Understanding Experiences of Self-Disgust and Encounters with Healthcare Professionals in People with Functional/Dissociative Seizures

Lucy Eaves

A thesis submitted in partial fulfilment of the requirements for the award of Doctorate in Clinical Psychology (DClinPsy)

Clinical and Applied Psychology Unit

Department of Psychology

The University of Sheffield

May 2024

Declaration

This thesis has been submitted for the award of Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted to any other institution, or for the purpose of obtaining any other qualifications.

Structure and Word Counts

Section One: Literature Review

i. Word count excluding references and tables: 7,997

ii. Word count including references and table: 14,081

Section Two: Empirical Study

i. Word count excluding references and tables: 7,957

ii. Word count including references and tables: 11,351

Total word count (combining lay summary, literature review and research report)

i. Word count excluding references and tables: 15,954

ii. Word count including references and tables: 25,432

Lay Summary

Literature Review

Functional/dissociative seizures (FDS) resemble epileptic seizures but are not caused by changes in the brain. Living with FDS has many challenges, including mental health difficulties, lack of awareness from other people and difficulty accessing medical care. Some studies say people with FDS (pwFDS) receive poor medical care due to having difficulties talking to and getting on with healthcare professionals (HCPs). However, little is known about pwFDS' experiences with HCPs. Therefore, we aimed to find all the current research on this area to improve our understanding. We found 20 studies and analysed these using a method call 'thematic synthesis.' This analysis found three themes relating to pwFDS' experiences with HCPs. In theme one: 'clinician uncertainty feeds patient uncertainty', pwFDS felt that HCPs did not understand their condition which made it difficult for them to also understand it. PwFDS found this frustrating and left them feeling unsure about their diagnosis. In theme two: 'not fitting into the model of medical illness', pwFDS felt HCPs did not believe their problems as their condition did not have clear physical causes. This led to pwFDS feeling neglected by HCPs. In theme three: 'stigma fuelling traumatic experiences with HCPs', pwFDS talked about the poor treatment by HCPs which traumatised them and led to avoidance of seeking medical care. From our findings, we suggest more work needs to be done to understand these issues better. Also, to improve healthcare for pwFDS, HCPs and services need to improve their knowledge and awareness of FDS.

Empirical Project

Trauma and mental health problems are common in pwFDS. The emotion, self-disgust, is where disgust is turned on the self in an unhelpful and distressing way. Self-disgust is a particularly distressing emotion, causing people to feel repulsed at themselves.

Self-disgust plays a role in many mental and physical health conditions, including depression and epilepsy, but is not yet understood in pwFDS. Therefore, this study aimed to gain a better understanding of this. We sent out a questionnaire to pwFDS to measure their self-disgust. Eight of the highest scoring participants took part in interviews to talk about self-disgust further. We used a method called ‘interpretative phenomenological analysis’ to analyse the interviews which created four themes. In the first theme, ‘understanding the origin of self-disgust as based in rejection’, childhood abuse introduced feelings of self-disgust and others’ negative reactions to FDS introduced self-disgust for FDS. In the theme two, ‘experiencing self-disgust as intense and inescapable’, self-disgust was felt as a long-term perspective of the self and an intense emotional experience. In theme three: ‘understanding the relationship between self-disgust and FDS’, participants felt self-disgust for what their bodies did during seizures, for having a condition that’s not physically explained and for having a disability. In theme four, ‘suppression and seclusion- attempting to cope with self-disgust’, participants attempted to cope with self-disgust through social withdrawal, emotional avoidance and hiding from themselves. Our findings helped understand the relationship between self-disgust and FDS and suggests way for future research to build on this.

Acknowledgements

Firstly, I want to express my sincerest gratitude to all participants of this study, who bravely came forward to share their stories. Without them, this research would not have been possible. Their commitment to raising awareness of functional/dissociative seizures was inspiring, and I hope this research honourably captures their experiences.

Special thanks to my research supervisors, Professor Markus Reuber, Professor Jane Simpson and Professor Jaime Delgadillo for their guidance and support throughout this process. This journey wasn’t always plain sailing but with their dedication, knowledge and expertise, I always knew I was in good hands. It has been a privilege to work with them.

Thank you also to FND Action, who supported recruitment for this project; and to FND Dimension, who supported the development of this project.

And to my fellow trainees- Erin, Rosa, Evie, Rachel and Jen, and all the 2021 cohort- I thank them for their friendship, laughter and endless support. Their compassion and intelligence is truly inspiring and I couldn’t have imagined a better bunch to get through this Doctorate with.

To my family and friends outside of the course, particularly Margaret, Jess and Christie, thank you for reminding me there is a life outside of the DClinPsy and a light at the end of the tunnel. I’m grateful also for your support and encouragement.

Last but not least, I want to express my deepest love and appreciation to my wonderful partner, Luke. I am so grateful for his unwavering support, patience, encouragement and exceptional culinary skills. His belief in me carried me through this course. I feel so lucky to have had him by my side.

Contents

Section One: Literature Review

Individuals with Functional/dissociative Seizures' Experience with Healthcare Professionals: A Systematic Review and Thematic Synthesis

Abstract

Objective

Research suggests people with functional/dissociative seizures (pwFDS) experience challenges accessing healthcare. PwFDS report communication problems, negative relationships with HCPs and receiving sub-standard care. However, no previous reviews have explored this issue from pwFDS' perspectives. Therefore, this systematic review aimed to explore pwFDS' perceptions of their encounters with HCPs.

Methods

Four databases were systematically searched for peer-reviewed qualitative studies. Twenty studies published 2004-2023 with 270 pwFDS were included and analysed using thematic synthesis. The Critical Appraisal Skills Programme checklist for qualitative research was utilised to appraise the quality of included studies.

Results

Three superordinate themes with five subthemes were developed: 'clinician uncertainty feeds patient uncertainty', 'not fitting into the model of medical illness', 'stigma fuelling traumatic experiences with HCPs'.

Conclusions

Findings highlight the difficult experiences pwFDS face in their encounters with HCPs. PwFDS experience uncertainty due to poor knowledge about FDS, stigmatising beliefs, and traumatising encounters with HCPs. Positive encounters were mentioned but these occurred in the minority of instances. Difficult encounters led pwFDS to avoid accessing medical support when needed.

Practitioner Points

- Healthcare services must improve training and awareness of FDS to reduce patient uncertainty and potential prejudice.
- Specialist services comprising multidisciplinary professionals should be set up to support delivery of sensitive and compassionate care.
- Clinical psychologists should be utilised to promote psychologically-informed care for medical teams and patients.

Keywords: Functional/dissociative seizures; healthcare encounters; stigma; systematic review; thematic synthesis

Introduction

Background

Living with a chronic health condition has many implications for an individual's quality of life (Roddis et al., 2016). Navigating healthcare systems and accessing medical treatments is a crucial part of living with chronic health conditions, often vital for maintaining wellbeing and functional abilities (Beatty et al., 2003). Patients' experiences of such encounters influence their views of healthcare systems, emotional wellbeing and ability to engage and sustain therapeutic relationships (Kornhaber et al., 2016; McColl-Kennedy et al., 2017).

For people with poorly understood health conditions, experiences of healthcare can be challenging due to stigma, discrimination and the provision of sub-standard care (Nyblade et al., 2019). An example of a group of patients who often report challenging encounters with healthcare professionals are those with functional/dissociative seizures (FDS; Robson & Lian, 2017).

FDS (also known as nonepileptic attacks or psychogenic nonepileptic seizures; Kerr & Stern, 2020) are paroxysmal disturbances in an individual's movement, consciousness, sensation or experience that superficially resemble epileptic seizures, but are not associated with epileptic activity (Brown & Reuber, 2016). FDS are one presentation of a broader condition - functional neurological disorder (FND) - a condition characterised by a range of symptoms including problems with movement, sensation and awareness, resembling neurological conditions but not associated with any physiological changes in the nervous system (Stone et al., 2020).

The underlying causal factors of FDS are not fully understood, but are hypothesised to involve complex interrelated psychological, social and biological factors, often associated with psychological stressors (Brown & Reuber, 2016). While there is some evidence for the use of antidepressants and anxiolytics to treat FDS, psychological interventions are the treatment of choice by most experts (Hingray et al., 2018). The National Institute for Clinical Excellence (NICE) recommends support from non-specialist multidisciplinary professionals to manage symptoms (NICE, 2021), which can decrease seizure frequency and improve daily functioning (Beimer & LaFrance, 2022). People with FDS (pwFDS) are commonly seen in neurology centres, accounting for up to 20% of patients in epilepsy units (Martin et al., 2003). Estimations vary due to a paucity of studies, but it is thought the prevalence of FDS is around 23.8/100,000(Villagrán et al., 2021).

FDS typically have a significant impact on a person's life (Aasadi-Pooya et al 2021). PwFDS experience greater levels of psychological difficulties, including anxiety and depression, compared to the general population and people with epilepsy (Diprose et al., 2016), and increased rates of suicide (Zhang et al., 2022). Trauma and adverse life experiences are also prevalent, occurring in 38-64% of pwFDS (Myers et al., 2019). Additionally, individuals report significantly impaired quality of life (Jones et al., 2016). Research has identified reduced rates of employment and increased reliance on social welfare payments among pwFDS (Asadi-Pooya et al., 2021). Relational difficulties are also commonly reported in this population (Villarreal, 2021). Findings from qualitative studies also support these data, with participants reflecting on the loss of independence, increased reliance on others' support and negative emotions associated with seizures, such as embarrassment, shame and loss of confidence (Myers et al., 2022; Rawlings & Reuber, 2016; Rawlings et al., 2017).

Another issue for pwFDS is lack of awareness and understanding from others, particularly healthcare professionals (HCPs), about their condition (Rawlings el al., 2016) - a factor contributing to the stigma associated with the diagnosis (Annandale et al., 2022). In qualitative studies, participants report experiencing stigma and discrimination from others due to their condition (Rawlings & Reuber, 2016). Stigma – defined as a “devaluation or discreditation of an individual due to the possession of a characteristic that distinguishes that person from others (Rawlings et al., 2017, p. 167; Goffman, 1990) - often accompanies the experience of epilepsy and seizures. PwFDS report more frequent and severe stigma, possibly due to the association of the diagnosis with mental illness and historical origins in hysteria (Trimble, 2018). A recent review also highlighted stigma around FDS is prevalent in many contexts and cultures across the world. This presents a major barrier to diagnosis and appropriate treatment, as well as having a profound impact on the lives of pwFDS. An international survey of people with FND found respondents felt their diagnosis negatively affected their treatment and felt traumatised by stigma. The majority of respondents also felt concerned and uncertain about their ability to access healthcare due to stigma (FND Hope, 2020).

While the experiences of HCPs with pwFDS has been explored quantitatively and qualitatively (Barnett et al., 2022; Rawlings et al., 2018), relatively little attention has focussed on pwFDS’ experience of HCPs. In studies that have focused on pwFDS’ perspectives of encounters with HCPs, participants report more communication problems, negative relationships, difficulty accessing services and support, and higher burden of poor care in comparison to participants with multiple sclerosis (O’Keeffe et al., 2021) and epilepsy (Rawlings et al., 2018; Robson & Lian, 2017). Participants have reported feeling traumatised by their encounters with HCPs (Robson & Lian, 2017). Traumatic encounters could be considered to be encounters that are perceived by the individual to be severely distressing, to the extent that they experience negative thoughts and emotions associated with it, changes in emotional wellbeing following encounters and attempts to avoid future encounters or situation that risk further traumatic encounters (Perrotta, 2019). In addition to the findings related to stigma and negative perceptions among HCPs, it is important to better understand pwFDS' perspectives of their encounters with HCPs as this may serve to improve clinician-patient relations.

Previous reviews

Previous systematic reviews have explored different issues and experiences of FDS. In a review of patients' accounts of living with FDS, participants highlight that encounters with HCPs were sometimes helpful but could be traumatising and distressing with efforts to seek validation ignored and doubted (Rawlings & Reuber, 2016; Rawlings et al; 2018). However, while these findings demonstrate the importance of patient perspectives, encounters with HCPs only formed part of a wider synthesis and therefore were not explored in-depth.

Furthermore, two recent reviews have explored the experience of stigma in pwFDS (Annandale et al., 2022) and FND (Foley et al., 2024). In these reviews, stigma was found to be pervasive in all aspects of pwFDS' and FND's lives, including amongst family, HCPs and wider social circles. Stigma threatened individuals' identity and posed a personal cost to them (Annandale et al., 2022; Foley et al., 2024). Again, these reviews highlight the healthcare challenges faced by pwFDS but were explored as part of a wider synthesis. Consequently, there remain gaps in our knowledge of the studies to date exploring pwFDS' experiences with HCPs.

Rationale for the current review

Having a better understanding of patients' perspectives of their encounters with HCPs may reveal ways to improve access and experiences of healthcare, and help improve clinician-patient interaction and service delivery models for pwFDS in the future.

Qualitative methodology highlights participants' unique personal journey, giving them a voice on issues pertinent to them, providing a humanising quality to research (Todres et al., 2009). Furthermore, qualitative systematic reviews can inform clinical decision making, policy and practice while evaluating the quality of evidence available and consolidating research on lived experience (Booth et al., 2016). Findings from previous research demonstrate that while pwFDS' experience with HCPs has been noted, it has yet to be explored in detail as a central component in a systematic review. There is therefore a need for a specific synthesis of experiences of FDS patients with HCPs.

Review aims

The specific review question is: what are pwFDS' perceptions of their encounters with HCPs?

Methods

The review question was formulated using the SPICE framework. This refers to setting, perspective, intervention/phenomenon of interest, comparison and evaluation, and is suited to qualitative research (Booth, 2006). This framework was chosen, as opposed to PICO (Population, Intervention, Control, Outcome), as the additional component of SPICE supported the development of a focused research question that captured points of interest to the review's aims (Davies, 2011; Glasper & Rees, 2013).

A systematic review and thematic synthesis was the chosen method for answering the research question as this method can broaden understanding of pwFDS' perceptions of HCP encounters through interpretation of data occurring across different studies (Grant & Booth, 2009; Thomas & Harden, 2008). Thematic synthesis is a flexible, systematic and transparent method to synthesise and interpret the findings of multiple qualitative studies and is considered a useful approach for healthcare policymakers and practitioners (Booth et al., 2016; Flemming et al., 2019).

There are many methods of qualitative evidence synthesis, each with their own strengths and weaknesses (Flemming & Noyes, 2021). Thematic synthesis was considered the most appropriate approach due to the review's aims of synthesising qualitative data and broadening our understanding regarding participants' perspectives of healthcare encounters. Thematic synthesis can draw on all elements of a paper to capture the essence and context of the studies' findings, which is important to this review's aims. This contrasts with meta-ethnography, another content-focused qualitative synthesis approach, for instance, where it is argued that the context of included studies can be lost in the bid to create a 'line of argument' (Flemming & Noyes, 2021).

Scoping searches relevant to the research question were performed using Google Scholar in December 2023 to gain an overview of the extant literature in the area. The review was registered on PROSPERO on 23rd January 2024 (CRD42024505299).

Search Strategy

A comprehensive search using four databases - Scopus, MEDLINE via Web of Science, PsycINFO via Ovid and CINAHL was conducted to identify literature published from January 2000 until 1st February 2024. These databases were selected because they include publications relevant to this review; covering healthcare, allied health professionals, health sciences, and behavioural and social sciences. These databases were also well suited to support evidence synthesis by meeting systematic search performance criteria regarding coverage of peer-reviewed journals, recall and precision (Gusenbauer & Haddaway, 2020). Date restrictions were applied in order to capture articles that reflect the more recent context of clinical practice and patient experiences.

The search terms are presented in Table 1. They were guided by the SPICE framework to capture articles relevant to the review question. Search terms were developed in consultation with supervisors and a specialist librarian. Search terms were used with Boolean operators and the symbol * was used for truncation. Titles, abstracts and keywords were searched. In addition to systematic searches, forwards citation searching using Google Scholar and manual backward searching was conducted on all included studies to locate additional relevant studies (Hinde & Spackman, 2014) Additional papers were sourced through recommendations from experts in the field. While searching the grey literature can broaden the scope of literature searches, limited guidance exists on how to do this systematically (Mahood et al., 2014). Therefore, the grey literature was not consulted for this review.

All studies were exported from each database and managed using EndNote 20 (Lorenzetti & Ghali, 2013). Duplicate records were removed manually prior to title and abstract screening.

Table 1

Search terms corresponding to the SPICE framework

SPICE	Search Terms
Setting	healthcare OR hospital OR “primary care” OR NHS OR “national health service” OR “emergency service*” OR emergency OR “secondary care” OR clinic OR “accident and emergency” OR community OR “community care” OR “healthcare provider”

	AND
Population	“functional dissociative seizure*” OR “functional seizure*” OR “dissociative seizure*” OR “functional neurological disorder” OR “nonepileptic seizure*” OR non-epileptic* OR “conversion disorder” OR “psycho* seizure*” OR “psychogenic nonepileptic seizure*” OR PNES OR FDS OR FND OR “nonepileptic attack disorder” OR NEAD OR pseudoseizure*
	AND
Intervention	encounter* OR interaction* OR experience* OR “health* encounter*” OR “patient experience*” OR “clinical encounter*” OR “clinical interaction” OR communication OR doctor-patient* OR nurse-patient OR “medical encounter*” OR “medical interaction*” OR “clinician interaction” OR “clinician encounter”
Comparison	N/A
	AND
Evaluation	experience* OR perception* OR view* OR attitude* OR perspective* OR reflection* OR opinion* OR explor* OR thought* OR belie* OR feel* OR qualitative

Study Selection

Study selection was determined by inclusion and exclusion criteria, presented in Table 2.

Table 2

Inclusion and exclusion criteria

Inclusion Criteria
1. Peer reviewed qualitative journal articles written in English that explore people with FDS’ encounters or interactions with healthcare professionals.
2. Studies that use a qualitative methodology for data collection- including interviews, focus groups and surveys with open ended/unstructured responses.

3. Studies that use a qualitative method of data analysis- including thematic analysis, interpretative phenomenological analysis, content analysis, narrative analysis, grounded theory
4. Mixed method studies that contain relevant and extractable qualitative data

Exclusion Criteria

1. Papers not written in English
2. Quantitative studies
3. Studies and analyses of patients' experiences outside of healthcare services or evaluations of specific interventions
4. Studies including people who do not experience functional seizures (i.e. FND without seizures, epilepsy or other neurological conditions)
5. Supplements, reviews, anecdotes, editorials, letters, theses
6. Lack of quotes to support synthesis interpretation

Screening

Following removal of duplicates, article titles and abstracts were screened and excluded based on inclusion and exclusion criteria (Table 2). Full-text articles of the titles that were not excluded were subsequently obtained and screened. A total of 50% (27) of these articles were ratified by an independent researcher (EE) against inclusion and exclusion criteria. One discrepancy was discussed and resolved. This resulted in 20 studies meeting criteria for inclusion in the review.

Data Extraction

Data extraction was completed in two phases. Firstly, publication and study characteristics, and key relevant findings were extracted and aggregated into a formatted table (Table 3). Data relating to pwFDS' experience with healthcare professionals was extracted and entered in NVivo (Lumivero, 2023) as part of the data synthesis. This included direct quotations, descriptive summaries, conceptual frameworks, contextual details and analytic interpretations.

Assessment of Quality

Quality assessments were completed on included studies to appraise their methodological quality, vigour and contribution (Carroll & Booth, 2015). There is a lack of consensus on what constitutes appropriate quality criteria for qualitative research, given the variety of appraisal tools to assess the quality of research (Majid & Vanstone, 2018). However, the Critical Appraisal Skills Programme checklist (CASP, 2018) was chosen to appraise studies in this review as this was devised for use in health-related qualitative syntheses and is endorsed by the Cochrane Qualitative and Implementation Methods Group (Long et al., 2020).

The CASP checklist consists of two screening questions and eight items that are designed to evaluate the validity, rigour and implications of research (Appendix A). All studies passed the initial screening questions. While the original version of the CASP does not include a scoring system, numerical outcomes have been suggested to summarise quality ratings (No= 0, Can't tell= 0.5, Yes= 1) (Butler et al., 2020). With a score range of 0-10, studies can be categorised as high (8.5-10), moderate (6-8) or low (<5.5) quality (Butler et al., 2020). There is debate about whether to exclude low quality studies from qualitative syntheses (Long et al., 2020). However, as no studies were of low quality in this review, exclusion was not considered.

All studies were appraised by the lead researcher (LE), and two independent reviewers (EE & ML). Twelve discrepancies in quality ratings were resolved through discussion.

Additionally, the ‘preferred reporting items for systematic review and meta-analyses’ (PRISMA; Page et al., 2021) 2020 checklist and the ‘enhancing transparency in reporting the synthesis of qualitative research (ENTREQ; Tong et al., 2012) frameworks were completed by an independent researcher (EE) to support transparency and quality in reporting (Appendix B-C).

Data Synthesis

Thematic synthesis (Thomas & Harden, 2008) involves a three-stage iterative process. Firstly, the researcher (LE) independently engaged in inductive line-by-line coding of the extracted data of included studies to understand the content and meaning of each study. This generated a collection of codes, which were then combined into broader ‘descriptive themes’. This considered the similarities and differences between codes whilst referring back to the papers from which they were derived, to ensure coherence and grounding in the views and experience of study participants. The synthesis produced at this stage remained close to the original findings of the included studies (Thomas & Harden, 2008). In the third stage of the synthesis, relationships between descriptive themes were considered and critiqued against the research question in an iterative process to produce ‘analytic themes’. This step in the analysis was completed as much of the data in the primary studies did not directly relate to the current study’s research question so data relevant to the research question had to be extracted. Additionally, this step sought to develop new interpretations that went beyond those of the original studies’ findings, in order to support the current study’s research question and aims to understand participants’ experiences with HCPs (Thomas & Harden, 2008). Themes were discussed and reviewed with the supervisory research team (MR and JS). See Appendix D for the arrangement of descriptive themes and codes in analytic themes.

Results

A total of 1,576 studies were retrieved from systematic searches of the selected databases. Following duplication removal, and title and abstract screening, 54 full-text articles were reviewed against the specified criteria for inclusion in the review. An additional nine papers were found through forwards and backwards searching of included articles and consultation with experts in the field (Figure 1).

Overall, 20 articles published between 2004 and 2023 met the criteria to be included in the review. The study characteristics are presented in Table 3. A total of 270 pwFDS from eight different countries were represented**.** Four studies included participants in more than one study identified by our literature search (e.g. Peacock et al., 2022; Pretorius & Sparrow, 2015; Rawlings et al., 2018a; Rawlings et al., 2018b; Read et al., 2020). Duplicated data between these studies was identified and highlighted during the coding stage of analysis to ensure that data was only coded once. One study comprised of HCPs' views (Read et al., 2020). Data provided by HCPs could easily be separated from patient data and excluded from the analysis. Three studies comprised of people with epilepsy and functional movement disorder (FMD) (Rawlings 2018a; Rawlings 2018b; Zeun et al., 2023). Again, data were easily separable. PwFDS' experiences with HCPs form a portion of the findings in the majority of included studies. Very few focused specifically on this topic, showing a paucity of research interest in this area.

Figure 1

PRISMA flow diagram

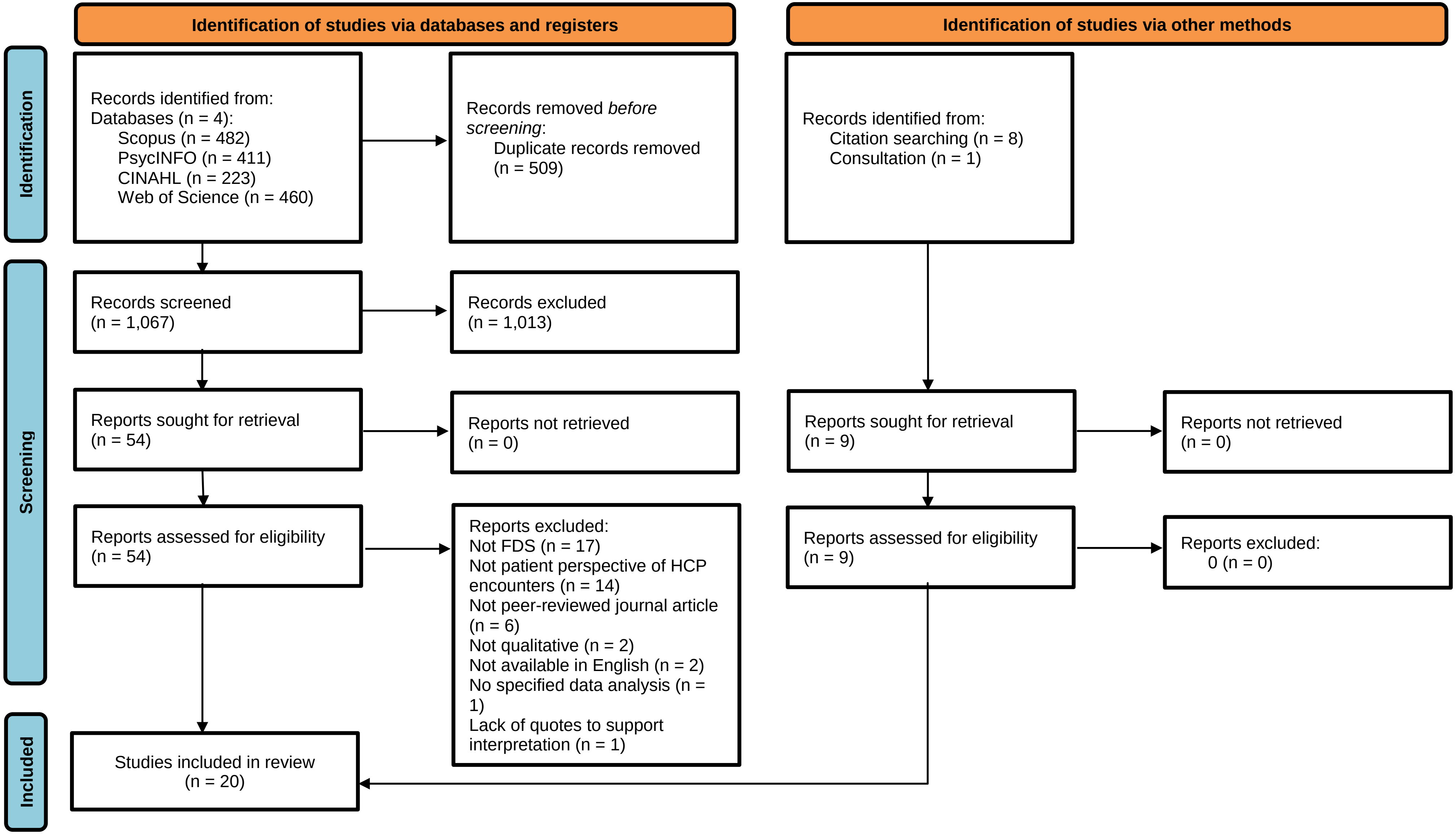


Table 3

Data extraction table- summary of study characteristics

Author (year)	Country	Recruitment	Participants	Terminology used to describe seizures	Healthcare settings and HCPs encountered	Data collection methods	Analysis	Relevant key findings and illustrative quotes
Baxter et al. (2012)	United Kingdom	Specialist neurology clinics across 3 centres	12 participants, aged 19-58. 8 females, 4 males	Psychogenic non-epileptic seizures (PNES)	Clinic consultations; HCPs not specified	Semi-structured interviews	Thematic analysis	The relevant theme, 'Getting answers' discussed participants' endeavours to make sense of PNES and managing unresolved questions and uncertainties Key quote: "*Nobody seems to be able to put their finger on it. That's the frustrating bit.*"
Dickinson et al. (2011)	Canada	Two major hospitals	5 participants- 3 female, 2 male; age 30-50	Nonepileptic seizures	Physicians	Semi-structured interviews- adapted McGill Illness Narrative Interview Schedule	Thematic content analysis	Relevant themes related to factors that had a beneficial or detrimental impact on illness experience, such as medical communication. Key quote: "*They just pretty much write you off and say, 'You know you don't have epilepsy, go see somebody else,' and don't tell you anything, don't give you any*

								suggestions… It's very difficult, because they don't; nobody realizes what it's like to be like this.”
Fairclough et al. (2014)	United Kingdom	NHS clinical neuropsychology waiting list	9 women and 3 men, aged 17-64. 1-35 years seizure experiences	Psychogenic nonepileptic seizures	Psychological therapy	Semi-structured interviews and questionnaires	‘Data driven’ thematic analysis	Relevant themes: post-diagnostic limbo and uncertainty apprehension about therapy, and need for validation. Key quote: *“I feel I've been left in limbo.”*
Goldstein et al. (2021)	United Kingdom	27 neurology/epilepsy services, 17 liaison psychiatry/neuropsychiatry services and 18 cognitive-behavioural services	21 females and 9 males, aged 18-80 who had participated in the randomised-controlled trial	Dissociative non-epileptic seizures	Psychological therapy; Healthcare professionals; neurologists; CBT therapists	Semi-structured interviews	Thematic framework analysis	Four main themes related the experience of receiving a diagnosis and experiences of engaging in CBT as part of a large clinical trial. Key quote: “*I think because she’d [neurologist] seen part of one [a seizure] and she explained it in the way that we would talk. And she just really explained how it actually happens and how they work. And for the first time I thought that’s me . . . and it all started to fall into place.”*
Green et al. (2004)	United Kingdom	Neuropsychiatry outpatient clinics	9 participants, 5 female, 4 male, aged	Non-epileptic seizures	Hospital; doctors; neurologist;	Semi-structured interviews	Interpretative phenomen	The relevant theme concerned being accepted by others, particularly doctors.

			30-65		consultant physician		ological analysis	Key quote: "*When I get taken to hospital [ ] they're very rude.[]I feel that they're thinking that I put it all on*"
Karterud et al. (2010)	Norway	Specialist hospital for epilepsy	10 participants; 6 female, 4 male aged 16-61	Psychogenic non-epileptic seizures	Health personnel; health providers; doctors	Semi-structured interviews	Systematic text condensation	Relevant themes related to 'transfer of responsibility' from health professionals to the participants due to having a PNES diagnosis, not feeling included in the diagnostic process. Key quote: *"I am so furious that I could kill someone when I am not believed. This is an unfair diagnosis. There isn't any help and I won't be respected."*
Karterud et al. (2015)	Norway	General Hospital	11 participants, aged 14-24 7 female participants aged 19-24	Non-epileptic seizures	Health professionals; doctor; healthcare providers	Semi-structured interviews	Systematic text condensation	Two relevant themes: Threatened self-image, being believed and belief in oneself and getting an explanation that makes sense. Key quote: "*As long as others understand me, and don't think I stage or simulate seizures, it is all right. It is just a seizure, I'm not really like this"*
Peacock et	United	Routine	5 female	Non-epileptic	Professor;	Free	Free	Three relevant themes related to

al. (2023)	Kingdom	hospital clinics	participants, aged 34-64	attack disorder (NEAD)	consultant; doctor; neurologist	Association Narrative Interview	Association Narrative Interview	legitimacy and medicalization of NEAD: the plausibility of stress-based explanations, explanations that help, medical ambivalence around medicalising. Key quote: *"And (the professor) wrote me a letter ... So, I took it into hospital and I give it'em and I said... and the Professor wrote: 'This lady does not do this at will. These are real... this is a real illness.' And I thought: Wow, thank you, Prof... you know. And I give it'em and said, 'Will you please put that in my records.'"*
Peacock et al. (2022)*	United Kingdom	Routine hospital clinics	5 female participants, aged 34-64	Non-epileptic attack disorder	Doctors; registrars	Free Association Narrative Interview	Free Association Narrative Interview	The relevant theme explored how participants experienced their diagnostic journey. Key quote: "*They do not understand NEAD – nobody I have met from… even doctors, even at my surgery they've never seen it*."
Pretorius (2016)	South Africa	Epilepsy unit at a private hospital	10 participants; 8 females, 2	Psychogenic non-epileptic seizures	Hospital; doctor; paramedics;	Semi-structured interviews	Thematic analysis	Two relevant themes; inexpert health providers as a barrier to diagnosis, and knowledgeable

			males; aged between 19-51		psychologists; neurologist; healthcare providers; psychiatrist			healthcare providers as a facilitator to diagnosis of PNES. Key quote: *“Once I went to Doctor B. He helped me through it, he was a good doctor, always looked after me.”*
Pretorius & Sparrow (2015)*	South Africa	Epilepsy unit at a private hospital	10 participants; 8 females, 2 males; aged between 19-51	Psychogenic non-epileptic seizures	Medical professionals- neurologists, psychologists, psychologists and first responders (emergency care technicians)	Semi-structured interviews	Thematic analysis	Medical professionals were seen as a challenge and a resource following diagnosis on the mirco- and macrosystem level. Key quote: “Some of them were really rude and. . . otherwise it’s just doctors that. . . they almost make you feel like you’re the problem.”
Rawlings et al. (2017)	United Kingdom	Membership-led organisations for individuals experiencing seizures and outpatient neurology clinics	19 participants, 16 females and 3 males, aged 20-69	Psychogenic nonepileptic seizures	Nurses; healthcare professionals; paramedics	Written narratives based on specific prompts from the researcher & questionnaires	Thematic analysis	Two relevant themes concerning participant’s perceptions of others’ reactions to their diagnosis and lack of understanding amongst HCPs. Key quote: “*We have a participant who’s mum has pseudo seizures and the nurses always mock her or say she is weird and fakes seizures – these are professionals and even*

								they don't understand it.”
Rawlings et al. (2018a)*	United Kingdom	Membership-led organisations for individuals experiencing seizures and outpatient neurology clinics	38 participants, of which 19 had PNES, 16 females and 3 males, median age 42	Psychogenic nonepileptic seizures	Healthcare professionals	Written narratives based on specific prompts from the researcher & questionnaires	Thematic comparison	Findings compared the experience of participants with epileptic and PNES. There was one key relevant theme: ‘treatment’ which included participants’ experience with HCPs and perceptions of treatment. Key quote: *“I came across a psychologist though, yesterday to be fair and she was amazing. Although she did not have much knowledge of functional neurological disorders apart from what she had to Google, she sat back and listened.”*
Rawlings et al. (2018b)*	United Kingdom	Membership-led organisations for individuals experiencing seizures and outpatient neurology clinics	49 participants, of which 20 had PNES, 17 females and 3 males, median age 39	Psychogenic nonepileptic seizures	Healthcare professionals; doctors; hospital; psychologist	Written narratives based on specific prompts from the researcher & questionnaires	Narrative analysis	Two narrative typologies included participants’ experience of HCPs: ‘losses from illness’, ‘feeling lost’. Key quote: *“it's frustrating as no health professional has given me any ideas or support”*
Read et al	United	CODES	21 females	Dissociative	CODES (trial)	Semi-	Thematic	Themes related to participants’

(2020)*	Kingdom	randomised controlled trial	and 9 males, aged 18-80	seizures	health professionals; research workers; psychiatrist; CBT therapist	structured interviews	framework analysis	experience of participating the CODES trial. Themes relating to their experience with HCPs: 1) participating in a treatment trial- ‘the only thing out there’, 2) treatment components perceived to be helpful. Key quote: *“he wants me to believe this thing (dissociative seizures) but he's given no help or advice tome rather than if I say the wrong word (epilepsy) he's quick to snap and say it's not that.”*
Robson & Lian (2016)	United Kingdom	Specialist outpatient neurology clinics	8 female participants, aged 18-65, 12.5 years median seizure experience	Psychogenic non-epileptic seizures	Doctors; clinical consultations	Video recordings of consultations with consultant neurologists	Critical discourse analysis	Three main themes are discussed: 1) explaining the diagnosis- how the diagnosis of PNES is delivered; 2) explaining the cause- investigation of the reasons doctors give to explain the causes of their seizures, 3) explaining treatment options- examination of treatment options recommended to patients. Patients’ responses to doctors’ explanations are highlighted. Key quote: *“Lilly: "I just had to*

								make sure I, it's not me doing it to myself because it's, um."
Robson & Lian (2017)	International online recruitment- United Kingdom and Ireland, United States and Canada, Australia, New Zealand and Norway	Patient and practitioner-led online support groups for people with non-epileptic seizures	135 participants, 118 females, 14 males and 3 transgender people, aged 18-60+	Non-epileptic seizures (NES)	General and specialist neurologists; specialist and non-specialist psychotherapists; doctors and nurses in the emergency department and general hospital settings; paramedics; general practitioners/ family physicians	Free-text surveys	Thematic discourse analysis	Six themes relating to participants' 'single worst healthcare interaction relating to NES' arose: negative and disrespectful encounters, lack of knowledge and awareness, illegitimate patients, disregard of patients' perspective, voluntary control and consequences. Key quote: *"The doctor told me I was faking. He stabbed my arms with a needle whilst I was paralyzed to prove I was faking […] He kept telling me I was faking and there is nothing wrong with me"*
Thompson et al. (2009)	United Kingdom	NHS psychotherapy waiting lists	8 female participants, aged between their 20s and 60s with 1-21	Nonepileptic seizures	Medical professionals; psychiatrist; GP counsellor;	Semi-structured interviews	Interpretative phenomenological analysis	Three relevant themes related to the impact of receiving the diagnosis of NES: being left in limbo, doubts and uncertainty and feeling like a human being again.

			years since seizure onset		neurologist			Key quote: *‘‘Just left in limbo land wondering what’s gonna happen.”*
Wyatt et al. (2014)	United Kingdom	Adult neuropsychology NHS service	6 participants, 4 female and 1 male, aged 29-55	Non-epileptic attack disorder (NEAD); Non-epileptic seizures	Healthcare professionals; ambulance crew; doctors; neurologists; psychologists	Semi-structured interviews	Thematic analysis	Three relevant themes are reported on: understanding NEAD, relationships with professionals and experience of psychological therapy Key quote: *“Everybody is trying to convince me that I am faking an epileptic seizure.”*
Zeun et al. (2023)	United Kingdom	FND charity websites and social media pages	7 participants with functional movement disorder, of which 1 reported experiencing seizures. This participant was male, aged 67	Not specified	Physiotherapists	Semi-structured interview	Interpretative phenomenological analysis	Three relevant themes were identified: 1) my brain, mind and body are all me, 2) Physiotherapy; what helps and what doesn’t, 3) barriers to treatment. Key quote: *“My physio has taken it upon herself to learn about FMD and she’s very graciously allowed me to help educate her and she’s done it herself and this is meant our sessions have been most enjoyable.”*

*Same participants as Peacock et al. (2023); *Same participants as Pretorius (2016); *Same sample as Rawlings et al. (2017); *Same participants at Goldstein et al. (2021)

Quality Appraisal Results

Table 4 details the critical appraisal summary of included studies using the CASP checklist. Overall, 16 studies were considered high quality, and four articles moderate quality. All studies had clear research aims but in two studies it was not clear if a qualitative methodology was appropriate or sufficiently justified. Fourteen studies demonstrated an appropriate research design, but three did not discuss their research design choice and three did not sufficiently justify it. The majority (*n* = 18) demonstrated appropriate recruitment and data collection to address their research aims. All studies mentioned receiving ethical approval, but only eight considered the relationship between the researcher and participants. The majority of studies (*n* = 10) did not mention this at all. All studies demonstrated rigorous data analysis and the majority had a clear statement of findings. Finally, 17 studies were deemed to be of value, with three not providing enough detail to demonstrate value.

