chronic conditions such as heart disease and diabetes (Petitte et al., 2015). But there is also a phenomenological framework for loneliness. In Motta and Larkin's evocative account of how IPA as a methodology could lend itself to theories of loneliness, they describe how philosophers of the phenomenological and hermeneutic tradition such as Heidegger, Hannah Arendt and Gadamer, posit loneliness as an ontological determination of our Being and, yet, on the other, as a cause for some of the most difficult problems of our times, such as the "phenomenon of self-alienation" (Motta & Larkin, 2023). Citing Arendt, for instance, the authors found that "*when our desire to be understood and recognized in our totality is frustrated, and our ability to disclose our full uniqueness to our friends is inhibited, we feel lonely to the degree that we do not appear as a self in the world*" (Arendt, 1951, p. 477). The idea of not being understood with these seizures led to an alienation from others but also an alienation from themselves, further exacerbated by the disruptive event of the seizure itself.

5.7 Attending to the Reflexive Echoes through a Feminist Lens

The extent to which participants voiced their perceptions of not being heard by some health professionals was one of the more unexpected observations of this study. From their accounts, participants disclosed how their understanding and their attributions about the seizures often felt discounted or dismissed. Attributions such as a very difficult and lonely pregnancy, a post Covid reaction, a pervasive feeling that it could not be just related to mental health, were all perceived as being met with a certain medical scepticism.

While I was very much the "outside" researcher, I felt such a personal resonance - more of a boom than a whisper (Goldspink & Engward, 2019) - with participants' perceived notions of not being listened to or validated. Their accounts also chimed with what felt like a much more systemic problem with the medical system at large. The women in this study often felt that they were not listened to, that the links or associations they made or experienced were not valid and that the assumption of trauma seemed to reduce their agency even further. Thirty years ago, Showalter wrote that feminist critics had highlighted how doctors' narratives tended to be prioritised while patients' narratives were modified (Showalter, 1993). In relation to FS, it would appear that the traditional, patriarchal doctor-patient relationship arguably has not progressed much since. These power dynamics within the caring professions prompt questions about the role of health professionals in propagating such cultures, where the clinician 'knows all'. My reflections on what participants experienced made me wonder about my own professional identity of being a trainee but about to become a doctor with the accompanying power imbalance that ensues.

The power dynamics as described in participants accounts can also be conceptualised within a far broader feminist perspective of how conditions that effect women more than men - such as the disorders that come under the umbrella of Functional Neurological Disorder (FND) - are treated with more discrimination both directly and indirectly by clinicians, researchers and the public (McLoughlin et al., 2023). McLoughlin, a Consultant Psychiatrist, wrote a seminal paper highlighting how FND as a condition was a reflection of this discrimination. As the paper pointed out, "*Dated 'conversion' theories, that trauma is always the underlying cause of functional symptoms, are too simplistic, often do not make sense to patients, and have rightly been removed as essential criteria from international classifications*." These authors believed that part of the problem lay in the lack of graduate and post graduate education in FND in the UK. As mentioned in this current study's introduction, these seizures have their origin in what used to be termed "hysteria" and are still called "pseudo seizures" by some health professionals (accompanied by a long historical side bar history on malingering and factitious behaviour). The idea that women might make these seizures up only serves to undermine and disempower further all attempts to navigate these seizures.

Returning to the specific FND presentation of FS, if we consider the seizure as a form of communication, the high levels of alexithymia in this population resonate with a broader understanding of how negative emotion expression may be culturally determined as characteristic of females but insidiously discouraged. Showalter (1985) argued that female disempowerment especially within the Victorian era, gathered into a ‘protest through the body’, as a means against role inertia and social and sexual restraint. She spoke of the “silenced hysterics compelled to express their protest or desire through the body” and we might be left to wonder whether these seizures could be conceptualised as an alternate means of emotional expression, be it from pain, or illness or stress or external triggers such as light or heat.

If social conditioning continues to suppress language in women, body language is left as an alternate means of emotion expression and a possible explanation as to why women are so disproportionately represented in more “psychogenic” presentations (Helman, 2007). Thus, with a culturally marginalised or ignored female role, in personal or social adversity, ‘ontological alienation’ of the self may arise (Lester, 2013; Ussher, 1991, 2007; Heidegger, 1962). In other words, a sense of self and place in the world may be lost. And perhaps, the Western epistemological view of mind-body separation, further undermines this reportedly fragmented sense of self (Bodenreider et al. 2004; Erikson et al. 2013).

5.8 Evaluation of the Research

To my knowledge, this is the first study to openly explore the sense making of Functional seizures with an interpretative methodology and with a focus solely on women. This research therefore contributes to the empirical gap in the literature on the lived experiences of women with functional seizures by highlighting the various attributions that interviewees attached to them. The accounts and sense making highlighted in this study illustrate the complexity of what for all of them was a sudden onset with no knowledge or understanding of what they were experiencing.

IPA was methodologically apposite for this study because as participants had been newly diagnosed with the seizures, their narratives were replete with what Smith has described as “hot cognitions”, as they tried to make sense of the diagnosis and what it meant for them and their lives. It allowed the research to remain close to the individuals’ experiences and therefore strengthen the credibility of the findings. Lastly, the interpretive element provides further psychological, metaphorical, and implicit depth to the findings (Willig, 2013). The findings also suggest that future research might benefit from more interpretative-phenomenological research to capture the multiplicity of meaning and diverse experience. This diversity and evolving nature of sense-making also pertains to the wide-ranging scope of Counselling Psychology.

The rigour and quality of this qualitative research can be measured against the fulfilment of four broad criteria (Yardley, 2008) which I believe have been fulfilled:

1. Sensitivity to context – by the acknowledgment of how findings in this study converged or deviated from relevant theoretical and empirical literature

2. Commitment and rigour – through my regular and repeated reflexivity and supervision

3. Transparency and coherence – through clearly highlighting how findings were made such as using direct quotes from transcripts

4. Impact and importance – this research furthers our understanding of the range of sense making and attributions made by women of their functional seizures.

5.9 Strengths and Limitations of the Research:

An underlying strength of the research is the qualitative and interpretative phenomenological approach taken, which offered access to many levels of the participants' experience and shone a light on the complexities and nuances of the experience of FS. A further strength is that the themes describe the lived experience of these seizures in rich, idiosyncratic detail.

There are a number of limitations. Given the double hermeneutic involved in IPA, the conclusions are based on the researcher's own interpretations, thus limiting any generalisation. While the decision to select women only for interview was a calculated one - due to the far higher ratio of women to men living with these seizures - future research might focus more on a mixed-gender sample? Furthermore, all participants were of White British ethnicity; while this is in line with the prevalence reported in UK studies, considering the findings across more diverse populations could enhance our understanding and offer deeper insights. Additional studies might also explore comparison of perspectives of subgroups of people with FS, such as those with an absence versus presence of psychological trauma (e.g., abuse), and/or those with chronic versus recent-onset Functional seizures.

Further limitations include the recruitment process itself, which in the end, attracted a more middle-class demographic than the typical demographic of people with FS found in the CODES trial (Goldstein et al., 2021), which found high levels of socio-economic deprivation based on household postcodes. The findings here may reflect the values and beliefs of a more privileged group of individuals with better access to educational, occupational, social media and social opportunity. Therefore, this group's experiences of seizures may differ from those of other groups. It is important to note that the sample also contained a much wider age range of participants than anticipated. Studies have shown that the average age of onset in women is before 40 and that research participants with an onset over the age of 55 tend to be men with health problems (Duncan et al, 2006). Recruiting individuals through the mental health charity FND Action and via the University may have enabled participants to feel more confident in entering into a one-on-one encounter with someone perceived to be of a professional background. Conversely, a limitation of that was the potential to overlook individuals with limited access to resources such as the internet or those who might have felt intimidated by or mistrusting of a zoom interview. A further limitation to being viewed as a professional was that I may have been perceived as an expert.

It should also be noted that an important possible influence on patients' responses in this study was any formulation provided by the participants' Neurologists or health professionals. All patients included in the sample had received a diagnosis of Functional seizures, and as highlighted in this study, some had received verbal explanations as to how the seizures might be related to psychological factors.