Table 4

Critical appraisal of the quality of included studies

Author (year)	Was there a clear statement of the research aims?	Is a qualitative methodology appropriate?	Was the research design appropriate?	Was the recruitment strategy appropriate?	Was the data collected in a way that addressed the research issue?	Has the relationship between the researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Overall Score	Quality rating
Baxter et al. (2012)	✓	?	✓	✓	✓	X	✓	✓	✓	✓	8.5	High
Dickinson et al. (2011)	✓	✓	?	✓	✓	X	✓	✓	?	✓	8	Moderate
Fairclough et al. (2014)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	9.5	High
Goldstein et al. (2021)	✓	✓	X	✓	✓	✓	✓	✓	?	?	8	Moderate
Green et al. (2004)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	9	High
Karterud et al. (2010)	✓	✓	?	✓	✓	X	✓	✓	✓	✓	8.5	High
Karterud et al. (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Peacock et al. (2023)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High

Peacock et al. (2022)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	9.5	High
Pretorius (2016)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	9	High
Pretorius & Sparrow (2015)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Rawlings et al. (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Rawlings et al. (2018a)	✓	✓	✓	✓	✓	X	✓	✓	✓	✓	9	High
Rawlings et al. (2018b)	✓	✓	✓	✓	✓	X	✓	✓	✓	?	8.5	High
Read et al (2020)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	9.5	High
Robson & Lian (2016)	✓	✓	X	✓	✓	X	✓	✓	✓	✓	8	Moderate
Robson & Lian (2017)	✓	✓	✓	✓	✓	X	✓	✓	✓	?	8.5	High
Thompson et al. (2009)	✓	X	✓	✓	✓	✓	✓	✓	✓	✓	9	High
Wyatt et al. (2014)	✓	✓	X	✓	?	X	✓	✓	✓	✓	7.5	Moderate
Zeun et al. (2023)	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	9.5	High

Thematic Synthesis

Two-hundred and seventy codes were produced through line-by-line coding of studies (Appendix E). Fourteen descriptive themes were developed (Appendix F). Analysis generated three analytic themes capturing pwFDS' experiences with HCPs (Table 5). The development of themes and synthesis was discussed with supervisors and modified based on feedback to ensure development of appropriate analytic themes that captured the essence of the data. Appendix G demonstrates the representation of studies between themes. See Appendix H for additional quotations.

Table 5

Summary of themes

Themes	Sub-themes
Clinician uncertainty feeds patient uncertainty	*Uncertainty about diagnosis*
	Mutual difficulty understanding FDS
	Anger in uncertainty
Not fitting into the model of medical illness	*Experiences of delegitimisation*
	Dismissed and rejected
Stigma fuelling traumatic experiences with HCPs	-

Clinician uncertainty feeds patient uncertainty

Across all studies, pwFDS experienced uncertainty, often exacerbated by clinicians' lack of awareness and knowledge of FDS. This spanned many different encounters and stages of pwFDS' healthcare journey, as discussed further in the following subthemes: 'uncertainty about diagnosis', 'mutual difficulty in understanding FDS' and 'Threat in uncertainty'.

Uncertainty about diagnosis

Many pwFDS saw multiple professionals before receiving a diagnosis, attributing this to HCPs' lack of knowledge about the condition. One participant commented: *"I was going from one doctor to another and nobody had a clue"* (Pretorius & Sparrow, 2015, p.36). This process was perceived as unhelpful due to receiving conflicting messages.

> *"they'll think it's something else and send you off in that direction and then when you go back you see somebody else who'll think oh no, you should have gone that way"* (Wyatt et al., 2014, p.803).

Conflicting information introduced a frustrating level of uncertainty, leaving pwFDS questioning the reliability of their diagnosis as *"they can't figure out whatever else it is"* (Wyatt et al., 2014, p.802). This damaged their confidence in the diagnosis: *"In two or three years' time they might tell me it's a different one"* (Fairclough et al., 2014, p.298).

These quotes suggest pwFDS took a passive role in this process, rather than viewing it as one of collaborative discovery for truth and certainty. This felt lack of collaboration and ambiguity seemed to trigger deep frustration and offense: "*is it any wonder I'm angry?"* (Karterud et al, 2010, p.42); creating a barrier to accessing treatment, with one pwFDS exclaiming:

> *"I just exploded, and I just said, 'I'm so unhappy with (this hospital) ... You're the third person I've seen: the doctor who told me these won't happen again. I don't want to hear that.' And I said, 'I just need to know what they are and if you can help me.'"* (Peacock et al. (2023, p.5)

PwFDS' perceptions of HCPs and care were shaped by broader healthcare experiences. The distress associated with uncertainty and feeling unheard was brought into encounters (Rawlings et al., 2017). As above, it seemed uncertain encounters created insecurity in the participant who experienced re-referrals as rejection. A fear of abandonment and uncertainty, present here and in other encounters, fuelled hopelessness (Pretorius, 2016) and fear: "*What if nobody can help me?"* (Karterud et al., 2010, p.42).

Conversely, pwFDS felt that HCPs taking a more collaborative approach to understanding confusing and complex information "*could have made professional uncertainty more tolerable*" (Wyatt et al., 2014, p.801). Furthermore, pwFDS felt reassured when information was delivered with certainty and confidence, and in a way they could understand (Goldstein et al., 2021; Thompson et al., 2009).

Mutual difficulty understanding FDS

PwFDS had difficulty understanding their condition following HCPs' difficulty explaining FDS; one pwFDS commented; *"I don't know how I can explain this to anybody else when I don't even understand it myself"* (Karterud et al., 2010, p.42). However, authors reported that "*information provided at diagnosis was viewed [by pwFDS] as limited and difficult to make sense of*" (Fairclough et al, 2014, p.298), and pwFDS felt doctors *"couldn't understand or explain it* [FDS]" (Pretorius & Sparrow, 2015, p.36). This, along with diagnostic uncertainty, highlighted a "*generalised lack of knowledge surrounding dissociative seizure among HCPs*" (Goldstein et al., 2021, p.83) resulting in "*bewilderment and desperation* [of pwFDS] *for clear information and guidance*" (Goldstein et al., 2021, p.83).

In contrast, pwFDS appreciated clear information. They found signposting to useful resources "*helpful and less isolating*" (Dickinson et al., 2011, p.457). Receiving information also supported acceptance of seizures in the long-term (Karterud et al., 2015). The benefits of clear information led pwFDS to advocate for better HCP education about their condition (Robson & Lian, 2017), believing this would support improved care overall (Karterud et al., 2010).

Moreover, in positive therapeutic relationships, pwFDS enjoyed educating HCPs themselves (Zeun et al., 2023), appreciating the collaboration and empowerment this provided. Positive therapeutic relationships with HCPs, though occurring in the minority of instances, were seen as "*key components* [to pwFDS'] *improvement*" (Read et al., 2020, p.5).

Anger in uncertainty

Repeated encounters with HCPs lacking knowledge or certainty about FDS were deeply frustrating and destabilising. The perceived "*chronic ignorance*" (Robson & Lian, 2017, p.7) resulted in a sense of loneliness: *"nobody realises what it's like to be like this"* (Dickinson, 2011, p.456).

Additionally, pwFDS felt that HCPs were oblivious to their concerns. The ensuing frustration suggests this was threatening to them, as seen in one pwFDS in Read (2020):

> *I actually feel like I could have strangled her (the therapist)… You're not just frightened of the seizure but what other people are going to do. Are they going to hurt you, are they going to kick you?"* (p.6)

In this example, the participant demonstrates extreme frustration, leading to hostility and violent fantasy expressed towards the therapist who fails to grasp the true nature of their concern. The physicality of their expressed concerns about how some HCPs responded to their seizures suggests the participant experienced high levels of threat due to their seizures, and perhaps from other healthcare encounters, making misunderstandings by HCPs a major concern.

Not fitting into the model of medical illness

The diagnosis of FDS presented many challenges in pwFDS' encounters with HCPs within a medicalised healthcare system. PwFDS felt the lack of biomarkers underpinning their symptoms led HCPs to dismiss and reject them. These experiences are explored further in the following subthemes 'experiences of delegitimisation' and 'dismissed and rejected'.

Experiences of delegitimisation

Most studies reported pwFDS felt the lack of biomarkers underpinning symptoms led HCPs to question the legitimacy of their medical problem. They felt the absence of positive test results invalidated their experiences: "*Cause you're not physically ill, they don't think you're ill"* (Wyatt et al., 2014 p.803); some HCPs refused to acknowledge their seizures (Rawlings et al., 2017). This made pwFDS feel HCPs did not believe they experienced seizures: "*I was told I had 'attacks' and that what I was experiencing were NOT seizures at all"* (Robson & Lian, 2017, p.6).

Others noted they encountered HCPs who did not believe in the existence of FDS: *"I haven't met a single one who believes this is an illness"* (Robson & Lian, 2017, p.7). This paved the way for pwFDS' symptoms being doubted: *"people… treat PNES as if it were an imaginary friend. Fake, irrational, and made up*" (Robson & Lian, 2017, p.7). Some believed that pwFDS could control their seizures: *"...doctor in the hospital said that because there were no abnormalities in my brain waves that it could be nothing else but voluntary*" (Robson & Lian, 2017, p.7). These beliefs made participants feel HCPs regarded them as "*hysterical and an attention-seeker*" (Robson & Lian, 2017, p.7), and recalled being shamed for seeking medical attention. Having the reality of their condition denied was extremely difficult for pwFDS, fostering self-criticism, fear of abandonment and hopelessness.

> *I already feel like a failure due to my inability to control the seizures, these experiences just go on to reinforce these feelings, and have resulted in suicide attempts* (Robson & Lian, 2017, p.9)

Repeated experiences of downplaying by HCPs resulted in participants anticipating further negative responses and fearing abandonment: "*I am sure that the doctor thinks that I'm making up stories and fantasizing (. . .). I do not want people to think I'm a bad person because I suffer from seizures"* (Karterud et al., 2015, p.110). To compensate, participants attempted to convince doctors they were not "*malingerers, that their symptoms are 'real'"* (Robson & Lian, 2016, p.12). Others felt embarrassed about their FDS, resulting in disengagement from services without accessing treatments (Karterud et al., 2010).

Alternatively, when doctors demonstrated acceptance, took pwFDS' concerns seriously, and utilised their position of power to advocate for the legitimacy of FDS, this helped pwFDS feel supported, reassured and empowered (Pretorius & Sparrow, 2015), as seen in the following comment:

> *(the Professor) wrote me a letter ... So, I took it into hospital and I give it'em and I said.. . and the Professor wrote: 'This lady does not do this at will. These are real... this is a real illness.' And I thought: Wow, thank you, Prof... And I give it'em and said, 'Will you please put that in my records.'* (Peacock et al., 2023, p.6)

In this example, the support of the participant's doctor empowered them to advocate for themselves to other HCPs, demonstrating how positive relationships between patients and HCPs can have a wider positive impact.

Dismissed and Rejected

In many studies, pwFDS felt HCPs did not care about them (Dickinson, 2011; Peacock, 2023) due to having a condition that could not be treated with medication: *"my* *situation was a hopeless one as far as his medical expertise was concerned"* (Robson & Lian, 2017, p. 6). They felt doctors were *"not supportive or empathetic when they realised that it was a mental health problem and not a medical issue"* (Pretorius, 2016, p.3). Participants felt as though they were unimportant to HCPs due to "*not having epilepsy*" (Robson & Lian, 2017, p.11), and that their concerns were dismissed on this basis:

> *He just said, 'I tell you what,'…'there are people like you out there.'…'Seen a few, met a few, but, you know, it's nothing serious, there's nothing to worry about.' He said, 'It's not epilepsy – be thankful for that.'* (Peacock et al., 2023, p.5)

The lack of positive biomarkers heightened pwFDS' fear of abandonment as it could be used to reject them: *"You know you don't have epilepsy, go see somebody else"* (Dickinson et al., 2011, p.456). Ostracisation (Rawlings et al., 2017) created deep shame for their condition - *"I felt very ashamed walking out of his office, because I wasn't a real epilepsy patient"* (Robson & Lian, 2017, p.9) - and anger in knowing they would have been taken seriously had they had epilepsy (Karterud et al., 2010). Ultimately, pwFDS felt abandoned by services: "*You just feel like you've been dumped*" (Thompson et al., 2009, p.511), left to deal with their condition on their own (Rawlings 2018), or 'fighting' with HCPs to access support (Dickinson et al., 2011, p.457). These experiences left pwFDS disillusioned and dissatisfied with medical culture more widely (Robson & Lian, 2017).

Stigma fuelling traumatic experiences with HCPs

Many pwFDS reported having traumatic encounters with HCPs who behaved unethically and unprofessionally. A pervasive stigma about FDS, rooted in lack of awareness, over-medicalisation and poorly evidenced beliefs amongst HCPs underlined this. This theme explores pwFDS' perceptions of these encounters further.

For some, the majority of interactions with HCPs were considered "*challenging"* (Pretorius, 2016, p.3). One participant in Robson and Lian (2017) went further, commenting: "*All interactions have been negative with blaming, shaming, humiliation, and emotional pain*" (p.4). The most traumatic interactions seemed to take place in acute medical settings, with *"paramedics and HCPs in emergency departments being described as the worst offenders"* (Rawlings et al, 2017, p.88).

It seemed lack of awareness and stigmatising beliefs provoked behaviour towards pwFDS that could be characterised as abusive: "*they went on to degrade me as a person*" (Robson & Lian, 2017, p.5). PwFDS reported encountering HCPs who regarded them with such little respect they spoke derogatively about them, as if invisible: *"…I recall coming out of a seizure at one point and hearing one of the paramedics say to his partner, 'I really think she's just faking this'…I was not able to respond*" (Robson & Lian, 2017, p.6).

Furthermore, participants also described *"disgraceful"* (Robson & Lian, 2017, p.6), traumatising encounters with HCPs who were verbally and physically abusive to them. Participants reported being "mocked", "laughed at" and shouted at (Rawlings et al., 2017 p.86; Wyatt et al., 2014, p.803). One participant recalled *"I can remember her just standing over me with her arms crossed just shouting 'get up you are wasting my time, why do I have to put up with patients like you'"* (Robson & Lian, 2017, p.8). Participants also spoke about professionals violently attempting to provoke a response in them to "*prove"* they were "*faking"* their seizure by having *"water thrown on their face"* or being *"stabbed with a needle"* (Robson & Lian, 2017, p.8), causing them to feel degraded, humiliated and ashamed.

Moreover, participants felt they had been "pre-judged" (Robson & Lian, 2017, p.9) for their seizures due to their needs being neglected and ignored by HCPs: "*They see 'pseudoseizures' on my chart and avoid me like I am an axe murderer"* (Robson & Lian, 2017, p.7). They report HCPs regarding their seizures as "*only psychiatric*" and telling others to "*just leave"* them (Karterud et al., 2010 p.42; Wyatt, 2014, p.802), or refusing to assess and treat unrelated symptoms: *"I had fallen and hurt my shoulder and I couldn't move it. They refused to take me to A&E because they said that would be giving in to the attention that I wanted"* (Robson & Lian, 2017, p.9).

These encounters with HCPs were experienced as an escalation of feeling unheard and being rejected (Rawlings et al., 2017). In these examples, pwFDS want to seek medical attention, but HCPs are perceived as unwilling to accept this and are willing to demonstrate that through hostility and violence.

PwFDS felt vulnerable, terrified and powerless during these encounters and felt HCPs *"don't… realise the potential consequences of their actions"* (Robson & Lian, 2017, p.10). Participants felt they could no longer trust HCPs, feared hospitals and avoided seeking healthcare due to previous adverse experiences (Rawlings et al., 2018a; Robson & Lian, 2017). PwFDS exhorted HCPs to treat them with *"dignity"* and *"respect"* as the abuse resulted in "*desperation"* and *"depression"* (Dickinson et al., 2011, p.457).

However, when pwFDS were *"listened to"* (Dickinson et al., 2011, p.457); shown patience, kindness and empathy (Pretorius, 2016), they felt validated, reassured and looked after. These basic attributes were perceived as fundamental as they provided a sense of humanity during encounters (Pretorius, 2016) and demonstrated to participants that HCPs were interested in helping them (Thompson, 2009). Indeed, positive relationships and helpful encounters proved important as participants felt these enabled "*coping and resilience*" in the long-run (Pretorius & Sparrow, 2015, p.37).

Discussion

The aim of this review was to collect and synthesise primary qualitative studies on pwFDS' experiences of encounters with HCPs. Three analytic themes were generated through analysis: (1) clinician uncertainty feeds patient uncertainty, (2) not fitting into the model of medical illness, and (3) stigma fuelling traumatic experiences with HCPs. A lack of knowledge and understanding of FDS underpinned many of pwFDS' experiences in this review. Moreover, while some pwFDS had positive experiences with HCPs, these were less prominent in the papers. These findings also reflect those of previous reviews regarding the effects of stigma in both FDS and FND, where pwFDS feel misunderstood and abused, with their experiences delegitimised (Annandale et al., 2022; Foley et al., 2024).

In theme one, pwFDS faced intolerable levels of uncertainty in their encounters with HCPs. Uncertainty, characterised by the individual's inability to establish the meaning of events relating to their illness, is often present in the experience of chronic illness (Mishel, 1990). Uncertainty can be difficult to manage, often associated with increased distress (Kurita et al., 2013), and reduced sense of coping (Brown et al., 2020).

Participants' uncertainty was fed by clinicians' uncertainty, due to a lack of awareness and knowledge of FDS. Studies frequently report HCPs lack of knowledge and confidence encountering FDS (Rawlings & Reuber, 2016). While participants in this review expressed frustration at the uncertainty, research suggests this feeling is mutual. For example, HCPs also experience frustration due to being unable to provide adequate diagnostic and treatment services as a result of their lack of knowledge and training in the area (du Toit & Pretorius, 2017).

Additionally, it was found that uncertainty created a sense of insecurity. This is not surprising as Barnett et al's (2022) review found HCPs often attempted to avoid patients with functional conditions by ‘passing the buck’ (p.1808), due to their uncertainty with how to manage them. It has also been suggested that some HCPs purposely avoid being transparent about a functional diagnosis or use jargonistic language to confuse patients and justify their rejection (Kanaan et al., 2009; Kanaan et al., 2011). If true, these findings provide context to participants’ confusion around explanations of their diagnosis and even suggests exploitation in a relationship with an inherent power imbalance.

Lack of knowledge about FDS among HCPs allows negative attitudes to persist and contributes to propagation of stigma, and discriminatory practices (Annandale et al., 2022). For instance, having a condition that does not fit the medicalised model of healthcare negatively impacted pwFDS’ encounters with HCPs. HCPs’ overreliance on biomedical understanding of illness lead them to delegitimise pwFDS’ experiences. PwFDS were accused of faking and rejected by HCPs on this basis. This tendency to question the legitimacy of FDS may illustrate why some pwFDS have traumatic encounters with HCPs (Worsely et al., 2011; Kinney et al., 2018).

Prevalence of stigmatising beliefs is unsurprising given the findings that HCPs hold implicit bias in favour of medical conditions with a biological explanation (e.g. multiple sclerosis) (Begley et al., 2022), and that the healthcare system is positively biased towards conditions that can be observed and counted (Brown & Baker, 2012). Studies comparing experiences of people with epilepsy and FDS corroborate this, with people with epilepsy appraising HCPs positively, viewing them as ‘supportive, and a valuable source of knowledge’ (p.7, Rawlings et al., 2018); whereas pwFDS report difficulties in their experiences with HCPs (Rawlings et al., 2018).

Biases are important to highlight as, even at an implicit level, bias reduces the likelihood of referral for best practice treatments (Begley et al., 2022). Also, another study found people with medically unexplained symptoms were treated worse than people with the corresponding medically-explained diagnosis, which negatively impacted patient outcomes (Looper & Kirmayer, 2004), demonstrating the detrimental effects of stigma. In other practitioner studies, HCPs express desire to help pwFDS, but are unaware of their stigmatising behaviours (Bailey, 2022; Samuels & Pretorius, 2023), which is important as it is recognised that only when stigmatising beliefs and behaviours are acknowledged, can positive change follow (Nyblade et al., 2019).

Additionally, according to attribution theory, decisions about another's behaviour are regularly based on perceived internal factors, neglecting to consider external influence (Banerjee et al., 2020). Empathy and motivation to help is stronger when the individual is perceived to have no internal control over their behaviour (Banerjee et al., 2020). Therefore, motivation to support pwFDS is reduced by bias and the inaccurate perception that they have control over their seizures.

The negative attitudes of HCPs could possibly be due to a sense of helplessness and inadequacy provoked by FDS. Nearly 90% of surveyed doctors admit their training does not equip them to manage functional conditions (de Liège et al., 2022). Negative attitudes amongst neurologists and nurses are significantly associated with the perception pwFDS are difficult to help (Lehn et al., 2019). Apprehension about working with this patient group is frequently described in the literature (Kinney et al., 2018; McNicholas & Pryce, 2022). Senior clinicians even reflect that FDS challenges their entire professional identity (Bailey, 2022), demonstrating wide-spread insecurity encountering FDS. However, the consequence of this is that patients feel they have to 'fight' (p. 457, Dickinson, 2011) to prove themselves to HCPs and access care, which can hinder the recovery process (Hadler, 1996).

PwFDS' experiences of HCPs' attitudes in this review are similar to finding of HCPs' attitudes toward people who self-harm (Karmen et al., 2015; Saunders et al., 2012). Reviews found HCPs perceived them as time-wasters and less worthy of medical care (Karmen et al., 2015). However, underlying these beliefs was a feeling of inadequacy and uncertainty about expectations of their professional roles (Karmen et al., 2015; Saunders et al., 2012). Consequently, patients felt denied their 'patient' status as their needs were determined to be self-inflicted, resulting in lack of empathy and deprioritised care (Macdonald et al., 2020). This speaks to the enduring stigma of mental health that exists within society and healthcare systems that seems to result in a disregard for physical symptoms manifested through distress or psychological processes.

The traumatising experiences with HCPs detailed in theme three, could be an enactment of the stigmatising beliefs held by HCPs. Most accounts of this occurred in acute medical departments. In addition to the implicit and systemic stigma, acute medical departments are generally fast-paced and under-resourced, which is known to reduce empathy (Coetzee & Laschinger, 2018). Research suggests these departments attract staff with certain personality types and temperaments that may not be congruent to the needs of pwFDS presenting to the emergency department (Bailey, 2022; Ertan et al., 2022).

In this study, pwFDS felt hopeless, which is directly associated with increased risk of suicide (Ribeiro et al., 2018), attempts at which were reported in this review. Further, stigma is significantly inversely correlated with quality of life (Robson et al., 2018), psychological distress and self-conscious emotions such as shame (Reuber et al., 2022). In particular, shame is enmeshed with stigma which has severe implications for patient outcomes. Shame has a greater physiological impact than other emotions researched to date, to the extent that it could activate the emotional and behavioural responses observed in FDS, suggesting stigma and resultant shame perpetuate FDS (Reuber et al., 2022).

Furthermore, negative experiences with HCPs can discourage pwFDS from seeking further help (Green et al., 2004), and contribute to poor engagement with treatments (Carton et al., 2003). Also, negative attitudes among HCPs promote negative attitudes among patients (Bennett et al., 2022). PwFDS report feeling like an ‘enigma’ to the medical community (p.101, Rawlings & Reuber, 2016), which could promote internalised stigma and difficulty accepting a diagnosis or explanations of FDS. Many patients believe their seizures are at least partly due to a physical problem (Whitehead et al., 2013), which can create strain on the clinician-patient relationship as patients struggle to understand and retain information, or demonstrate ‘resistance’ to explanations of FDS (Monzoni et al., 2011), leaving them feeling abandoned and ‘unheard’ (Rawlings et al., 2017). This rejection could underlie self-stigma or anticipation of the stigma received from healthcare and society for their condition (Annandale et al., 2022), possibly creating further barriers to accessing treatment.

The HCP-patient relationship could represent an attachment relationship to patients (Maunder & Hunter, 2016). PwFDS often have insecure attachment styles due to traumatic life events (Holman et al., 2008; Villagrán et al., 2022), and the fear of abandonment expressed by pwFDS in this review could be an expression of this. According to attachment theory - the idea that previous relational styles influence emotions and reactions in future relationships - a secure attachment is built upon a consistent, secure base (Bowlby, 1979). The uncertainty, rejection, and neglect experienced by pwFDS in their relationship with HCPs in this study suggest HCPs offer an inherently insecure base for pwFDS. This is important to consider as insecure attachment is associated with poorer long-term outcomes (Villagrán et al., 2022) and patient experiences of discomfort and dissatisfaction (Maunder & Hunter, 2016).

Strengths, Limitations and Future Research Directions

This was the first systematic review to explore pwFDS' experiences of encounters with HCPs. A comprehensive search strategy was used with transparent reporting (Tong et al;, 2012). The moderate to high quality appraisal ratings of included studies and independent ratification of quality assessment and study inclusions are strengths of this review.

The CASP checklist is beneficial for evidencing trustworthiness in clinical research (Williams et al., 2020). However, the CASP has been criticised for its weaker evaluation of methodological quality and consideration for the contribution the study makes to the field (Majid & Vanstone, 2018). For example, Robson and Lian's (2017) study were based on biased, closed questioning, therefore presenting a limited perspective of participant experience which was not considered by the CASP. Quality appraisal is valuable to the review process, but it is important to consider how scoring and interpretation can differ with tools used.

Additionally, all studies in this review are from Western, high-income countries, possibly due to the exclusion of papers not published in English. Consequently, this review only represents the perspectives of a limited demographic, which is particularly concerning given the suggestion that stigma around FDS is greater in low-income countries, compared to high-income countries (Hingray et al., 2018). Future research should include perspectives of individuals from low-income, non-Western countries are needed to gain a broader understanding of FDS experiences.

A date restriction was applied to promote the inclusion of studies relevant to current healthcare experiences, although it could also be argued that perspectives from over 20 years ago also hold little relevance currently due to the development of recent research into FDS. However, the results from older studies in this review (e.g. Green et al., 2004) remain similar to results from the recent studies, suggesting little change to patients' experiences with HCPs in this time period.

This review also highlighted the paucity of research focused on patients' perspectives of healthcare experiences with few papers specifically exploring this topic. Therefore there is limited information about differences between professional groups (i.e. neurologists, psychiatrists, psychologists, psychotherapists, emergency department staff etc). Attitudes of HCPs may also vary along the course of the disorder. Future research would benefit from exploring these gaps in knowledge.

Focusing on HCP encounters represents only part of a broader societal issue of misunderstanding and stigma towards mental health and functional conditions. Given the perseverance of the negative attitudes and behaviours found in this review, and its impact on participants, more research is needed to understand the experience of pwFDS in relation to education, employment and society. Developing a greater understanding may promote the development of support and reduce discrimination pwFDS regularly face.

Clinical Implications

Findings highlighted a need for more FDS training for HCPs. It is crucial that awareness is increased as this can reduce stigma associated with the condition, and equip HCPs with the knowledge and confidence to support pwFDS (Medina et al., 2021). Clinical psychologists could support this by offering reflective practice groups, informed by psychological approaches such as the Power Threat Meaning Framework. This is a trauma-informed model that focuses on the role and impact of psychosocial adversity in psychological distress (Read & Harper, 2022). Developing an understanding of FDS from such perspectives could reduce stigma and improve HCP-patient relations (Read & Haper, 2022).

Better HCP knowledge could improve information and explanations given to pwFDS, supporting trust and the therapeutic relationship. For patients, gaining knowledge and learning how to live with their health condition could promote acceptance and adaptation as patients are able to understand their condition, make informed decisions relating to a range of activities, preventing the condition becoming a burden to their life (Roddis et al., 2016). HCPs are well positioned to provide accurate and helpful information, with Roddis et al.'s (2016) findings suggesting the long-term benefits of this.

Research indicates patients are more receptive to information they can personally connect with and is crucial for diagnosis acceptance as it can support the construction of personal meaning to a diagnosis (Thompson et al., 2009). Tailored information could be offered through psychological assessment and clinical psychologists could offer formulation and psychoeducation. Psychoeducation may also help to improve relations as it may provide patients with an understanding of their which narrows the gap between their own perspective and that of the clinicians (Underwood et al., 2024). Clinical psychologists could also support a more psychologically-informed and holistic understanding of FDS through consultation with medical colleagues (Read & Harper, 2022).

Clinical guidance for the management of FDS is lacking. Given the paucity of awareness of FDS, accessing 'non-specialist' care to manage FDS as recommended by NICE (2021), is likely to increase the risk of patients encountering practitioners who are not equipped to support them. Conversely, a specialist integrated multidisciplinary approach has shown to improve patient quality of life and employment outcomes (Palmer et al., 2023). Moreover, specialist psychological therapy, such as cognitive behavioural therapy for FDS, can improve quality of life, functioning and perceived burden of FDS, compared to standard medical care alone (Goldstein et al., 2020), supporting the need for more specialist support and updated clinical guidelines.

Lack of engagement and poor clinic attendance is prevalent among pwFDS. Although factors contributing to this are complex, the findings from this review suggest difficult encounters with HCPs are a contributing factor. Although changing the medicalised culture of the healthcare system will take time, addressing communication and relational issues arising in encounters between HCPs and patients using basic clinical skills such as active listening and empathy may contribute to improved HCP-patient relations and outcomes (Kornhaber et al., 2016).

Conclusion

This is the first meta-synthesis of pwFDS' experience of their encounters with HCPs. Findings highlighted that pwFDS experience difficult and traumatising encounters with HCPs that result in their needs going unmet and a desire to avoid seeking medical support. As a priority, healthcare services need to improve training and awareness of FDS, and provide more specialist services to promote the delivery of sensitive and compassionate care. The review findings informed recommendations for prospective research and clinical practice.

References

**Papers included within the qualitative synthesis*

Annandale, M., Vilyte, G., & Pretorius, C. (2022). Stigma in functional seizures: A scoping review. *Seizure, 99*, 131-152. https://doi.org/10.1016/j.seizure.2022.05.016

Asadi-Pooya, A. A., & Homayoun, M. (2020). Driving in patients with psychogenic nonepileptic seizures. *Epilepsy & Behavior, 105*, 106991. https://doi.org/10.1016/j.yebeh.2020.106991

Asadi-Pooya, A. A., Brigo, F., Tolchin, B., & Valente, K. D. (2021). Functional seizures are not less important than epilepsy. *Epilepsy & Behavior Reports*, *16*, 100495. https://doi.org/10.1016/j.ebr.2021.100495

Bailey, C. (2022). *A Qualitative Exploration of Emergency Practitioner's Perspectives Towards Functional Seizures and Self-Harm Behaviours*. Lancaster University (United Kingdom).

Banerjee, D., Gidwani, C., & Rao, T. S. (2020). The role of "Attributions" in social psychology and their relevance in psychosocial health: A narrative review. *Indian Journal of Social Psychiatry*, *36*(4), 277-283. http://doi.org/10.4103/ijsp.ijsp_315_20

Barnett, C., Davis, R., Mitchell, C., & Tyson, S. (2022). The vicious cycle of functional neurological disorders: a synthesis of healthcare professionals' views on working with patients with functional neurological disorder. *Disability and Rehabilitation*, *44*(10), 1802-1811. https://doi.org/10.1080/09638288.2020.1822935

*Baxter, S., Mayor, R., Baird, W., Brown, R., Cock, H., Howlett, S., ... & Reuber, M. (2012). Understanding patient perceptions following a psycho-educational intervention for psychogenic non-epileptic seizures. *Epilepsy & Behavior*, *23*(4), 487-493. https://doi.org/10.1016/j.yebeh.2011.12.002

Beatty, P. W., Hagglund, K. J., Neri, M. T., Dhont, K. R., Clark, M. J., & Hilton, S. A. (2003). Access to health care services among people with chronic or disabling conditions: patterns and predictors. *Archives of Physical Medicine and Rehabilitation*, *84*(10), 1417-1425. https://doi.org/10.1016/S0003-9993(03)00268-5

Begley, R., Farrell, L., Lyttle, N., Alty, J., Curran, D., Williams, S., & Graham, C. D. (2023). Clinicians' implicit and explicit attitudes about the legitimacy of functional neurological disorders correlate with referral decisions. *British Journal of Health Psychology*, *28*(2), 604-618. https://doi.org/10.1111/bjhp.12643

Beimer, N. J., & LaFrance Jr, W. C. (2022). Evaluation and treatment of psychogenic nonepileptic seizures. *Neurologic Clinics*, *40*(4), 799-820.

Booth, A. (2006). Clear and present questions: formulating questions for evidence based practice. *Library Hi Tech*, *24*(3), 355-368. https://doi.org/10.1108/07378830610692127

Booth, A., Noyes, J., Flemming, K., Gerhardus, A., Wahlster, P., Van Der Wilt, G. J., ... & Rehfuess, E. (2016). Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions. *Bremen (DE): Integrate-HTA,* 1-38.

Bowlby, J. (1979). The Bowlby-Ainsworth attachment theory. *Behavioral and Brain Sciences, 2*(4), 637-638. Doi:10.1017/S0140525X00064955

Brown, A., Hayden, S., Klingman, K., & Hussey, L. C. (2020). Managing uncertainty in chronic illness from patient perspectives. *Journal of Excellence in Nursing and Healthcare Practice*, *2*(1), 1. https://doi.org/10.5590/JENHP.2020.2.1.01

Brown, B. J., & Baker, S. (2012). *Responsible citizens: Individuals, health, and policy under neoliberalism*. Anthem Press.

Brown, R. J., & Reuber, M. (2016). Towards an integrative theory of psychogenic non-epileptic seizures (PNES). *Clinical Psychology Review*, *47*, 55-70. https://doi.org/10.1016/j.cpr.2016.06.003

Butler, J., Gregg, L., Calam, R., & Wittkowski, A. (2020). Parents' perceptions and experiences of parenting programmes: A systematic review and metasynthesis of the qualitative literature. *Clinical Child and Family Psychology Review*, *23*(2), 176-204. https://doi.org/10.1007/s10567-019-00307-y

Carroll, C., & Booth, A. (2015). Quality assessment of qualitative evidence for systematic review and synthesis: Is it meaningful, and if so, how should it be performed? *Research Synthesis Methods*, *6* (2), 149–154. https://doi.org/10.1002/jrsm.1128

Carton, S., Thompson, P. J., & Duncan, J. S. (2003). Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure*, *12*(5), 287-294. https://doi.org/10.1016/S1059-1311(02)00290-X

Coetzee, S. K., & Laschinger, H. K. (2018). Toward a comprehensive, theoretical model of compassion fatigue: A n integrative literature review. *Nursing & Health Sciences*, *20*(1), 4-15. https://doi.org/10.1111/nhs.12387

Critical Appraisal Skills Programme. (2018). *CASP Qualitative Checklist.* https://casp-uk.net/checklists/casp-qualitative-studies-checklist-fillable.pdf

Davies, K. S. (2011). Formulating the evidence based practice question: a review of the frameworks.

De Liège, A., Carle, G., Hingray, C., Lehn, A., Autier, L., Degos, B., & Garcin, B. (2022). Functional neurological disorders in the medical education: an urgent need to fill the gaps. *Revue Neurologique*, *178*(8), 788-795. https://doi.org/10.1016/j.neurol.2022.03.018

*Dickinson, P., Looper, K. J., & Groleau, D. (2011). Patients diagnosed with nonepileptic seizures: their perspectives and experiences. *Epilepsy & Behavior*, *20*(3), 454-461. https://doi.org/10.1016/j.yebeh.2010.12.034

Diprose, W., Sundram, F., & Menkes, D. B. (2016). Psychiatric comorbidity in psychogenic nonepileptic seizures compared with epilepsy. *Epilepsy & Behavior*, *56*, 123-130. https://doi.org/10.1016/j.yebeh.2015.12.037

du Toit, A., & Pretorius, C. (2017). Psychogenic nonepileptic seizures: Namibian healthcare providers' perceptions and frustrations. *Seizure*, *50*, 43-52. https://doi.org/10.1016/j.seizure.2017.06.004

Dworetzky, B. (2016). The Impact of PNES is about more than counting events. *Epilepsy Currents*, *16*(5), 314-315. https://doi.org/10.5698/1535-7511-16.5.314

Ertan, D., Aybek, S., LaFrance Jr, W. C., Kanemoto, K., Tarrada, A., Maillard, L., ... & Hingray, C. (2022). Functional (psychogenic non-epileptic/dissociative) seizures: why and how?. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(2), 144-157. https://doi.org/10.1136/jnnp-2021-326708

*Fairclough, G., Fox, J., Mercer, G., Reuber, M., & Brown, R. J. (2014). Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures. *Epilepsy & Behavior, 31*, 295-303. https://doi.org/10.1016/j.yebeh.2013.10.025

Flemming, K., & Noyes, J. (2021). Qualitative Evidence Synthesis: Where Are We at? *International Journal of Qualitative Methods, 20*. https://doi.org/10.1177/1609406921993276

Flemming, K., Booth, A., Garside, R., Tunçalp, Ö., & Noyes, J. (2019). Qualitative evidence synthesis for complex interventions and guideline development: clarification of the purpose, designs and relevant methods. *BMJ Global Health*, *4*(Suppl 1), e000882. https://doi.org/10.1136/bmjgh-2018-000882

FND Hope (2020). *FND Hope Stigma Survey*. https://www.fndhope.org.uk/fnd-hope-research/

Foley, C., Kirkby, A., & Eccles, F. J. (2024). A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder. *Disability and Rehabilitation*, *46*(1), 1-12. https://doi.org/10.1080/09638288.2022.2155714

Glasper, E. A., & Rees, C. (2013). *How to write your nursing dissertation [electronic resource]*. Wiley-Blackwell

Goffman, E. (1990). *Stigma : notes on the management of spoiled identity*. Penguin.

*Goldstein, L. H., Robinson, E. J., Pilecka, I., Perdue, I., Mosweu, I., Read, J., ... & Chalder, T. (2021). Cognitive-behavioural therapy compared with standardised medical care for adults with dissociative non-epileptic seizures: the CODES RCT. *Health*

Technology Assessment (Winchester, England), *25*(43), 1. http://doi.org/10.3310/hta25430

Grant, M. J., & Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal, 26*(2), 91-108. https://doi.org/10.1111/j.1471-1842.2009.00848.x

*Green, A., Payne, S., & Barnitt, R. (2004). Illness representations among people with non-epileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model. *Seizure*, *13*(5), 331-339. https://doi.org/10.1016/j.seizure.2003.09.001

Gusenbauer, M., & Haddaway, N. R. (2020). Which academic search systems are suitable for systematic reviews or meta-analyses? Evaluating retrieval qualities of Google Scholar, PubMed, and 26 other resources. *Research Synthesis Methods*, *11*(2), 181-217. https://doi.org/10.1002/jrsm.1378

Hadler, N. M. (1996). If you have to prove you are ill, you can't get well: the object lesson of fibromyalgia. *Spine*, *21*(20), 2397-2400.

Hinde, S., & Spackman, E. (2015). Bidirectional citation searching to completion: an exploration of literature searching methods. *Pharmacoeconomics*, *33*, 5-11. https://doi.org/10.1007/s40273-014-0205-3

Hingray, C., El-Hage, W., Duncan, R., Gigineishvili, D., Kanemoto, K., LaFrance Jr, W. C., ... & Reuber, M. (2018). Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: an international survey by the ILAE PNES Task Force. *Epilepsia*, *59*(1), 203-214. https://doi.org/10.1111/epi.13952

Holman, N., Kirkby, A., Duncan, S., & Brown, R. J. (2008). Adult attachment style and childhood interpersonal trauma in non-epileptic attack disorder. *Epilepsy Research, 79*(1), 84-89. https://doi.org/10.1016/j.eplepsyres.2007.12.015

Jones, B., Reuber, M., & Norman, P. (2016). Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: a systematic review. *Epilepsia*, *57*(2), 171-181. https://doi.org/10.1111/epi.13268

Kanaan, R. A., Armstrong, D., & Wessely, S. C. (2011). Neurologists' understanding and management of conversion disorder. *Journal of Neurology, Neurosurgery & Psychiatry, 82*(9), 961-966. https://doi.org/10.1136/jnnp.2010.233114

Kanaan, R., Armstrong, D., & Wessely, S. (2009). Limits to truth-telling: neurologists' communication in conversion disorder. *Patient Education and Counseling*, *77*(2), 296-301. https://doi.org/10.1016/j.pec.2009.05.021

Karman, P., Kool, N., Poslawsky, I. E., & van Meijel, B. (2015). Nurses' attitudes towards self-harm: A literature review. *Journal of Psychiatric and Mental Health Nursing*, *22*(1), 65-75. https://doi.org/10.1111/jpm.12171

*Karterud, H. N., Knizek, B. L., & Nakken, K. O. (2010). Changing the diagnosis from epilepsy to PNES: patients' experiences and understanding of their new diagnosis. *Seizure, 19*(1), 40-46. https://doi.org/10.1016/j.seizure.2009.11.001

*Karterud, H. N., Risør, M. B., & Haavet, O. R. (2015). The impact of conveying the diagnosis when using a biopsychosocial approach: a qualitative study among adolescents and young adults with NES (non-epileptic seizures). *Seizure*, *24*, 107-113. https://doi.org/10.1016/j.seizure.2014.09.006

Kerr, W. T., & Stern, J. M. (2020). We need a functioning name for PNES: consider dissociative seizures. *Epilepsy & Behavior, 105*. https://doi.org/10.1016/j.yebeh.2020.107002

Kinney, M. O., Hunt, S. J., & McKenna, C. (2018). A self-completed questionnaire study of attitudes and perceptions of paramedic and prehospital practitioners towards acute seizure care in Northern Ireland. *Epilepsy & Behavior, 81*, 115-118. https://doi.org/10.1016/j.yebeh.2018.02.003

Kornhaber, R., Walsh, K., Duff, J., & Walker, K. (2016). Enhancing adult therapeutic interpersonal relationships in the acute health care setting: an integrative review. *Journal of multidisciplinary healthcare*, *9*, 537–546. https://doi.org/10.2147/JMDH.S116957

Kurita, K., Garon, E. B., Stanton, A. L., & Meyerowitz, B. E. (2013). Uncertainty and psychological adjustment in patients with lung cancer. *Psycho-Oncology*, *22*(6), 1396-1401. https://doi.org/10.1002/pon.3155

Lehn, A., Bullock-Saxton, J., Newcombe, P., Carson, A., & Stone, J. (2019). Survey of the perceptions of health practitioners regarding Functional Neurological Disorders in Australia. *Journal of Clinical Neuroscience, 67*, 114-123. https://doi.org/10.1016/j.jocn.2019.06.008

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), 31-42. https://doi.org/10.1177/2632084320947559

Looper, K. J., & Kirmayer, L. J. (2004). Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of Psychosomatic Research*, *57*(4), 373-378. https://doi.org/10.1016/j.jpsychores.2004.03.005

Lorenzetti, D. L., & Ghali, W. A. (2013). Reference management software for systematic reviews and meta-analyses: an exploration of usage and usability. *BMC Medical Research Methodology*, *13*, 1-5. https://doi.org/10.1186/1471-2288-13-141

Lumivero (2023) *NVivo.* (Version 14). www.lumivero.com

MacDonald, S., Sampson, C., Turley, R., Biddle, L., Ring, N., Begley, R., & Evans, R. (2020). Patients' experiences of emergency hospital care following self-harm: systematic review and thematic synthesis of qualitative research. *Qualitative Health Research*, *30*(3), 471-485. https://doi.org/10.1177/1049732319886566

Mahood, Q., Van Eerd, D., & Irvin, E. (2014). Searching for grey literature for systematic reviews: challenges and benefits. *Research Synthesis Methods*, *5*(3), 221-234. https://doi.org/10.1002/jrsm.1106

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: a compendium of quality appraisal tools. *Qualitative Health Research*, *28*(13), 2115-2131. https://doi.org/10.1177/1049732318785358

Martin, R., Burneo, J. G., Prasad, A., Powell, T., Faught, E., Knowlton, R., ... & Kuzniecky, R. (2003). Frequency of epilepsy in patients with psychogenic seizures monitored by video-EEG. *Neurology*, *61*(12), 1791-1792. https://doi.org/10.1212/01.WNL.0000098890.13946.F5

Maunder, R. G., & Hunter, J. J. (2016). Can patients be ‘attached’to healthcare providers? An observational study to measure attachment phenomena in patient–provider relationships. *BMJ Open*, *6*(5), e011068. https://doi.org/10.1136/bmjopen-2016-011068

McColl-Kennedy, J. R., Danaher, T. S., Gallan, A. S., Orsingher, C., Lervik-Olsen, L., & Verma, R. (2017). How do you feel today? Managing patient emotions during health care experiences to enhance well-being. *Journal of Business Research, 79*, 247-259. https://doi.org/10.1016/j.jbusres.2017.03.022

McNicholas, O., & Pryce, H. (2022). Clinical physiologists’ experiences of working with people with nonepileptic attack disorder: A qualitative study. *Epilepsy & Behavior*, *127*, 108501. https://doi.org/10.1016/j.yebeh.2021.108501

Medina, M., Giambarberi, L., Lazarow, S. S., Lockman, J., Faridi, N., Hooshmad, F., ... & Bajestan, S. N. (2021). Using patient-centered clinical neuroscience to deliver the diagnosis of functional neurological disorder (FND): results from an innovative educational workshop. *Academic Psychiatry*, *45*, 185-189. https://doi.org/10.1136/bmjebm-2018-111132

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, *22*(4), 256-262. https://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Monzoni, C. M., Duncan, R., Grünewald, R., & Reuber, M. (2011). Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. *Patient Education and Counseling*, *85*(3), e189-e200. https://doi.org/10.1016/j.pec.2011.07.014

Myers, L., Gray, C., Roberts, N., Levita, L., & Reuber, M. (2022). Shame in the treatment of patients with psychogenic nonepileptic seizures: The elephant in the room. *Seizure*, *94*, 176-182. https://doi.org/10.1016/j.seizure.2021.10.018

Myers, L., Trobliger, R., Bortnik, K., Zeng, R., Saal, E., & Lancman, M. (2019). Psychological trauma, somatization, dissociation, and psychiatric comorbidities in patients with psychogenic nonepileptic seizures compared with those in patients with intractable partial epilepsy. *Epilepsy & Behavior*, *92*, 108-113. https://doi.org/10.1016/j.yebeh.2018.12.027

National Institute for Health and Care Excellence. (2021, January 8). *Quality statement 5: Functional neurological disorders in adults.* National Institute for Health and Care Excellence. https://www.nice.org.uk/guidance/qs198/chapter/Quality-statement-5-Functional-neurological-disorders-in-adults

Nyblade, L., Stockton, M. A., Giger, K., Bond, V., Ekstrand, M. L., Lean, R. M., ... & Wouters, E. (2019). Stigma in health facilities: why it matters and how we can change it. *BMC Medicine*, *17*, 1-15. https://doi.org/10.1186/s12916-019-1256-2

O'Keeffe, S., Chowdhury, I., Sinanaj, A., Ewang, I., Blain, C., Teodoro, T., ... & Yogarajah, M. (2021). A service evaluation of the experiences of patients with functional neurological disorders within the NHS. *Frontiers in Neurology*, *12*, 656466. https://doi.org/10.3389/fneur.2021.656466

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. E., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M. Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … & Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *International Journal of Surgery, 88,* Article 105906. https://doi.org/10.1136/bmj.n71

Palmer, D. D., Gamble, M., Higgins, M., Maley, J., & Watson, E. (2023). Outcomes of an integrated multidisciplinary clinic for people with functional neurological disorder. *Movement Disorders Clinical Practice*, *10*(6), 967-973. https://doi.org/10.1002/mdc3.13757

*Peacock, M., Bissell, P., Ellis, J., Dickson, J. M., Wardrope, A., Grünewald, R., & Reuber, M. (2023). 'I just need to know what they are and if you can help me': Medicalization and the search for legitimacy in people diagnosed with non-epileptic attack disorder. *Epilepsy & Behavior*, *148*, 109485. https://doi.org/10.1016/j.yebeh.2023.109485

*Peacock, M., Dickson, J. M., Bissell, P., Grunewald, R., & Reuber, M. (2022). Beyond the medical encounter: can the free association narrative interview method extend psychosocial understandings of non-epileptic attack disorder?. *Journal of Psychosocial Studies*, *15*(1), 36-51. https://doi.org/10.1332/147867321X16490906486279

Perrotta, G. (2019). Psychological trauma: definition, clinical contexts, neural correlations and therapeutic approaches. *Current Research in Psychiatry and Brain Disorders Review Article*, *2019*(1).

*Pretorius, C. (2016). Barriers and facilitators to reaching a diagnosis of PNES from the patients' perspective: preliminary findings. *Seizure*, *38*, 1-6. https://doi.org/10.1016/j.seizure.2016.03.007

*Pretorius, C., & Sparrow, M. (2015). Life after being diagnosed with psychogenic non-epileptic seizures (PNES): a South African perspective. *Seizure*, *30*, 32-41. https://doi.org/10.1016/j.seizure.2015.05.008

Rawlings, G. H., & Reuber, M. (2016). What patients say about living with psychogenic nonepileptic seizures: a systematic synthesis of qualitative studies. *Seizure*, *41*, 100-111. https://doi.org/10.1016/j.seizure.2016.07.014

Rawlings, G. H., & Reuber, M. (2018). Health care practitioners' perceptions of psychogenic nonepileptic seizures: a systematic review of qualitative and quantitative studies. *Epilepsia*, *59*(6), 1109-1123. https://doi.org/10.1111/epi.14189

Rawlings, G. H., Brown, I., & Reuber, M. (2017). Deconstructing stigma in psychogenic nonepileptic seizures: an exploratory study. *Epilepsy & Behavior*, *74*, 167-172. https://doi.org/10.1016/j.yebeh.2017.06.014

Rawlings, G. H., Brown, I., & Reuber, M. (2017). Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *68*, 153-158. https://doi.org/10.1016/j.yebeh.2016.10.035

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

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

*Rawlings, G. H., Brown, I., Stone, B., & Reuber, M. (2018). Written accounts of living with epilepsy or psychogenic nonepileptic seizures: A thematic comparison. *Qualitative Health Research, 28*(6), 950-962. https://doi.org/10.1177/1049732317748897

Read, J., & Harper, D. J. (2022). The power threat meaning framework: Addressing adversity, challenging prejudice and stigma, and transforming services. *Journal of Constructivist Psychology, 35*(1), 54-67. https://doi.org/10.1080/10720537.2020.1773356

*Read, J., Jordan, H., Perdue, I., Purnell, J., Murray, J., Chalder, T., ... & Goldstein, L. H. (2020). The experience of trial participation, treatment approaches and perceptions of change among participants with dissociative seizures within the CODES randomized controlled trial: a qualitative study. *Epilepsy & Behavior, 111*, 107230. https://doi.org/10.1016/j.yebeh.2020.107230

Reuber, M., Roberts, N. A., Levita, L., Gray, C., & Myers, L. (2022). Shame in patients with psychogenic nonepileptic seizure: A narrative review. *Seizure, 94*, 165-175. https://doi.org/10.1016/j.seizure.2021.10.017

Ribeiro, J. D., Huang, X., Fox, K. R., & Franklin, J. C. (2018). Depression and hopelessness as risk factors for suicide ideation, attempts and death: meta-analysis of longitudinal studies. *The British Journal of Psychiatry, 212*(5), 279-286. https://doi.org/10.1192/bjp.2018.27

*Robson, C. & Lian, O. S. (2016). "Are You Saying She's Mentally Ill Then?" Explaining Medically Unexplained Seizures in Clinical Encounters. *Forum: Qualitative Social Research, 17*(1), Art. 2, http://nbn-resolving.de/urn:nbn:de:0114-fqs160122.

*Robson, C., & Lian, O. S. (2017). “Blaming, shaming, humiliation”: stigmatising medical interactions among people with non-epileptic seizures. *Wellcome Open Research, 2*. https://doi.org/10.12688/wellcomeopenres.12133.2

Robson, C., Myers, L., Pretorius, C., Lian, O. S., & Reuber, M. (2018). Health related quality of life of people with non-epileptic seizures: the role of socio-demographic characteristics and stigma. *Seizure*, *55*, 93-99. https://doi.org/10.1016/j.seizure.2018.01.001

Roddis, J. K., Holloway, I., Bond, C., & Galvin, K. T. (2016). Living with a long-term condition: Understanding well-being for individuals with thrombophilia or asthma. *International Journal of Qualitative Studies on Health and Well-being*, *11*(1), 31530. https://doi.org/10.3402/qhw.v11.31530

Samuels, T., & Pretorius, C. (2023). Healthcare providers’ perspectives on stigma when working with people with functional seizures. *Seizure: European Journal of Epilepsy*, *112*, 121-127. https://doi.org/10.1016/j.seizure.2023.10.002

Saunders, K. E., Hawton, K., Fortune, S., & Farrell, S. (2012). Attitudes and knowledge of clinical staff regarding people who self-harm: a systematic review. *Journal of Affective Disorders*, *139*(3), 205-216. https://doi.org/10.1016/j.jad.2011.08.024

Stone, J., Burton, C., & Carson, A. (2020). Recognising and explaining functional neurological disorder. *BMJ, 371*. https://doi.org/10.1136/bmj.m3745

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8,* 1-10. https://doi.org/10.1186/1471-2288-8-45

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

Todres, L., Galvin, K. T., & Holloway, I. (2009). The humanization of healthcare: A value framework for qualitative research. *International Journal of Qualitative Studies on Health and well-being, 4*(2), 68-77. https://doi.org/10.1080/17482620802646204

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology, 12,* 1-8. https://doi.org/10.1186/1471-2288-12-181

Trimble, M. R. (2018). Psychogenic Nonepileptic Seizures. Historical Overview. In S. C. Schachter & J. W. C LaFrance (Eds.), *Gates and Rowan's Nonepileptic Seizures*(4th edition, 19-30). Cambridge University Press.

Underwood, R., Falshaw, L., & McFarlane, F. (2024). Psychoeducation interventions for people with non-epileptic seizures: a scoping review. *Seizure: European Journal of Epilepsy*. https://doi.org/10.1016/j.seizure.2024.05.013

Villagrán, A., Eldøen, G., Duncan, R., Aaberg, K. M., Hofoss, D., & Lossius, M. I. (2021). Incidence and prevalence of psychogenic nonepileptic seizures in a Norwegian county: a 10-year population-based study. *Epilepsia, 62*(7), 1528-1535. https://doi.org/10.1111/epi.16949

Villagrán, A., Lund, C., Duncan, R., & Lossius, M. I. (2022). The effect of attachment style on long-term outcomes in psychogenic nonepileptic seizures: results from a prospective study. *Epilepsy & Behavior*, *135*, 108890. https://doi.org/10.1016/j.yebeh.2022.108890

Villarreal, L. D. (2021). *Understanding Emotional Experiences and Partner Relationships Among Individuals with Psychogenic Non-Epileptic Seizures* (Doctoral dissertation, Arizona State University).

Whitehead, K., Kandler, R., & Reuber, M. (2013). Patients' and neurologists' perception of epilepsy and psychogenic nonepileptic seizures. *Epilepsia*, *54*(4), 708-717. https://doi.org/10.1111/epi.12087

Williams, V., Boylan, A. M., & Nunan, D. (2020). Critical appraisal of qualitative research: necessity, partialities and the issue of bias. *BMJ Evidence-Based Medicine*, *25*(1), 9-11.

Worsely, C., Whitehead, K., Kandler, R., & Reuber, M. (2011). Illness perceptions of health care workers in relation to epileptic and psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *20*(4), 668-673. https://doi.org/10.1016/j.yebeh.2011.01.029

*Wyatt, C., Laraway, A., & Weatherhead, S. (2014). The experience of adjusting to a diagnosis of non-epileptic attack disorder (NEAD) and the subsequent process of psychological therapy. *Seizure*, *23*(9), 799-807. https://doi.org/10.1016/j.seizure.2014.06.012

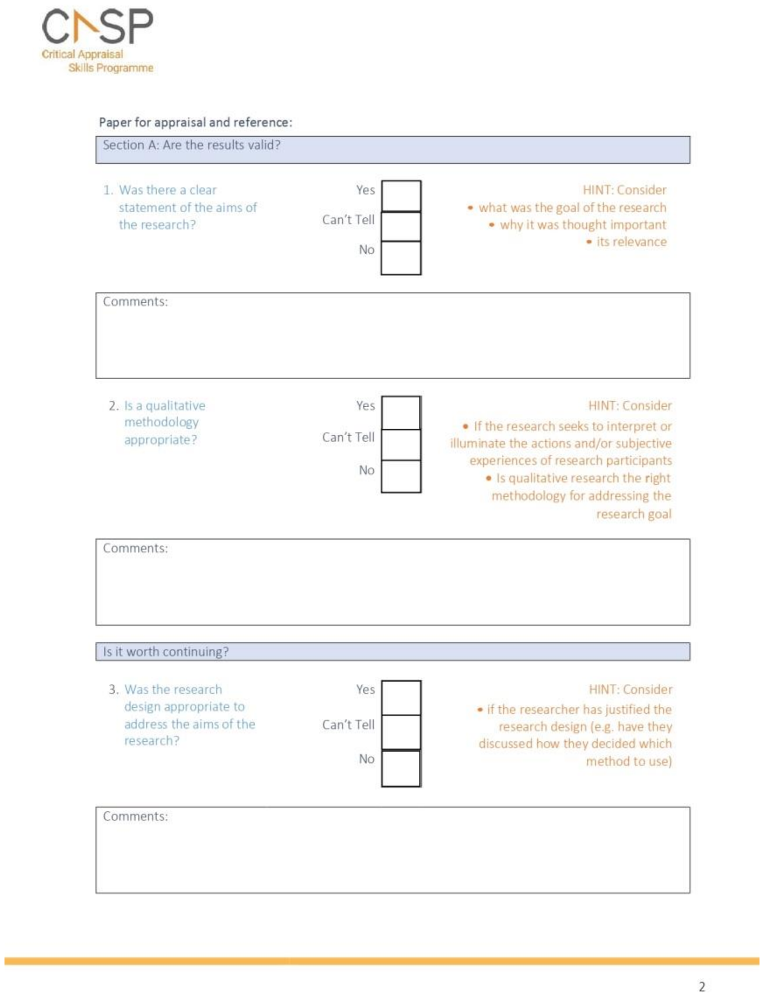
*Zeun, D., & Hunter, H. (2023). Physiotherapy management of functional movement disorders: the patient perspective. *Disability and Rehabilitation*, 1-9. https://doi.org/10.1080/09638288.2023.2272709

Zhang, L., Beghi, E., Tomson, T., Beghi, M., Erba, G., & Chang, Z. (2022). Mortality in patients with psychogenic non-epileptic seizures a population-based cohort study. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(4), 379-385. https://doi.org/10.1136/jnnp-2021-328035

List of Appendices

Appendix A

CASP Tool



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

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

Yes ☐
Can't Tell ☐
No ☐

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

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

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

Comments:

Is it worth continuing?

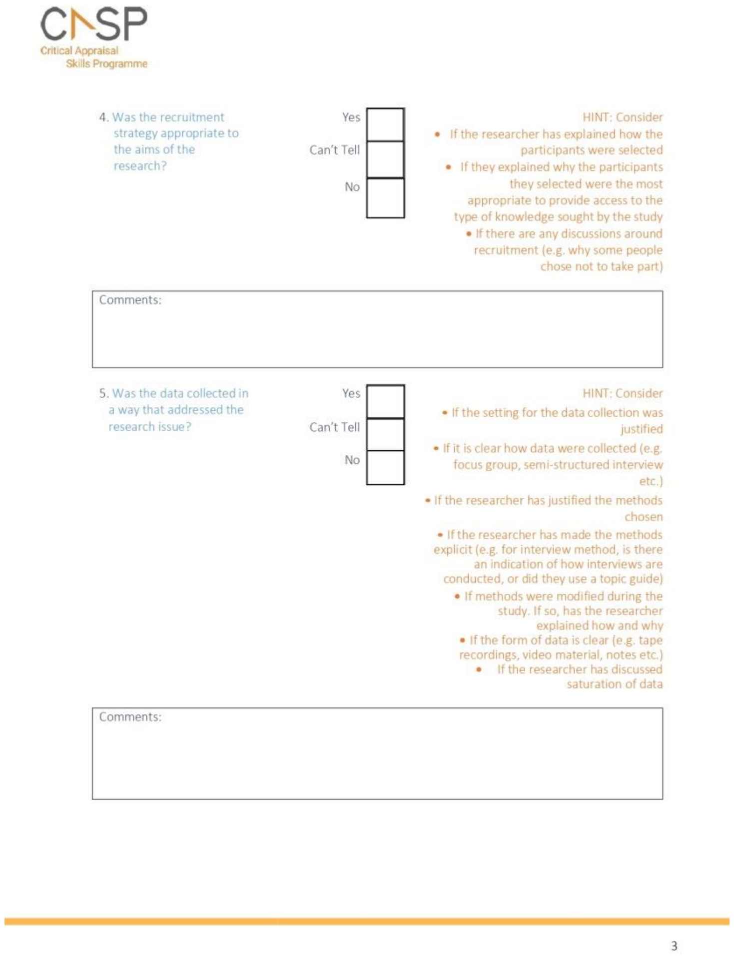
3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

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

Comments:

2



CASP
Critical Appraisal
Skills Programme

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

Yes ☐
Can't Tell ☐
No ☐

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

Comments:

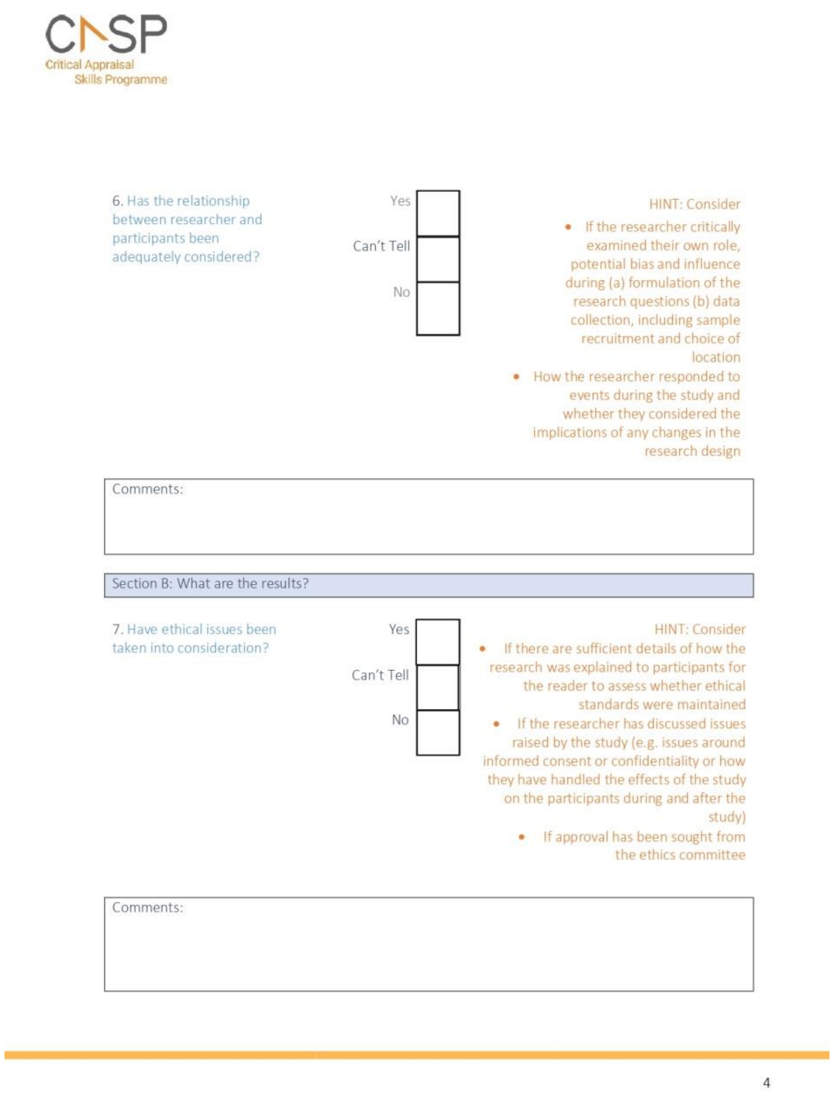
5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

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

Comments:

3



Critical Appraisal Skills Programme

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

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider

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

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐

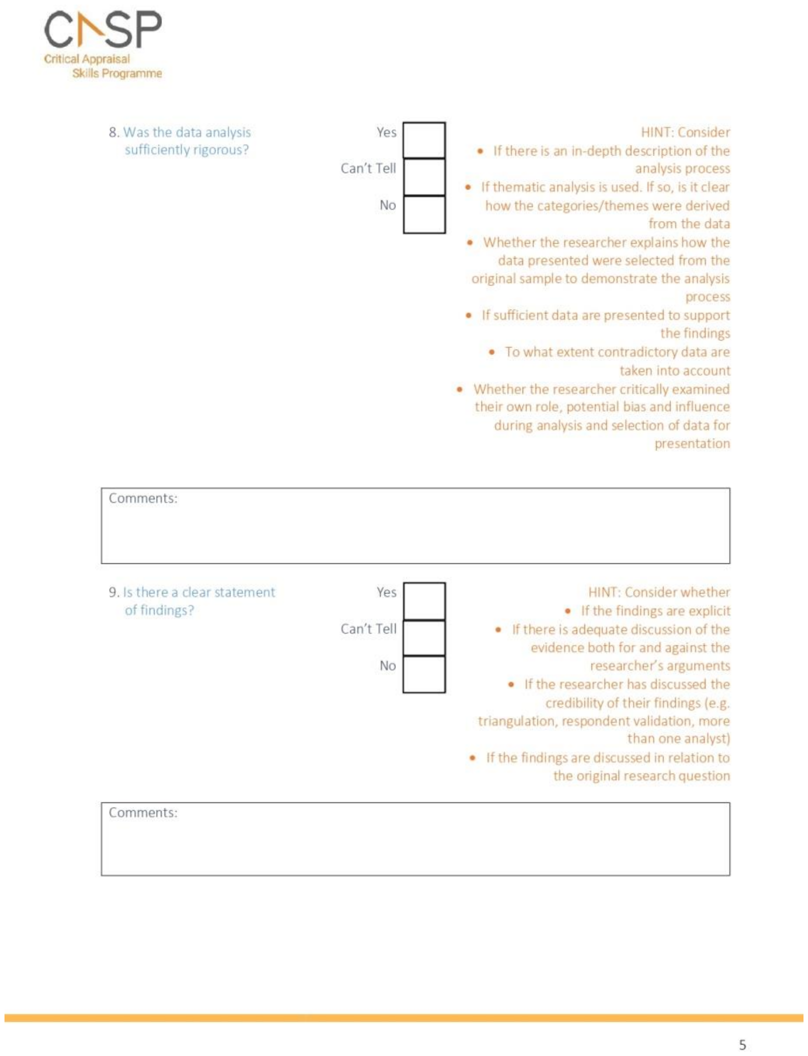
Can't Tell ☐

No ☐

HINT: Consider

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

Comments:



Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider

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

Comments:

9. Is there a clear statement of findings?

Yes ☐

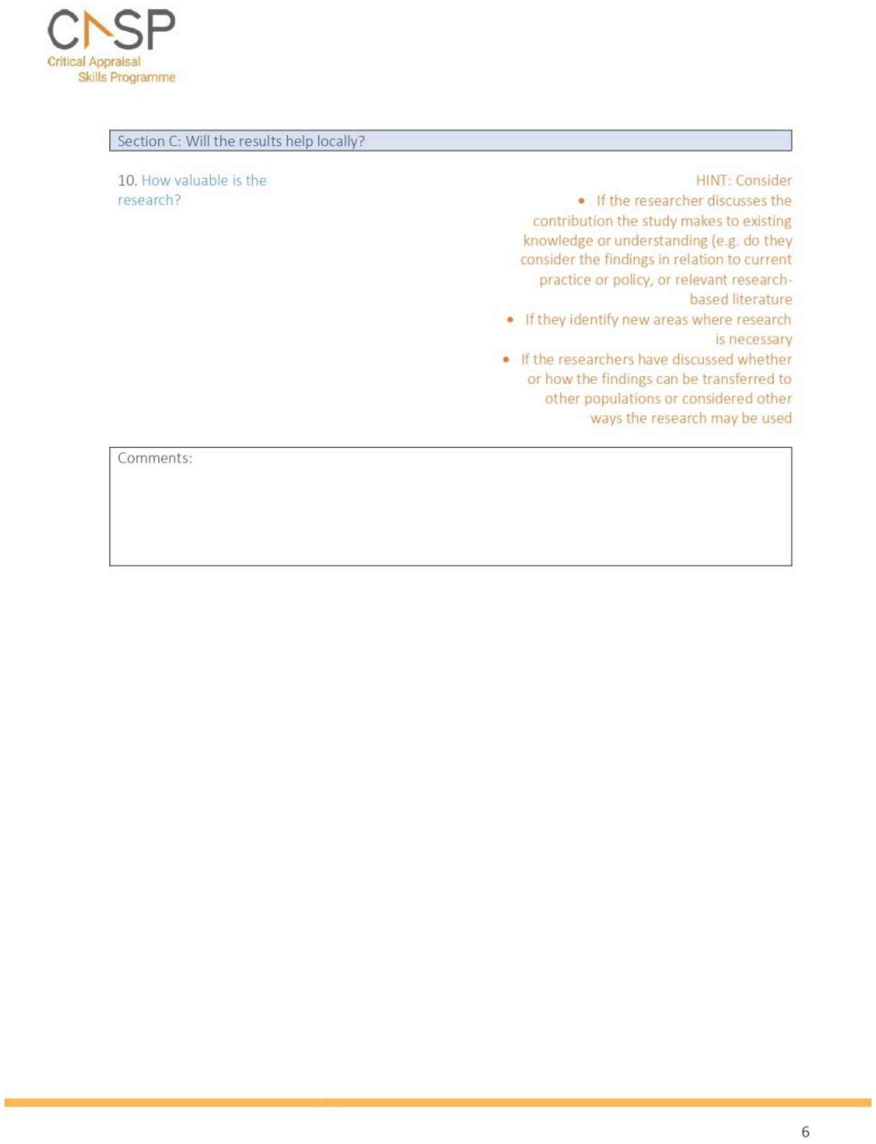
Can't Tell ☐

No ☐

HINT: Consider whether

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

Comments:



CASP
Critical Appraisal
Skills Programme

Section C: Will the results help locally?

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

Comments:

Appendix B

PRISMA 2020 Checklist

	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	7-8
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	8
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	12
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	10
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	11
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	12-13
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	13-14
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were	12-15

	Item #	Checklist item	Location where item is reported
		compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	12-13
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	13-14
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	13-15; Figure 1
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	14-15
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 3 & 4
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	9, 14
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	13-14
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Table 4
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	13-14

	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	15
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A
Study characteristics	17	Cite each included study and present its characteristics.	Table 3
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	26; Table 4
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 3
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	26; Table 4
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			

	Item #	Checklist item	Location where item is reported
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	37-41
	23b	Discuss any limitations of the evidence included in the review.	41-43
	23c	Discuss any limitations of the review processes used.	41-43
	23d	Discuss implications of the results for practice, policy, and future research.	43-44
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	10
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	10
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	ii
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix C

ENTREQ Checklist

(Adapted from Tong et al., 2007)

Number	Item	Guide and Description	Location	Checked by independent reviewer (EE)
1	Aim	State the research question the synthesis addresses.	8	✓
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology.	9	✓
3	Approach to searching	Indicate whether the search was pre-planned or iterative.	10	✓
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. *in terms of population, language, year limits, type of publication, study type*).	12	✓
5	Data sources	Describe the information sources used and when the searches conducted; provide the rationale for using the data sources.	10	✓
6	Electronic search strategy	Describe the literature search.	11	✓
7	Study screening methods	Describe the process of study screening and sifting	12-13	✓
8	Study characteristics	Present the characteristics of the included studies	17-25; Table 3	✓
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion.	15-16; Figure 1	✓

10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings	13-14	✓
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings	13	✓
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	14	✓
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	14, 26-27; Table 4	✓
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies?	13	✓
15	Software	State the computer software used, if any.	11 & 13	✓
16	Number of reviewers	Identify who was involved in coding and analysis.	14	✓
17	Coding	Describe the process for coding of data.	14	✓
18	Study comparison	Describe how comparisons were made within and across studies.	14	✓
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	14	✓
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	29-37	✓
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies	29-37	✓

Appendix D

Analytic Theme Development

The tables in this appendix show how analytic themes were developed from descriptive themes (in italics) and the codes that were contained within the descriptive themes.