One final limitation is the interview process itself. I wondered whether given some participants' beliefs about the potential link between emotional distress and seizures and the unpredictability of seizures, that some avoided discussing certain topics or feelings because of concern that this might trigger a seizure during the online interview. In the end I reflected that conducting the interviews online (rather than face to face in some unknown neutral space) might have helped put participants at ease, in terms of women feeling safe with family/partner around them and in a space that was familiar.

My own understanding of Functional seizures from my previous research work in a treatment trial may have directly or indirectly influenced the development of the research themes. In IPA, this is explicitly acknowledged, as there is a double hermeneutic where the development of themes are based upon my interpretation of the participants' interpretation of their experience. Reflexivity aims to ensure that these interpretations are made explicit.

5.10 Contribution of the Research to Counselling Psychology:

Gaining insight into how people with Functional seizures make sense of them is critical to any psychological intervention. Counselling Psychologists are in a unique position to work more flexibly and integratively with clients who experience these seizures and to keep in mind the potential for how seizures have the potential to disrupt self-concepts as borne out in this study. Consciously opening the discussion regarding clients' unique beliefs about what may have led to the onset of seizures and what attributions they have, might be a useful guide to work with alongside therapeutic interventions. This study has highlighted how critical it is for clients to feel as though their interpretations of the seizures are considered important, valuable and compatible with psychological interventions. Approaching these beliefs also with a semantic sensitivity should also be a priority for anyone working therapeutically with these clients. Listening to their shifts in theories about aetiology and risk factors, and working with their beliefs about how they see themselves in the seizure moment would also be valuable in terms of clients feeling understood and less othered.

Some participants in this study felt they might be able to access just a small amount of control over the seizures and it would seem that the introduction of any perception of control may be important to individuals with FS. Again, it is here that psychology might offer the greatest contribution to people with FS and the use of a formulation driven intervention might be beneficial in terms of reducing feelings of disempowerment.

5.11 Implications and Suggestions for Clinical Practice:

This study showed how the majority of participants felt abandoned or not properly listened to at the point of diagnosis and were, in the main, left without a treatment pathway. People with FS are often assessed and managed within Neurology services due to their initial presentation, but given that outcomes are often poor, there is a clear need for better integration of psychological and psychiatric input to assessment and treatment for these groups and better explanations as to why this is the case. Studies have shown that patients with Functional Seizures are followed up in Neurology comparatively less than epilepsy patients for example, so more follow up appointments with Neuropsychiatry or Neuropsychology might be helpful in reiterating the diagnosis? While it is understandable that Neurologists would not want to continue to see someone who does *not* have epilepsy, it is crucial that people are referred to some kind of treatment pathway.

Participants perceptions were often that they felt they had been told to go away, look at a website and go and find therapy. Only one participant had had a really positive experience post diagnosis in which she was sent to a ward that catered for FND and which was run by nursing staff. In terms of psychological input, there exists here a golden opportunity for Counselling Psychologists to use a more integrative therapy to help people try and come to terms with the diagnosis and support them in considering ways of coping with the seizures such as grounding techniques.

The findings relating to trauma aetiology in this study deviate from the normative characterisation of FS found in the research literature, and suggest that closer understanding of this lived experience, in particular focusing on life stressors rather than a trauma focus, can help us to understand the pertinent and specific experiences pertaining to this group.

5.12 Research Reflexivity:

The first reflexive statement discussed my thoughts around the literature review and pre-recruitment or data collection. This second reflexive statement will give an insight into my thoughts and experiences with the interviews, analysis and discussion process. Throughout the process, I have kept a reflective diary, used supervision and personal therapy to reflect on my beliefs and assumptions about functional seizures. I have attempted to ‘bracket’ (Smith et al., 2009) my own personal opinions, feelings and responses as much as I could in order to reduce their influence on the interpreting of the data. The double hermeneutic of IPA highlights the importance of reflexivity – that is, the researcher’s awareness not just of their own biases and influences but also an understanding that a complete study of (participant) subjectivity is impossible.

The recruitment for this study was a far more straightforward process than I had imagined. In the end, I had a surplus of eligible potential participants and had to ask FND Action to take down the recruitment poster from their website which is exactly what the charity had predicted. Women were very keen to take part, to give voice and in so doing, make sense of their experience of seizures.

In terms of the interviews themselves, one of the most salient reflections was the extent to which participants could only make sense of their seizures outside of trauma narratives. I expected to hear accounts that carried far more problematic relational issues than I did. As a Counselling Psychologist trainee, I hoped that my training allowed me to be acutely sensitive to what was foregrounded and what remained peripheral. In many ways their accounts highlighted the finite nature of both an ontological and epistemological understandings of seizures. I wrote in my reflective journal that at times, the wide range of attributions they had for the seizures left me feeling overwhelmed and wondered whether this was a projection of their own confusion. I also saw a parallel process in participants attempts to make sense of the seizures and my attempts in the data analysis to make sense of their accounts, what was important and prioritised and what could be left out. I often reflected on participants' emphasis on telling me that they were able to see or hear (but could not speak) during a seizure, and wondered whether that came from a need to convince me that their condition was genuine.

I experienced a real internal conflict over the perception by some that therapy would not be helpful for them. As a trainee Counselling Psychologist, I had reflected on how that had made me feel and how I could have ignored it or been more defensive about it but I also felt it was hugely important to capture this ambivalence or more accurately, resistance to therapy.

Overall, the engagement with and discussion around seizures during the research interviews seemed to allow the participants to gain further, shared insights of their experiences. For one participant, there was a clear moment of realisation when she linked the increase in her migraine medication to the fact that she had had almost no seizures since – she did not think the two events were a coincidence. Perhaps through the inter-subjective process of the research interview, participants were able to become more self-aware in relation to their sense making, which adds to the evidence of the importance of follow-up following diagnosis. Perhaps the narrative story-telling by the participants in this study did, in the end, serve to foster in them a sense of unity – individual stories with a beginning, middle and end, acting as counterpoint to the disconnect and disruption of the seizure.

5.13 Conclusion:

The present findings highlight and contribute to the evidence demonstrating the devastating impact that FS have on people’s lives and the struggle for acceptance. Taken together, this research has provided the following findings:

- **The range of attributions and sense making of people with FS of their seizures can be as varied and heterogenous as the seizures themselves.**

- **The emphasis on the role of trauma as an aetiology made by health professionals can lead to alienation, disempowerment and undermine any acceptance of the diagnosis. The possibility of life stressors, which for some may be linked to physical pain, might be a more helpful way of explaining the diagnosis**

- **Health professionals need to work more flexibly and in a more holistic, person-centred way with this group, and to consider threatened identities in the face of these seizures**

- **The need for improved and more psychologically-informed diagnostic conversations surrounding the onset of seizures**

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APPENDICES:

Appendix 1

PARTICIPANT POSTER

Exploring women’s perspectives on the experience of Functional Seizures

About the study

I am a Counselling Psychology doctorate student at Roehampton University and I am looking for women to meet with to help us better understand how people with a diagnosis of Dissociative Seizures (Non-Epileptic Attack Disorder), understand their seizures. It is hoped that the research will enable us to better understand how we can make sense of them from the perspective of those with lived experience, and ultimately inform better healthcare.

We are looking to interview 8 women who have had a Functional (Dissociative) seizure in the past 3 months but who have ***not*** received any psychological treatment. If you are aged 18 years old or over and have this diagnosis, then you might be eligible to take part and I would be very interested to hear from you.

What can you expect?

The one-to-one interview (with me) will last approximately 60-90 minutes and will take place either remotely (over zoom) or at your home, at an agreed date and time. Interviews will be confidential and your identity will be protected.

How can I get involved?

If you are interested and would like to find out if you are eligible or simply to know more about the study, please contact the Principle Investigator Julie Read, at readj4@reohampton.ac.uk or mobile 07873 640556.

An initial phone call will take place between any potential participants and the researcher to discuss if you are eligible to take part in the study.

If participation is deemed eligible, taking part in the study will be treated on a first come first serve basis. Participation in this study is voluntary. You can withdraw your data up until data analysis, at which point it will be pseudonymised.

Appendix 2

Women's perspectives on the experience of Functional Seizures

Participant Information Sheet

Thank you for considering taking part in this study!

This information sheet offers an overview of the current research and why I am doing it. It also provides details of what will be asked of you if you decide to take part. It is important that you understand what participating in the research will mean for you, so that you have a thorough understanding of the research if you decide to participate. If you have any further questions please feel free to ask me.

Who is organising the research?

The research is being organised by myself, Julie Read, and two research supervisors in the School of Psychology at the University of Roehampton. I am a trainee Counselling Psychologist and I am doing this research as part of my Doctorate in Counselling Psychology.

This research has been approved under the procedures of the University of Roehampton's Research Integrity and Ethics Committee to make sure that the study is safe to go ahead. This approval means that this study is deemed as safe and has a low risk of causing harm to people.

What is the study about?

We are looking to interview eight women who are currently experiencing Functional (Dissociative) Seizures (also known as Non-Epileptic Attack Disorder or Psychogenic Non-Epileptic Seizures) and who have received a diagnosis of this by a Neurologist using the gold standard video-electroencephalograph (VEEG) or EEG. We want to gain a better understanding of how women think about and experience their seizures. We are particularly interested in exploring how women make sense of these seizures, and why they think they are having them.

Why are we researching this?

Studies have shown that for some people with a diagnosis of Functional Seizures, the diagnosis itself has given rise to more questions and confusion than answers. We are curious to know how it has impacted their lives and what sense they make of them. Gaining a better understanding of this from women with lived experience of DS will add to the growing scientific knowledge and can potentially allow for us to develop more targeted psychological and health service interventions.

Who can take part in this study?

- If you are a woman aged 18 years or over
- If you currently have a VEEG or EEG diagnosis of Functional (Dissociative Seizures) AND have had a seizure in the past 3 months
- If you do not have separate diagnoses of epilepsy OR psychosis
- If you have NOT received any psychological treatment for them
- If you are English speaking
- If you are registered with a GP Surgery

Do I have to take part in this study?

No. Taking part in this research is completely voluntary. If you agree to take part now you can still change your mind later on (see below).

If I do decide to take part, what would be asked of me?

Firstly, I would get in touch with you by phone to discuss if you are eligible to take part in the research. If you are eligible to take part, then we will arrange a time and date for the interview. In the interview, you would be asked to provide some details about yourself, such as your age, nationality, GP contact details and how long you have experienced the seizures. I would then invite you to share your experience of these Seizures and ask you some questions about your perspective and experience of them. You can say as much or as little as you would like to and the conversation would be audio recorded on a password protected and encrypted audio recorder. After we have finished the interview, you would be invited to ask me any questions you might have.

Where will the meeting and interview take place?

The interview will take place either online over zoom or in your home if you would prefer. It will be at a time and date that is mutually convenient.

Are there any disadvantages to me for taking part in the research?

We have designed the study so there are as few risks as possible to the people involved. You will be asked to dedicate approximately one hour and a half of your time to take part both in the interview and to answer a few social-demographic questions beforehand. In the interview you may want to talk about some of your past experiences. We understand that talking about these and your seizures may bring up uncomfortable feelings or upsetting memories. If you do feel uncomfortable when talking about your experiences or if you become upset at any point, you can choose to not answer and we can move onto a different question, take a break or stop the interview all together. There will be no pressure to discuss or answer anything you do not want to. If you decide to finish the interview early, that is not a problem. I will talk to you afterwards to see how you found the experience and whether you would like any further support. Our priority is keeping you safe. If you would like a friend or family member there in a separate room, that is fine. If you feel that there is a chance you may have a seizure during the interview, we will agree a plan of action beforehand.

Are there any advantages to me for taking part in the research?

By taking part in this research, you would be helping to advance and improve the knowledge about Dissociative Seizures. As someone with lived experience, you would be contributing to the psychological research surrounding them and helping to add to knowledge by taking part.

Will anyone know what I say in the interview?

What you discuss in the interview is confidential. However, in extreme circumstances, during the interview if you say that you are at risk of harm or someone else is at risk of harm, then we might have to break the confidentiality of the interview, such as contacting relevant safeguarding officers at the University of Roehampton and/or your GP.

Will I be recognised from this?

When we write up the findings of the study, we will ensure your data is non-identifiable (so no-one knows it is you). This is done by removing your name and any other identifying information about you. All your personal data will be kept confidential (e.g. your name or GP contact details). All the interview data will be pseudonymised to protect confidentiality. Therefore, no-one should be able to identify you when the study is written up.

What will you do with the audio recording of the interview?

The audio recording will be transcribed by myself and made into a Word document. The audio recording would not include identifiable information such as your name or address, therefore no-one (apart from me) will know it is you in the recording. The information given at the beginning of the interview, when you are asked to fill out the brief form with me (giving a few demographic details), will not be audio recorded and will not be part of the transcription.
Please note that the audio recording cannot be edited. Therefore, if you say in the interview for example *'My mum is called Lois'* or *'I grew up in Liverpool'* then this information will stay on the recording. However, I will remind you to try and avoid revealing any identifying information in the interview.

What is data and what is GDPR?

Data is basically another word for information. Data in this study will be the answers you provide in the brief questionnaire that you fill out at the beginning of the interview as well as what we discuss in the main section of the interview. All data collected as part of this research will be stored on a password protected and encrypted device that only I have access to. This is in line with the UK General Data Protection Regulation (UK GDPR; 2021) which sits alongside the UK Data Protection Act (2018). It ensures that people process personal data lawfully, e.g. that organisations do not share people's personal information to third parties without permission and that people's personal information is erased in the appropriate timeframe. It is important that we look after the data you share with us and treat it in the right way. Therefore, this study handles data in line with the University of

Roehampton's Data Protection Guidance for Research (2018) and in line with the UK GDPR and the UK Data Protection Act (2018)

How long will the data collected in the study be stored for?

Anonymised data can be kept indefinitely by the researcher. The audio recordings will be stored for ten years after completion of the research. During this time, the audio recordings might be used for other research projects only if you give permission for this. The consent forms will be stored for six years after completion of the research. After these timeframes, all data will be destroyed.

What will happen to the results of the research?

The results of this research will be written up as a doctoral thesis. The thesis may be submitted to or published in Psychology journals. The findings of the study might also be presented at research conferences via oral presentations or research posters.

What if I change my mind about wanting to be in the study?

If you change your mind about wanting to be a participant in this study then that is absolutely fine. If it is prior to the interview, you can cancel the interview by contacting me as soon as possible. If you change your mind during the interview, then we can conclude the interview straight away. If you change your mind after the interview, you will need to contact me as soon as possible and provide your participant ID number so we can locate your data and remove your data from the analysis. If you change your mind after data analysis, your data may not be erased but will only be used in a de-identified form as part of an aggregated dataset. I will contact you when we get to the stage of data analysis, just so you are kept informed.

Why do you need to know my GP's contact details?

Your GP will only be contacted in the case of an emergency. Collecting these details are a precaution for your own safety and mental wellbeing. If you feel or I feel that you are becoming distressed at any point in time we will discuss how you are feeling and whether you might need to contact a member of your support network. If I feel concerned about your safety I may need to break the confidentiality of the interview and contact relevant safeguarding officers at the University of Roehampton and/or your GP. If I feel it is vital for your safety then I will contact the local A&E department immediately. Contact details of GPs will be deleted after the interviews have taken place.

What if I have any concerns about the study?

If you have any concerns, please talk to us about it as soon as possible, by using the contact details at the end of this information sheet.

What does ‘providing consent’ actually mean?

To give or provide consent means that you fully understand what this research is about and what is being asked of you as a participant in the study. It also means that you understand how the data from the interview might be used in the future.

I would like to take part, what do I do now?

If you would like to take part, please get in touch with me (Julie Read) by using the contact details below. I will set up an initial meeting with you and provide you with a consent form.
Please note: If you have any concerns about any aspect of your participation or any other queries then please raise this with me, Julie Read. You can also contact the Director of Studies. However, if you would like to contact an independent party please contact the Dean of the School of Psychology.