Clinician Uncertainty Feeds Patient Uncertainty	
Lack of knowledge and understanding amongst HCPs	
Never heard of it They've never seen NEAD Did not understand their condition Chronic ignorance didn't know what he was on about	Lack of awareness prevalent Lack of experience Lack of knowledge Lack of understanding Don't listen
Difficulty establishing a joint understanding	
Difficulty reaching a common understanding of NEAD Patient doesn’t understand how treatments will help seizures Jargon and power imbalance during consultations	
Difficulty on part of patient to absorb and retain information	
Can't remember the explanations Difficulty understanding diagnosis struggled to retain information Difficulty understanding diagnosis Hard to make sense of info during consultations	
Lack of information and support provided	
Needed more explanation Wanting guidance treatment options not well discussed Lack of information provided Not provided resources for how to cope Not given any information	Need for explanation Desperate for information Limited information Information given not pitched at right level
HCP encounters fail to address or reduce uncertainty	
Unresolved questions and uncertainty Uncertainty anger from lack of certainty led to disengagement from services Worry about treatment working bewilderment	
Communication breakdown	
Lack of understanding leads to dissatisfactory interactions being lectured- inherent power imbalance Dealing with HCPs barrier to	
Not believed or taken seriously	
accused of attention-seeking Nobody knows what its like	
Demeaning/belittling/abusive interactions	
Not listened to	
Rejected and abandoned	
At a loss for what to do Passed around professionals	

HCPs uninterested in hearing their story worry that no one can help Lack of knowledge fuels rejection Dismissive	
Distrust and avoidance of healthcare due to difficult experiences	
uncertain expectations due to past negative experiences with services Negative experiences with HCPS affected access to specialist care	
Emotional impact of difficult encounters	
Anger Angry at Dr who diagnosed NES Did not feel validated Frustration Hopelessness and frustration drives desperation for treatment	helplessness Hopeless Terrifying Stressed
Things that participant feel would be helpful	
Better understanding among HCPs will help Collaborative or shared understanding would have been helpful Needs to be more knowledge out there	
Positive interactions with supportive HCPs	
Positive relationship with one HCP supported engagement with therapy Psychologist willing to help them understand psychologists spend time with you, patience Repeated explanation helped understanding Neurologist made an effort helpful and beneficial good therapeutic relationship key to improvement	
Knowledgeable HCPs enabled better patient understanding	
Dr's certainty reassuring Feeling understood reduced loneliness and isolation Explanation can be helpful highly skills, asking the right questions Information about NES helpful professional educating themselves benefits sessions professionals eager to learn knowledgable HCPs positive	
Things that participants feel would be helpful	
Collaborative or shared understanding would have been helpful Better understanding among HCPs will help Needs to be more knowledge out there	

Not fitting into the model of medical illness	
Lack of knowledge and understanding amongst HCPs	
Enigma for professionals treatment without knowing what's going on Patients recognise difficulties for HCPs Dr refusal to admit knowing less than pt	HCPs unwilling to learn about NEAD Dr unwilling to compromise Lack of experience
Difficulty establishing a joint understanding	
Managing complex and contradicting information	
Difficulty on part of patient to absorb and retain information	
HCPs unwilling to learn about NEAD	

Lack of information and support provided	
Needed more explanation Nobody tells you anything No help or information given No help or advice	NES not explained not given ideas or support Limited information
HCP encounters fail to address or reduce uncertainty	
Discharged without answers Unresolved questions and uncertainty Uncertainty No treatment offered- sent home anger from lack of certainty led to disengagement from services Reliance on medical models results in ambiguity	
Communication breakdown	
Drs become frustrated Bad communication Miscommunication Disconnect between patient and HCP Lack of trust Not included in care Source of tension	Frustrated by too many questions Defensive about psychological explanation Anger at psychological explanation defensive Not feeling understood Paternalistic
Not believed or taken seriously	
Illegitimate seizures viewed as a fraud HCPs don't believe NEAD exists Told there is nothing wrong with them accused of being hysterical Dr believed condition voluntary due to lack of biomarkers treated as a fake Blamed seen as faking PNES treated as imaginary Lack of biomarkers leads to belief NEAD illegit legitimacy questioned by professionals	less legitimate made to feel I was wasting their time making up sotries Not epilepsy so believe they can control it Not believed Not taken seriously seen as unimportant severity fo condition discounted Made me feel like it was my fault Worry they will be accused of faking
Demeaning/belittling/abusive interactions	
rejected and blamed Made to feel worthless HCPs did not listen unsupportive and unempathetic no compassion or understanding Patient wishes not respected made to feel guilty Not listened to	
Rejected and abandoned	
Abandoned by professionals Abandoned by services alienated let down and ostracized Nobody seems to care	Dismissive Rejection Wouldn't assess injuries due to NEAD ashamed to not have epilepsy (rejection) Feel rejected

Lack of biomarkers leads to dismissal Lack of knowledge fuels rejection disinterested dumped Cessation of investigations frustrating, felt rejected Written off Been failed by doctors I feel I'm on my own Dismissed	Feeling alienated felt excluded from medical care felt like I was wasting their time difficulty getting diagnosis resulted in feeling rejected Disregard leads to feeling alienated left in limbo Getting help is impossible
Distrust and avoidance of healthcare due to difficult experiences	
Can't be open with some professionals dissatisfaction with medical culture loss of faith in doctors	
Emotional impact of difficult encounters	
Anger Experiences invalidated fed up of fighting Feel like a failure attempted suicide due to treatment	
Knowledgeable HCPs enabled better patient understanding	
Helpful to be understood and taken seriously	
Positive interactions with supportive HCPs	
Helpful to be believed Relief for being believed Drs helpful in advocating the legitimacy of PNES to others Felt looked after by Dr- good Dr helpful and felt listened to Helpful physicians listen Positive relationship with HCP helped to not feel judged Reassurance in Dr's advocacy reassuring Patient used Drs power to their advantage offered help for the future	

Stigma fuelling traumatic experiences with HCPs	
Lack of knowledge and understanding amongst HCPs	
Nurse didn’t understand	
Communication breakdown	
Lack of trust misunderstood communicating with professions active struggle stigmatising communication with doctor	
Not believed or taken seriously	
HCPs don't believe NEAD exists accused of faking Made to feel like they're faking accused of attention-seeking	Drs can be blaming Accused of time wasting accused of wasting NHS resource Blamed

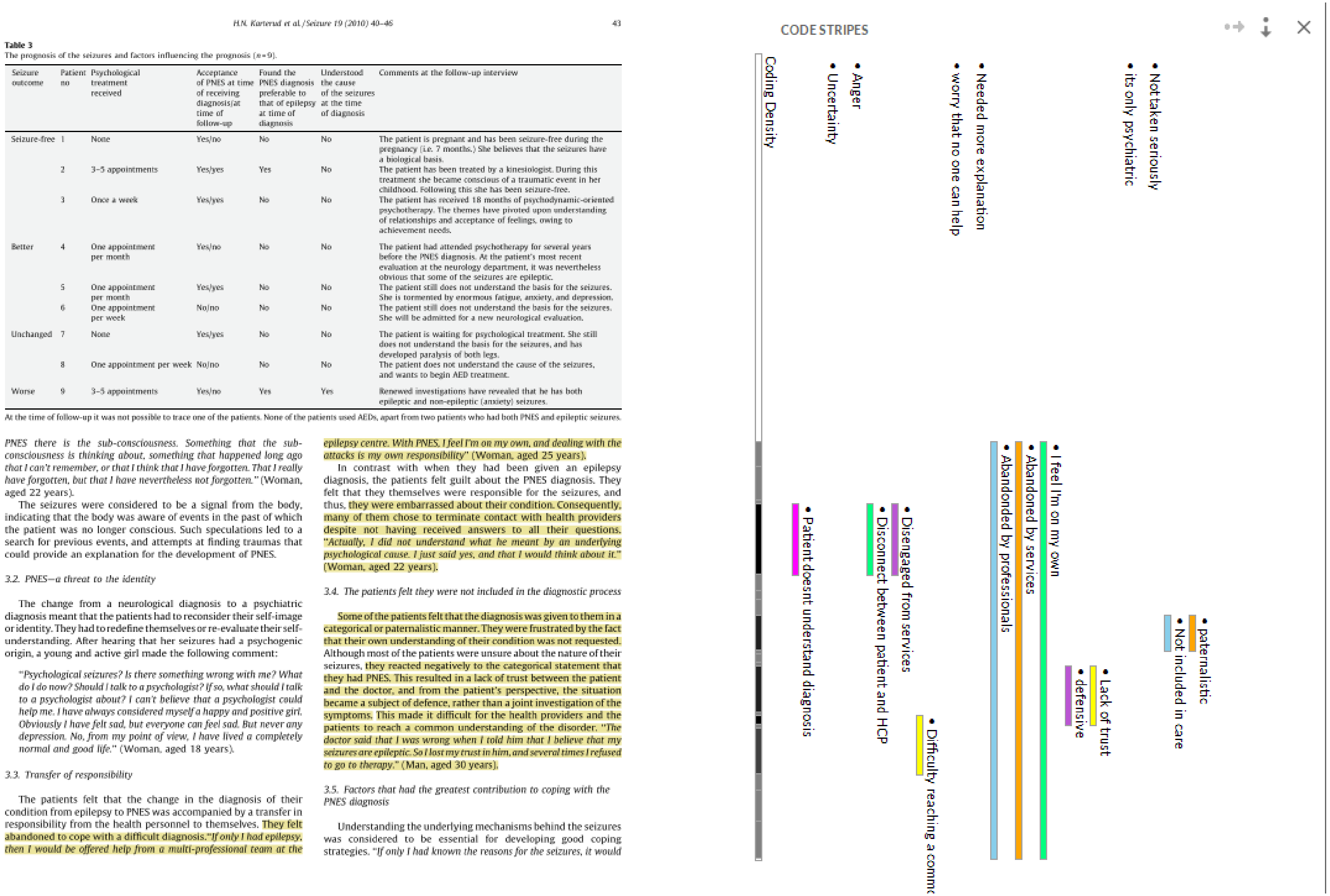
accused of being hysterical accused of having voluntary control accused of making it up Accused of malingering treated as a fake	They think I put it all on made to feel I was wasting their time Not taken seriously its only psychiatric
Demeaning/belittling/abusive interactions	
abusive treatment in hospital abusive treatment in hospital was traumatic be grateful its not epilepsy all interactions have been negative Degrading Degrading interaction Disrepectful behaviours Inappropriate treatment by HCP (mean) encountered dr who were rude shocking encounters Shared disrespect between professions towards pt Rude and offensive Poor treatment in hospital Laughed in my face Parameds speaking about patient infront of them Paramedics made rude comments Paramedics and ER HCPs worst offenders Not listened to	Not heard Made to feel invisible hospital staff very rude Hostility was shouted at by nurse Traumatic hospital treatment Told to just leave her mocked, called weird More negative expereinces than positive Neg interactions with HCPs typical, the norm Negative experiences with HCPs very common Treated as a joke Discriminated against Disrespectful attitudes Lack of awareness feed disrespect Looked at me like I was crazy HCPs not wanting to listen
Rejected and abandoned	
Nobody seems to care Dismissed Wouldn't assess injuries due to NEAD	
Distrust and avoidance of healthcare due to difficult experiences	
avoided seeking medical treatment avoided services due to adverse experiences couldn't trust HCPs anymore reluctance to seek medical attention Afraid of the ER now Now dislike paramedics and most of medical profession	
Emotional impact of difficult encounters	
Anger Hopeless Humiliated terrifying offended They think I put it all on	
Things that participant feel would be helpful	
Importance of respect and dignity	
Positive interactions with supportive HCPs	
Dr pleasant and approachable Finally listened to He is just that kind of person, not just a	Trusting therapist helpful to therapy Taken seriously- attentive and validating Taking an interest

doctor Helpful to be believed Positive dr attitude helped her feel looked after Psychiatrist positive and non-judgemental	Relief for being believed Kindness and empathy important Right HCPs good source of coping and resilience

Appendix E

Example of Line-by-Line Coding in NVivo

(Karterud et al., 2010)



H.N. Karterud et al. / Seizure 19 (2010) 40–46 43

Table 3
The prognosis of the seizures and factors influencing the prognosis ($n = 9$).

Seizure outcome	Patient no	Psychological treatment received	Acceptance of PNES at time of receiving diagnosis/at time of follow-up	Found the PNES diagnosis preferable to that of epilepsy at time of diagnosis	Understood the cause of the seizures at the time of diagnosis	Comments at the follow-up interview
Seizure-free	1	None	Yes/no	No	No	The patient is pregnant and has been seizure-free during the pregnancy (i.e. 7 months.) She believes that the seizures have a biological basis.
	2	3–5 appointments	Yes/yes	Yes	No	The patient has been treated by a kinesiologist. During this treatment she became conscious of a traumatic event in her childhood. Following this she has been seizure-free.
	3	Once a week	Yes/yes	No	No	The patient has received 18 months of psychodynamic-oriented psychotherapy. The themes have pivoted upon understanding of relationships and acceptance of feelings, owing to achievement needs.
Better	4	One appointment per month	Yes/no	No	No	The patient had attended psychotherapy for several years before the PNES diagnosis. At the patient's most recent evaluation at the neurology department, it was nevertheless obvious that some of the seizures are epileptic.
	5	One appointment per month	Yes/yes	No	No	The patient still does not understand the basis for the seizures. She is tormented by enormous fatigue, anxiety, and depression.
	6	One appointment per week	No/no	No	No	The patient still does not understand the basis for the seizures. She will be admitted for a new neurological evaluation.
Unchanged	7	None	Yes/yes	No	No	The patient is waiting for psychological treatment. She still does not understand the basis for the seizures, and has developed paralysis of both legs.
	8	One appointment per week	No/no	No	No	The patient does not understand the cause of the seizures, and wants to begin AED treatment.
Worse	9	3–5 appointments	Yes/no	Yes	Yes	Renewed investigations have revealed that he has both epileptic and non-epileptic (anxiety) seizures.

At the time of follow-up it was not possible to trace one of the patients. None of the patients used AEDs, apart from two patients who had both PNES and epileptic seizures.

PNES there is the sub-consciousness. Something that the sub-consciousness is thinking about, something that happened long ago that I can't remember, or that I think that I have forgotten. That I really have forgotten, but that I have nevertheless not forgotten." (Woman, aged 22 years).

The seizures were considered to be a signal from the body, indicating that the body was aware of events in the past of which the patient was no longer conscious. Such speculations led to a search for previous events, and attempts at finding traumas that could provide an explanation for the development of PNES.

3.2. *PNES—a threat to the identity*

The change from a neurological diagnosis to a psychiatric diagnosis meant that the patients had to reconsider their self-image or identity. They had to redefine themselves or re-evaluate their self-understanding. After hearing that her seizures had a psychogenic origin, a young and active girl made the following comment:

> "*Psychological seizures? Is there something wrong with me? What do I do now? Should I talk to a psychologist? If so, what should I talk to a psychologist about? I can't believe that a psychologist could help me. I have always considered myself a happy and positive girl. Obviously I have felt sad, but everyone can feel sad. But never any depression. No, from my point of view, I have lived a completely normal and good life.*" (Woman, aged 18 years).

3.3. *Transfer of responsibility*

The patients felt that the change in the diagnosis of their condition from epilepsy to PNES was accompanied by a transfer in responsibility from the health personnel to themselves. They felt abandoned to cope with a difficult diagnosis."*If only I had epilepsy, then I would be offered help from a multi-professional team at the epilepsy centre. With PNES, I feel I'm on my own, and dealing with the attacks is my own responsibility*" (Woman, aged 25 years).

In contrast with when they had been given an epilepsy diagnosis, the patients felt guilt about the PNES diagnosis. They felt that they themselves were responsible for the seizures, and thus, they were embarrassed about their condition. Consequently, many of them chose to terminate contact with health providers despite not having received answers to all their questions. "*Actually, I did not understand what he meant by an underlying psychological cause. I just said yes, and that I would think about it.*" (Woman, aged 22 years).

3.4. *The patients felt they were not included in the diagnostic process*

Some of the patients felt that the diagnosis was given to them in a categorical or paternalistic manner. They were frustrated by the fact that their own understanding of their condition was not requested. Although most of the patients were unsure about the nature of their seizures, they reacted negatively to the categorical statement that they had PNES. This resulted in a lack of trust between the patient and the doctor, and from the patient's perspective, the situation became a subject of defence, rather than a joint investigation of the symptoms. This made it difficult for the health providers and the patients to reach a common understanding of the disorder. "*The doctor said that I was wrong when I told him that I believe that my seizures are epileptic. So I lost my trust in him, and several times I refused to go to therapy.*" (Man, aged 30 years).

3.5. *Factors that had the greatest contribution to coping with the PNES diagnosis*

Understanding the underlying mechanisms behind the seizures was considered to be essential for developing good coping strategies. "*If only I had known the reasons for the seizures, it would*

Appendix F

Descriptive Themes with Codes

Lack of knowledge and understanding amongst HCPs

Participants commented that there was a distinct lack of knowledge and understanding of FDS among HCPs, and whilst some were willing to learn more, often HCPs seemed unwilling to listen and learn about the condition to help their patient.

Enigma for professionals
HCP unfamiliarity with NES barrier to diagnosis
Never heard of it
Trying to understanding
They've never seen NEAD
anger at HCP prevented listening
Did not understand their condition
Chronic ignorance
didn't know what he was on about
Lack of awareness prevelant
treatment without knowing what's going on
Patients recognise difficulties for HCPs
Lack of experience
Lack of knowledge
Lack of understanding
nurse didn't understand
Dr refusal to admit knowing less than pt
HCPs unwilling to learn about NEAD
Dr unwilling to compromise
Don't listen

Difficulty establishing a joint understanding

Participants described difficulties reaching joint understandings with HCPs. Some participants disagreed with their diagnoses which affected their trust in HCPs

Difficulty reaching a common understanding NEAD
Patient doesnt understand how treamtments will help seizures
Managing complex and contradicting information

Difficulty on part of patient to absorb and retain information

The difficulty understanding FDS was also shared by ppts as they often reported struggling to understand and retain information about their diagnosis and treatment options, perhaps due to the use of difficult to understand jargon in consultations.

Can't remember the explanations
Difficulty understanding diagnosis
struggled to ratin information
Difficulty understanding diagnosis
HCPs unwilling to learn about
Hard to make sense of info during consultations
Jargon and power impalance duirng consultations (barrier to understanding diagnosis)

HCP encounters fail to address or reduce uncertainty

Participants often reported a lack of certainty about their conditions, from being certain of their diagnosis, to being unsure what treatments are most appropriate for them or if the treatment offered will be effective. The lack of certainty around their condition was difficult to manage and resulted in some disengaging from support.

Discharged without answers
Unresolved questions and uncertainty
Uncertainty
No treatment offered- sent home
Reliance on medical models results in ambiguity
Worry about treatment working
bewilderment

anger from lack of certainty led to disengagement from services apprehension about treatment	

Communication breakdowns	
Participants described a breakdown in communication with HCP. Some participants felt doctors took a paternalistic approach to their communication, and used medicalised jargon which was difficult to understand and resulted in them feeling not understood. Some even described stigmatising interactions with HCPs. Communication difficulties with HCPs eroded participant's trust in HCPs; communication was described an active struggle and presented a significant barrier to accessing care for participants.	
Drs become frustrated Bad communication Miscommunication Disconnect between patient and HCP Lack of trust Lack of understanding leads to dissatisfactory interactions misunderstood being lectured- inherent power imbalance Not included in care Source of tension	communicating with professions active struggle stigmatising communication with doctor Frustrated by too many questions Defensive about psychological explanation Anger at psychological explanation defensive Dealing with HCPs barrier to Not feeling understood Paternalistic

Lack of information and support provided	
Participants reported not being provided with much information about their condition from healthcare providers, and sometimes treatment options were not discussed with them, adding to their felt uncertainty of their condition. Participants expressed wanting and needing guidance to support their coping with their diagnosis, and some	
Needed more explanation Nobody tells you anything No help or information given No help or advice Wanting guidance treatment options not well discussed Lack of information provided NES not explained	Not provided resources for how to cope not given ideas or support Not given any information Need for explanation Desperate for information Limited information Information given not pitched at right level

Not believed or taken seriously	
Participants often came across HCPs who held judgemental and stigmatising beliefs about the legitimacy of FDS that resulted in them not being believed that they were indeed experiencing seizures, or if they were believed, they were accused of faking them or having voluntary control of them. Participants felt that because their seizures were not epilepsy, or they were "only psychiatric", they were not taken seriously or viewed as important.	
Illegitimate seizures viewed as a fraud HCPs don't believe NEAD exists Told there is nothing wrong with them	Took a long time to be taken seriously They think I put it all on seen as faking PNES treated as imaginary

<table>
<tr><td>accused of faking
Made to feel like they're faking
accused of attention-seeking
accused of being hysterical
accused of having voluntary control
accused of making it up
Accused of malingering
Dr believed condition voluntary due to lack of biomarkers
treated as a fake
Drs can be blaming
Accused of time wasting
accused of wasting NHS resource
Blamed
Nobody knows what its like</td><td>Lack of biomarkers leads to belief NEAD illegit
legitimacy questioned by professionals
less legitimate
made to feel I was wasting their time
making up sotries
Not epilepsy so believe they can control it
Not believed
Not taken seriously
seen as unimportant
severity fo condition discounted
Made me feel like it was my fault
Worry they will be accused of faking
Needing proof of legitimacy
its only psychiatric</td></tr>
</table>

<table>
<tr><td colspan="2">Rejected and abandoned</td></tr>
<tr><td colspan="2">Participants felt that HCPs did not care about their FDS, which led to them being rejected and abandoned by services. They felt at a loss for what to do to get support and worried that no one would be able to help them. This lonely and alienating and made them feel shame for having FDS.</td></tr>
<tr><td>Abandoned by professionals
Abandoned by services
alienated
let down and ostracized
Nobody seems to care
Lack of biomarkers leads to dismissal
Lack of knowledge fuels rejection
disinterested
dumped
Cessation of investigations frustrating, felt rejected
Written off
Been failed by doctors
At a loss for what to do
I feel I'm on my own
Passed around professionals</td><td>HCPs uninterested in hearing their story
Dismissed
Dismissive
Rejection
Wouldn't assess injuries due to NEAD
ashamed to not have epilepsy (rejection)
Feel rejected
Feeling alienated
felt excluded from medical care
felt like I was wasting their time
difficulty getting diagnosis resulted in feeling rejected
Disregard leads to feeling alienated
worry that no one can help
left in limbo
Getting help is impossible</td></tr>
</table>

<table>
<tr><td colspan="2">Demeaning/belittling/abusive interactions</td></tr>
<tr><td colspan="2">Negative interactions with HCPs were very prevalent, and seemed to be a result of a lack of understanding about FDS. Lack of understanding seemed to forge a lack of compassion for participants when they presented to services. The experiences were degrading and deeply traumatic. They spoke about hearing HCPs accuse them of faking when they thought the patient could not hear, being mocked, shouted at and physically assaulted(?) by staff.</td></tr>
<tr><td>abusive treatment in hospital
abusive treatment in hospital was traumatic
be grateful its not epilepsy
all interactions have been negative
Degrading
Degrading interaction
Disrepectful behaviours</td><td>Made to feel worthless
HCPs did not listen
hospital staff very rude
Hostility
was shouted at by nurse
unsupportive and unempathetic
Traumatic hospital treatment</td></tr>
</table>

Inappropriate treatment by HCP (mean) encountered dr who were rude shocking encounters Shared disrespect between professions towards pt rejected and blamed Rude and offensive Poor treatment in hospital Laughed in my face Parameds speaking about patient infront of them Paramedics made rude comments Paramedics and ER HCPs worst offenders Not listened to Not heard Made to feel invisible	Told to just leave her mocked, called weird More negative expereinces than positive Neg interactions with HCPs typical, the norm no compassion or understanding Negative experiences with HCPs very common Treated as a joke Discriminated against Disrespectful attitudes Lack of awareness feed disrespect Patient wishes not respected Looked at me like I was crazy made to feel guilty HCPs not wanting to listen

Emotional impact of difficult encounters with HCPs	
Difficult experiences with HCPs resulted in many difficult emotions for participants. Many felt angry about their treatment and at HCPS for giving them a diagnosis of FDS. They felt terrified, humiliated, hopeless and worthless to the extent that some had contemplated ending their life.	
Anger Angry at Dr who diagnosed NES Did not feel validated Experiences invalidated fed up of fighting Feel like a failure Frustration Hopelessness and frustration drives desperation for treatment	helplessness Hopeless Humiliated Terrifying terrifying Stressed offended attempted suicide due to treatment They think I put it all on

Positive interactions with supportive HCPs	
Although positive interactions were felt to be experienced a minority of the time, there were many instances where participants described interactions and encounters with kind and empathic professionals that they felt were beneficial and helpful and helped them to feel validated, reassured and looked after	
helpful and beneficial Dr pleasant and approachable Drs helpful in advocating the legitimacy of PNES to others Felt looked after by Dr- good Dr Finally listened to good therapeutic relationship key to improvement He is just that kind of person, not just a doctor helpful and felt listened to Helpful drs in the minority Helpful physicians listen Helpful to be believed Positive relationship with HCP helped to not feel judged Positive relationship with Dr unexpected	Positive relationship with one HCP supported engagement with therapy Psychiatrist positive and non-judgemental Psychologist willing to help them understand psychologists spend time with you, patience Trusting therapist helpful to therapy Taken seriously- attentive and validating Taking an interest She sat back and listen, hopes were raised Reassurance in Dr's advocacy reassuring Relief for being believed Repeated explanation helped understanding Right HCPs good source of coping and resilience People who treat them well are in the minority

Positive interactions at specialist services Positive dr attitude helped her feel looked after	Kindness and empathy important Patient used Drs power to their advantage offered help for the future Neurologist made an effort

Knowledgeable HCPs enabled better patient understanding
Participants who perceived HCPs as knowledgeable and understanding of FDS were seen as helpful and enabled them to feel reassured and taken seriously. Its seemed a knowledgeable professional promoted mutual understanding as patients received helpful information. Clinicians who demonstrated an eagerness to learn more about FDS were positively regarded and still seen as helpful.
Dr's certainty reassuring Feeling understood reduced loneliness and isolation Explanation can be helpful Helpful to be understood and taken seriously highly skills, asking the right questions Information about NES helpful professional educating themselves benefits sessions professionals eager to learn knowledgable HCPs positive

Things that participants feel would be helpful
Some participants could explain what they would have wanted from HCPs to improve their experiences with them, including a better understanding of FDS and a stronger therapeutic relationship to foster collaboration and a shared understanding
Better understanding among HCPs will help

Distrust and avoidance of healthcare due to difficult experiences
Negative experiences with HCPs resulted in a distrust of HCPs and the wider medical culture. It made participants feel afraid of going to hospital and seeking medical; they lost their faith in HCPs. Some felt this prevented them from accessing specialist support and they felt uncertain about what to expect from future care.
avoided seeking medical treatment avoided services due to adverse experiences Can't be open with some professionals couldn't trust HCPs anymore dissatisfaction with medical culture uncertain expectations due to past negative experiences with services relucance to seek medical attention Afraid of the ER now Now dislike paramedics and most of medical profession loss of faith in doctors Negative experiences with HCPS affected access to specialist care

Appendix G

Study representation in themes

	Baxter et al. (2012)	Dickinson et al. (2011)	Fairclough et al. (2014)	Goldstein et al. (2021)	Green et al. (2004)	Karterud et al. (2010)	Karterud et al. (2015)	Peacock et al. (2023)	Peacock et al. (2022)	Pretorius (2016)	Pretorius & Sparrow (2015)	Rawlings et al. (2017)	Rawlings et al. (2018a)	Rawlings et al. (2018b)	Read et al (2020)	Robson & Lian (2016)	Robson & Lian (2017)	Thompson et al. (2009)	Wyatt et al. (2014)	Zeun et al. (2023)
Clinician uncertainty feeds patient uncertainty																				
Uncertainty about diagnosis			✓	✓		✓		✓		✓	✓	✓			✓		✓	✓	✓	
Mutual difficulty understanding FDS		✓	✓	✓		✓	✓				✓		✓		✓		✓		✓	✓
Anger in uncertainty	✓	✓												✓	✓		✓			
Not fitting into the model of medical illness																				
Experiences of delegitimisation			✓		✓	✓	✓	✓			✓	✓				✓	✓		✓	
Dismissed and rejected		✓				✓		✓		✓		✓		✓			✓	✓		
Stigma fuelling traumatic experiences with HCPs	✓	✓				✓				✓	✓	✓	✓				✓	✓	✓	

Appendix H

Selection of additional illustrative quotes

Theme	Sub-theme	Quote
Clinician uncertainty feeds patient uncertainty	*Uncertainty about diagnosis*	*I struggled for a long time. . .it felt like I was going from one doctor to another and nobody had a clue*. (Pretorius & Sparrow 2015, p.36)
		The neurologist was so vague, he didn't really know what he was on about (Wyatt et al., 2014, p.803)
		So many health professionals understand very little about the condition, and therefore treatment/interactions can seem/be very unsatisfactory (Robson & Lian, 2017, p.6)
		The first doctor told me that I will never get better and that there was really no help for me. This was a very time difficult for me. I had no hope. (Pretorius, 2016, p.3)
		I am... it does worry me but not in the sense that like, if it is psychological, I'd like to know what it is so I can obviously deal with that, so it doesn't happen again." "I've been more stressed since being diagnosed with this than I was before (Peacock et al., 2023, p.4)
		Participants described being uncertain of the way forward, seemingly due to a lack of recommendations or a plan post-diagnosis. (Fairclough et al., 2014, p. 299)
		half of all participants from the total of30 interviewed expressly indicated that they had felt understood by the CODES health…which in turn, stopped them feeling so alone and isolated (Read et al., 2020, p.4)
	Mutual difficulty understanding FDS	*My physio… very graciously allowed me to help educate her and she's done it herself and this is meant our sessions have been most enjoyable* (Zeun et al., 2023, p.5)
		'Not being able to understand it myself, I suppose I don't blame them (Wyatt et al., 2014, p.803)
		I shouldn't really have a do at [them] I suppose 'cause he's probably just as confused as I am (Wyatt et al., 2014, p.803)
		The best thing was when the doctor gave some advice and you got more information, and you were relieved to

		find out that you could not simulate the seizures. When I had learned more about NES, then I accepted it (Katerud et al., 2015, p. 110) *I came across a psychologist though, yesterday to be fair and she was amazing. Although she did not have much knowledge of functional neurological disorders apart from what she had to Google, she sat back and listened . . . So my hopes are raised a little more with the extra help that I may receive (but I won't hold my breath)* (Rawlings et al., 2018, p. 956)
	Anger in uncertainty	*None of them listen [...] or can even tell you what a nonepileptic seizure is* (Robson & Lian, 2017, p.7) *He laughed in my face at the diagnosis of FND [Functional Neurological Disorder] and NEAD and said 'what's that'. I realised I knew more than he did about my problems. I don't see him anymore* (Robson & Lian, 2017, p.7) *Nobody seems to be able to put their finger on it. That's the frustrating bit. Nobody can say well yes, you know but that's it* (Baxter et al., 2012, p. 489) *I find the majority of all in these fields don't care or want to learn about PNES (*Robson & Lian, 2017, p. 8) *There needs to be more knowledge out there for medical professionals. They are here to help us, not traumatize us* (Robson & Lian, 2017, p.6)
Not fitting into the model of medical illness	*Experiences of delegitimisation*	*when tests showed that I did not have epilepsy she was totally dismissive and rude she said there is nothing I can do to help you* (Robson & Lian, 2017, p. 7) *He kept referring to non-epileptic seizures as 'your kind of seizures'* (Robson & Lian, 2017, p.9) *if neurologists don't see it in a scan it doesn't exist* (Robson & Lian, 2017, p.7) *Participants believed that the diagnosing neurologist viewed NEAD as unimportant or doubted their symptoms* (Wyatt et al., 2014, p.800) *Once participants had been told that their seizures were "associated with stress", HCPs were described as*

		being less likely to take them or their symptoms seriously (Rawlings et al., 2017, p.88) *It just reaches a point where you just think; actually you're not listening to a word I'm saying, so it doesn't matter. I could come into you and say, 'I turned blue last week and then I went purple.' And they'd go, 'oh really.' But they wouldn't take it on board, they wouldn't listen* (Fairclough et al., 2014, p.300) *I feel like they're thinking that I put it all on* (Green et al., 2004, p.335) *I was also told several times I was faking it for attention. . .not only in the emergency room, also by my psychiatrist* (Pretorius, 2016, p.3) *However, doctors played a more existential role as well, in convincing the participants that the disorder is in fact real, and not them faking it.* (Pretorius & Sparrow, 2015, p. 37)
	Dismissed and rejected	*I was discharged again without any explanation and just left .. . it was frustration, it was anger, it was well, am I just wasting people's time? You just feel like you've been dumped* (Thompson et al., 2009, p. 511) *At emergency they didn't do any treatment. They even wanted me sent home* (Dickinson et al., 2011, p. 457) *If only I had epilepsy, then I would be offered help from a multi-professional team at the epilepsy centre. With PNES, I feel I'm on my own, and dealing with the attacks is my own responsibility* (Karterud et al., 2010, p.43) *I went to see another neurologist and he was totally disinterested... absolutely dismissive, totally uninterested, and I felt like I was wasting his time* (Peacock et al., 2023, p.5)
Stigma fuelling traumatic experiences with HCPs		*Such hostility […] I always feel guilty, ghastly, 'failing to get better', etc. I had a (minor) head injury, just glued. I felt so humiliated by her antagonism when I was already emotionally really vulnerable* (Robson & Lian, 2017, p.9) *We have a participant who's mum has pseudo seizures and the nurses always mock her or say she is weird and fakes seizures – these are professionals and even they don't understand it.* (Rawlings et al., 2017, p. 86) *[GP] laughing straight into my face saying I have no epilepsy* (Wyatt et al., 2014, p. 803)

	Julie complained that her consultant physician told her to 'buck up her ideas' and get back to work (Green et al., 2004, p. 336) *Participants described having avoided health care services in the past because of previous adverse experiences* (Rawlings et al., 2018, p. 956) *PNES: "What a life, but at least most days now I don't end up at that shitty hospital where the doctors treat you like shit and call you a fake* (Rawlings et al., 2018, p. 956)

This page is intentionally left blank

Section Two: Empirical Study

An Interpretative Phenomenological Analysis of the Experience of Self-Disgust in people with Functional/dissociative Seizures

Abstract

Objective

Psychological distress and trauma is common among people with functional/dissociative seizures (pwFDS). Self-disgust, a maladaptive internalisation of disgust, is implicated in many mental and physical health conditions. It has been explored in various conditions, but has yet to be understood in FDS. This study therefore aimed to gain an understanding of the experience of self-disgust in pwFDS.

Methods

This study employed a qualitative design with interpretative phenomenological analysis (IPA) methodology. Following initial screening for self-disgust, purposive sampling was used to recruit eight eligible participants to undergo semi-structured interviews about their experiences of self-disgust.

Results

In the larger sample (n= 108), 85.18% of participants reported high levels (>31) of self-disgust. IPA produced four themes ‘understanding the origin of self-disgust as based in rejection’, ‘experiencing self-disgust as intense and inescapable’, ‘understanding the relationship between self-disgust and FDS’ and ‘suppression and seclusion- attempting to cope with self-disgust’.

Conclusions

Self-disgust may be relevant to a subpopulation of pwFDS. A bi-directional relationship between self-disgust and FDS exists that likely arises from internalisation of traumatic experiences. Participants’ attempts to reduce self-disgust provided short-term relief.

Practitioner Points

- Practitioners should be aware of self-disgust during assessments as it may be important to inform psychological interventions.
- Existing psychological interventions may be helpful to support pwFDS' experience of self-disgust.
- There is a need for specific FDS training among healthcare, and other, professions to increase awareness and reduce the stigma associated with the condition.

Keywords: functional/dissociative seizures; self-disgust; qualitative; interpretative phenomenological analysis

Introduction

The emotional experiences that accompany living with a physical health condition are often underrecognised (Turner & Kelly, 2000). Yet, living with a health condition presents challenges to psychological wellbeing and quality of life (Scott et al., 2007). People living with stigmatised health conditions may experience additional challenges due to lack of understanding, stigma and discrimination (Stangl et al., 2019). An example of one such condition causing people to face such social and emotional challenges is functional/dissociative seizures (FDS; Annandale et al., 2022).

FDS (also known as psychogenic nonepileptic seizures or nonepileptic attacks [Wardrope et al., 2021]) are episodes of reduced awareness or consciousness that involve involuntary movements, and changes in sensation and perceptions. FDS resemble epileptic seizures, but are not associated with ictal epileptiform discharges in the brain (Devinsky et al., 2011). FDS are one manifestation of functional neurological disorder (FND), which refers to the experience of a variety of symptoms including problems with movement, sensation and awareness that resemble neurological conditions but are not associated with pathophysiological changes in the nervous system (Aybek et al., 2022).

FDS are thought to be caused by interplay of psychological, social and biological factors, often associated with psychological stressors (Brown & Reuber, 2016). The estimated prevalence of FDS is 23.8/100,000, although this estimate is tentative due to a lack of studies (Wardrope et al., 2021; Asadi-Pooya, 2023). Support from multi-disciplinary professionals is recommended by the National Institute for Clinical Excellence (NICE; 2021; Winton-Brown et al., 2023). Antidepressants may help improve seizure severity, but the most commonly recommended treatment is psychological therapy (Hingray et al., 2018).

Psychological distress is commonly associated with FDS, with increased prevalence of mental health problems, including anxiety and depression (Diprose et al., 2016), and rates of suicide (Zhang et al., 2022). Post-traumatic stress disorder occurs in 38-64% of people with FDS (pwFDS), with high rates of childhood trauma and adverse life events (Myers et al., 2019). Additionally, over 90% of pwFDS report suffering detrimental effects of stigma. This includes reduced healthcare access, distress and negative self-conscious emotions (Annandale et al., 2022; Link & Phelan, 2006; Reuber et al., 2022).

Self-conscious emotions including guilt, embarrassment, shame and pride impact an individual's evaluation of oneself and their personal identity goals (intrapersonal) and how they are viewed by others (interpersonal) (Gilbert, 1997; Sznycer, 2019; Tracy & Robbins, 2004). Such emotions can be experienced negatively, particularly when related to trauma (Tran et al., 2019) and health concerns (Harrison et al., 2016; Robertson et al., 2021). Studies show that, in addition to shame, pwFDS are more likely to experience negative self-directed emotions such as low self-esteem and low self-compassion (Clegg et al., 2019; Dimaro et al., 2015).