RESEARCHER: Julie Read

Email: readj4@roehampton.ac.uk

Mobile: 07873 640556

Director of Studies:	**Dean of School:**
Professor Rosie Rizq	Dr Yannis Fronimos
School of Psychology,	School of Psychology
Whitelands Campus,	Whitelands Campus
University of Roehampton,	University of Roehampton

Parkstead House,

Holybourne Avenue,

SW15 4JD

Email: r.rizq@roehampton.ac.uk

Phone: 020 8392 3000 ext 7372

Parkstead House,

Holybourne Avenue

SW15 4JD

Email: yannis.fronimos@roehampton.ac.uk

Phone: 020 8392 3627

Appendix 3:

Consent form

Study title: Women's perspectives on the experience of Functional Seizures

Thank you again for considering taking part in this research. Before taking part, it is important that you understand and agree to the statement below. Please ask me if you need any clarification or have any questions or concerns.

Brief Description of Research Project;

The aim of this research is to improve our understanding of how women with a diagnosis of Dissociative Seizures make sense of their seizures so that we can improve treatments and support for them. I will be interviewing eight women either remotely (via the online platform zoom) or in their homes to ask some open-ended questions about their lived experiences and understanding. The interviews should not last longer than an hour in total and if you would prefer to have a family member or friend with you for support during the interview, that will be fine.

Data Protection:

Data will be protected in line with the UK General Data Protection Regulation (UK GDPR; 2021) which sits alongside the UK Data Protection Act (2018). It ensures that people process personal data lawfully, e.g. that organisations do not share people's personal information to third-parties without permission and that people's personal information is erased in the appropriate timeframe. In this study and in accordance with GDPR, personal data (such as name, age, ethnicity) will be stored securely for ten years after project completion, after which it will be destroyed. All other data will be pseudonymised and will be kept for ten years after completion of the study, after which it will be destroyed. While the results of the research may be published in research papers, presented at conferences or seminars, all data will be kept confidential. All data at publication will be pseudonymised.

You have the right to withdraw from the study without having to give a reason up until data analysis (at which point data will be pseudonymised, which basically means the linkability between you and the data are reduced). If this happens during the interview and you want to stop, we can end the interview immediately. If this happens after the interview, then you will need to contact me and provide your ID number. The ID number will be allocated within the data-set and your data will not be included in analysis. If you contact me and wish to withdraw after data analysis then your data may still be included and may not be erased, but will only be used in a de-identified form as part of an aggregated dataset. I will contact all participants to inform you when the data analysis process is starting. The University's Data Privacy Notice for Research Participants accompanies this form (Appendix 4).

Investigator contact details:

Julie Read
School of Psychology
Whitelands College
Holybourne Avenue
Roehampton
SW15 4JD
Mobile: 07873640556
Email: readj4@roehampton.ac.uk

CONSENT STATEMENT:

- I agree to take part in this research and am aware that I am free to withdraw my data up until data analysis without giving a reason by contacting Julie Read. I understand that if I do withdraw after data analysis, my data may not be erased but will only be used in a de-identified form as part of an aggregated dataset. I understand that if I do withdraw after data analysis, my data can be included for publication (but it will be de-identified).
- I understand that the personal data collected from me during the course of the project will be used for the purposes outlined above in the public interest. I understand that this data will be pseudonymised.
- I understand that audio-recorded data will be stored by the researcher for ten years after completion of the study, at which point it will then be destroyed.
- I understand that my consent form will be stored for six years after completion of the research.
- I understand that the researcher will provide me with a list of useful agencies that I can contact after the interview if I feel any physical or emotional discomfort.

- By signing this form, you are confirming that you have additionally read this study's 'Participant Information Sheet'.
- By signing this form you are confirming that you have been informed about and understand and agree with the Data Privacy Notice for Research Participants.
- The information you have provided will be treated in confidence by the researcher and your identity will be protected in the publication of any findings. The purpose of the research may change over time, and your data may be reused for research projects by the University in the future. If this is the case, you will normally be provided with additional information about the new project.

Name ………………………………….

Signature ………………………………

Date ……………………………………

Please note: if you have a concern about any aspect of your participation or any other queries please raise this with the investigator (or if the researcher is a student you can also contact the Director of Studies at the address below). However, if you would like to contact an independent party, please contact the Dean of School. Contact details for the Dean and the School of Psychology, University of Roehampton, can also be found on the department's webpage: https://www.roehampton.ac.uk/psychology/.

Director of Studies:
Rosie Rizq
School of Psychology
Whitelands Campus
University of Roehampton
Parkstead House
Holybourne Avenue
SW15 4JD
email: r.rizq@roehampton.ac.uk
Phone: 020 8392 3000 ext 7372

Dean of School of Psychology:
Dr Yannis Fronimos
School of Psychology
Whitelands Campus
University of Roehampton
Parkstead House
Holybourne Avenue
SW15 4JD
yannis.fronimos@roehampton.ac.uk
Phone: 020 8392 3627

Should the Dean of School change over the lifecycle of the research project the new Dean of School will become the independent contact. Contact details for the new Dean of School can be obtained from the investigator.

Appendix 4

DATA PRIVACY NOTICE FOR RESEARCH PARTICIPANTS

Research Participants - How the University of Roehampton uses your personal data

Why have I been directed here or been given this form?

This statement explains how the University of Roehampton handles and uses personal data collected from research participants. This includes data collected directly from research participants or where the data has been received from a third party.

Who will process my personal data?

This statement applies to all research conducted by the University of Roehampton and its members.

What is the purpose of the personal data processing?

You will have been informed about the specific types of personal data that will be used in connection with the research project you are participating in, and the nature and purpose of the research project. You will have been informed of any data sharing with participating research institutions, transfers outside of the European Union, and any automated decision making that affects you.

In some cases, your data may have been shared with the University by another organisation for the purposes of conducting research. The University may also re-use personal data it already holds for the purposes of conducting new research. The University will only use personal data in this way where it is legally entitled to do so. In all cases, the University will normally contact you to give you details of the research unless this would be impossible or involve disproportionate effort, or would significantly undermine the research objectives.

The University may in exceptional circumstances release personal data to appropriate authorities without seeking the permission of or notifying the data subject, but will only do so in compliance with its legal obligations.

What is the legal basis of the processing?

In the majority of cases, your personal data (including, where appropriate, sensitive personal data) is used to carry out research, including scientific, historical and statistical research, in the public interest. Where the research is commercial in nature or funded by a private company, the legal basis for processing is likely to be legitimate interests. If the personal data being used for research purposes falls into one of the special categories of personal data, including criminal convictions data, the lawful basis will usually be that the processing is necessary for archiving purposes in the public interest, scientific or historical research purposes.

What are my rights as a data subject?

The General Data Protection Regulation and Data Protection Act 2018 provide exemptions for personal data processing in relation to research activities.

You have the right to opt-out of any further processing. If you do opt-out, your personal data may not be erased but will only be used in an anonymised form as part of the dataset. (Please note that this is separate to withdrawing your participation from the research project itself).

In accordance with accepted ethical standards, you will not be named in any published materials unless you have given your explicit permission for this to happen.

The University considers that other statutory rights held by personal data subjects do not apply where the personal data is being processed for the purposes of research. If you would like to request a copy of the personal data then you can contact the lead researcher. Where practicable, they will provide you with a copy of this data. However, they are under no obligation to do so.

How long is my information kept for?

Your data will be kept in accordance with the University of Roehampton's Record Retention Schedule. Research data may be retained indefinitely in an anonymised form by researchers. The University may also reuse your personal data for a different research project. If it does, the University will make reasonable attempts to inform you about this reuse and its impact on your rights as a data subject.

Occasionally a researcher will leave the University and begin working for another organisation. In this case, your personal data may be transferred to the new organisation so that the research project can continue. If this happens, you should be provided with updated privacy information by the new organisation.

The University is committed to protecting all personal data for which it acts as a controller. Your information will be safely held on a secure system.

Who can I contact?

The University has a Data Protection Policy which sets out how personal data will be used across the whole University. Further information about data protection can also be found on the University's website. https://www.roehampton.ac.uk/corporate-information/policies/.
If you would like to receive hard copies of any policies relating to Data Protection please contact the University Data Protection Officer.

If you would like to make a general query about how your data is being used as part of a research project, you should contact the researcher whose details you will already have been provided with.

If you would like to make any further enquiries or raise any concerns with respect to your personal data, or your rights as a data subject, you can contact the University's Data Protection Officer, Alison Bainbridge, at a.bainbridge@roehampton.ac.uk.

How do I complain?

If you have any concerns about the University's handling of your personal data, you have the right to make a complaint about to the Information Commissioner's Office and can do so at http://ico.org.uk/concerns/.

Appendix 5

Socio-demographic Questionnaire

Participant unique identifier:

These questions aim to collect some background information about who you are and how you describe yourself. All data gathered during this study will be held securely. It will only be used in accordance with the permissions that you gave in the consent form.

Questions 1-3 are general demographic questions. Question 4 is to gather information needed specific to this study.

Age

1.What is your age?

18-24 years ☐

25-34 years ☐

35-44 years ☐

45-54 years ☐

55-64 years ☐

65+ years ☐

Race/Ethnicity

2. Choose one section from A-F and tick the appropriate box to show your ethnic group

A: White
☐ British, English, Northern Irish, Scottish or Welsh
☐ Irish
☐ Gypsy or Irish traveller
☐ Any other white background, please specify
B: Mixed or multiple ethnic groups
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other mixed or multiple ethnic background, please specify
C: **Asian of Asian British**
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Any other Asian background, please specify
D: Black, African, Caribbean or Black British
☐ Caribbean
☐ African
☐ Any other black British, African, or Caribbean background, please specify
E: Other ethnic group
☐ Arab
☐ Any other ethnic group, please specify
F: Prefer not to say
☐

Mental Health History

3. Do you have a psychiatric diagnosis?

☐ Yes
☐ No
☐ Prefer not to say

6. Please place a ✓ in the relevant box or boxes if any of the mental health conditions below apply to you.

Bipolar Disorder	☐
Post-Traumatic Stress Disorder (PTSD)	☐

Generalised Anxiety Disorder (GAD)	☐
Schizoaffective Disorder	☐
Depression	☐
Personality Disorder – e.g. Borderline, Schizoid, Emotionally Unstable	☐
Dissociative Identity Disorder (DID)	☐
Prefer not to say	☐

Dissociative Seizures

4. How long have you been having Dissociative Seizures? Please write in the space provided	
What was the length of time (approximately) between the onset of DS and a video-electroencephalographic (VEEG) diagnosis from a Neurologist?	

GP Contact Details

Name of GP:	
GP Address/Phone Number:	

Do you have a carer?

What is your employment status?

Appendix 6

Semi-structured Interview Schedule

1. Can you tell me about the first time you experienced a seizure? (this aims to set the scene and is intended to offer the participant the opportunity to begin at their own beginning).

2. When you first experienced the seizures, what did you think was the cause?

3. Did you have any way of explaining to yourself what was happening to you? A kind of theory of your own at the time?

Prompt: Can you tell me about that?

4. When did you receive your DS diagnosis?

Prompt: 'How did you feel once you heard that you had DS?

5. As a diagnosis, did it make sense to you?

6. What have Neurologists or other health professionals told you about the possible cause of your seizures?

8. Have you found these discussions with health professionals helpful or unhelpful in terms of your own understanding?

9. Have you been offered any form of treatment for your DS?

Prompt: any medical treatment? Any psychological treatment? What do you make of the treatment you’ve had?

Appendix 7

University of
Roehampton
London

DEBRIEF

Thank you so much for taking part in the study today!

The purpose of this research

Our aim in speaking to you today was to get an idea of how you tell your story about how you make sense of your Functional seizures?

The purpose of this study is therefore to gain a greater understanding of whether the way people

Debrief

Sometimes during an interview, people get thoughts, feelings, concerns, or questions that they want to talk about afterwards.

It is important that you have the chance to reflect on the interview, and to take a moment to consider whether there is anything you want to talk about? The following questions might help you to do this:

- How do you feel having completed the interview?

- How did it feel to be interviewed?

- Has the interview brought any thoughts of feelings up for you?

- Do you have any questions or concerns about the interview process, or about what happens next?

- Do you think there were any questions I should have asked that I didn't?

- Is there anything else you would like to share at this point?

Thank you for your contribution to this research, and I hope you enjoyed taking part.

If you think of any questions you would like to ask once I have gone, or if you need further support, then you can contact me:

Julie Read
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Whitelands College
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Phone: 07962077092
Email: readj4@roehampton.ac.uk

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Please note: If you are worried about any aspect of this study, or have any other questions please ask me, Julie, (or the Director of Studies, Rosie Rizq). However, if you would rather talk to someone at the university who isn't directly involved in the research, you can contact the Dean of School:

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Finally, if you feel you might need further emotional support following this interview, please see below contact details of helplines you might find useful.

SANE Emotional support, information and guidance for people affected by mental illness 0300 304 7000	Rethink Support and advice for people living with mental illness 0300 5000 927	Samaritans Confidential support for people experiencing feelings of distress or despair 24 hours free helpline: 116 123

Appendix 8: Sample of transcript with IPA exploratory notes and experiential statements

EXPERIENTIAL STATEMENTS	P003:	EXPLORATORY NOTES
	JR: Can you tell me about the first time you experienced a seizure?	
Derealisation – brain switched off – she has disappeared Seizure felt like stroke Does not link loads of work with stress	P003: Yeah, I think it, I don't really remember the first proper seizure in that I had full body jerks but I do remember a first episode where I felt disconnected to the world and that was at work. And I saw a patient and they'd left and then I was going through some tasks at work and I looked at something on my computer. I thought oh that's a lot (laughs), that's a lot of work to do and it was like my brain just switched off and I couldn't stop staring at this particular space on the wall. And I just, I think I went completely vacant and I came around, and I work in a GP surgery so it's lone working and I just felt very confused, extremely confused. I had no idea where I was or what was going on and I was panicking. Erm, I thought I was having a stroke erm and so I went to see one of my colleagues and got her to check my blood pressure (laughs) which was alright, not too bad. And she was like are you really stressed and I was like I don't think so. I don't remember thinking there was a lot of work to do but not hugely stressed. Anyway, I went home that day and it went on from there. Yeah. And over time, they developed into bigger attacks with more body movement but I don't really remember having the first bodily movement. But the first one I really remember was more the absence one I think.	Remembers feeling "disconnected to the world" overwhelmed by workload – "brain just switched off" "vacant" "Panicking" and "confused" by derealisation – thinks it's a stroke so gets blood pressure checked Seizures get worse very quickly "bigger attacks with more body movement"
	Do you have both types? Both hyperkinetic and hypokinetic?	

	P003: Yes..yes.	Has both hyper and hypo seizures
	JR: OK. And when it first happened did you have a way of explaining to yourself or have a theory at the time that you could draw on?	
Confusion - not having a stroke but not OK	P003: I thought I had a stroke. I was having a stroke and something had disconnected between my mind and body. But I couldn't have told you what, erm, but I was reassured by my blood pressure being normal so I thought I'm probably not having a stroke (laughs) but I am clearly not OK. And maybe my anxiety is through the roof.	Stroke Questions whether this is anxiety?
Could it be anxiety?	JR: So you have another theory going on that maybe this is anxiety?	
	P003: Yeah, maybe.	
	JR: So did that change when you get this diagnosis? I'm just realising that your formal diagnosis is very recent. It's only a month old.	Formal diagnosis is month old
Has lots of competing theories about DS Onset is time of stress Illnesses in family/Covid Disconnection between brain and speech	P003: Yeah, really recent. I've had a lot of different theories in the time. Around the time when they started happening a lot of different things were going on. At the beginning of last year for about two or three months, everyone in the household was poorly with something, for three months. I had this really awful tonsillitis and I don't even have tonsils and my throat was just massive. I couldn't eat and couldn't speak and couldn't do anything for two weeks and was really poorly with it. We all got covid and then my children got chicken pox and then the children got something else. It was just constant for weeks and weeks and weeks. Afterwards, I just felt that my brain was just not working. It just wasn't working. I would be talking and the wrong thing was coming out of my mouth which	Lots of theories about DS Long period of constant illness in family- then caught Covid "It was just constant for weeks and weeks and weeks" Thinks brain has stopped working and doesn't connect with what she's saying Loss of memory makes her fearful