Another emotion with potential relevance to experiences of pwFDS is self-disgust- a maladaptive generalisation (or internalisation) of disgust, directed towards oneself (Powell et al., 2015). Disgust is a universal, basic emotion developed to promote self-preservation by avoiding potential contaminants (Rozin et al., 2008). Disgust can be triggered by a range of elicitors such as bodily contaminants and secretions, undesirable physical attributes, certain animals and their secretions, unsanitary environments, sociomoral violations and immoral character traits (Rozin et al., 1999). As with other basic human emotions, disgust can become dysfunctional resulting in the development and propagation of a number of mental health difficulties (Rozin et al., 2008).

Disgust reactions can also be self-elicited (Power & Dalgleish, 2015). Self-disgust has been conceptualised as an extension of other self-conscious emotions such as self-loathing or shame (see Powell et al., 2015 for more on this debate). However, self-disgust can be delineated from other emotions due to its relationship with revulsion and disgust (Powell et al., 2014). For example, the visceral nature and distinct disgust appraisals (e.g. "I make people feel sick") are specific to self-disgust (Powell et al., 2014). One can experience feelings of shame or guilt without disgust, and vice versa (Powell et al., 2015). Another distinguishing aspect of self-disgust is the psychological and behavioural responses it elicits. While both shame and disgust can lead to social avoidance, self-disgust can also result in self-cleansing or dissociating from the "disgusting self" (p.124, Clarke et al., 2019).

It is also believed self-disgust characterises an emotion schema originating from childhood "disgust-based" trauma or abuse, shaped by subsequent trauma or changed self-perception (Powell et al., 2014). An initial reaction of self-disgust can be triggered by negative evaluation of one's own characteristics or behaviour, or by external stimuli that later become associated with a part of the self. As the initial reaction is reinforced through rumination or disgust-based feedback from others, it can evolve into a dominant framework that shapes one's self-perception (Powell et al., 2015; Clarke et al., 2019).

Some argue that self-disgust is a psychometrically valid construct, the exploration of which has clinical value in developing understanding of experiences in mental and physical health conditions (Clarke et al., 2019). Self-disgust is implicated in the perpetuation of a number of mental health difficulties including depression and trauma (Clarke et al., 2019), and increased suicidality (Mason et al., 2022). Self-disgust may also mediate the relationship between childhood trauma and later development of psychosis (Simpson et al., 2020). Self-disgust can also be detrimental to people's adaptation to physical health problems such as colostomy (Jin et al., 2020) and cancer treatments (Azlan et al., 2017). In these studies, self-disgust perpetuated psychological distress, and negatively affected acceptance of the condition and engagement with treatment (Jin et al., 2020; Powell et al., 2016).

Additionally, in a recent qualitative study (Mayor et al., 2022), self-disgust was found to be highly relevant in experiences of epilepsy, which, as with FDS, is often associated with stigma and shame (Mayor et al., 2022). Participants' difficulties with epilepsy symptoms and other people's disgust-based reactions to them resulted in internalisation of disgust and their seizures. Participants felt betrayed and disgusted by their body and vulnerability. To cope, participants would avoid situations that risked eliciting self-disgust and distanced themselves from relationships (Mayor et al., 2022). The importance of self-disgust's role in mental health difficulties and adjustment to physical health conditions warrants further investigation in conditions not yet studied.

Rationale

No previous research has explored the experience of self-disgust in pwFDS. However, the importance of self-disgust to the experiences of mental and physical health conditions similar to, or directly involved in FDS itself, demonstrate the potential relevance of this emotion in pwFDS. Research has consistently shown pwFDS are more likely to experience difficult emotions more intensely than people with epilepsy (Clegg et al., 2019; Dimaro et al., 2015). If self-disgust followed the same rule, pwFDS may experience self-disgust more intensely. Additionally, given the high levels of trauma in pwFDS, and the potential role trauma plays in the development of self-disgust, a relationship could exist between self-disgust and FDS.

Furthermore, self-disgust is an extremely distressing emotion with serious implications. It is associated with unique behaviours not seen in other emotional experiences, such as self-cleansing and dissociation from the self (Clarke et al., 2019). The repulsive nature of self-disgust drives people to socially isolate, perpetuating distress and suicidality (Mason et al., 2022), demonstrating the importance that self-disgust is better understood.

Better understanding self-disgust in FDS could also have clinical benefits. Qualitative exploration could help elucidate experiences of self-disgust from participants' perspectives. Having a better understanding improve clinician's awareness of how this emotion is experienced to inform assessment, formulation and interventions for pwFDS. Additionally, while psychological interventions for self-conscious emotions have been described and adapted for self-disgust (Gilbert 2014; Gilbert, 2015), improving the understanding of how self-disgust is experienced could support the efficacy of other interventions for pwFDS.

Research aims

The experience of self-disgust in pwFDS is currently empirically unexplored. Therefore, this study aimed to gain an in-depth, rich understanding of subjective experiences of self-disgust in pwFDS. A qualitative methodology was used with the specific research question: how is self-disgust experienced and understood in individuals with FDS?

Methodology

Ethical approval (050804) granted by the University of Sheffield for this study (Appendix A).

Research Design

A qualitative design with interpretative phenomenological analysis (IPA) methodology was utilised. IPA draws on hermeneutic phenomenology to understand how humans experience and understand a particular phenomenon (Larkin & Thompson, 2012).

Through ‘double hermeneutics’, the researcher attempts to interpret participants’ own interpretations and meanings ascribed to their unique lived experiences, aiming to develop a deeper understanding (Smith et al., 2022). IPA’s focus on idiography aims to ‘give a voice’ to individual narratives while considering ‘convergence and divergence’ between participants in shared themes (p.4, Larkin & Thompson, 2012; p. 10, Smith et al., 2011).

Numerous qualitative research methods exist, each with strengths and weaknesses (Harper & Thompson, 2012). IPA is a widely-used and valued method within clinical and health psychology research as it allows the exploration of participants’ interpretation of their bodily and illness experiences. This is beneficial in fields dominated by a biomedical understanding of disease and illness where patients’ voices may go unheard (Brocki & Wearden, 2006).

IPA was chosen over other qualitative methods as its focus on idiography allowed for close engagement with the unique features of each participant’s account before developing themes across the dataset. This contrasts with reflective thematic analysis, for example, where across-group theme construction occurs much earlier in the analysis process (Braun & Clarke, 2021). While thematic analysis can produce breadth, IPA’s in-depth engagement supports a richer, deeper understanding and interpretation of participants’ experiences (Braun & Clarke, 2021).

Participants

Initially, 108 participants- adults who experienced FDS- completed the Self-Disgust Rating Scale (SDS; Overton et al., 2008; Appendix B), the psychometric properties of which are discussed below.

Purposive sampling was used to recruit eight of the highest scoring participants for semi-structured interviews. This sampling strategy aimed to capture a reasonably homogenous sample of participants who could represent a perspective on self-disgust in FDS (Smith et al., 2022). Homogeneity on parameters relevant to the research question allowed a rich and meaningful exploration of the subjective experience of self-disgust in FDS (Smith et al., 2022). IPA benefits from a concentrated focus on a small number of participants, balancing the ability of the researcher to absorb and process the experience of each individual in-depth, and identifying recurrent observations across the group (Smith et al., 2022). Therefore, eight participants were deemed sufficient to produce rich data to address the research question (Smith et al., 2022). The inclusion and exclusion criteria applied to those invited to participate in interviews are summarised in Table 1.

Demographic information of interview participants was collected (Table 2). Most participants were female (n = 7), aged 28-59 (M = 43.5). Years experiencing seizures ranged widely (Range= 3-34), with participants experiencing seizures for an average of 15 years. Participants experienced extremely high levels of self-disgust, with the average score on the SDS being 75.37 (SD = 3.96).

Table 1

Study inclusion/exclusion criteria

Inclusion Criteria	Justification/Notes
Aged 18 years or over	This research focuses on adults and to manage ethical considerations around consent and safeguarding (BPS, 2021)
UK resident	To keep the sample fairly homogenous (Smith et al., 2022)
Have a formal diagnosis of FND, and experience functional/dissociative seizures with loss of consciousness	FND is a broad and heterogeneous category (Aybeck & Perez, 2022). Focussing on one subset of the condition can keep the sample fairly homogenous (Smith et al., 2022)
Score >31 on the SDS (Overton et al., 2008).	The rationale for this cut off is explained in the measures section below. This was to identify people for whom self-disgust was most relevant
Is willing and able to be interviewed in English	Although it was recognised that the study would potentially lose valuable insights from non-English speakers, due to the hermeneutic nature of IPA, it would be difficult to interpret an individual's unique experiences of self-disgust from their own language use through interpreted interviews (Pietkiewicz & Smith, 2014). Therefore interviews were conducted in English to allow for in-depth insights from the individual's perspective (Smith et al., 2022).

Exclusion Criteria	Justification/Notes
If the participant does not have the capacity to consent	For ethical reasons (BPS, 2021)
Unable to access the internet or phone	Participants will be required to access the internet or phone to participate in the research interview

Table 2

Demographic Information of Participants

Participant	**Age**	**Gender**	**Ethnicity**	**Education Level**	**Employment Status**	**Year diagnosed with FDS**	**Years experiencing seizures**	**Self-disclosed difficulties**	**SDS score**
Grace	41	Not specified	White British	Further Education	Unemployed	2023	34	Dissociative Identity Disorder C-PTSD* Myalgic Encephalomyelitis	80
Sarah	28	Female	White British	Further Education	Unemployed		13	PTSD Elher-Danlos Syndrome Borderline Personality Disorder Depression	78
Jane	42	Female	White British	Further Education	Medically retired	2019	>30	Fibromyalgia Learning Difficulties	71
Rachel	50	Female	White Other	Post-graduate Education	Unemployed	2022	6	Depression	79
Steve	59	Male	White British	GCSE	Unemployed	2018	8	Anxiety Depression	79
Lauren	38	Female	White British	Undergraduate Education	Unemployed	2022	3	Fibromyalgia Anxiety Depression	71

								Eating Disorders	
Helen	50	Female	White British	GCSE	Unemployed	2023	20	Tourette’s Syndrome Obsessive Compulsive Disorder	72
Kelly	40	Female	White British	Further Education	Unemployed	2018	6	Borderline Personality Disorder C-PTSD* Depression Anxiety Underactive Thyroid Myalgic Encephalomyelitis	73

**C-PTSD denotes complex post-traumatic stress disorder*

Participant and Public Involvement (PPI)

Feedback was sought during development of the study on proposals and study materials from experts by experience and professionals in the field. A member of the UK charity FND Dimensions provided feedback on the interview schedule (Appendix C) and information sheet (Appendix D), including the use of terminology and content. Through correspondence with professional experts, advice was also given regarding ethical considerations for the study and recruitment processes.

Materials

Measure

To measure self-disgust and identify participants eligible for interview, the *Self-Disgust Rating Scale* (Overton et al., 2008; Appendix B) was used. This is a self-report measure of disgust towards the self, containing 18 items, with four items relating to each of three self-disgust constructs: appearance, general self-concept and behaviour- and six neutral filler statements. Participants rate how much they agree with descriptions on a 7-point Likert scale (1= *strongly agree,* 7= *strongly disagree).* Possible scores range from 12 to 84. Higher scores indicate higher levels of self-disgust. The SDS has good internal consistency (α = .91; Overton et al., 2008; α = .88; Simpson et al., 2010).

As in previous studies exploring self-disgust in clinical populations (Mayor et al., 2022; Powell et al., 2015), participants who scored greater than 31 were considered for interview. This represented a score of more than one standard deviation above the mean in non-clinical samples (Overton et al., 2008).

Semi-structured interview

Spoken semi-structured interviews are commonly used in IPA, based on the approach's aims of understanding the individual's story (Smith et al., 2022). The interview schedule used in this study was informed by the study's aims and relevant literature (Smith et al., 2022), and developed in consultation with research supervisors and pwFDS (Appendix C).

Procedure

FND Action, a specialist FND charity, agreed to support recruitment for this study. A study advert (Appendix E) was shared on their X feed and website. The advert specified the topic of this study was 'difficult emotions' to reduce the risk of negative reactions to the study topic before participants reached the information sheet, where the true focus of the study was disclosed. Participants accessed a Qualtrics survey to read the participant information sheet (Appendix D), complete a consent form (Appendix F), and complete the SDS (Appendix B). The online survey specified a cohort would be invited to take part in a further in-depth qualitative interview and consent to be contacted for this was gained. Participants were given a debrief sheet at this point (Appendix G). Online recruitment took place September-October 2023.

The 20 participants with the highest SDS scores were contacted, by email, to be invited to interview (Appendix H). Eleven people responded to invitation, but three cancelled or did not attend, resulting in eight interviews being conducted. Interviews took place November-December 2023.

Semi-structured interviews were conducted by the researcher (LE) over the university approved video technology, Google Meet. Confidentiality and withdrawal rights were explained, and participant demographic information was gathered at the beginning of the interview. Video interviews were recorded, converted into an audio file and stored on the

University secure drive. The median interview duration was 84.5 minutes (*M*= 86.37). At the end of the interview, the debrief sheet containing the researcher's contact details and signposting to sources of support was reissued (Appendix G). The first three interviews were transcribed by the researcher (LE), and the remaining five were transcribed by an approved University of Sheffield transcriber (see Appendix I for transcriber agreement).

Data Analysis

Interview transcripts were analysed by LE using an inductive and iterative approach, following IPA guidelines described by Smith et al. (2022) and Murray and Wilde (2020). Each transcript was analysed individually, before findings were integrated across cases.

Firstly, each participant's transcript was read and audio recordings listened to on repeat to facilitate immersion in the data. Exploratory noting and coding was then completed (see Appendix J). Exploratory notes were organised and summarised in experiential statements that captured an understanding of the participant's original words, thoughts and interpretations (Appendix J). Exploratory notes and statements were discussed in supervision and reflective notes were kept to consider the researcher's responses. Experiential statements were then organised and grouped into personal experiential themes (PETs). This entailed interpretative engagement with the data, and considered the use of language, emergent narratives, inferred mindsets and moods (Eatough & Smith, 2017). Interpretative narrative summaries were produced for each PET (Murray & Wilde, 2020; Appendix K).

This process was repeated for each participant and treated as an independent inquiry. The patterns of similarities and differences across the PETs generated a set of group experiential themes (GETs; Appendix L). This was with the aim of highlighting similarities and differences between experiences across participants. This process was dynamic and iterative whereby the GETs were grounded in the data. A table of GETs detailing participant representation was generated (Appendix M).

Research Quality

To ensure research quality, the following principles for evaluating IPA studies' quality were followed (Nizza et al., 2021): constructing a compelling, unfolding narrative; developing a vigorous experiential and/or existential account; close analytic reading of the participants' words; and attending to convergence and divergence.

For example, the researcher's interpretations were grounded in the available data with verbatim examples provided to demonstrate theme development and a coherent narrative. Illustrative quotes were accompanied by analytic commentary to build a rich, cohesive story. Close attention was paid to the experiential and existential significance of self-disgust to participants through incorporating data with interpretation. The sense of participants' experience was shown through interpretative analysis 'that went beyond the immediacy of what happened to the participants and their comments on it' (p. 374, Nizza et al., 2021). To demonstrate commitment to interpretation and idiographic depth, the researcher engaged in close analytic reading of the participant quotes to explore their significance and fuller meaning. Focus was directed both at immediate quotes and the context of the wider transcript (Nizza at al., 2021). Participant similarities and differences were attended to in an effort to demonstrate patterns of connection whilst highlighting participants' unique experiences (Smith et al., 2011). To convey this, information on prevalence, similarities and differences, and idiographic details have been included in the study themes (Nizza at al., 2021). The credibility of theme development and interpretation was checked and discussed with supervisors during regular supervision and correspondence.

Additionally, steps were taken during data collection to facilitate an interview that reflected true lived experience. For example, the researcher demonstrated warmth and compassion, and employed active listening skills to build rapport and help comfort the participant (Yardley, 2008). The sensitive nature of the interviews was acknowledged, and participants were reminded of the voluntary nature of participation and their right to withdraw at any time.

The process of IPA was clearly outlined so all stages of this research can be checked independently. All documents and relevant data were kept securely through the research process, enabling independent audit and evaluation (Tracy, 2010; Yin, 2014) (Appendix N). Tong et al.'s (2007) Consolidated Criteria for Reporting Qualitative Studies checklist guided report write-up to ensure the quality of reporting results, and checked by an independent researcher (EE) (Appendix O).

Reflexivity

Qualitative research is fundamentally shaped and affected by researcher subjectivity (Olmos-Vega et al., 2023). To ensure subjectivity maintains a positive impact on qualitative research, researchers are encourage to engage in reflexivity to facilitate awareness and acknowledgement of their own preconceptions (Jamieson et al., 2023; Olmos-Vega et al., 2023; Yardley, 2015). For context, the lead researcher (LE) was a trainee clinical psychologist with experience of working with individuals with mental and physical health conditions. In this case, there was no personal experience of the researcher that was used to inform analysis (Appendix P). A reflective log was kept throughout the research process to maintain awareness of how the researcher's perspectives influenced the study (Appendix Q; Yardley, 2015; Omlos-Vega et al., 2023). Reflexivity is also embedded within the double hermeneutic nature of IPA where the researcher attempts to make sense of participants making sense of their self-disgust experience (Smith et al., 2022).

Results

The majority (85.18%) of participants scored above 31, and were therefore eligible to participate in the interview. The mean SDS score across the larger sample was 52 (*SD* = 16.24), suggesting high levels of self-disgust. The mean SDS score among participants interviewed was 75.37 (*SD* = 3.96).

The IPA analysis produced four GETs with subthemes (Table 3). Themes were illustrated with participant quotes and analytic commentary. Appendix M shows the participant representation in each GET. See Appendix R for additional supporting quotes.

Table 3

Group Experiential Themes and subthemes

GET	Sub-theme
Understanding the origin of self-disgust as based in rejection	Historical abuse laying the foundation for self-disgust Others' repulsion introducing shame and disgust for FDS
Experiencing self-disgust as intense and inescapable	A chronic and unchangeable belief An intense emotional experience
Understanding the relationship between self-disgust and FDS	Seizures and self-disgust: A vicious cycle Deviation from the medical norm: Disgust for FDS A drain and a burden: Self-disgust related to disability
Suppression and seclusion- attempting to cope with self-disgust	Avoiding exposure through social withdrawal Emotionally suppressing the unbearable self-

	disgust
	Hiding oneself to deny reality of self-disgust

Understanding the origin of self-disgust as based in rejection

This theme relates to participants' negative experiences with others and their contribution to the development of negative self-concept, and subsequently self-disgust. There were two distinct experiences of rejection: through a history of abuse and external repulsion by the public for their FDS.

Historical abuse laying the foundation for self-disgust

Most participants had experienced abuse from others which created a sense of inferiority and worthlessness, fuelling an "*inner-critic*" (Kelly) that led to shame regarding who they were.

> "*So, that all comes from emotional abuse from my mother, like nothing was ever good enough, always questioned everything I ever did, just made me feel pathetic, you know? And if I did get something right it was… "You stupid bitch" I get called, and I think it's just an accumulation of all that sort of stuff*" (Kelly)

For some, shame and disgust-based bullying during adolescence permanently damaged their self-esteem and body image. The relentlessness of the criticism led to messages becoming internalised. Bullying made Jane feel ashamed of health conditions and confirmed her body was disgusting; to the extent she was unworthy of living.

> *"Oh I've been called… smelly, trampy, pisshead, I was told that I was a waste of space, I was told that erm I would have been better off dead."* (Jane)

Four participants had experienced sexual assault, from which intense distress and disgust left them with a perpetual sense of being contaminated by something repulsive: *"I* *never feel clean, ever feel clean"* (Helen). Unable to cleanse the self from these feelings, they became internalised, eventually culminating in self-disgust.

Others' repulsion introducing shame and disgust for FDS

All participants received negative reactions for having seizures due to a "*massive lack of knowledge*" (Sarah) about FDS, leading to troubling public experiences.

> *"they were all running in and out, so I think every member of my ward… saw me with this big wet patch and then they just left me to sleep on the sofa and didn't give me a blanket or anything, I just felt very exposed ..and so that was pretty humiliating"* (Helen)

Participants received cruel and judgemental comments, like "*he's a right fool*" (Steve), having seizures referred to as "*weird shit*" (Sarah). Participants could sense people's disgust in their body language: "*there is just that little look… and you just know what they're thinking*" (Steve), as though their seizures made them an object of disgust.

Notably, lack of understanding and compassion pervaded among healthcare professionals (HCPs). Poor treatment by HCPs was frequent, making participants feel they had "*feigned illness*" (Rachel) written in their record.

> *"I couldn't communicate that I need the loo…So I managed to, like an eel slithering out of water; I managed to kind of flop off the bed onto the floor… I was pushing myself along with the knowledge inside of my body, trying to get the loo. And the nurses stopped me and they were kind of shouting at me*" (Rachel)

Rachel's comparison of herself to an animal illustrates the degradation she felt by her treatment. The comparison of herself to a disgust-evoking animal reveals the extent of her self-disgust in this instance. Participants felt dismissed by HCPs due to having a functional condition. Consequently, participants were not given space and privacy - *"people were sitting around eating their lunch while I was having this mega attack and wetting myself"* (Helen) - as though they were not worthy of respect, which compromised their dignity. Such interaction made participants feel their suffering was disbelieved, provoking shame for their seizures. Some felt they should 'prove' (Grace) themselves, worsening their condition and reinforcing their sense of worthlessness and self-hatred.

> *"To have people telling you they don't believe you, or it can't be that bad, or get up off the floor. You just think, when it's reflected back at you, if it looks like a duck and it quacks like a duck, then it's a duck, isn't it? Yeah, so I am worthless, aren't I?"* (Rachel)

Ultimately, participants' feelings resulting from repeated experiences of revulsion by others became internalised: *"I feel disgusted in myself, erm but in the eyes of other people"* (Steve).

Experiencing self-disgust as intense and inescapable

Self-disgust was experienced in two ways: as a strongly held, chronic, unchangeable belief, and as an intense emotional experience triggered by certain elicitors.

A chronic and unchangeable belief

Self-disgust was described as a feeling that ran deeper than hatred; a sense the body was innately bad or rotten: *"But it was when I thought about it, especially then like just how bad that it was, you know, I would always just be like 'oh I'm vile.' Vile seems to be the word"* (Kelly). Self-disgust was a constant, inescapable feeling that seemed to *"hang around like some hideous smell in the air"* (Rachel).

Some participants experienced self-disgust from early childhood. With this chronicity, self-disgust became enmeshed in their being: "*I don't see that it is that, I see that I am that*" (Grace). Thinking of themselves elicited repulsion and nausea *"When I think of me, I just think 'eugh'"* (Grace) - as though something inside needed to be expelled.

> *"I feel like just sick… it's like I need to release but at the same time it makes me feel disgusting, like I feel sick. I hate myself, like I don't like that feeling"* (Lauren)

In these examples, the distinguishing feature of self-disgust was the association with revulsion and nausea, demonstrating the emotion's distinction from other self-conscious emotions such as shame or guilt.

Participants did not understand why others would want to be near them due to their disgusting nature, making them suspicious of those who did.

> *"I am so adamant that my body's bad, disgusting… it makes you think stupid things like 'is she just with you because of sympathy?'… There's that little bit in my head that can't give the hundred percent trust again."* (Kelly)

Over time, self-disgust wore away at participants, leaving them struggling to *"find the good or the pleasure in anything"* (Kelly), to a point of hopelessness for a future without self-disgust.

An intense emotional experience

Self-disgust was also experienced as discreet, intense emotional episodes that were consuming, uncontrollable and frightening.

> *"it's like you're on a roller-coaster going downhill and you want to stop the rollercoaster but the rollercoaster's not in your control… you just feel like it's never gonna end"* (Steve)

Self-disgust could manifest as intense anger and hatred at the self, a *"labyrinthine"* (Rachel) of feeling, thought and emotion, the intensity of which could lead to vomiting, seizures and wishes of death, as if death was the only escape from self-disgust: "*I end up in an extreme state where… I just want to end it"* (Sarah).

> *"I just get so annoyed, so frustrated, and so upset that I physically end up nearly throwing up because of how I feel about myself…you get emotionally worked up. And if you get too emotionally worked up you end up in a seizure."* (Sarah)

For many, self-disgust led participants to intense self-criticism, where contempt for themselves could be heard in their voice. The intensity of the revulsion seemed to lead participants lose respect for themselves, in such a way that was distinct from shame or guilt, as demonstrated by Rachel's comparison to this disgust-evoking Stars Wars character.

> *"I'm stuck in this. I am doing this to myself, I am angry with myself. I hate myself. I am doing this to myself, it's just a kind of spiral of doom… I mean, look at the state I'm in! Look at me, this lump on the sofa, this Jabba the Hutt-like lump on the sofa who's pontificating at you. This was never me!"* (Rachel)

Participants could not look at themselves in the mirror due to the self-disgust elicited by their own image. For some, their reflection reminded them of their trauma, perpetuating self-disgust.

> *"if I did look in the mirror… all I could see was that, that trauma, massive like horrible-looking teenager"* (Jane)

Understanding the relationship between self-disgust and FDS

All participants felt disgust for their FDS, following internal and external revulsion. Self-disgust in the context of FDS was felt on three levels: during seizures, for having a functional disorder and for having a life-altering, disabling condition.

Seizures and self-disgust: A vicious cycle

During seizures, participants felt completely out of control, as if their body had been taken over by someone else, like a *"body snatcher scenario"* (Lauren). Some remained aware during seizures and felt they could *"see"* themselves, like an *"out of body experience"* (Steve), which elicited deep shame and revulsion for their bodies:

> *"I could see myself and how big and fat and ugly I looked with this big wet patch around my, you know… I'm throwing myself about, and I'm pulling funny faces and I'm clawing my hands up… I just felt disgusting, I just felt ugly, I just felt horrible"* (Helen)

Two participants re-experienced traumatic events during seizures that played out *"like little tiny clips"* (Steve), provoking guilt, frustration and self-disgust:

> *"I was sexually assaulted by a stranger… and I always have that feeling* [during seizures]*…like someone's taken over my body and…I always, like get flashbacks"* (Lauren)

Participants' disgust for their seizures also emerged from feeling they were *"showing weakness when I'm trying to be strong"* (Kelly). The vulnerability elicited further disgust, as though the seizures revealed a private, shameful part of themselves.

Self-disgust during seizures was so intense, participants wished they could disappear: *"I just want the ground to swallow me up"* (Grace), and to *"curl up and die"* (Jane) as the feelings were too unbearable to live through.

Deviation from the medical norm: Disgust for FDS

Participants experienced difficulty accepting FDS. Rachel perceived FDS as a betrayal by her body which was deeply frustrating and provoked "*utter self-revulsion."* Some participants doubted the legitimacy of their seizures "*because I didn't have that bit of paper or scan that showed other people 'look this is what's happening, I'm not making it up'*" (Kelly); and jostled between acknowledging the legitimacy of their seizures and blaming themselves, as though their self-disgust always made a part of them believe they were "*doing it to themselves*" (Helen). This seemed to result from the external stigma for FDS: *"it affects me because of the shame of it, the stigma of it"* (Grace).

Knowing people who had died from epilepsy added "sheer guilt" for having FDS and compounded Helen's experience.. Knowing "*they* [seizures] *won't harm*" her elicited self-disgust and perpetuated the stigmatising belief that her functional seizures were not legitimate.

> *"I just felt so disgusted that his seizures killed him. Mine won't kill me, how's that fair?... her beloved brother died of epilepsy and now her daughter's having seizures all over the place which aren't real. I know they are real but you know what I mean."* (Helen)

A drain and a burden: Self-disgust related to disability

Participants could not accept having a life-altering, disabling condition. Losing jobs that gave them purpose and "*offered something to the world*" (Rachel) made them feel like *"a* *drain on society*" (Sarah) and *"worthless"* (Helen). Work provided protection from self-disgust. The resulting isolation from unemployment intensified self-disgust.

> *"you're just left with you, and it makes you question like so much… like what do you have to offer people…and it just makes you the person that you don't recognise anymore… you feel like you're on your own and your own worst enemy"* (Kelly)

Struggling daily with their disability wrecked participants' self-esteem. Thinking about their losses deepened their frustration and self-disgust.

> *"I can't stand being that way. It makes you feel useless…You feel disgusted that you can't do simple things like the weekly grocery shop by yourself because you might have a seizure"* (Sarah)

Feeling useless and incapable made them feel a burden and that they were "*letting everyone down*" (Helen), unworthy of receiving care from others.

> *"I hate that I'm imposing on him like that, yeah? Because, when he met me, I was capable. I was earning a decent salary…And now I'm dependent on him… it's awful for him. I don't want that for him. I want better for him."* (Rachel)

Participants felt so deeply disgusted with who they were, they could not accept themselves, and felt they deserved the experienced societal repulsion

Suppression and seclusion- attempting to cope with self-disgust

Some participants had positive methods of alleviating self-disgust; through therapy, maintaining hobbies or drawing on support from trusted relatives. However, most attempted to cope in ways that provided temporary relief but ultimately maintained self-disgust.

Avoiding exposure through social withdrawal

Most participants withdrew socially or ended relationships, feeling they were a threat to others: *"you worry about going in places because you consider yourself a health and safety hazard"* (Sarah). While this was partly purposed at protecting others from them, participants also sought to protect themselves from others' anticipated disgust: *"you don't want to do something that may put somebody else off"* (Steve).

Self-disgust also hindered participants' self-help efforts. For instance, Steve withdrew from psychological therapy as revealing his self-disgust was too unbearable: *"you don't wanna let him* [therapist] *in to see that disgust in you."*

The resulting isolation provoked loneliness and social exclusion, but the risk of exposing themselves to further external repulsion was too great.

> *"if I wanted to meet a new person… I think do I do it? Do I not do it? It's like no I don't wanna risk it, I don't wanna risk the hurt and the pain and the embarrassment."* (Jane)

Emotionally suppressing the unbearable self-disgust

Most participants avoided their emotions to cope. For some, this required conscious effort: *"I will just pop the lid back on and then erm maybe get ridiculously drunk"* (Helen). For others, emotional avoidance was an automatic dissociative process: *"you don't realise you're doing it"* (Jane). During interviews, participants displayed avoidance through avoiding answering questions, or referring to self-disgust in past tense, as the concept was too painful to connect with in the present.

Some participants had chronic patterns of emotional *"suppression"* (Lauren), putting a *"front"* (Grace) to convince others, and themselves they were coping: "*no one would be able to tell* [self-disgust] *was a problem*" (Grace). This functioned both as self-protection from self-disgust, and to protect others: *"I've kind of trained myself to do it from a really young age so that people don't worry about me"* (Lauren).

However, emotional avoidance was ineffective, and self-disgust would eventually resurface or worsen: "*then all the little stupid things become like a big thing"* (Steve). Some felt emotional avoidance predisposed FDS, adding another layer of emotional difficulty as self-disgust and FDS perpetuated each other.

> *"I honestly do feel like that's why I have the seizures now, but then they bring…* [self-disgust] *to the forefront and then it's, it's like a cycle, a constant cycle."* (Lauren)

Hiding oneself to deny reality of self-disgust

For some, covering mirrors or wearing ill-fitting clothes temporarily allowed them to deny how they presented to the world, providing relief. Participants' reflections reminded them of how they and their bodies changed through having FDS, eliciting further disgust.

"I can't stand to look in the mirror because it makes me feel sick of the way I've ended up with seizures and the way they're affecting me every day" (Sarah)

Attempting to hide their bodies with clothes seemed to serve as protection from further disgust responses. For instance, Jane wore baggy clothes *"cos I didn't want people looking at me."*

Eventually, these methods failed to provide protection, as participants would inevitably be faced with their image again, continuing the cycle of self-disgust

Discussion

The aim of this study was to understand the subjective experiences of self-disgust in pwFDS. In the 108 participants who completed the SDS, 85.2% scored above the level previously established as indicating high levels of self-disgust in clinical samples, with the overall mean score being 52, suggesting self-disgust is relevant in pwFDS. Four GETs with 10 subthemes were identified; ‘understanding the origin of self-disgust as based in rejection’, ‘experiencing self-disgust as intense and inescapable’, ‘understanding the relationship between self-disgust and FDS’ and ‘suppression and seclusion- attempting to cope with self-disgust’. These findings are similar to the wider literature on the development, role and experience of self-disgust (Clarke et al., 2019; Powell et al., 2015).

The findings regarding historical trauma as a predisposing factor for self-disgust align with the idea of self-disgust as an emotion schema, developing in childhood as a result of trauma and abusive familial relationships (Powell et al., 2015). The study’s findings that self-disgust began in some participants’ formative years are also similar to findings that other self-conscious emotions, like shame, emerge around the age of three (Kelly et al., 2000). Additionally, humiliation from shame and disgust-based bullying may have created a sense of inferiority to others, found to increase self-criticism and self-disgust in individuals with depression (Garcia, 2015). Participants who disclosed sexual trauma felt perpetually contaminated, suggesting an internalised disgust response (Badour et al., 2013), a common predisposing factor in FDS, along with emotional abuse and family dysfunction (Reuber et al., 2007).

FDS is a highly stigmatised condition (Annandale at al., 2022). Stigma can promote disgust and result in social rejection (Terrizzi et al., 2023), which contributes to the promotion of negative self-conscious emotions, including self-disgust (Sznycer, 2019; Powell et al., 2015).Conversely, disgust has been proposed as a causal link between stigma and health conditions (Azlan et al., 2020). Participants’ experiences with HCPs in the current study are similar to those in previous studies where participants endured abusive behaviours from HCPs, resulting in trauma and avoidance of medical care (Eaves, in press). This study also highlights the personal cost of this rejection, as participants internalised negative reactions, resulting in feelings of worthlessness and self-disgust, similarly to how people with epilepsy internalised the negative reactions of others in Mayor and colleagues' (2022) study.

The enduring nature of self-disgust has previously been similarly described (e.g. Mayor et al., 2022). Again, while ever-present, self-disgust could be intensified by elicitors such as the participant's own reflection. As a discrete emotional experience, self-disgust had a corporeal quality, and was experienced viscerally, stimulating nausea and vomiting, suggested to be a disgust-based rejection of the self (Jones, 2015).

Results also suggest an association between FDS and self-disgust, consistent with the idea emotional overwhelm can elicit functional symptoms (Ertan et al., 2022; Roberts & Reuber, 2014). Participants also made a link between their self-disgust, hopelessness and increased suicidal ideation, known to increase risk of suicide (Ribeiro et al., 2018). Moreover, self-disgust has been shown to upscale the trajectory towards suicide (Mason et al., 2022), demonstrating the seriousness of self-disgust to emotional wellbeing.

Interestingly, findings suggest a complex, bi-directional relationship where self-disgust triggered seizures, but FDS also exacerbated self-disgust. This relationship is similar to the conceptualisation of shame's role in the onset and exacerbation of FDS (Reuber et al., 2022). FDS could be considered to serve a protective function from unbearable and overwhelming stimuli, such as self-disgust, providing relief by facilitating escape (dissociation) from consciousness and the body. However, rather than providing relief, participants' disgust for and during seizures means FDS may add another dimension to, and exacerbate, self-disgust (Reuber et al., 2022).

For participants, having FDS represented a deviation from social conformity and desirability eliciting self-disgust and illustrating the intra- and interpersonal nature of self-disgust (Sznycer, 2019). During seizures, self-disgust was triggered by loss of bodily control and secretion of bodily fluids. As with participants' reactions in other health condition, symptoms caused revulsion, subsequent shame, embarrassment and self-loathing (Jones et al., 2008).

Participants' disgust for the exposure of perceived weakness and vulnerability may reflect socio-moral self-disgust, where they may feel inferior due to their bodies not conforming to social health and behavioural norms (Roberts & Goldenberg, 2007). This is also evidenced in the way participants experienced FDS as betrayal. Participants' difficulty accepting FDS suggests socio-moral disgust due to the deviation from the culturally accepted biomedical understanding of physical health conditions. Stigma of FDS may underlie this, and may represent internalisation of such stigma (Annandale et al., 2022). Nonetheless, self-disgust experienced on this level negatively impacts adjustment to health conditions where aspects of the self are rejected, negatively impacting outcomes and mortality due to avoidance (Reynolds et al., 2015).

Likewise, participant's revulsion for their disability may indicate internalised ableism, where societal prejudice about disability becomes internalised (Campbell, 2009). In the current study, socio-moral self-disgust may stem from participants' difficulty to maintain capitalistic cultural standards of economic competence and productivity through employment and independence, shown to negatively impact on self-esteem and confidence (Marks, 1999; Peacock et al., 2023; Reeve, 2015). Unconscious, internalised messages about disabled people as 'other' and disgusting may also contribute to this (Reeve, 2015). Conversely, participants valued their previous employment, which served to protect them from self-disgust., the loss of which exacerbated negative self-directed feelings, a well-documented impact of unemployment (Paul & Moser, 2009).

Physically avoidant behaviours are frequently reported coping strategies in pwFDS (Brown & Reuber, 2016). Social withdrawal is also documented as a response to self-disgust (Clarke et al., 2019; Rozin et al., 2008). Social avoidance in the context of disgust can theoretically be beneficial to maintaining relationships (Reynolds et al., 2015). However, increased isolation and loneliness resulting from this increases depression and suicidal ideation (Mason et al., 2022; Ypsilanti et al., 2019), indicating disgust-driven social withdrawal ultimately perpetuates distress.

Emotional suppression and avoidance is also reported in FDS (Roberts & Reuber, 2014; Novakova et al., 2015). Avoidance or suppression of self-disgust could be considered a rejection of the self. Indeed, studies show people with high levels of self-disgust attempt to dissociate or cognitively avoid the 'disgusting' parts of the self (Espeset et al., 2012). Participants also denied the presence of self-disgust, as though acknowledging the emotion was inherently threatening to the integrity of their personality (Jones, 2015). Similarly, covering mirrors to conceal themselves could be further evidence of denial or dissociation (Jones, 2015). Suppressive strategies provided only temporary relief for participants In fact, expressive suppression has been shown to play a predictive role in self-disgust (Lazarus et al., 2019) and emotional avoidance perpetuates difficulties associated with poorer quality of life (Jones et al., 2016).

The current study's findings are similar to Mayor and colleagues' (2022) study on self-disgust in epilepsy. In both studies, self-disgust directly related to the experience of seizures and negative reactions of others. While the small scale of both studies limits direct comparisons between the two patient groups, epileptic and dissociative seizures are both stigmatised and linked to self-disgust. Given the closer link between trauma and FDS, and the increased tendency of pwFDS to dissociate (Dimaro et al., 2014), pwFDS might have a more critical self-perception, suggesting self-disgust could be a greater issue for this patient group.

Strengths, limitations and future directions

This was the first study to explore the unique lived experiences of self-disgust in pwFDS. The selected methodology of IPA allowed for an in-depth exploration of the topic. However, although this study aimed for a homogenous sample regarding the experience of FDS and self-disgust, there was variation in ages, education, socio-economic backgrounds, and additional diagnoses, which may have impacted the experience of self-disgust. The sample also included one male; potentially impacting on homogeneity of experience, given different genders may experience emotions differently (Else-Quest et al., 2012). However, the male's experience of self-disgust in this study was qualitatively similar to the female participant's experience.

The SDS (Overton et al., 2008) was used to screen for self-disgust in this study. This measure has good psychometric properties, but has been criticised for lacking definitional clarity when delineating self-disgust from related concepts (Clarke et al., 2019). Whilst this raises questions as to whether participants' descriptions of self-disgust truly correspond to feelings of disgust towards the self, the references to visceral sensations such as nausea and revile that lead to avoidance, suggests participants were describing genuine feelings of disgust.

Furthermore, whilst the remarkably high prevalence of self-disgust reported in this study suggests self-disgust may be relevant for some pwFDS this may be an overrepresentation of the true prevalence of self-disgust in this population. The transparency of study adverts possibly attracted those who experienced self-disgust, and had an interest in discussing this for research. However, exploration of the quantitative findings from the screening questionnaire goes beyond the scope of this study, warranting further research.

From participants' experiences, a bidirectional relationship between trauma, self-disgust and FDS was identified. This relationship is likely highly complex and inferences from this are tentative, going beyond the scope of this study. However, this suggestion is aligned with findings in studies demonstrating self-disgust's mediation role in other experiences such as PTSD, depression and suicidality (Brake et al., 2017). Future studies should seek to elucidate the relationship further.

Clinical Implications

This study explored self-disgust as it already existed in those who identified it as being relevant to them. Notwithstanding, the results suggest self-disgust could be important to consider in relation to FDS and psychological distress, and should be explored. Participants also noted how little self-disgust is understood and spoken about. Therefore, practitioners should be aware of self-disgust and assess for it, as it may be important for informing interventions for pwFDS.

FDS remains undertreated (Brown & Reuber, 2016), and findings from this study suggest patients experiencing self-disgust may have additional difficulty accessing and engaging in psychological therapy due to the role of avoidance in self-disgust. However, therapeutic approaches such as cognitive behavioural therapy, psychodynamic psychotherapy and mindfulness have been found to reduce seizures frequency (Carlson & Perry, 2017) and improve functioning and quality of life in pwFDS (Gaskell et al., 2023; Goldstein et al., 2021). Therefore, additional consideration should be given to supporting engagement and developing the therapeutic relationship in those experiencing self-disgust. Additionally, compassion focused therapy (CFT) could also be beneficial to those experiencing self-disgust (Gilbert, 2014). CFT works by targeting the emotional components underlying self-disgust and changing the relationship with the self, which could be effective at alleviating the grip of self-disgust (Gilbert, 2014; Kiliç et al., 2021; Whelton & Greenberg, 2005).

This study demonstrated the negative reactions of others towards participants contributed to the development and maintenance of self-disgust. Societal approaches to improve awareness and understanding, and reduce the stigma of FDS, may be beneficial to reducing self-disgust and supporting the overall wellbeing of pwFDS. Improved knowledge and empathy for FDS amongst HCPs should also be undertaken. Clinical psychologists could support this by offering consultation informed by psychological frameworks such as the Power Threat Meaning Framework. This is a model that focuses on the role and impact of psychosocial adversity in psychological distress, supporting a trauma-informed, holistic understanding of someone's presenting concerns (Read & Harper, 2022). Additionally, measures to reduce critical, disgust-based experiences during childhood could be beneficial to preventing the development of self-disgust (Powell et al., 2014).

Conclusion

This research sought to understand the experience of self-disgust in people with FDS. Findings suggest self-disgust is relevant to a substantial subpopulation of pwFDS. IPA analysis identified a bi-directional relationship between self-disgust and FDS that correlates to internalisation of traumatic experiences and stigma. Strategies to cope with self-disgust provided short-term relief but ultimately perpetuated the cognitive-affective state. Further research is warranted to understand interventional approaches for self-disgust in the context of FDS.

References

Annandale, M., Vilyte, G., & Pretorius, C. (2022). Stigma in functional seizures: A scoping review. *Seizure*, *99,* 131-152. https://doi.org/10.1016/j.seizure.2022.05.016

Asadi-Pooya, A. A. (2023). Incidence and prevalence of psychogenic nonepileptic seizures (functional seizures): a systematic review and an analytical study. *International Journal of Neuroscience, 133*(6), 598-603. https://doi.org/10.1080/00207454.2021.1942870

Aybek, S., & Perez, D. L. (2022). Diagnosis and management of functional neurological disorder. B*mj, 376*. https://doi.org/10.1136/bmj.o64

Azlan, H. A., Overton, P. G., Simpson, J., & Powell, P. A. (2017). Differential disgust responding in people with cancer and implications for psychological wellbeing. *Psychology & Health*, *32*(1), 19-37. https://doi.org/10.1080/08870446.2016.1235165

Azlan, H. A., Overton, P. G., Simpson, J., & Powell, P. A. (2020). Disgust propensity has a causal link to the stigmatization of people with cancer. *Journal of Behavioral Medicine*, *43*(3), 377-390. https://doi.org/10.1007/s10865-019-00130-4

Badour, C. L., Feldner, M. T., Blumenthal, H., & Bujarski, S. J. (2013). Examination of increased mental contamination as a potential mechanism in the association between disgust sensitivity and sexual assault-related posttraumatic stress. *Cognitive Therapy and Research*, *37*, 697-703. https://doi.org/10.1007/s10608-013-9529-0

Brake, C. A., Rojas, S. M., Badour, C. L., Dutton, C. E., & Feldner, M. T. (2017). Self-disgust as a potential mechanism underlying the association between PTSD and suicide risk. *Journal of Anxiety Disorders*, *47*, 1-9. https://doi.org/10.1016/j.janxdis.2017.01.003

Braun, V., & Clarke, V. (2021). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, *21*(1), 37-47. https://doi.org/10.1002/capr.12360

Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87-108. https://doi.org/10.1080/14768320500230185

Brown, R. J., & Reuber, M. (2016). Psychological and psychiatric aspects of psychogenic non-epileptic seizures (PNES): a systematic review. *Clinical Psychology Review*, *45,* 157-182. https://doi.org/10.1016/j.cpr.2016.01.003

Brown, R. J., & Reuber, M. (2016). Towards an integrative theory of psychogenic non-epileptic seizures (PNES). *Clinical Psychology Review*, *47*, 55-70. https://doi.org/10.1016/j.cpr.2016.06.003

Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. Springer.

Carlson, P., & Perry, K. N. (2017). Psychological interventions for psychogenic non-epileptic seizures: a meta-analysis. *Seizure*, *45*, 142-150. https://doi.org/10.1016/j.seizure.2016.12.007

Clarke, A., Simpson, J., & Varese, F. (2019). A systematic review of the clinical utility of the concept of self-disgust. *Clinical Psychology & Psychotherapy*, *26*(1), 110-134. https://doi.org/10.1002/cpp.2335

Clegg, S., Sirois, F., & Reuber, M. (2019). Self-compassion and adjustment in epilepsy and psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *100*, 106490. https://doi.org/10.1016/j.yebeh.2019.106490

Devinsky, O., Gazzola, D., & LaFrance Jr, W. C. (2011). Differentiating between nonepileptic and epileptic seizures. *Nature Reviews Neurology*, *7*(4), 210-220. https://doi.org/10.1038/nrneurol.2011.24

Dimaro, L. V., Roberts, N. A., Moghaddam, N. G., Dawson, D. L., Brown, I., & Reuber, M. (2015). Implicit and explicit self-esteem discrepancies in people with psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *46*, 109-117. https://doi.org/10.1016/j.yebeh.2015.03.032

Diprose, W., Sundram, F., & Menkes, D. B. (2016). Psychiatric comorbidity in psychogenic nonepileptic seizures compared with epilepsy. *Epilepsy & Behavior*, *56*, 123-130. https://doi.org/10.1016/j.yebeh.2015.12.037

Dovidio, J. F., Penner, L. A., Calabrese, S. K., & Pearl, R. L. (2018). Physical health disparities and stigma: Race, sexual orientation, and body weight. In: B. Major, J. F. Dovidio & B. G. Link (Eds). *The Oxford handbook of stigma, discrimination, and health*, 29-51. Oxford University Press

Eatough, V. & Smith, J. A. (2017) Interpretative phenomenological analysis. In: Willig, C. and Stainton-Rogers, W. (eds.) *Handbook of Qualitative Psychology*. (2nd Edition, pp. 193-211). London, UK: Sage, pp. 193-211. ISBN 9781473925212

Eaves, L., Simpson, J., Reuber, M. & Delgadillo, J. (In Press). *Individuals with Functional/dissociative Seizures' Experience with Healthcare Professionals: A*

Systematic Review and Thematic Synthesis. (Doctoral dissertation, University of Sheffield)

Else-Quest, N. M., Higgins, A., Allison, C., & Morton, L. C. (2012). Gender differences in self-conscious emotional experience: a meta-analysis. *Psychological bulletin*, *138*(5), 947–981. https://doi.org/10.1037/a0027930

Ertan, D., Aybek, S., LaFrance Jr, W. C., Kanemoto, K., Tarrada, A., Maillard, L., ... & Hingray, C. (2022). Functional (psychogenic non-epileptic/dissociative) seizures: why and how?. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(2), 144-157. https://doi.org/10.1136/jnnp-2021-326708

Espeset, E. M., Gulliksen, K. S., Nordbø, R. H., Skårderud, F., & Holte, A. (2012). The link between negative emotions and eating disorder behaviour in patients with anorexia nervosa. *European Eating Disorders Review*, *20*(6), 451-460. https://doi.org/10.1002/erv.2183

Garcia, A. T. L. (2015). *From Humiliation to Feeling Depressed: The Role of Shame, Self-Disgust and Hated Self* (Doctoral dissertation, Universidade de Coimbra (Portugal)).

Gaskell, C., Power, N., Novakova, B., Simmonds-Buckley, M., Reuber, M., Kellett, S., & Rawlings, G. H. (2023). A meta-analytic review of the effectiveness of psychological treatment of functional/dissociative seizures on non-seizure outcomes in adults. *Epilepsia*, *64*(7), 1722-1738. https://doi.org/10.1111/epi.17626

Gilbert, P. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of Medical Psychology*, *70*(2), 113-147. https://doi.org/10.1111/j.2044-8341.1997.tb01893.x

Gilbert, P. (2014). The origins and nature of compassion focused therapy. *British Journal of Clinical Psychology, 53*(1), 6-41. https://doi.org/10.1111/bjc.12043

Gilbert, P. (2015). Self-disgust, self-hatred, and compassion-focused therapy. In: P. A. Powell, P. G. Overton, & J. E. Simpson (Eds). *The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust*. (223-242). Karnac Books Ltd.

Gilbert, P., Clarke, M., Hempel, S., Miles, J. N., & Irons, C. (2004). Criticizing and reassuring oneself: An exploration of forms, styles and reasons in female students. *British Journal of Clinical Psychology*, *43*(1), 31-50. https://doi.org/10.1348/014466504772812959

Goldstein, L. H., Robinson, E. J., Pilecka, I., Perdue, I., Mosweu, I., Read, J., ... & Chalder, T. (2021). Cognitive-behavioural therapy compared with standardised medical care for adults with dissociative non-epileptic seizures: the CODES RCT. *Health Technology Assessment (Winchester, England)*, *25*(43), 1. http://doi.org/10.3310/hta25430

Harper, D., & Thompson, A. R. (2012). *Qualitative Research Methods in Mental Health and Psychotherapy : A Guide for Students and Practitioners* (1st ed.). John Wiley & Sons, Ltd.

Harrison, S. L., Robertson, N., Goldstein, R. S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease: a mixed-methods study. *Chronic Respiratory Disease*, *14*(1), 22-32. https://doi.org/10.1177/1479972316654284

Hingray, C., El-Hage, W., Duncan, R., Gigineishvili, D., Kanemoto, K., LaFrance Jr, W. C., ... & Reuber, M. (2018). Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: an international survey by the ILAE PNES Task Force. *Epilepsia*, *59*(1), 203-214. https://doi.org/10.1111/epi.13952

Hingray, C., Ertan, D., Reuber, M., Lother, A. S., Chrusciel, J., Tarrada, A., ... & El-Hage, W. (2022). Heterogeneity of patients with functional/dissociative seizures: Three multidimensional profiles. *Epilepsia*, *63*(6), 1500-1515. https://doi.org/10.1111/epi.17230

Jamieson, M. K., Govaart, G. H., & Pownall, M. (2023). Reflexivity in quantitative research: A rationale and beginner's guide. *Social and Personality Psychology Compass*, *17*(4), e12735. https://doi.org/10.1111/spc3.12735

Jin, Y., Ma, H., & Jiménez-Herrera, M. (2020). Self-disgust and stigma both mediate the relationship between stoma acceptance and stoma care self-efficacy. *Journal of Advanced Nursing*, *76*(10), 2547-2558. https://doi.org/10.1111/jan.14457

Jones, B., Reuber, M., & Norman, P. (2016). Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: a systematic review. *Epilepsia*, *57*(2), 171-181. https://doi.org/10.1111/epi.13268

Jones, D. (2015). Psychodynamics of self-disgust: Expulsion and attack as attempts to retain integrity of the personality. In: P. A. Powell, P. G. Overton, & J. E. Simpson (Eds). *The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust*. (207-222). Karnac Books Ltd.

Jones, J. (2008). Impact of exudate and odour from chronic venous leg ulceration. *Nursing Standard.*, *22*(45). https://doi.org/info:doi/

Kelley, S. A., Brownell, C. A., & Campbell, S. B. (2000). Mastery motivation and self-evaluative affect in toddlers: Longitudinal relations with maternal behavior. *Child Development, 71*(4), 1061-1071. https://doi.org/10.1111/1467-8624.00209

Kılıç, A., Hudson, J., McCracken, L. M., Ruparelia, R., Fawson, S., & Hughes, L. D. (2021). A systematic review of the effectiveness of self-compassion-related interventions for individuals with chronic physical health conditions. *Behavior Therapy*, *52*(3), 607-625. https://doi.org/10.1016/j.beth.2020.08.001

Larkin, M., & Thompson A. R. (2012) Interpretative Phenomenoloigcal Analysis in Mental Health and Psychotherapy Research. In D. Harper & A. R. Thompson. *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners.* (pp. 99-116). John-Wiley & Sons, Oxford. 10.1002/9781119973249

Lazuras, L., Ypsilanti, A., Powell, P., & Overton, P. (2019). The roles of impulsivity, self-regulation, and emotion regulation in the experience of self-disgust. *Motivation and Emotion*, *43*, 145-158. https://doi.org/10.1002/erv.2183

Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet*, *367*(9509), 528-529. https://doi.org/10.1016/S0140-6736(06)68184-1

Marks, D. (1999). Dimensions of oppression: Theorising the embodied subject. *Disability & Society, 14*(5), 611-626. https://doi.org/10.1080/09687599925975

Mason, D., James, D., Andrew, L., & Fox, J. R. (2022). ‘The last thing you feel is the self-disgust’. The role of self-directed disgust in men who have attempted suicide: A grounded theory study. *Psychology and Psychotherapy: Theory, Research and Practice*, *95*(2), 575-599. https://doi.org/10.1111/papt.12389

Mayor, R., Gunn, S., Reuber, M., & Simpson, J. (2022). Experiences of stigma in people with epilepsy: A meta-synthesis of qualitative evidence. *Seizure*, *94*, 142-160. https://doi.org/10.1016/j.seizure.2021.11.021

Murray, C. D. & Wilde, D. J. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In C. Walshe & S. G. Brearly (Eds). *Handbook of theory and methods in applied health research : questions, methods and choices*. Edward Elgar Publishing.

Myers, L., Trobliger, R., Bortnik, K., Zeng, R., Saal, E., & Lancman, M. (2019). Psychological trauma, somatization, dissociation, and psychiatric comorbidities in patients with psychogenic nonepileptic seizures compared with those in patients with intractable partial epilepsy. *Epilepsy & Behavior*, *92*, 108-113. https://doi.org/10.1016/j.yebeh.2018.12.027

National Institute for Health and Care Excellence. (2021, January 8). *Quality statement 5: Functional neurological disorders in adults.* National Institute for Health and Care Excellence. https://www.nice.org.uk/guidance/qs198/chapter/Quality-statement-5-Functional-neurological-disorders-in-adults

Nizza, I. E., Farr, J., & Smith, J. A. (2021). Achieving excellence in interpretative phenomenological analysis (IPA): Four markers of high quality. *Qualitative Research in Psychology*, *18*(3), 369-386. https://doi.org/10.1080/14780887.2020.1854404

Novakova, B., Howlett, S., Baker, R., & Reuber, M. (2015). Emotion processing and psychogenic non-epileptic seizures: A cross-sectional comparison of patients and healthy controls. *Seizure*, *29*, 4-10. https://doi.org/10.1016/j.seizure.2015.03.007

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, *45*(3), 241-251. https://doi.org/10.1080/0142159X.2022.2057287

Overton, P. G., Markland, F. E., Taggart, H. S., Bagshaw, G. L., & Simpson, J. (2008). Self-disgust mediates the relationship between dysfunctional cognitions and depressive symptomatology. *Emotion, 8*(3), 379–385. https://doi.org/10.1037/1528-3542.8.3.379

Paul, K. I., & Moser, K. (2009). Unemployment impairs mental health: Meta-analyses. *Journal of Vocational Behavior*, *74*(3), 264-282. https://doi.org/10.1016/j.jvb.2009.01.001

Peacock, M., Bissell, P., Ellis, J., Dickson, J. M., Wardrope, A., Grünewald, R., & Reuber, M. (2023). 'I just need to know what they are and if you can help me': Medicalization and the search for legitimacy in people diagnosed with non-epileptic attack disorder. *Epilepsy & Behavior, 148*, 109485. https://doi.org/10.1016/j.yebeh.2023.109485

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, *20*(1), 7-14. DOI: 10.14691/CPPJ.20.1.7

Powell, P. A., Azlan, H. A., Simpson, J., & Overton, P. G. (2016). The effect of disgust-related side-effects on symptoms of depression and anxiety in people treated for cancer: A moderated mediation model. *Journal of Behavioral Medicine, 39*(4), 560-573. https://doi.org/10.1007/s10865-016-9731-0

Powell, P. A., Overton, P. G., & Simpson, J. (2014). The revolting self: An interpretative phenomenological analysis of the experience of self-disgust in females with depressive symptoms. *Journal of Clinical Psychology*, *70*(6), 562-578. https://doi.org/10.1002/jclp.22049

Powell, P. A., Simpson, J. E. & Overton, P. G., (2015). An Introduction to the Revolting Self: Self-Disgust as an Emotion Schema. In: P. A. Powell, P. G. Overton, & J. E. Simpson (Eds). *The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust*. (1-24) Karnac Books Ltd.

Powell, P. A., Simpson, J., & Overton, P. G. (2015). Self-affirming trait kindness regulates disgust toward one's physical appearance. *Body Image*, *12*, 98-107. https://doi.org/10.1016/j.bodyim.2014.10.006

Power, M., & Dalgleish, T. (2015). *Cognition and emotion: From order to disorder*. Psychology press. https://doi.org/10.4324/9781315708744

Read, J., & Harper, D. J. (2022). The power threat meaning framework: Addressing adversity, challenging prejudice and stigma, and transforming services. *Journal of Constructivist Psychology*, *35*(1), 54-67. https://doi.org/10.1080/10720537.2020.1773356

Reeve, D. (2015). Disgust and self-disgust: a disability studies perspective. In: P. A. Powell, P. G. Overton, & J. E. Simpson (Eds). *The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust*. (53-74). Karnac Books Ltd.

Reuber, M., Howlett, S., Khan, A., & Grünewald, R. A. (2007). Non-epileptic seizures and other functional neurological symptoms: predisposing, precipitating, and perpetuating factors. *Psychosomatics*, *48*(3), 230-238. https://doi.org/10.1176/appi.psy.48.3.230

Reuber, M., Roberts, N. A., Levita, L., Gray, C., & Myers, L. (2022). Shame in patients with psychogenic nonepileptic seizure: A narrative review. *Seizure, 94*, 165-175. https://doi.org/10.1016/j.seizure.2021.10.017

Reynolds, L. M., McCambridge, S. A. & Consedine, N. S. (2015). Self-disgust and adaptation to chronic physical health condition: implications for avoidance and withdrawal. In: P. A. Powell, P. G. Overton, & J. E. Simpson (Eds). *The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust*. (75-88). Karnac Books Ltd.

Ribeiro, J. D., Huang, X., Fox, K. R., & Franklin, J. C. (2018). Depression and hopelessness as risk factors for suicide ideation, attempts and death: meta-analysis of longitudinal studies. *The British Journal of Psychiatry, 212*(5), 279-286. https://doi.org/10.1192/bjp.2018.27

Roberts, N. A., & Reuber, M. (2014). Alterations of consciousness in psychogenic nonepileptic seizures: emotion, emotion regulation and dissociation. *Epilepsy & Behavior*, *30*, 43-49. https://doi.org/10.1016/j.yebeh.2013.09.035

Roberts, T., & Goldenberg, J. L. (2007). Wrestling with nature. In J. L. Tracy, R. W. Robins & J. P. Tangney (Eds). *The self-conscious emotions: Theory and research*, (389-406). The Guildford Press, New York.

Robertson, N., Gunn, S., & Piper, R. (2022). The Experience of Self-conscious Emotions in Inflammatory Bowel Disease: A Thematic Analysis. *Journal of Clinical Psychology in Medical Settings*, *29*(2), 344-356. https://doi.org/10.1007/s10880-021-09778-0

Rozin, P., Haidt, J., & McCauley, C. R. (1999). Disgust: The body and soul emotion. In T. Dalgleish & M. J. Power (eds.), *Handbook of cognition and emotion, 429*, 445.

Rozin, P., Haidt, J., & McCauley, C. R. (2008). Disgust. In L. F. Barrett, M. Lewis, & J. M. Haviland-Jones (2016). *Handbook of emotions* (Fourth edition.). (pp 815-928). The Guilford Press

Scott, K. M., Bruffaerts, R., Tsang, A., Ormel, J., Alonso, J., Angermeyer, M. C., ... & Von Korff, M. (2007). Depression–anxiety relationships with chronic physical conditions: results from the World Mental Health Surveys. *Journal of Affective Disorders, 103*(1-3), 113-120. https://doi.org/10.1016/j.jad.2007.01.015

Simpson, J., Helliwell, B., Varese, F., & Powell, P. (2020). Self-disgust mediates the relationship between childhood adversities and psychosis. *British Journal of Clinical Psychology, 59*(2), 260-275. https://doi.org/10.1111/bjc.12245

Simpson, J., Hillman, R., Crawford, T., & Overton, P. G. (2010). Self-esteem and self-disgust both mediate the relationship between dysfunctional cognitions and depressive symptoms. *Motivation and Emotion*, *34*(4), 399-406. https://doi.org/10.1007/s11031-010-9189-2

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, *5*(1), 9-27. https://doi.org/10.1080/17437199.2010.510659

Smith, J. A., Flower, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method and research* (2nd ed.). SAGE Publications Ltd.

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., C. Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*, 1-13. https://doi.org/10.1186/s12916-019-1271-3

Sznycer, D. (2019). Forms and functions of the self-conscious emotions. *Trends in Cognitive Sciences*, *23*(2), 143-157. https://doi.org/10.1016/j.tics.2018.11.007

Terrizzi, J. A., Jr, Pond, R. S., Jr, Shannon, T. C. J., Koopman, Z. K., & Reich, J. C. (2023). How does disgust regulate social rejection? a mini-review. *Frontiers in Psychology*, *14*, 1141100. https://doi.org/10.3389/fpsyg.2023.1141100

The British Psychological Society (2021, April). *BPS Code of Human Research Ethics.* https://doi.org/10.53841/bpsrep.2021.inf180

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal For Quality in Health Care*, *19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

Tracy, J. L., & Robins, R. W. (2004). " Putting the Self Into Self-Conscious Emotions: A Theoretical Model". *Psychological Inquiry*, *15*(2), 103-125. https://doi.org/10.1207/s15327965pli1502_01

Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837-851. https://doi.org/10.1177/1077800410383121

Tran, H. N., Lipinski, A. J., Peter, S. C., Dodson, T. S., Majeed, R., Savage, U. C., & Beck, J. G. (2019). The association between posttraumatic negative self-conscious cognitions and emotions and maladaptive behaviors: Does time since trauma exposure matter?. *Journal of Traumatic Stress*, *32*(2), 249-259. https://doi.org/10.1002/jts.22388

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *The Western Journal of Medicine*, *172*(2), 124–128. https://doi.org/10.1136/ewjm.172.2.124

Wardrope, A., Dworetzky, B. A., Barkley, G. L., Baslet, G., Buchhalter, J., Doss, J., ... & Reuber, M. (2021). How to do things with words: two seminars on the naming of functional (psychogenic, non-epileptic, dissociative, conversion,…) seizures. *Seizure*, *93*, 102-110. https://doi.org/10.1016/j.seizure.2021.10.016

Whelton, W. J., & Greenberg, L. S. (2005). Emotion in self-criticism. *Personality and Individual Differences, 38*(7), 1583-1595. https://doi.org/10.1016/j.paid.2004.09.024

Winton-Brown, T., Wilson, S. J., Felmingham, K., Rayner, G., O’Brien, T. J., O’Brien, P., ... & Kanaan, R. (2023). Principles for delivering improved care of people with functional seizures: Closing the treatment gap. *Australian & New Zealand Journal of Psychiatry, 57*(12), 1511-1517. https://doi.org/10.1177/00048674231180509

Yardley, L. (2008). Demonstrating Validity in Qualitative Psychology. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (pp. 235–251). SAGE Publications. https://doi.org/10.1017/CBO9781107415324.004

Yardley, L. (2015). Demonstrating validity in qualitative psychology. In J.A. Smith (Eds.). *Qualitative psychology: A practical guide to research methods*, *3*, 257-272.

Yin, R. K. (2014). *Case study research : design and methods* (Fifth edition.). SAGE.

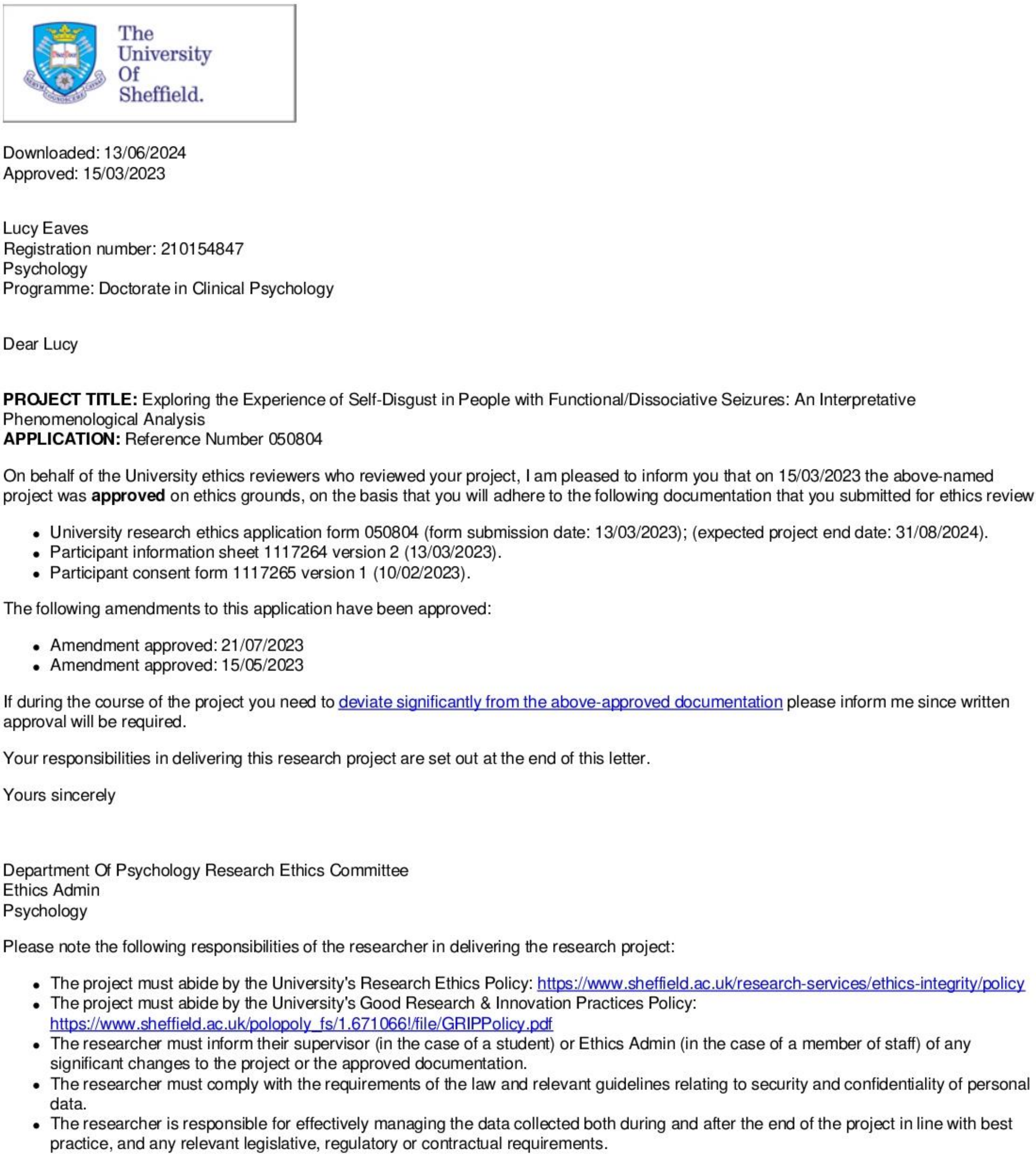
Ypsilanti, A., Lazuras, L., Powell, P., & Overton, P. (2019). Self-disgust as a potential mechanism explaining the association between loneliness and depression. *Journal of Affective Disorders*, *243*, 108-115. https://doi.org/10.1016/j.jad.2018.09.056

Zhang, L., Beghi, E., Tomson, T., Beghi, M., Erba, G., & Chang, Z. (2022). Mortality in patients with psychogenic non-epileptic seizures a population-based cohort study. *Journal of Neurology, Neurosurgery & Psychiatry*, *93*(4), 379-385. https://doi.org/10.1136/jnnp-2021-328035

List of Appendices

Appendix A

Ethical Approval



Downloaded: 13/06/2024
Approved: 15/03/2023

Lucy Eaves
Registration number: 210154847
Psychology
Programme: Doctorate in Clinical Psychology

Dear Lucy

PROJECT TITLE: Exploring the Experience of Self-Disgust in People with Functional/Dissociative Seizures: An Interpretative Phenomenological Analysis
APPLICATION: Reference Number 050804

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 15/03/2023 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 050804 (form submission date: 13/03/2023); (expected project end date: 31/08/2024).
- Participant information sheet 1117264 version 2 (13/03/2023).
- Participant consent form 1117265 version 1 (10/02/2023).

The following amendments to this application have been approved:

- Amendment approved: 21/07/2023
- Amendment approved: 15/05/2023

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Admin
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Admin (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Self-disgust Rating Scale

Overton et al., 2008

Item no.	Content of item
1	I find myself repulsive
2	I am proud of who I am
3	The way I behave makes me despise myself
4	I hate being me
5	I enjoy the company of others
6	I like the way I look
7	Overall, people dislike me
8	I enjoy being outdoors
9	I feel good about the way I behave
10	I do not want to be seen
11	I am a sociable person
12	I often do things I find revolting
13	Sometimes I feel happy
14	I am an optimistic person
15	It bothers me to look at myself
16	Sometimes I feel sad
17	I detest aspects of my personality
18	My behaviour repels people

For each item, the participant must rate how much they agree with the description on a 7-point Likert scale (1= *strongly agree,* 7= *strongly disagree).* Possible scores range from 12 to 84, with higher scores indicating higher levels of self-disgust.

A total self-disgust score is found by summing scores to the 12 statements relating to the three self-disgust constructs (appearance, general self-concept, behaviour), after reverse coding several variables (Items 1, 3, 4, 7, 10, 12, 15, 17, 18) so that a high score indicated high self-disgust. Maximum score 84, minimum score 12.

Appendix C

Interview Schedule

Introduction

Thank you for agreeing to take part in this research. I am interested in exploring the experience of difficult emotions, in particular self-disgust, among people with functional/dissociative seizures. Self-disgust is a particular negative emotion people feel about themselves that can happen as a result of events in their life or other people's reactions. I will be asking you questions about your experience with functional seizures (nonepileptic attacks), how this impacts on you emotionally and explore your experiences with the emotion self-disgust. This study is exploring your experience with self-disgust as you have identified it as an emotion you experience. This study in no way implies you or your condition is disgusting or that you ought to feel that way.

This interview will be covering sensitive topics that you may find upsetting. Your participation in this study is completely voluntary. You can choose not to answer any particular question, take a break or revisit the interview when you feel more able to participate, just let me know. You also have the right to withdraw from the study within two weeks of the interview without giving a reason. Do you think this is something you are able to participate in today?

This interview will last for approximately 60-90 minutes. With your permission, the interview will be audio-recorded and transcribed.

If you experience a seizure during the interview today, how can I best support you? Is there anything in particular I could do to help you? [Complete seizure safety plan]

The things we talk about today are confidential and all of your information from the recording will be anonymised, so you can not be identified. The only exception to this would be if I felt concerned about you or someone you talk about today. If needed, we could talk to a healthcare professional such as your GP to help support you. If this were to happen, I would discuss this with you first.

Do you have any questions before we begin?

[Record the process of consent- checking that the interviewee has read, understood and signed the Consent Form]

Demographics

1. Please specify your age
2. Please specify your gender. Male/Female/Non-binary/Other/Prefer not to say
3. Ethnicity
4. Employment and education
5. Do you experience functional/dissociative seizures (nonepileptic seizures), as diagnosed by a medical professional?
6. How long have you experienced functional/dissociative seizures for?
7. Do you have any other diagnoses at all?

Experience of FDS

- When did you first start experiencing functional/dissociative seizures (FDS)?
- How long did it take from first experiencing symptoms to receiving a diagnosis?
- How did find your journey to receiving a diagnosis of FND?
- How often do you experience your FDS?
- What happens when you have a seizure?
- What impact do FDS have on your life currently?
- Are there activities/situations that are difficult as a result of having FDS?

Completion of the self-disgust scale

- How did you find completing the questionnaire on feelings of self-disgust?
- What are your thoughts and feelings because of this?

Experience of difficult emotions and self-disgust

- What do you understand about self-disgust?
    - *What do you understand about the disgust emotion in general?*
- How does self-disgust relate to you?
    - *Please give as much detail as possible. Are there any thoughts or feelings related to these experiences?*
    - *Why do think these feelings developed?*
- Can you describe times when you have felt disgusted with yourself?

    - *Can you think of any specific examples that could be shared?*
    - *What do you think made you feel self-disgust then? What prompted the feelings?*
- How do feelings of self-disgust affect you?
    - *Is there anything you do more of/less of/ differently?*
- When did feelings of self-disgust first emerge?
    - *Was this before having FDS symptoms?*
- Have your feelings of self-disgust varied more or less since you first experienced symptoms?
    - *Is there any relationship with the course of your condition? What effects do the feelings have on your condition? What aspects of behaviour are more affected?*

Coping with self-disgust

- How do you manage your feelings of self-disgust?
    - *Is there anything that has helped you cope with these feelings?*
- Are you able to reduce your feelings of self-disgust?
    - *What do you do?*

Other feelings and cognitions

- How do you feel about your experience of self-disgust?
    - *Are there any other emotions associated with this?*
- What thoughts do you have about yourself generally?
- Is there anything that makes you feel more positive?
    - *Can you describe times or situations when you felt less self-disgusted?*
- Are there times when you feel more confident?
    - *Can you tell me more about those times? What positive thoughts/emotions did you have in these circumstances?*

Debrief and interview close

Thank you for taking part in this research today. I will be analysing all the interviews I have conducted in order to look at some similarities and differences in people’s experiences. I will then write a report of my findings. We hope these findings will be helpful for informing treatments for FND to better meet people’s needs.