Theory of remembering historic sexual assault that has resurfaced	was just not what I felt that what my brain was thinking, my mouth was saying something completely different. It was scaring me and I was forgetting everything. My husband would talk to me and I wouldn't remember what he said. Another theory was that after researching the non-epileptic seizures and dissociative seizures was that a lot of women who have had sexual assault can develop dissociative seizures. And the only thing I could think of was that a few weeks before my seizures came on, I was watching a television programme about sexual assault and it brought back a bit of a repressed memory for me of when I was 17 and a man assaulted me. And I hadn't thought about it for well…..for ever. And I wondered whether that could have been a bit of a trigger because it had upset me for the few weeks leading up to that first initial seizure.	Starts research and links seizures to theory of sexual assault ie past trauma Repressed memory – recollection after TV programme – brought up emotion of event Felt upset by memory of assault
	JR: It sounds like some memory had just come up and really upset you?	
Disconnect with what she experienced in the assault and how she felt	P003: Yes, I hadn't realised what I had been through. I hadn't even considered it being a sexual assault until I watched this programme, because I don't know what it said on it. I realised that I didn't allow myself to think it, so I just completely blocked it out. Although I was aware it had happened, I had never given it any thought about how it had made me feel. I have wondered whether that had started things off or whether it was an accumulation of lots of little stressors all around the same time. And it's just ended up in my brain going "just stop".	Minimising and blocking of past assault Hadn't thought about how assault had made her feel Questions whether this is an accumulation of stressors Brain says "Just stop"
	JR: And possibly not helped by the physical illnesses that you had all have had? Did you say they were	

	in Jan 21 or Jan 22? So it was this year?	
	P003: Yeah	
	So at the beginning of this year you have these three months of constant illnesses, when someone in the family is always ill and with nasty things, chicken pox…	
Constant illness in run up to seizures	P003: Oh yes and we had scarlet fever mixed into it.	More illness
	JR: And then it left you with this feeling of what sounds like a disconnection anyway between what your brain is thinking and what you are saying?	
	P003: Yeah	
	JR: OK. And you're forgetting things and then you watched this programme?	
	P003: Yeah	
	JR: And that really upset you?	
	P003: Yeah	
	JR: So, when you got this diagnosis of Dissociative Seizures which you've just got in this letter, how did you feel about that? You know the words "non-epileptic attack disorder", "functional seizure", dissociative seizures, what did you make of that?	
Undermined by not being taken seriously Disconnect between her feeling that it can't be mind yet message she receives is that it is Life changing symptoms	P003: At first, I think I had had a bit of a warning that it would come because of the first appointment with the Neurologist, she said I think you've probably got this, go away and look it up but we will confirm with tests. I was given a website – that's what you'll I hear loads of time – I was given the website Neurosymptoms.com and I was told to go away and look at it. I was actually quite angry for quite a long time because I felt that something serious was going on in my brain and they were just telling me it was in my head. And mentally I have been in much worse, darker places before. And I felt OK and I just felt my main issue was having these physical	Given website Neurosymptoms.org Feels that something is seriously wrong with her but no one is taking it seriously – "it's all in your head" "angry" at not being taken seriously "I felt that something serious was going on in my brain and they were just telling me that it was in my head" Mismatch between any sign of depression and anxiety and seizures ie she has been

	symptoms, not my mind. I didn't feel my mind was bad enough to have such physical overwhelming symptoms that have completely changed my life. And I still don't to be fair. I have had a lot worse go on. I obviously, well I am very early on in this and I've got a long way to go and a lot more things to come to terms with. I don't know what's going to come. But to go back to the question I felt very angry that I wasn't being taken very seriously.	in worse mental places before Physical symptoms have "completely changed my life"
	JR: What sense did you make of the actual diagnosis? Did you feel well how that would be as I have been in worse places?	
Dissociation makes no sense to how she experiences seizures	P003: yeah so I mean, (coughs) sorry I've got a bid of a cold. In some ways I could understand it but the term dissociation really confuses me because I don't feel like I dissociate. I don't think I have before in the past. I don't feel like I completely check out and not know… I don't feel like I do it. But when I think of my first episode at work then that probably was dissociating but I've never experienced before not that I know of. The only time I've been sat for an hour and not realised was when I was very young and I'd come home from school one day and time just went, I realised oh it's 5 o'clock and not really realising what had happened in the time. That's the only time I've experienced something like that. But when I have the seizure I don't feel like I'm checking out. I still very much part of where I am and My body is just saying no.	Questions what "dissociation" really means – "I don't feel like I dissociate" Only time she dissociated was at work Feels she is very much present when she has seizure but body stops "says no" and she can't interact
	JR: Saying no?	
	Yeah.	
	JR: But you can still hear and see?	
	P003: See.	
	JR: But you can't interact.	
	P003: No, I can't interact.	

	JR: So, as a diagnosis you're angry because they've given you this website and told you to go away and make yourself better. But it sounds like the diagnosis didn't make sense to you?	
Her theory is a physical one – brain tumour/MS/mini stroke	P003: No, I felt that something more physical was going on.	Feels that seizure is part of something physical (does she mean organic? ie can be tested)
	JR: Did you have an idea what that could be?	
	P003: I wondered brain tumour for a long time or MS. But I didn't have the weakness for MS so I thought probably not. But I definitely wondered if it was a small tumour or a mini stroke or something?	Thinks that small brain tumour, mini stroke or MS are possibilities
	JR: So very kind of worrying, things that would be terrifying to have. So, I guess in relation to that how does it feel to have a diagnosis of DS?	
	P003: Oh it's better than having a brain tumour for sure.	
	JR: I wasn't being glib sorry. So actually it didn't make sense but compared to what you were looking at in relation to the others, thank goodness it's this rather than the others. So, when you got the letter to confirm it's functional seizures, how did you feel?	
Disconnect between what she experiences and what she's told Message she receives it's all about your mental health – because she has anxiety and depression so nothing else is investigated or queried	P003: I just remember feeling a bit annoyed (laughs) because it's just I think I wanted there to be a physical reason and for it not to be my mental health. Or anything to do with my mental health. Because I feel like a lot of things that I've ever gone to the GP about are blamed on my mental health. And I don't feel like it's that bad so I just don't understand why. I get it's confusion that I feel.	Confusion between body and mind Wanted it to be a "physical" reason rather than her mental health Feels that lots of things are blamed on her mental health but she doesn't think she is in a bad place with MH
	JR: And this is very new isn't it and you're at the start really of this. But there was a feeling that you didn't want it to be your mental	

	health. And maybe that's because other things were going on?	
	P003: Yeah yeah	
	JR: And in terms of your mental health it was about anxiety and depression?	
	P003: Yeah yeah.	
	JR: And did anyone, the neurologist or any other health professionals, tell you about the possible cause of them?	
No one has explained what seizures are	P003: Erm, no. no.	
	JR: So no one has given you an idea?	
Told diagnosis will help her engage better with therapy – not her understanding of how she engages	P003: No. All I was told was that as I was going to therapy for a little time at the time, they said I would engage better in therapy with a diagnosis. Because I'd said to them I'm in therapy but we're not getting anywhere. But that's the only thing they kind of hinted towards. But there was no specific this is what can cause them. It was just look at this website.	Told to keep having therapy and that diagnosis would help her engage better Felt that therapy wasn't helping Told "just look at this website"
	JR: So, you get the diagnosis for anxiety and depression about 7 years ago, but when you have therapy for general things this year, was it for mood?	
	P003: Well, I was upset, I was off work and I was struggling with that. I would go to her – she's kind of someone I go to fairly regularly because I just feel I'm someone who needs to talk through things.	Identifies as someone who needs to talk things through and engages well
	JR: But they said you would engage better if you had a new diagnosis?	
	P003: Yes, which I didn't feel was true because I engage really well in therapy.	Doesn't think therapeutic engagement would benefit from DS diagnosis
	JR: So this is a bit of a long question. But in terms of your discussions with health professionals, can you tell me what's helpful or unhelpful?	
Website is both helpful and unhelpful because leaves more questions unanswered	P003: They've led me to this website which is very, very good. And it does make sense. And you	Feels that website left her with more questions because of broader FND context

	do think well I've done that and I've done that. OK right, they could be right. But also, the website they lead you too is about Functional Neurological Disorder rather than just NEAD, so you're reading all about these other things which could be going on. But at the same time. Sorry to go back to the question. It's not helpful because you're left with more questions after doing so because it's an absolute minefield and the reason why they send you to the website is because they just don't know why this happens. And you're left feeling very isolated because you don't know why this is happening to you?	Finds website "It's an absolute minefield" Feeling of isolation and disconnection
	JR: And why now?	
Sense of being abandoned with no treatment plan	P003: Yeah, exactly, exactly. So they've helped me leading me to something which could help me understand but I also feel that I am being left with no treatment, no plan going forwards and a lot of unanswered questions. Yeah.	Left with unanswered questions and no treatment plan
	JR: So you've completely encapsulated both the helpful and the unhelpful, helpful because you've got the diagnosis and a website but unhelpful because there's no treatment pathway. In terms of the treatment that they have offered you, what have you been offered so far?	
	P003: They haven't offered me any treatment. In the letter it said something like I needed to have some continued support from the mental health team. But I am not under the mental health team erm, and when I did go to them at the beginning, they said I didn't meet their criteria for care. So, I am a lot better than I was at the time of that initial interview with mental health. So, I can't imagine that I would meet the criteria for them now just because I have this new diagnosis.	Confusion over whether she should be seen by MH team or not