We have discussed some difficult topics today. How do you feel? If you like, we can go through relaxation exercise to help you feel calmer.

Do you feel that you need to talk about anything further? The debrief sheet has some sources of support listed but if you feel you would like further support after you leave today, you can contact your GP.

[Provide debrief form]

Appendix D

Participant Information Sheet

Participant Information Sheet

Title of Project: Exploring the Experience of Difficult Emotions in People with Functional/Dissociative Seizures

We would like to invite you to take part in a research study. It is important that you understand why the research is being done and what it will involve for you before you agree to participate in the study. Thank you for reading this information sheet.

What is the purpose of this study?

People living with functional/dissociative (nonepileptic) seizures (FDS) face many challenges. Some people with FDS feel bad about themselves because of their seizures or because of other people's responses to their seizures. Previous research suggests that low self-esteem and other negative emotions affect the lives of some people with FDS. This study is designed to explore the experience of *self-disgust* in people who have FDS. It is important to note that the name of this emotion does not suggest that people or their medical conditions are disgusting or ought to feel disgust in relation to themselves. In this study we will first identify individuals who experience this emotion by asking all participants to complete a short questionnaire. We will then invite some of the participants who have reported that they experiences self-disgust to take part in an interview intended to explore how this emotion has affected them

We think that this study is important because self-disgust is a strong emotion which can play a large role in triggering emotional difficulties or causing them to continue. Finding out more about self-disgust in FDS could help clinicians better understand people's difficulties and to tailor treatments to suit their needs.

This study is being carried out as part of a Doctorate in Clinical Psychology (DClinPsy) research project based at the University of Sheffield.

Why am I being asked to take part?

You have been invited to participate in this study because you have experience functional/dissociative seizures.

Who can take part in this study?

To be included in the study, you must be aged 18 or over. You should be able and to willing and able to read and write in English, and to be interviewed in English. You must also be a resident of the United Kingdom, and your diagnosis of functional/dissociative seizures (nonepileptic attack disorder) must have been made by a physician (GP, neurologist or psychiatrist). If you do not match these criteria, we cannot include you in this study.

Do I have to take part?

No, participation in this study is entirely voluntary. Reading this information sheet and consent form on the next page will help you decide whether you would like to take part. If you do decide to take part, you can type your name in the appropriate field of the consent form, and then go on to answer the questionnaire.

You can discontinue from the study at any point, without giving a reason. However, if you choose to take part and you change your mind, you can withdraw within 2 weeks without giving a reason. After 2 weeks of completing the interviews, withdrawing will not be possible because I will have started the process of analysing your data.

What will happen if I take part?

After reading this information sheet, you can proceed to the next page to read a consent form. This form will also ask for your consent to be contacted to participate in the second part of the study and you will be asked to provide your contact details. If you consent to participate, you can sign this form to proceed to the study questionnaire.

This study comprises of two parts. In the first part, you will be asked to complete a short questionnaire online which should take no longer than 15 minutes. This is to see if self-disgust is something that you feel.

For the second part of the study, a small number of participants who score highly on the questionnaire will be invited to participate in a 60-90 minute interview where you will be asked some questions about your experiences of self-disgust. If you are selected to take part in this stage of the study, you will be contacted via telephone or email (please indicate which is your preferred method) by the lead researcher within 2 weeks.

If you wish, you can be provided a copy of the questions being asked in the interview, although this will be a guide.

The interview will take place either by telephone or Google Meet/Microsoft Teams at a time convenient to you.

This interview will be recorded and then transcribed using an approved University of Sheffield transcriber. The interview data will be analysed using interpretative phenomenological analysis. All interview data will pseudonymised (names changed and personally identifiable information removed) 2 weeks following the interview taking place. Pseudonymised data will then be kept within the secure University of Sheffield data storage service and only accessible to the research team.

What are the benefits of taking part?

There are no immediate benefits for people participating in the project. However, you will have an opportunity to share your experiences and contribute to clinical research. We hope this study will help us better understand the experiences of people with functional seizures. The results of this study could help clinicians tailor treatments to suit patient’s needs. A written report of the findings will be complied for publication to a peer-reviewed journal.

What are the possible disadvantages and risks of taking part?

There are no major risks associated with this study. However, some of the questions within the short questionnaire and interview may touch upon topics which some people find sensitive. There will be information for sources of support will be provided following completion of the questionnaire should you need to access further support. Additionally, if you feel that there is a problem at any time, you can let the researcher know.

If you experience any distress while sharing your experience, the researcher will be able to discuss this with you and discuss what further support might be of help. If you have concerns about your mood during or after the study, please take the following action:

- Consider getting in touch with your GP. GPs can provide assessment and advice about mental health difficulties and signpost you to relevant services.
- If you are in a crisis, you should contact emergency services (999 or 111).
- If you have thoughts about harming yourself, please contact the Samaritans on telephone number 116 123. This is a free line that is available 24 hours a day.

How will we use information about you?
We will need to use information from you for this research project.

This information will include your name and email address. All the information we collect about you will be kept strictly confidential. Your details will be stored separately from the information you provide by answering the questionnaire and completing the interview. We will use your contact details to offer you a summary of the study outcome once the research has been completed. You can choose to opt in or out of this. Otherwise, your personal data/medical records and data files may only be used for checks by regulatory authorities and the Sponsor of the research (The University of Sheffield and Sheffield Teaching Hospital) to make sure that we have followed all rules about how research should be carried out. Your data will be always kept confidential.

Only the research team will be able to see your name or contact details. When we analyse your data, it will be identified by a study number rather than your name or other personal data. All interview data will be pseudonymised during transcription. You will not be identifiable in any reports or publications.

We will keep all information about you safe and secure. Your data will be temporarily stored on the University filestore until you complete the interview then they will be destroyed. If you email and do not choose to participate, your contact details will be destroyed. All pseudonymised data from this research will be kept on the University secure filestore for up to 10 years following completion of this research to allow for potential further analysis of the data.

The only exception to this would be if during the interview the researcher became concerned about a risk of harm to yourself (for example, suicidal risk), or someone (for example, a child or another adult) you talk about (for example, risk of neglect or physical harm). If this situation does arise, the researcher would discuss the need to break confidentiality with you. The aim of this would always be to support yourself and those you mention and ensure safety.

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

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

- at www.hra.nhs.uk/information-about-patients/
- at https://www.sheffieldclinicalresearch.org/for-patients-public/how-is-your-information-handled-in-research/
- at Patient Data and Research leaflet - Health Research Authority (hra.nhs.uk)
- by contacting the research team via the contact details indicated at the end of this document.

You can also read the following section about what happens with your data in the study in detail:

The Sheffield Teaching Hospital National Health Foundation Trust (STH NHSFT) will act as the Sponsor and Joint Data Controller for this study. The University of Sheffield will also act as a joint data controller. This means, that we will be responsible for looking after your information and using it properly. All your data will be stored securely in password protected files at a secured University of Sheffield data drive, accessible only to members of the research team. After the completion of the study, the University of Sheffield will archive all the study documents for 10 years, and then securely dispose them. All information collected during this study will be kept confidential.

If you are recruited via Sheffield Teaching Hospitals NHS FT (STH NHSFT), members of your direct clinical team may use your name, NHS number and contact details to contact you about the research study. You will only be contacted by a member of the research team if you give them permission to do so. The researchers in this study will have no access to your clinical records unless you are under their care at the STH.

Your data will be pseudo-anonymous. This means that your study number can be used to link your survey answers and your personal details. This will allow us to email you to request your participation in the interview stage of the study. When data-analysis commences, your personal data (e.g. email address, name) will be separated from your questionnaire and interview data and stored in separate files. Your questionnaire data will be assigned a study participant ID, so researchers will not be able to identify you when performing statistical analysis. You will not be identified in any reports or publications.

All your data will be managed according to the latest General Data Protection Regulation (GDPR) laws. For more information, please see: Patient Data and Research leaflet - Health Research Authority

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)). As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your ethnic origin and health), we also need to let you know that we are applying the following condition in law: that the use of your data is ‘necessary for scientific or historical research purposes’.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above, you will not be personally identified in any reports or publications.

You can opt in to receive the results of this study by giving the researcher consent to email you about a summary of the study results. We will not contact you about these without your consent.

Who is organising and funding the research?
This study is being conducted by Lucy Eaves (Trainee Clinical Psychologist), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Lucy is being supervised by Professor Markus Reuber, who is based at the University of Sheffield, and Professor Jane Simpson, who is based at Lancaster University. The research is being carried out in collaboration with the National Health Service (NHS), specifically the Neurology Department based at Sheffield Teaching Hospitals NHSFT. The study is funded by the University of Sheffield.

Who has ethically reviewed the project?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the (Research Ethics Committee - specify after approval)

This project has also been ethically approved by the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure.

What if something goes wrong and I wish to complain about the research?
If you would like to make a complaint about this project, in the first instance you should contact the lead researcher or their supervisor.

If you do not feel satisfied that your complaint has been dealt with appropriately you can contact Sheffield Patient Services Team on 0114 2712400 or email: STH.PALS@nhs.net. You can also contact the Sheffield Teaching Hospitals NHS Foundation Trust Patient partnership team at address: Patient partnership department, B floor, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF. Tel: 0114 2712450. Alternatively, you can contact the DClinPsy Programme Director, Gillian Hardy g.hardy@sheffield.ac.uk, or Professor Paul Overton and Dr Rebecca Denniss, Chairs of the University Ethics Committee on p.g.overton@sheffield.ac.uk and r.j.denniss@sheffield.ac.uk respectively.

If your complaint relates to how your personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice and you can contact the information governance team at STH via email: sth.infogov@nhs.net

If you have further questions about the study, please feel free to contact the research team on the contact details below.

Contact Information

Lead Researcher: Lucy Eaves
Address: Department of Psychology, University of Sheffield, Catherdral Court, 1 Vicar Lane, Sheffield, S1 2LT
Email: leaves1@sheffield.ac.uk
Telephone: Please leave a message with research officer, Amrit Sinha on +44 (0) 114 222 6650 and Lucy will return your call.

First Supervisor: Professor Markus Reuber
Address: Department of Neuroscience, Academic Neurology Unit, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF
Email: m.reuber@sheffield.ac.uk
Telephone: +44 (0) 114 226 8763

Second Supervisor: Professor Jane Simpson
Address: Health Innovation One, Sir John Fisher Drive, Lancaster University,
Lancaster, LA1 4AT
Email: j.simpson2@lancaster.ac.uk
Telephone: +44 (0) 1524 592858

Third Supervisor: Professor Jaime Delgadillo
Address: Department of Psychology, University of Sheffield, Catherdral Court, 1 Vicar Lane, Sheffield, S1 2LT
Telephone: +44 114 222 6614
Email: j.delgadillo@sheffield.ac.uk

Appendix E

Study Advert

Study Advert V1 30.06.23

STH Project Number: STH 22783

The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Do you experience functional/dissociative seizures (also known as non-epileptic attacks)? Would you be willing to share your experience of difficult emotions?

We'd like to hear from you!

Title of Project: **Exploring the Experience of Difficult Emotions in People with Functional/Dissociative Seizures (FDS)**

Who can take part?

You can take part in this study if you have received a clinical diagnosis of FDS (non-epileptic attacks) and experience a loss of consciousness.
You are a UK resident.
You are age 18 or above.

What will I have to do if I take part?

In this study we explore difficult emotions. You will first be asked to complete a short questionnaire about your emotions. Then, we will be inviting a small number of individuals to take part in an interview where they will be asked questions about their experiences with difficult emotions.

Why should I take part?

People with seizures are often stigmatised and experience difficult emotions. This study will help us to better understand the difficult emotions which can be associated with functional/dissociative seizures. Our results could help us to develop better treatments for people with these seizures.

For more information:

If you would like to find out more and participate, please follow this link:
Include QR code (as generated by Qualtrics survey platform) that will lead participants to Qualtrics survey platform including PIS, consent form, questionnaire and debrief sheet.

Contact details:

If you have further questions about the study, please contact:
Lucy Eaves, Trainee Clinical Psychologist (DClinPsy)
Email: leaves1@sheffield.ac.uk
Phone: Please leave a message with research officer Amrit Sinha on 0114 2226650 and Lucy will return your call. (Mon-Sat, 9am-5pm)
Alternatively, you can contact the research supervisor (Professor Markus Reuber, Tel: 0114 2268763, Email m.reuber@sheffield.ac.uk) if you have any further questions.

Appendix F

Consent Form

The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Consent Form

Title of Project: Exploring the Experience of Difficult Emotions in People with Functional/Dissociative Seizures

Name of Researcher: Lucy Eaves

Participant Identification Number:

Please tick the appropriate boxes	**Yes**	**No**
Taking Part in the Project		
I can confirm that I have read and understood the project information sheet, and any questions about this I may have had have been answered by the researchers. I can confirm that I fully understand what is expected of me within this study. *If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.*	☐	☐
I have been given the opportunity to ask questions about the project and have them answered.	☐	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected. In addition, should I not wish to answer any question(s), I am free to decline. If I take part in the interview study, I understand that if I participate, I have 2 weeks from the date of the interview to withdraw. This is because transcription will be completed.	☐	☐
I understand that taking part in the project will include completing the online survey.	☐	☐
I understand that there is an interview study which participants in the online questionnaire study can take part in. I agree to be contacted about this interview study. Please provide your contact details for participation in the interview study **Name** **Email address and contact number**	☐	☐

How my information will be used during and after the project		
I understand my personal details (e.g. name, email address and contact number) will not be revealed to people outside the project. I understand that regulatory authorities or representatives of the Sponsor (Sheffield Teaching Hospitals NHS FT or University of Sheffield) may inspect data files or my medical records/personal data to ensure researchers have adhered to all research regulations. I give permission for these individuals to access my data. I understand that my data will be kept confidential at all times.	☐	☐
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I can confirm that I: 1. Am aged 18 years + 2. Have a formal diagnosis of functional/dissociative (nonepileptic) seizures made by a medical professional 3. Experience function/dissociative seizures with impairment of my awareness 4. Am willing to talk about my experience of self-disgust 5. Agree to take part in the above project	☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐
So that the information you provide can be used legally by the researchers		

Participant Electronic Signature Date

Researcher Electronic Signature Date

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet over email. A copy of the signed and dated consent form will be placed in the project's main record (e.g. site file), which is located on a secure, password protected file.

Appendix G

Participant Debrief Form

Debrief Sheet

Thank you for taking part in this study and sharing your experiences with me.

If you have any queries about the study or have any further questions, please do not hesitate to contact me using the details below:

Lucy Eaves	Email: leaves1@sheffield.ac.uk
University of Sheffield	Telephone: +44 (0) 114 222 6650
Department of Psychology	
Floor F, Cathedral Court	
1 Vicar Lane	
Sheffield S1 2LT	

Feel free to also contact the research supervisors (Professor Markus Reuber, Email: m.reuber@sheffield.ac.uk, Tel: +44 (0)114 2268763; Professor Jane Simpson, Email: j.simpson2@lancaster.ac.uk, Tel: +44 (0) 1524 592858) if you have any further questions.

If you wish to make a complaint or have any concerns and do not want to speak to the researcher team, you can contact Sheffield Patient Services Team on 0114 2712400. Email STH.PALS@nhs.net or you can contact Sheffield Teaching Hospitals NHS Foundation Trust Patient partnership team at: Patient partnership department, B floor, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF. Tel: 0114 2712450.

If you do feel that you wish to withdraw from the study, please email myself or Professor Markus Reuber (m.reuber@sheffield.ac.uk) with your participant identification number **within 2 weeks** of the interview. You do not have to provide a reason for withdrawing.

Some of the responses you shared in this study may have been sensitive and/or distressing so you may have some further questions. If you have concerns about your mood, please take action as follows:

- Consider getting in touch with your GP. GPs can provide assessment and advice about mental health difficulties and signpost you to relevant services.
- If you are in a crisis, you should contact emergency services (999 or 111).
- If you have thoughts about harming yourself, please contact the Samaritans on telephone number 116 123. This is a free line that is available 24 hours a day.

For further information and support:

	FND Dimensions is a UK patient-led charity that offers support to people living with FND and their caregivers. The offer online and local peer support groups and advice on external support services. Website: https://fnddimensions.org/
	Further information about FND and Nonepileptic Attacks can be found on the following websites: www.neurosymptoms.org www.nonepilepticattacks.info

Appendix H

Participant Invitation Email

Dear Sir/Madam,

Re: Exploring the experience of difficult emotions in people with functional/dissociative seizures

Thank you for completing the short questionnaire and consenting to be contacted to further participate in this study. Your score on the questionnaire suggested that the emotion self-disgust might be something that you experience. It is important to note that this does not imply that you or your condition is disgusting or that you ought to feel this way.

I am interested in hearing more about your experiences with difficult emotions and self-disgust. I would like to invite you to take part in an interview to talk about this further.

As mentioned in the information sheet you read before completing the questionnaire, this interview is expected to last about 60-90 minutes and will take place online, either over Google Meet or Microsoft Teams, or on the phone. With your permission, the interview will be audio-recorded and transcribed. The interview will be confidential and all of your information from the recording will be anonymised.

To arrange a time to be interviewed, please reply to this email with dates and times you will be available. If you would like to see the questions you will be asked prior to the interview, please let me know.

If you have any questions about the research project, please contact me (Lucy Eaves) by email at leaves1@sheffield.ac.uk. Also feel free to contact the research supervisors (Professor Markus Reuber, Email: m.reuber@sheffield.ac.uk, Tel: +44 (0)114 2268763; Professor Jane Simpson, Email: j.simpson2@lancaster.ac.uk, Tel: +44 (0) 1524 592858) if you have any further questions.

I look forward to hearing from you.

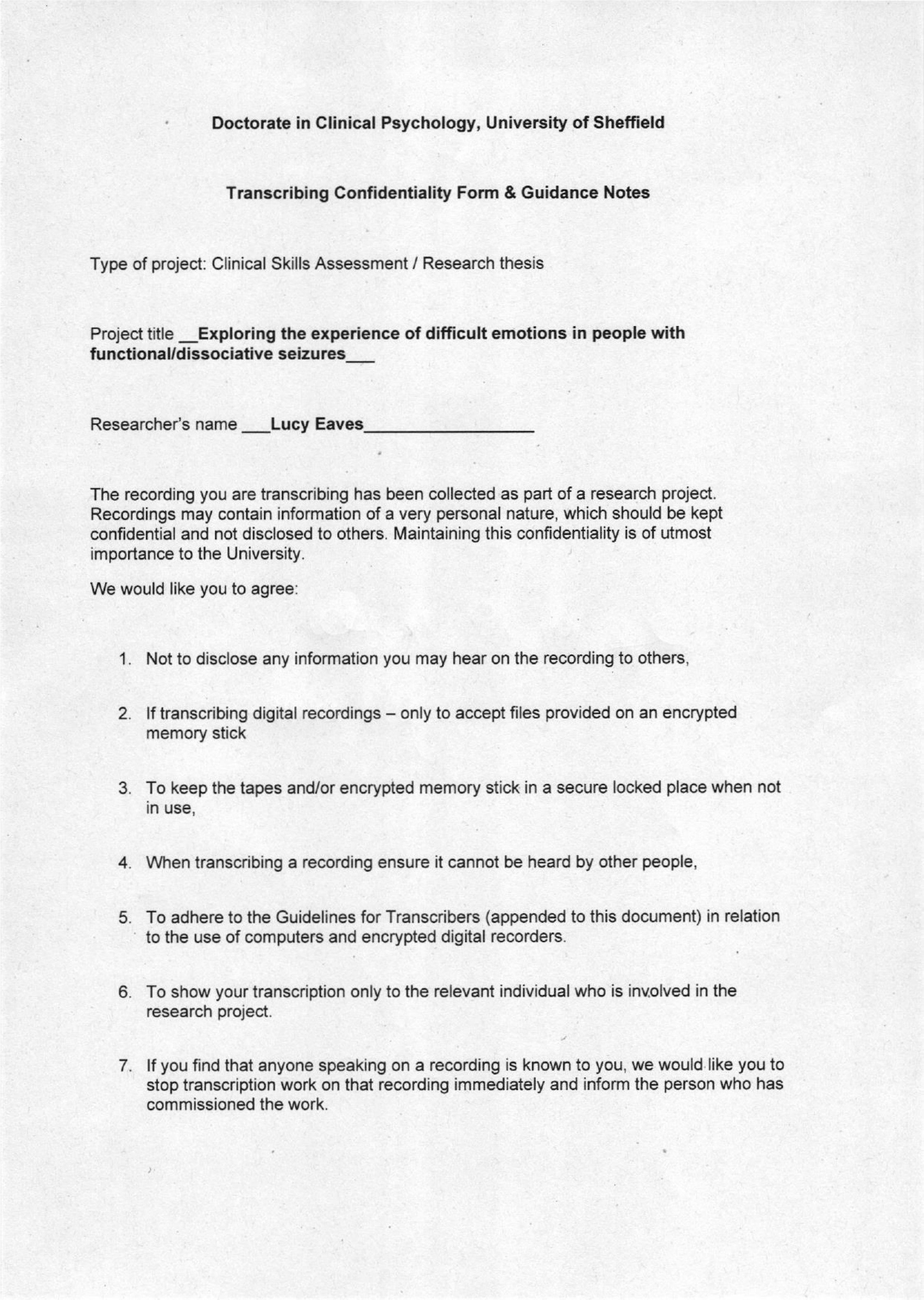
Yours sincerely,

Lucy Eaves

Trainee Clinical Psychologist

Appendix I

Signed Transcriber Agreement



Doctorate in Clinical Psychology, University of Sheffield

Transcribing Confidentiality Form & Guidance Notes

Type of project: Clinical Skills Assessment / Research thesis

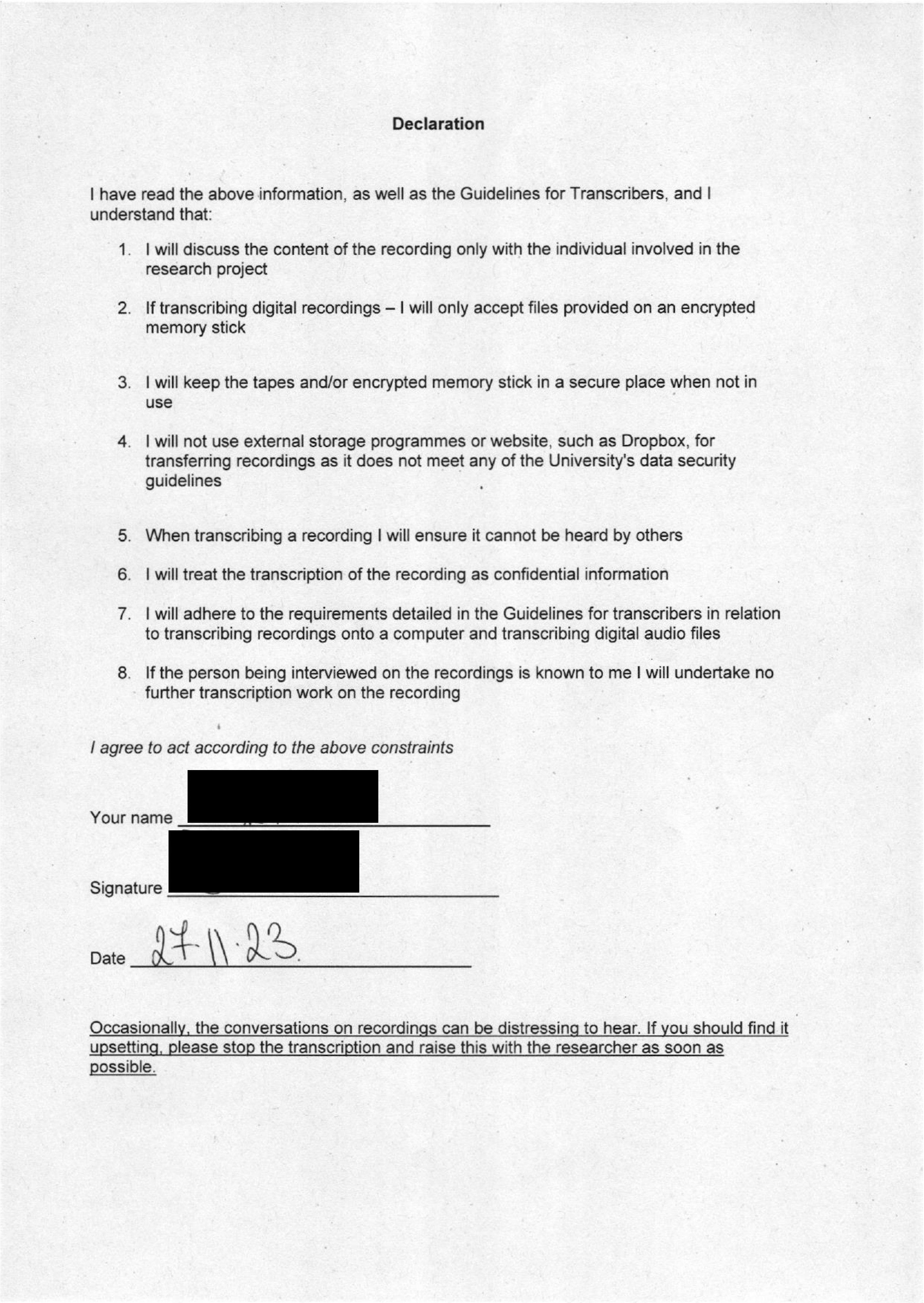
Project title __**Exploring the experience of difficult emotions in people with functional/dissociative seizures**___

Researcher's name ___**Lucy Eaves**__________________

The recording you are transcribing has been collected as part of a research project. Recordings may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University.

We would like you to agree:

1. Not to disclose any information you may hear on the recording to others,
2. If transcribing digital recordings – only to accept files provided on an encrypted memory stick
3. To keep the tapes and/or encrypted memory stick in a secure locked place when not in use,
4. When transcribing a recording ensure it cannot be heard by other people,
5. To adhere to the Guidelines for Transcribers (appended to this document) in relation to the use of computers and encrypted digital recorders.
6. To show your transcription only to the relevant individual who is involved in the research project.
7. If you find that anyone speaking on a recording is known to you, we would like you to stop transcription work on that recording immediately and inform the person who has commissioned the work.



Declaration

I have read the above information, as well as the Guidelines for Transcribers, and I understand that:

1. I will discuss the content of the recording only with the individual involved in the research project
2. If transcribing digital recordings – I will only accept files provided on an encrypted memory stick
3. I will keep the tapes and/or encrypted memory stick in a secure place when not in use
4. I will not use external storage programmes or website, such as Dropbox, for transferring recordings as it does not meet any of the University's data security guidelines
5. When transcribing a recording I will ensure it cannot be heard by others
6. I will treat the transcription of the recording as confidential information
7. I will adhere to the requirements detailed in the Guidelines for transcribers in relation to transcribing recordings onto a computer and transcribing digital audio files
8. If the person being interviewed on the recordings is known to me I will undertake no further transcription work on the recording

I agree to act according to the above constraints

Your name [redacted]

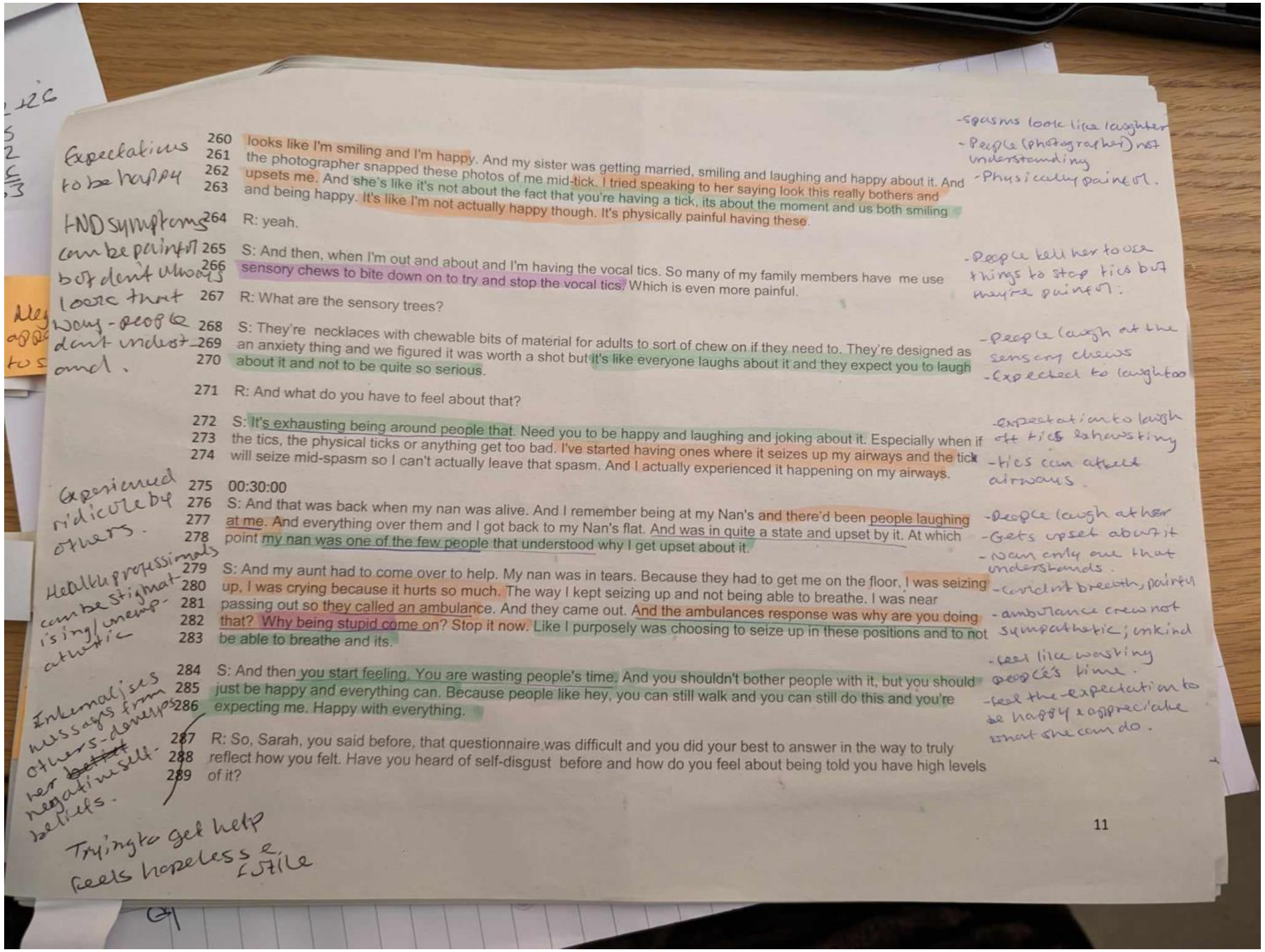
Signature [redacted]

Date 27·11·23.

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please stop the transcription and raise this with the researcher as soon as possible.

Appendix J

Transcript Coding Example (pseudonymised)



looks like I'm smiling and I'm happy. And my sister was getting married, smiling and laughing and happy about it. And the photographer snapped these photos of me mid-tick. I tried speaking to her saying look this really bothers and upsets me. And she's like it's not about the fact that you're having a tick, its about the moment and us both smiling and being happy. It's like I'm not actually happy though. It's physically painful having these.

R: yeah.

S: And then, when I'm out and about and I'm having the vocal tics. So many of my family members have me use sensory chews to bite down on to try and stop the vocal tics. Which is even more painful.

R: What are the sensory trees?

S: They're necklaces with chewable bits of material for adults to sort of chew on if they need to. They're designed as an anxiety thing and we figured it was worth a shot but it's like everyone laughs about it and they expect you to laugh about it and not to be quite so serious.

R: And what do you have to feel about that?

S: It's exhausting being around people that. Need you to be happy and laughing and joking about it. Especially when if the tics, the physical ticks or anything get too bad. I've started having ones where it seizes up my airways and the tick will seize mid-spasm so I can't actually leave that spasm. And I actually experienced it happening on my airways.

00:30:00

S: And that was back when my nan was alive. And I remember being at my Nan's and there'd been people laughing at me. And everything over them and I got back to my Nan's flat. And was in quite a state and upset by it. At which point my nan was one of the few people that understood why I get upset about it.

S: And my aunt had to come over to help. My nan was in tears. Because they had to get me on the floor. I was seizing up. I was crying because it hurts so much. The way I kept seizing up and not being able to breathe. I was near passing out so they called an ambulance. And they came out. And the ambulances response was why are you doing that? Why being stupid come on? Stop it now. Like I purposely was choosing to seize up in these positions and to not be able to breathe and its.

S: And then you start feeling. You are wasting people's time. And you shouldn't bother people with it, but you should just be happy and everything can. Because people like hey, you can still walk and you can still do this and you're expecting me. Happy with everything.

R: So, Sarah, you said before, that questionnaire was difficult and you did your best to answer in the way to truly reflect how you felt. Have you heard of self-disgust before and how do you feel about being told you have high levels of it?

11

Expectations to be happy

FND symptoms can be painful but don't always look that way - people don't understand.

Experienced ridicule by others.

Health professionals can be stigmatising/unempathetic

Internalises messages from others - develops her ~~belief~~ negative self-beliefs.

Trying to get help feels hopeless & futile

-spasms look like laughter
-People (photographer) not understanding
-Physically painful.

-People tell her to use things to stop tics but they're painful.

-People laugh at the sensory chews
-Expected to laugh too

-Expectation to laugh off tics exhausting
-tics can affect airways.

-People laugh at her
-Gets upset about it
-Nan only one that understands.
-couldn't breath, painful
-ambulance crew not sympathetic; unkind

-feel like wasting people's time.
-feel the expectation to be happy & appreciate what she can do.

Appendix K

Personal Experiential Themes with Narrative Summary Example (pseudonymised)

Feelings of inferiority significant precursor to self-disgust *(Jane)*	
- Childhood abuse- invalidated, dismissed, dominated. Taught she was inferior p.10 - Belittling messages through childhood abuse p.4 - Childhood emotional abuse- told “you don’t matter” p.4 - Blamed and punished for requiring care p.7 - Early experiences of inferiority, being treated like she was invisible made her feel unworthy p.18 - Felt inferior to other students p.7 - Internalised and believed what others said p.22 - Such low self-worth would allow herself to be abused by others- “others’ punch bag” p.23 - Internalised the messages from other- lowered confidence p.9 - Internalised messages from others p.11 - Low self-worth resulting from child abuse lead to abusive relationship where pattern repeated and self-disgust is perpetuated p.10 - Others’ abuse triggered self-disgust & low self-worth > gets into abusive relationship where she was manipulated > perpetuated own self-disgust p.11 - Wouldn’t challenge the abuse due to self-disgust and low self-confidence p.9 - Attempts to defend herself met with challenge- confirms low self-worth and self-disgust p.16-17 - Self-disgust resulted from emotional abuse p.9	Jane spoke about experiencing persistent and pervasive bullying and abuse throughout her life. Of note, early abuse involved belittling and domination which forged the belief that she was worthless. She reflected on experiences of feeling invisible to people, such as when professionals spoke to her mum rather to her which made her feel inferior. Developed strongly held belief that she is inferior to others, that she of low worth. The patterns of abuse repeated when she entered into abusive relationships. Eventually the messages were internalised. Her self-worth was so low, she assumed that the negative things people said about her were true. Admitted during the interview that this is what eventually developed her self-disgust.

Disgust & avoidance from others perpetuates self-disgust *(Jane)*	
- Has multiple chronic health conditions- has big impact on her life p.3 - Bullied at school for having health conditions p.6 - Stemmed from disgust-based bullying p.17 - No one would want to go near her because her health conditions make her disgusting p.10 - Disgust-based responses from others for health conditions- introduced shame around health problems p.7 - Disgust responses worry and anger her p.21 - Had seizures at school and was bullied for them p.6 - Internalised disgust responses p.20	Jane had multiple health conditions from birth and she was bullied relentlessly for them. The bullying was often disgust-based responses for being wet due to bladder problems and ridicule from the seizures. No one wanted to go near her at school- confirming to her she must be disgusting and thus avoided. This introduced shame for her health conditions. The negative, and disgust-based reactions she received were worrying and angering but eventually became internalised, contributing to her self-disgust.

Self-disgust creates shame and disgust of seizures *(Jane)*	
• Seizures add insult to injury p.14 • Secretive about seizures due to shame p.7 • Avoided events with people who didn't know she had seizures to prevent them finding out p.7 • Sighs when reflecting on people finding out about seizures- because of the pain and discomfort of the shame p.7 • Full-blown seizure symptoms "horrible" p.19 • Seizures adding to the shame- embarrassed of them as they could be unpredictable and always visible p.7 • People said she is disgusting when having a seizure p.20 • Disgust of the seizure- compelled to apologise to someone for having to witness it p.15 • Terrible verbal abuse during seizures p.21 • Others' responses to seizures in public affect her self-esteem. P.15 • Disgust of seizures come from lack of understanding by others p.22	Jan felt the seizures just added insult to injury regarding her health problems. The shame and disgust she felt for herself during a seizure drove her to be secretive about the seizures and avoided going out to prevent people finding out about them. However, seizures were unpredictable and therefore could not be hidden which intensified shame around them- could not prevent other people seeing her in vulnerable, "horrible" state. Having seizures in public was difficult as people often did not understand them or she received verbal abuse during seizures. Remaining aware meant she could see herself be vulnerable and have the knowledge of how others perceive her, intensifying the self-disgust. Had such shame and disgust for herself during a seizure, she said she apologised to someone for them having to witness her seizure. Sighing while reflecting on this- indicative of frustration and difficulty of her experiences.