	JR: Sorry when were you told to go to the Mental health team?	
	P003: Back in July.	
	JR: OK, so that was in response to the seizures?	
GP increases medication in light of viewing seizures as anxiety and stress – a sense that because she has MH problems, then seizures have to fit in to this.	P003: I think they originally thought that what I was experiencing was not seizures but extreme anxiety and stress. So they upped my medication. And it wasn't until I said look these movements, these tremors these kind of shaking, they are like fits, they were like Oh, OK. I said I wanted to be referred to neurology because I think I am having seizures and my family were telling me I was having seizures. And they were like OK. So the mental health came before. I don't know what the timeline is sorry.	Originally goes to GP because they thought seizures were extreme anxiety and stress and upped medication. Feels Neurology may have answers
	JR: So who were you under at that point when you start to have the symptoms and they say it's extreme anxiety ?	
	P003: The GP.	
	JR: I see that makes complete sense. This doesn't fit entirely into an anxiety attack so they send you to Neurology and they give you the Neurology.org website. But they've not offered you physio or anything like that.	
Asked for referral to Neuropsych	P003: No. I've asked the GP to refer me to Neuropsych but I don't think they've done that yet. Cos that was something I had to call about.	
	JR: How does that fit with you?	
Feels isolated and abandoned by being far from centres of expertise Feels lost without experts	P003: I think it depends who you get. It's a postcode lottery. I'm on a Facebook group for non-epileptic seizures and some people get on with it and some people like St George's people get really great treatment. But if you're not near these central places. There is a place near here that is tertiary care that has a neuropsychiatry centre. I just want to see someone	Feels that follow up care is random and post code lottery Feels that no one has expertise in DS

	that knows what they're talking about. That's all really.	
	JR: And your experience so far is not that?	
	P003: No.	
	JR: And can I ask what medication you're on?	
	P003: Sertraline. Originally when they thought I was just having anxiety they increased the Sertraline. I've been all over the place with my anti-depressants. I was originally on Sertraline but then I thought that the Sertraline increase gave me the (seizure) symptoms so I asked them to change it. They changed it to Venflaxin but I felt absolutely horrendous on that but I thought just keep going. And my mental health took a real nosedive on it. I was gaining weight, so I asked them to change it back to a lower dose of Sertraline as I had felt fine on it and they've done that and I've felt much better since. That's all I am on. They never tried anti epileptics or anything like that for me.	Prescribed increased Sertraline but think it's linked to seizures so stop
	JR: So at the moment, it sounds like, just as you say, you're at the beginning of this and it's quite difficult to find the people who understand it to get the right treatment but maybe there's hope in neuropsychiatry?	
	P003: Yeah	
	JR: And right now that's where your mind is at?	
Feels she will try anything to save her career which has already been compromised as she can't do patient facing work	P003: That's where my mind is at. And also CBT. I've got an assessment booked with a CBT provider to see if this is something they deal with but I imagine it's fairly specialised, I have no idea. I will see if that is something I can try. At the moment I am willing to try anything because it's having an impact on my career, so…	Wants CBT because seizures are impacting her career
	JR: It sounds like you're really anxious about that and obviously	

	it's not great to feel even more anxious about that.	
	P003: Yeah, yeah.	
	JR: But they've changed your job already?	
Seizures have compromised her work and her career - can't see patients	P003: Well, it's because I'm still getting paid at my band 6 wage and I am still doing some band 6 roles but because I'm not patient facing, I can't do all of them. So, I think they feel that.....in general practice it's all about money…..and if I can't carry out my role to the full and they can't afford to replace me, then I think they are considering either redeploying me or dismissing me on medical grounds so they can then afford to have a nurse to do the services they need to provide. I understand their position but at the same time I am still hopeful that I will get better.	Her future employment is compromised by seizures
	JR: Yeah	
	P003: And I can carry on my job.	
	JR: OK. And at the moment, have the seizures got worse or reduced or changing in their presentation?	
Unpredictability of seizures – good weeks, bad weeks Epileptic sounding triggers – flashing lights and moving images Consciously thinks "it's not going to affect me tonight" – mind over matter? If she is startled, this will trigger a seizure	P003: Yeah, this week, great week. I've haven't had very many at all. Some weeks I have them every day. Er, no, this week's been great. It depends on…well, I don't know what it depends on really. I'm mainly not very good with flashing lights and by fast-moving images. That's generally my trigger. So, driving at night-time well I can't drive any more. So, in the car at night time and pretty much anything on TV sets me off. So, this week I've just been watching TV and thinking it's not going to affect me tonight and it's kind of been alright (laughs). So, I keep trying to do that and it's so far worked this week. But these are the times I get a warning though. I do have some when I don't have any warning and that's generally when I am startled. So as soon as I	Describes vacillating nature of seizures No idea what might make them worse or better Describes epileptic type triggers. Flashing lights/TV fast moving images Some seizures have warning sign, others don't One seizure triggers more

	get something unexpected then it generally is, once I have one they just are worse for a little while until…. But this is probably the longest time I've gone without a seizure.	
	JR: I'm really glad, really glad. So that's all my questions so is there anything you'd like to ask?	
	P003: For the research, what are you hoping to learn from it?	
	JR: I wanted to understand what women felt about why they had them? And to turn it on its head and to ask you rather than the neurologists or neuropsych. It felt important to do that so it is a small study so you can't generalise. But I felt it important to turn the tables and ask women what they thought.	
Questions why health professionals only thought about her MH – feels seizures were shoehorned into this	P003: Yeah, because basically you're told it's your mental health, as with a lot of things. And although she never outrightly said it, the neurologist definitely inferred as if it was my mental health. And the GP thought it was my mental health. And although it probably is my mental health, there are other things to be considered and you kind of want someone to validate those feeling, that maybe something physical did trigger it off. Even if that's an unlikely scenario, just to have someone just reassure you a bit.	Professionals have told her it's her mental health – she wants someone to validate a physical trigger Feelings haven't been validated by relying on mental health probability
	JR: I totally understand. It feels like the perfect storm when I hear these stories. It's not one thing but a range of things. And some may be psychological but others not but maybe it's the coming together of those things. But that's what I'm hearing.	
Frustration of having medical background but can't understand this – doesn't fit	P003: Cos I'm medical I'm quite interested in how it works so it's really frustrating to not understand it. From what I've read it's interesting to be between physical neurology and psychology	Mismatch between her medical background and fact that she can't understand seizures.

	– it’s so closely linked together and listening to the research about the MRI scans which show higher energy in certain areas of the brain but hopefully there will be more research and people like you to help people like me.	

Appendix 8 (contd.)

P003 Initial themes

Tension between Physical or mental health Cause

Constant illness and Covid in family in lead up to seizures

“everyone in the household was poorly with something, for three months”

. At the beginning of last year for about two or three months, everyone in the household was poorly with something, for three months.

Onset of seizures follows long period of family illnesses followed by “brain was just not working”.

Seizure felt like stroke

Erm, I thought I was having a stroke erm and so I went to see one of my colleagues and got her to check my blood pressure (laughs) which was alright, not too bad.

Tensions of being told it was anxiety but didn’t feel she was anxious

Does not link loads of work with stress

Confusion - not having a stroke but not OK

Lots of competing theories about DS p.

I’ve had a lot of different theories in the time. Around the time when they started happening a lot of different things were going on.

Fighting to be heard by medical professionals

GP increases medication in light of viewing seizures as anxiety and stress – seizures have to fit in to mental health model.

I think they originally thought that what I was experiencing was not seizures but extreme anxiety and stress. So they upped my medication. And it wasn't until I said look these movements, these tremors these kind of shaking, they are like fits, they were like Oh, OK. I said I wanted to be referred to neurology because I think I am having seizures and my family were telling me I was having seizures.

Asked for referral to Neuropsych

P003 Disconnection

Derealisation – brain switched off – she has disappeared

"I felt disconnected to the world "

Disconnect between life changing symptoms and how she feels mentally

Disconnection between brain and speech

Disconnect from memory – (remembering historic sexual assault only now)

Disconnect between her feeling that it is to be brain and message she receives that it's her mind

And mentally I have been in much worse, darker places before. And I felt OK and I just felt my main issue was having these physical symptoms, not my mind. I didn't feel my mind was bad enough to have such physical overwhelming symptoms that have completely changed my life.

Questions why health professionals only considered her mental health – feels seizures were shoehorned into it / neglected as discrete thing

Yeah, because basically you're told it's your mental health, as with a lot of things. And although she never outrightly said it, the neurologist definitely inferred as if it was my mental health. And the GP thought it was my mental health. And although it probably is my mental health, there are other things to be considered and you kind of want someone to validate those feeling, that maybe something physical did trigger it off. Even if that's an unlikely scenario, just to have someone just reassure you a bit.

Frustrated at having a medical background but can't understand this – doesn't fit

P003 FEELING ABANDONED

No one has explained what seizures are

“All I was told was that as I was going to therapy for a little time at the time, they said I would engage better in therapy with a diagnosis.

Sense of being abandoned without a treatment plan

Feels isolated and abandoned by being far from centres of expertise

Feels lost without experts (she has medical background)

Undermined by not being taken seriously fuels abandonment

I was given a website – that’s what you’ll I hear loads of time – I was given the website Neurosymptoms.com and I was told to go away and look at it. I was actually quite angry for quite a long time because I felt that something serious was going on in my brain and they were just telling me it was in my head.

Website is both helpful and unhelpful because leaves more questions unanswered

P003 **ENVIRONMENT**

Epileptic sounding triggers – flashing lights and moving images

I’m mainly not very good with flashing lights and by fast-moving images. That’s generally my trigger

Consciously thinks “it’s not going to affect me tonight” – mind over matter?

If she is startled, this will trigger a seizure

So, in the car at night time and pretty much anything on TV sets me off. So, this week I’ve just been watching TV and thinking it’s not going to affect me tonight and it’s kind of been alright (laughs).

So as soon as I get something unexpected then it generally is, once I have one they just are worse for a little while until….

P003 **COMPROMISED SELF**

Feels she will try anything to save her career which has already been compromised as she can’t do patient facing work

Seizures have compromised her work and career – can’t see patients

Unpredictability of seizures – good weeks, bad weeks

Yeah, this week, great week. I’ve haven’t had very many at all. Some weeks I have them every day. Er, no, this week’s been great. It depends on…well, I don’t know what it depends on really. I’m mainly not very good with flashing lights and by fast-moving images. That’s generally my trigger.

APPENDIX 9: GROUP EXPERIENTIAL THEME – UNDER SIEGE

P001 -

BODY UNDER SIEGE

Recollects feeling unwell in run up to first seizure p.1

It was strange to think about because that week as well I hadn't felt very well. It was really weird cos I wasn't feeling well. And I thought oh it's just my period. And I had thought my period was actually due that Saturday st my period coming. But my period didn't come – instead I just started having seizures

Thinks seizures are Covid related

And then the seizures started. I honestly don't know. At the moment it's looking like POTS, post covid POTS (*Postural Tachycardia syndrome*).

Believes it's post covid POTS

I did some research into it and people can develop POTS after developing covid.

P001 BODY OF PAIN

Referred to Rheumatology due to joint pain

Hyper mobility issues – joint pain?

So my joints are quite weird. That's the best way to look at it. So I have this one (points), I've dislocated both my thumbs, sometimes my shoulders go, my knees and hips.. I'm quite tight and it's hard to relax. It got worse after Covid and they get quite painful. And I had wanted to see a Rheumatologist to see if I had fibromyalgia. I ended up having to take codeine just to walk.

Body under siege

Queries whether pain is factor in seizures

I had read something. I can't remember what it was. And again it gives a list of potential triggers and pain was one of them. And I was like…mmmm. I'm always in pain, some days are worse and some are better.

Pain as trigger for seizure – body under siege

If I am in more pain, I sometimes seize more

P004 - PAIN - Seizures in context of pain from migraine and fibromyalgia

Theory of NEAD makes sense due to link with pain + and emotion p.6

he actually had a theory that, as well because my fibromyalgia was a bit out of control with the pain. And his theory was that because the pain hadn't been managed that well, that that actually triggered the seizures and the functional symptoms. And that made sense as well to me. And also, I knew that mentally I wasn't in the best place because of everything, like the pain, being off work. You know I knew that I was still, I'm still grieving my Dad, and hadn't really dealt with that

Dissociation as means of protection from pain makes sense p.7

it was a really useful way of….He said it's your brain's way of protecting you. It's dissociating you from that pain, which made complete sense. I felt really out of control, I felt like my pain is still not

P001 Seizures could be heart-related?

After I had started having seizures, we were trying to work out like how, is there a connection? One of the things that happens is that my heart beats quite quickly before I have a seizure. And my hands go numb. And I have an Apple Watch and I can see my heart rate would go up to 110 and 150 and then I would end up having a seizure at that point. And then it would go back to normal

THEORY OF STRESS

P002 THEORY OF STRESS

Theory of burn out has to change to something more multi-dimensional

And he (Neurologist) says to you it's a real thing, it isn't all in your head. But I think now it's more multi-faceted, more multi mm, there's more dimensions..

Seizure as manifestation of stress saturation

"So it felt like my body said and my brain said that's it, I can't cope, something's got to give, it just shut down because it couldn't cope anymore."

"I was burnt out".

Theory that mental health is risk factor, not cause

P005 - C

One that would suggest that the relief and removal of stress prompted it, and the second one, you have the idea, if we are to consider what is going on around you, is that something has become really stressful, very difficult, no way out?

"Brain shuts down" due to stress – makes sense p.4

"My brain shuts down and I can't cope. So why should my brain shut down when I'm all excited and happy and I think it's going to be good?

Terrified that stress of minor ones will cause them to change into bigger seizures p.10

"I could possibly make them turn it into this. If I'm feeling this and I am terrified because I'm feeling this feeling, that could exacerbate it and turn it into… But it's the wetting myself and being out in public and being completely hopeless. I can hurt myself as well, I fell down the stairs and broke my shoulder in June. I feel unsafe outside. "

Theory – combination of factors because it's brain p.12

There's never going to be one thing if it's something to do with the brain. It's never going to be that simple, it's got to be a combination of factors somehow.

Environmental trigger - theory of supermarket lights? P.2

"At the time, I thought it was the lights in Sainsburys as I always get visual auras so I

P006

THEORY OF PREGNANCY AS TRIGGER

Body under attack p.2

It had been a rough pregnancy. I found out I was pregnant when I was about two weeks pregnant because I was already sick, I was already vomiting…….. But by 5 weeks pregnant I was tachycardic…

Medicine can't control pregnancy symptoms p.2

I was sick and on medication, I was on three types of medication just to try to let me eat anything. I couldn't even keep water down most of the pregnancy.

Body under siege from pregnancy, hyperemesis and covid

Nothing was working so I was in and out of hospital for the sickness because I was dehydrated and lacking in things. Then I got Covid (laughs) in the middle of it too so er then the Covid and the hyperemesis, the sickness, just sort of floored me so that, with the fast heart you know was just grim, so that pretty much continued the whole pregnancy

Body has extreme reaction to pregnancy p.3

But I was drained physically, mentally just exhausted because you felt so horrible most days

Theory = this is her body saying I can't cope p.4

After the three that week at the time I said could this be that my body is just drained, that my body is done? You know I'm physically exhausted and mentally exhausted and spending most days just lying feeling sick and in pain.