Self-disgust experienced as belief and emotional experience *(Jane)*	
• Self-disgust enduring, lifelong emotions p.17 • Self-disgust always been there p.18 • Self-disgust is self-blame p.9 • Self-disgust is sense of not liking self p.9 • Paranoia and sense of inferiority p.9 • Vicious cycle of low mood & self-disgust p.19 • Self-disgust associated with other negative self-directed emotions p.14 • Gets angry- lashes out p.19 • Self-disgust made her hateful p.22 • Sighing when speaking about self-disgust – expression of anger/ frustration/disappointment for what she has put up with P.9	Self-disgust was described as both a long-term perception and belief about the self, and an intense discrete emotional experience. Self-disgust was difficult for Jane to describe just she recognised it as an overwhelming sense of not loving herself, self-blame, paranoia and inferiority. She knew she experienced more self-disgust when her mental health was overall worse, but this became a vicious cycle. The anger and intensity of self-disgust would drive anger, and Jane would violently lash out- becoming irritable and punching walls. She recognised self-disgust as associated with other negative self-directed emotional- distinct but experienced with a general sense of negativity. During reflection on self-disgust, Jane sighed, possibly as an expression of anger, frustration or disappointment for having this feeling for herself.

Attempting to be invisible to protect from the disgust *(Jane)*	
• Doesn't look in the mirror, can't bear to see her image- avoidance p.11	To protect herself from the disgust of others due to belief that she is disgusting, she

- Paranoid about her own visibility to others p.12 - Uses clothes to try and make herself invisible p.12 - Would wear dirty, ripped clothes due to self-disgust p.12 - Felt so worthless, wouldn't take care of own appearance p.12 - Self-fulfilling prophecy- disgust for appearance but neglects and makes appearance more "disgusting" p.12 - Self-disgust makes her not want to care for herself p.19	attempts to make herself invisible. She spoke about wearing dirty, ripped clothes (could be considered "disgusting" clothes) possibly in effort to draw attention away from her. Would also try to wear dark and oversized clothes to hide her body. Didn't make an effort to maintain her appearance and she had such revulsion for herself that she didn't feel worthy of caring to herself. Becomes self-fulfilling prophecy as, as Jane admitted, this was ineffective way of coping and did not make her invisible and going out in public in unkempt state increases the risk of eliciting disgust responses from others.

Vulnerability is an elicitor of self-disgust *(Jane)*	
- More self-disgust when feeling more vulnerable p.19 - Disgust at her own vulnerability- no love or respect for herself p.9 - Disgust for bullying and abuse she went through p.9 - Remains aware during seizures p.5 - Seeing self in vulnerable state during seizure elicits self-disgust- doesn't want people near her p.16 - Self-disgust from seizures so intense she wishes the would kill her p.14 - Needing help from others is awful- embarrassment, disgusted p.14 - "out of body" dissociation from body during seizure. Can "see" herself having the seizure-in a vulnerable state p.16 - Disgust at someone having to see her in vulnerable state p.14 - Disgusted at her appearance p.9 - Looking in the mirror reminded her of her past trauma/ older version herself she feels disgust for p.9 - Disgust at her image in mirror- reminder of her trauma & disgust she had for herself as a child p.11 -	Examples of times Jane felt self-disgust often involved times when she was physically vulnerable. She's so disgusted in herself and her body during times of vulnerability that she couldn't hold compassion or respect for herself. Jane spoke of repulsion at her reflection in the mirror, saying she would see herself as a child- the girl who was obese, unwell and was bullied relentlessly for it- i.e. a very vulnerable version of herself and she was disgusted to see it. Not reflecting on her current appearance- perhaps as a way of separating her current self from the disgust. FDS is a very visible display of her vulnerability and is so disgusted by herself during them, she wished they would kill her. She described dissociating from her body during seizures, and "seeing" what she looks like during the seizure with elicits strong repulsion for her body- describing it as disgusting and embarrassing in its vulnerable state. Describing a time where she needed support after falling in the shower, she reflecting on it being so awful and shameful due to someone having to see her being physically vulnerable- naked and visible. Already repulsed by her own body, having someone see it in a vulnerable way triggers stronger repulsion.

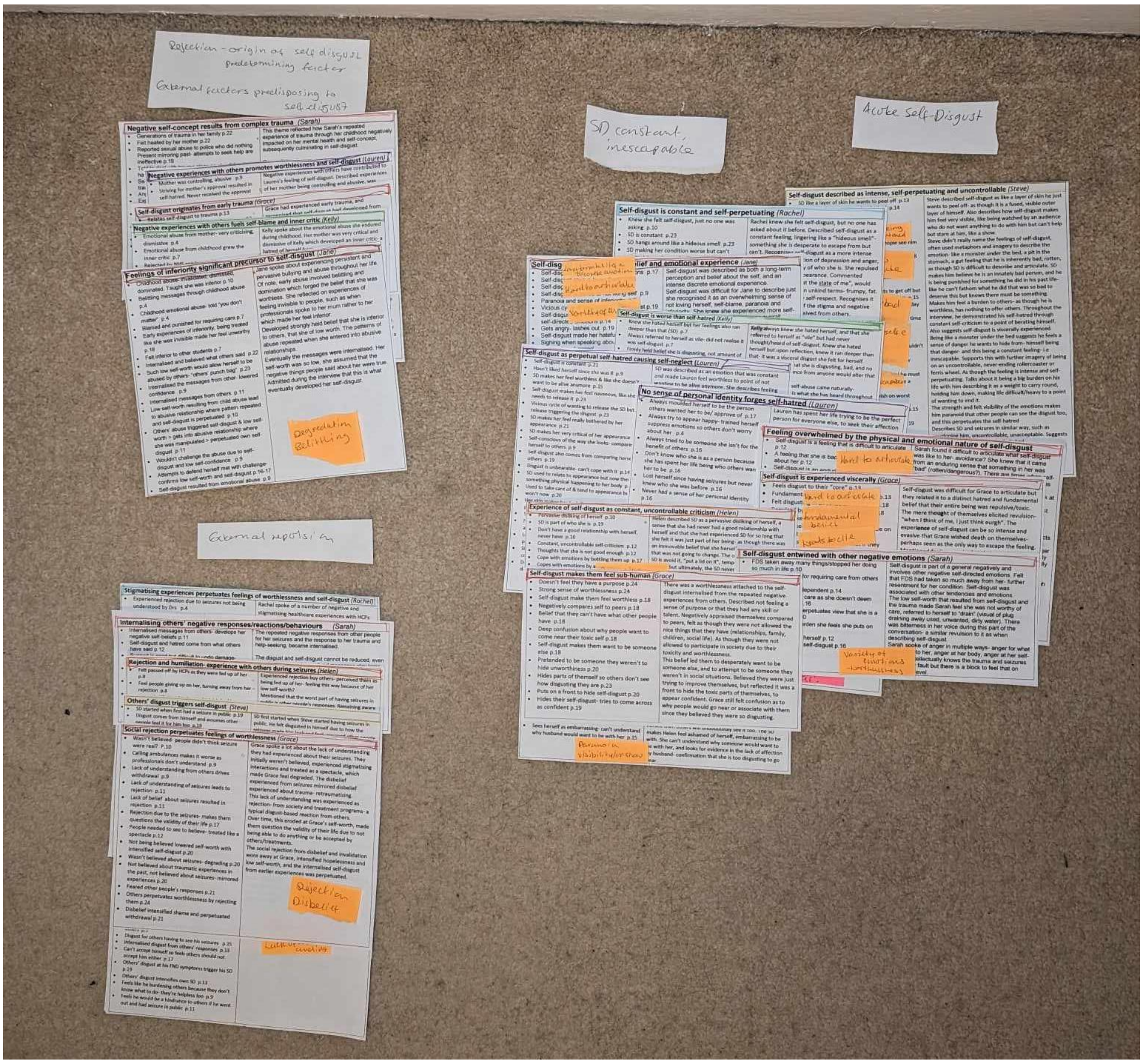
So disgusted, just wants to be invisible from others *(Jane)*	
• Self-disgust and paranoia trigger anxiety p.13 • “out of body” experience during seizures are horrible because can see herself in vulnerable “disgusting” state and aware/sees others’ responses which perpetuates self-disgust and just wants to be left alone p.17 • Feels so disgusted/embarrassed during seizure just wants to be left alone p.17 • Shame of having disgust makes her want to die p.20	Jane described paranoia for people seeing- a worry that people would see how disgusting she truly is, and thus wanted to be invisible. The paranoia kept her vigilant to other people in public, to see how they appraised her and the anxiety made her feel that everyone was looking at her and thinking that she was disgusting. When having a seizure, Jane wanted to be left alone, even if people were supporting her, due to disgust and embarrassment of what her body does during a seizure, as though she wants to protect others from the toxicity of her body and herself from their potential reactions and thus potentially perpetuating feeling of self-disgust. In an example of feeling self-disgust following a seizure in public, Jane said she just wanted to “curl up and die from the embarrassment.” The intensity of self-disgust makes Jane wish death upon herself and indicated the desire to be away and invisible from people, with death being the ultimate form of invisibility.

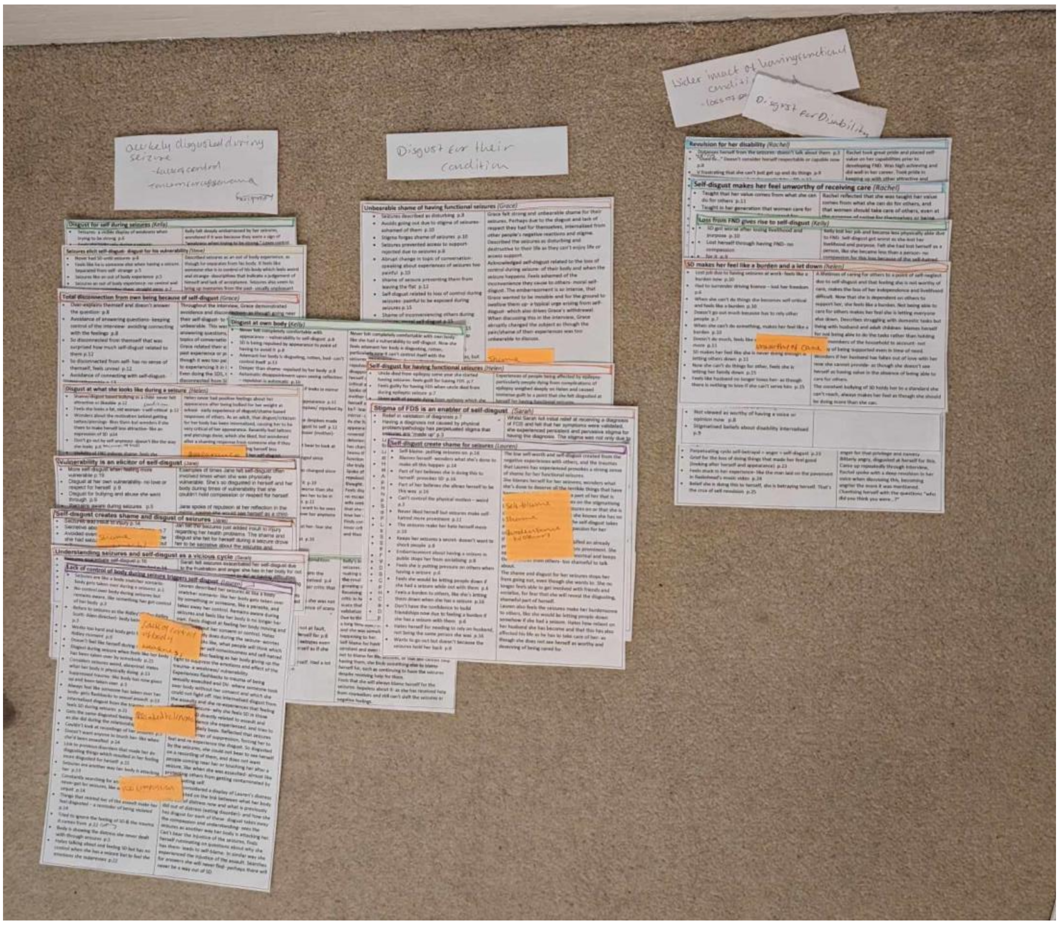
Avoidance and withdrawal – protection from the disgust *(Jane)*	
• Avoidance to protect from self-disgust p.11 • Can’t hide the seizures, so hides herself p.8 • Doesn’t want to draw attention to herself due to shame and inferiority p.7 • Bottled up anger from self-disgust- withdrew so no one could see the emotional vulnerability p.22 • Avoidance due to fear of others’ disgust due to having disgust for herself p.13 • Fear at being looked at by others pushes her to lock herself away p.13 • Yearns for connection but connection is too risky – prefers to be alone p.13 • Being single/alone preferable so doesn’t have to be near or vulnerable with someone again p.24 • Quick avoidance of reflecting on avoidance or worry about visibility p.12	Strong theme of avoidance to protect self from disgust. The fear of being seen by others and her disgusting self, drove her to lock herself away as she could not bear their disgust. Attempted to hide seizures from others for a long time to prevent ridicule and disgust responses, but seizures are unpredictable and inevitably can’t be hidden- so she avoided attending social events. She didn’t want to draw attention to herself so kept emotions and difficult experiences (near-death experiences) to herself. Preferred to withdraw so she could express emotions by herself, rather than risk a response from someone else. Jane spoke about wanting a relationship but feeling too vulnerable in her self-disgust and past experience to risk getting close to someone. Being alone was preferable to having a relationship- where she would have to reveal her vulnerable, “disgusting” self.

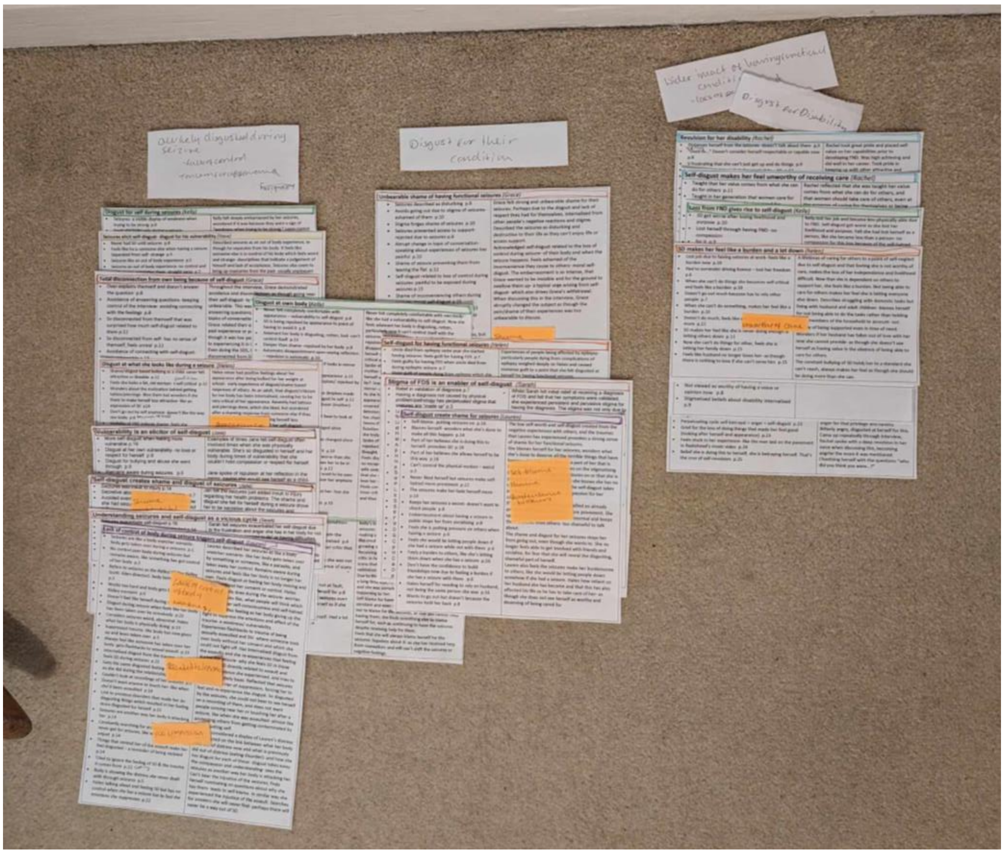
Dissociation from the unbearable self-disgust *(Jane)*	
- Dissociation from the memories p.4 - Self-disgust was so unbearable- dissociated from the feeling- froze p.23 - Emotion on bad days is unbearable so dissociates p.19 - Hasn't thought about self-disgust before due to avoidance or dissociation p.8 - "used to" – dissociated from self-disgust in interview. Not acknowledging it in the present p.11 - Always trying to put positive spin on reflection- the reality of the current feeling of self-disgust too much to bear P.13	Throughout the interview, Jane indicated dissociation from self-disgust, emotions in general and memories. She spoke from the start about dissociating from the memories of abuse as they were too painful to remember. Speaking about an example of self-disgust, she spoke about being "numb", "not knowing what to do"- as though the feeling of self-disgust was so unbearable it drove her body to numbness to protect itself. Throughout the interview, Jane spoke of difficult feelings and experiences in past tense. She couldn't acknowledge the experience self-disgust in the present, despite recently completing SDS where she scored in extremely highly for self-disgust. It was as though she needed to distance herself from the emotion- in a similar she distances from others to protect herself from disgust. She also often put a positive spin on things, or giving people the benefit of the doubt when reflecting on difficult experiences with others possibly due to it being too unbearable to think of others having disgust for her, or for her to continue to have the difficult feelings of self-disgust.

Appendix L

Group Experiential Theme Sorting




Disgust for their condition
Wider impact of having functional condition
Disgust for Disability
Revulsion for her disability (Rachel)
Self-disgust makes her feel unworthy of receiving care (Rachel)
Loss from FND gives rise to self-disgust (Kelly)
SD makes her feel like a burden and a let down (Helen)
Unbearable shame of having functional seizures (Grace)
Disgust at own body (Kelly)



Appendix M

Participant Representation Matrix

	Grace	Sarah	Jane	Rachel	Steve	Laruen	Helen	Kelly
Understanding the origin of self-disgust as based in rejection								
Historical abuse laying the foundation for self-disgust	SD originates from early trauma	Negative self-concept results from complex trauma	Disgust and avoidance from others perpetuates SD Feeling of inferiority significant precursor to SD			Negative experiences with others promotes worthlessness and SD	Experience of SD as constant, uncontrollable criticism Disgust at what she looks like during a seizure	Negative experiences with others fuels self-blame and inner critic
Others' repulsion introducing shame and disgust for FDS	Social rejection perpetuates feelings of worthlessness	Internalising others' negative responses/reactions/behaviours Stigma of FDS is an enabler of self-disgust	Disgust and avoidance from others perpetuates SD	Stigmatising experiences perpetuates feelings of worthlessness and SD	Others' disgust triggers SD	Negative experiences with others promotes worthlessness and SD	Rejection and humiliation-experience with others during seizures	Negative experiences with others fuels self-blame and inner critic
Experiencing self-disgust as intense and inescapable								
A chronic and unchangeable belief	SD is experienced viscerally	Feeling overwhelmed by the physical and emotional nature of SD	SD experienced as belief and emotional experience	SD is constant and self-perpetuating	SD described as intense, self-perpetuating and uncontrollab	No sense of personal identity forges self-hatred	Experience of SD as constant, uncontrollable criticism	Disgust at own body SD is worse than self-

					le	SD as perpetual self-hatred cause self-neglect		hatred
An intense emotional experience	SD makes them feel sub-human SD is experienced viscerally	SD entwined with other negative emotions Feeling overwhelmed by the physical and emotional nature of SD	Vulnerability as an elicitor of SD SD experienced as belief and emotional experience	SD is constant and self-perpetuating	SD described as intense, self-perpetuating and uncontrollable	SD as perpetual self-hatred cause self-neglect		SD is worse than self-hatred Disgust at own body
Understanding the relationship between self-disgust and FDS								
Seizures and self-disgust: A vicious cycle	Unbearable shame of having functional seizures	Understanding seizures and SD as a vicious cycle	SD creates shame and disgust for seizures Vulnerability as an elicitor of SD Disgust and avoidance of others perpetuates SD (quotes		Seizures elicit SD-disgust for his vulnerability	Negative experiences with others promotes worthlessness and SD Lack of control of body during seizures trigger SD	Disgust at what she looks like during seizure Rejection and humiliation-experience with others during seizures	Disgust at own body Disgust for self during seizures

			from p20)					
Deviation from the medical norm: Disgust for FDS	Unbearable shame of having functional seizures			Revulsion for her disability	Seizures elicit SD-disgust for his vulnerability	SD creates shame for seizures SD as perpetual self-hatred cause self-neglect Lack of control of body during seizures trigger SD	SD for having functional seizures	Disgust at own body Negative experiences with others fuels self-blame and inner critic
A drain and a burden: Self-disgust related to disability		SD entwined with other negative emotions Internalising others' negative responses/reactions/behaviours		Revulsion for her disability SD makes her feel unworthy of receiving care Self-disgust is constant, and self-perpetuating	Seizures elicit SD-disgust for his vulnerability	SD as perpetual self-hatred cause self-neglect	SD makes her feel and burden and let down Disgust at what she looks like during seizure	Loss from FND gives rise to SD
Suppression and seclusion- attempting to cope with self-disgust								

Avoiding exposure through social withdrawal	Withdrawal - protecting self and others from disgust	Withdrawal- a mechanism of protecting self and others	Avoidance and withdrawal - protection from the disgust	Revulsion for her disability	Withdraws to protect self and others from disgust	SD as perpetual self-hatred cause self-neglect		Disgust for self during seizures
Emotionally suppressing the unbearable self-disgust	Total disconnection from own being because of SD Self-disgust makes them feel sub-human	Difficulty engaging with the idea of SD Negative self-concept results from complex trauma	Dissociation from the unbearable SD Avoidance and withdrawal - protection from the disgust	Revulsion for her disability	Tries to block out SD to protect himself from it	Detachment - coping with the unbearable feeling of SD No sense of personal identity forges self-hatred Lack of control of body during seizures trigger SD	Experience of SD as constant, uncontrollable criticism	
Hiding oneself to deny reality of self-disgust	Self-disgust is experienced viscerally	Becoming invisible- protecting against the toxicity of the self	Attempting to be invisible to protect from the disgust					Disgust at own body

Appendix N

Audit Checklist

(Adapted from Tracy, 2010)

Worthy Topic	
1. Is the topic of research relevant and justified?	**Yes** / Partially / No
Rich Rigor	
2. Does the study include clear theoretical constructs?	**Yes** / Partially / No
3. Does the study comprise of rich data?	**Yes** / Partially / No
4. Does the study describe the sample and provide demographic information?	**Yes** / Partially / No
5. Does the study describe how self-disgust is conceptualised?	**Yes** / Partially / No
6. Does the study sufficiently justify and describe the data analysis process?	**Yes** / Partially / No
7. Has the data been thoroughly coded adhering to the chosen analysis (IPA)?	**Yes** / Partially / No
8. Has the researcher engaged in a reflexive process to define personal and group experiential themes?	**Yes** / Partially / No
Sincerity	
9. Does the researcher record self-reflexivity including values, biases, and personal experiences of FDS and/or difficult emotions and self-disgust?	**Yes** / Partially / No
10. Does the research address the chosen methods limitations?	**Yes** / Partially / No
Credibility	
11. Are participant quotes evidenced for themes and subthemes?	**Yes** / Partially / No
12. Has the researcher engaged in appropriate supervision to support research quality?	**Yes** / Partially / No
Resonance	
13. Are the research findings documented clearly and insightfully?	**Yes** / Partially / No
Significant Contribution	
14. Does the study extend current knowledge of FDS and self-disgust?	**Yes** / Partially / No
15. Does the study provide implications for clinical practice?	**Yes** / Partially / No
16. Does the study make recommendations for research?	**Yes** / Partially / No
Ethical	
17. Does the research have ethical approval?	**Yes** / Partially / No
18. Are the participants' experiences appropriately represented?	**Yes** / Partially / No
Meaningful Coherence	
19. Does the study achieve its reported aims?	**Yes** / Partially / No
20. Does the study relate its findings with previous research?	**Yes** / Partially / No

Name of Researcher Lucy Eaves **Researcher Signature** L.A.Eaves

Name of Auditor Erin Evans **Auditor Signature**

Appendix O

The Consolidated Criteria for Reporting Qualitative Studies checklist (COREQ) (Tong et al., 2007)

No Item	Guide questions/description	Location	Checked by independent reviewer (EE)
Domain 1: Research team and reflexivity			
Personal characteristics			
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Procedure,	✓
2. Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Appendix P	✓
3. Occupation	What was their occupation at the time of the study	Reflexivity, Appendix P	✓
4. Gender	Was the researcher male or female?	Appendix P	✓
5. Experience and training	What experience or training did the researcher have?	Reflexivity, Appendix P	✓
Relationship with participants			
6. Relationship established	What did the participants know about the researcher?	Appendix D & H	✓
7. Participant knowledge of the interviewer	Was a relationship established prior to study commencement? *e.g. personal goals, reasons for doing the research*	Research quality, Appendix D, C, H,	✓
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *e.g. Bias, assumptions, reasons and interests in the research topic*	Reflexivity, Appendix P & Q	✓
Domain 2: Study design			
Theoretical framework			
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Research Design	✓

Participant selection			
10. Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participants	✓
11. Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*	Procedure	✓
12. Sample size	How many participants were in the study?	Participants, Procedure	✓
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Procedure	✓
Setting			
14. Setting of data collection	Where was the data collected? *e.g. home, clinic, workplace*	-	X
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Procedure, Appendix C	✓
16. Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Participants, Table 2	✓
Data collection			
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	PPI, Materials, Procedure, Appendix C	✓
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	-	X
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Procedure	✓
20. Field notes	Were field notes made during and/or after the interview or focus group?	Reflexivity, Appendix Q	✓
21. Duration	What was the duration of the interviews or focus group?	Procedure	✓
22. Data saturation	Was data saturation discussed?	Participants	✓
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	-	X

Domain 3: analysis and findings			
Data analysis			
24. Number of data coders	How many data coders coded the data?	Data Analysis	✓
25. Description of coding tree	Did authors provide a description of the coding tree?	Data Analysis, Appendix K	✓
26. Derivation of themes	Were themes identified in advance or derived from the data?	Data Analysis	✓
27. Software	What software, if applicable, was used to manage the data?	-	X
28. Participants checking	Did participants provide feedback on the findings?	-	X
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.*g. participant number*	Results, Appendix R	✓
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Results, Discussion	✓
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results	✓
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results, Discussion	✓

Appendix P

Reflexive Statement

I (LE), the lead researcher, am a cisgender female, in my late twenties who does not have experience of a long-term health condition or functional symptoms. As a trainee clinical psychologist, with an interest in clinical health psychology, I have experience of working with people who have mental and physical health problems. My previous qualifications are a BSc in Psychology and MSc in Clinical Neurology. Although I have come across people with functional symptoms through my work, I have never worked closely with someone who has FDS.

My professional experience as a psychologist within clinical health settings had its strengths as I did not hold prior assumptions or expectations about people’s experiences of FDS or of self-disgust. My training equipped me to be open and curious about people’s experiences which complimented the IPA methodology of seeking to understand the participant’s truth from their perspective. However, at times in the early stages of recruitment, my lack of real-world experience with FDS felt like a limitation as I had limited awareness of the interpersonal and systemic issues facing pwFDS beyond what has been reported in research. I ensured to educate myself, take on-board feedback from experts and keep a reflective diary throughout the research process to maintain awareness of how my perspectives influenced the study.

Appendix Q

Reflective Diary Excerpts

Reflections on interviews:

Due to experiences during project planning, i.e. criticism and aversion to project and difficulty getting people on board with it, I felt quite apprehensive about interviewing people on their self-disgust. Even though I had a very good response to the initial screening questionnaire and had a lot of potential participants to interview, I worried about I would encounter further criticism in interviews. Initially, I felt tentative in interviews, not wanting to offend or cause distress in any way which stopped me from really digging into people's experiences, finding myself skirting over interesting topics quite quickly. However, participants were very open and willing to talk about their experiences. Reminding myself participants had opted to participate in interviews, provided informed consent and that I had made the option to withdraw very clear helped me to be more free and open in my line of questioning in interviews, while also being mindful and sensitive of how participants were responding emotionally to the questions.

Participant 2 chose to keep her camera off for the interview. She spoke so clearly and frankly about her experiences, even the most traumatic experiences of sexual violence. I noticed I had a reaction to this, and ppt must have noticed as well as she stopped to ask if I was okay and said she noticed my facial expression change. I was quick to reassure her but it might be helpful to acknowledge to the participant how difficult their experiences have been. However, I want to try to avoid going into therapist mode with too much summarising, although it is difficult with the style of interview as it does feel very clinical given the topic.

Participant 3 referred to self-disgust in the past tense throughout the interview and seemed to avoid answering questions about the feeling of self-disgust in the present, even denied it. Initially came out the interview wondering if I had any material to go on from this interview. On reflection, this might be how she copes with self-disgust, like its too painful to acknowledge in the present. I'm learning more about self-disgust as I go along these interviews, and this has reminded me to also keep an eye on what is not being said.

Participant 4- I felt a bit confused about what some of this participant spoke about at times, referring to her arrogance in her lack of disability prior to FDS. I've listened to the audio a few times to make sense of this. I was not understanding in the interview, and I wonder if this is because having done a few interviews already I had begun to create an idea about the experience of self-disgust and was bringing this preconception into the interview. This ppt's experience of self-disgust is more on a moral level, rather than bodily which I haven't come across yet. Going forward, I need to be more mindful of parking assumptions and pre-conceptions from previous interviews.

Reflection during analysis:

I'm struck by the magnitude of trauma these participants have endured. I was certainly naïve to this going into the project, but it perhaps makes sense that horrific experience lead to horrific and intense emotions. Going through transcripts, I can hear participants' revulsion in their voices- like this blunt, painful self-hatred or intense anger in participant 4. I notice my own visceral reaction this. All this is quite upsetting and I'm having to be mindful of this. I'm noticing I need regular breaks and separation from the transcripts and this has allowed me to come back and engage productively with the analytic process.

Participant 5 really struggled to articulate themselves in the their interview, and I'm noticing the same block during the analysis. He spoke about emotional and behavioural avoidance, and trying to block self-disgust and I feel this might be why he struggled to express himself. But as a consequence, I'm finding it hard to draw conceptual interpretation. It's interesting to reflect on this as in clinical practice, I could reflect on the relationship dynamic in supervision and with the patient, and work with them on this in therapy. As a researcher, I notice I have to work through this block, and realise that forms part of the interpretation.

I'm having to remind myself to stay in the researcher position throughout this analysis. I'm noticing my temptation to formulate and apply psychological theory. I have to divert myself back to the participant's experience, sticking with IPA philosophy.

Similarly to interviews, I am noticing the influence of my analysis of previous participants on the current analysis. I'm finding myself drawn to similar experiences, and grouping statements in a similar way. I'm noticing as I'm going through ppt 8's analysis that I'm finding the PET grouping difficult due to this. I am reminding myself to bracket and re-focus on her experiences.

Appendix R

Selection of additional participant quotes

Group Experiential Theme	Sub-theme	Quote
Understanding the origin of self-disgust as based in rejection	Historical abuse laying the foundation for self-disgust	- *Your mum is the person who's meant to care for you and nurture you and look after you, erm and when you don't have that, you lose your self-worth and your confidence* (Lauren). - *I still feel disgusted at the thought of what happened* [the rape], *I just feel. The thing is its like erm, I, it takes me about an hour to have a shower because I literally have to scrub my skin to death* (Helen). - *Everyone would call me fat so… I never thought of myself as particularly attractive* (Helen). - *My therapist used to say it's not that you're disgusting it's that disgusting things happened to you. And I was like, oh no no no! Noo. And logically everyone else that can see that and think that but I can't apply that to me* (Grace). - *I knew I didn't particularly like myself. Growing up the way I did, I've always been taught that I'm not exactly a good person or there's these things about me that are bad and it's all my fault* (Sarah).
	Others' repulsion introducing shame and disgust for	- *Everyone laughs about it and they expect you to laugh…its exhausting* (Sarah) - *I just felt like a freak… like everyone was just coming in for a good look… like I was some part of an exhi-, some Victorian exhibition or something* (Helen) - *When you think health and safety hazard you think of things that haven't been cleared up properly, loose cable wires. Not a person… You're a danger to people around you and it's kind of hard to experience*

	FDS	*positive feelings about yourself when you're being told. You are literally a health and safety hazard which by definition is a danger to other people* (Sarah) - *I think other people have looked at me and thought (LAUGH)' he's a bit of a funny one that one, I will keep away from him'* (Steve) - *you've got two professionals there going "you're making this up, this is bullshit" and for a good while, I believed that* (Kelly) - *I've been into hospital after having seizures. I've been told I'm making it up even though I blacked out completely in front of them but because they couldn't see any physical trace on any of their* [machines]. *I had normal tests. They decided I was making it up.* (Sarah)
Experiencing self-disgust as intense and inescapable	A chronic and unchangeable belief	- *I wouldn't say I understand* [self-disgust], *I just know what I feel* (Sarah) - *I really feel like I am absolutely disgusting. Like really. Really really in every single way…. Its just I am disgusting at the core (points inwards to self)… When I think about me its just eurgh (repulsed expression and gesticulation)* (Grace) - *I used to think whatever I put on I was fat and I was frumpy and I never looked nice and I never, I never took, like I never made the effort, it was like I couldn't give a shit if I had like dirty rotten clothes or not clean clothes that were ripped and stuff… and I think… look at the state of you, sort yourself out' sort of thing and stuff and it was like Id wear clothes to the point where they'd literally fall off me and break* (Jane) - *It doesn't matter what anybody said I wouldn't be able to hear it because in my head I'm the way I think I am and that's it… slagging myself off or picking apart certain bits of my body and stuff just comes naturally and feels right which erm is weird, erm, but then also makes me question what NAME- (Partner) sees, so I'm like "why are you with me, I'm a horrible person", erm and "don't look at me I'm fat and vile", everything's*

		vile. (Kelly) - *Yeah this is all I know now so put this emotion onto your back and you're having to carry it and lug it around all the time and you can have days where it's not so bad to lug around and just cope and then there's other days when I think I'm not going to be able to carry that no more, I just can't cope with it.* (Steve) - *there's no way at the moment I can see myself never feeling disgusted in myself* (Steve).
	An intense emotional experience	- *It's like do you know when you have that feeling when you're a small child and if you've ever feel that there is something under your bed or something and you get like a worked up kind of thing and you get that feeling in your gut and it's horrible* (Steve) - *it just sort of is it envelops you…surrounds you… I think because some of this disgust, that's when I can get really bad about myself and its err a feeling you can't control… it over takes me in that way where I could, where I don't want to be here anymore* (Steve) - *I'll go through days where I can't physically look at myself. I get extremely frustrated about myself"* (Sarah). - *It is occasionally physical and I do end up feeling sick with how extreme the emotion gets. End up in tears then end up experiencing anger…And then when I experience anger it triggers a seizure, so It ends up in a whole spiral.* (Sarah) - *I've seen me during seizures and stuff pull chunks of my hair and that out… a lot of the time it was self-punishing because … erm at some points it was just pure rage, but I would never take my rage out on someone else, that anger's always angled towards myself* (Kelly) - *Seeing my body made me feel disgusting erm and also there would be times where I could see like a spike of my mother and there was one time in the bathroom I turned around, saw her face in the little mirror and I put my fist through the mirror* (Kelly).

Understanding the relationship between self-disgust and FDS	Seizures and self-disgust: A vicious cycle	- *I can't communicate with my body anymore* (Lauren). - *I must look like a crazy person, erm and that's really horrible, especially when you know, you wet yourself and things like that then you really do look like you're drunk*. (Helen) - *I felt disgusted in myself having to put them, to show them what I was going through… I didn't want anybody else to see that* (Steve). - *the seizures like clearly, clearly is triggering the emotion that maybe I should have been feeling about what had happened but again it makes me feel disgusting again because I'm remembering those moments* (Lauren) - *But then the seizures. Yeah that's another thing. Like that is really awful because you come out of them and I'm like it's really shameful. So i think if I relate it to them specifically then It's not very nice. Its not very nice to feel that I lose the control in front of other people And it is quite shameful* (Grace) - *I was physically having to use my arms to pull myself across the floor to be able to do anything…I was in tears it and I just hated the fact that I was doing it. And hated that I was even doing that… you end up feeling so negative about yourself that you're like. Why am I even here? What's the point?* (Sarah) - *I'm conscious I know I'm doing it and like I could be getting soaking.. in my head I'm like 'oh my god I'm making a mess' or erm I'm just, I just feel horrible doing it and it's embarrassing.* (Kelly)
	Deviation from the medical norm:	- *Like, I should be able to stop myself from having them even though logically it's not really something I choose. It's just something that happens.* (Sarah) - *because my body is done.(tearful). Everybody seems to think that it's psychosomatic. Yeah, okay that's fine. I don't have a problem with that. But how can my head do this to me? How do I get myself out of this then?*

	Disgust for FDS	*But you know, this is my own head doing this to me. Stop it, stop it now. You know.* (Rachel) - *it's like you don't want to talk about it or discuss it and that with people because it is disgusting,.. I just, I think I put it on myself… then it makes those feelings of disgust because its me putting that on myself and if I let myself believe that (*Lauren) - *And I don't know if I'll ever feel that, because even though I understand why I've got it or why I was more likely to get it, but there's still that part of me that cant not blame myself in some way* (Kelly)
	A drain and a burden: Self-disgust related to disability	- *I just want a brain and I want to use it, you know? But I'm worthless* (Rachel). - *I've gone from being a radiator to a drain, right? Yeah…I was doing my bit and I was helping and I was adding value to the world… And now I feel like I'm just taking it and taking and taking* (Rachel) - *what the heck is so special about me in my own head that makes me think that I wouldn't suffer? That I wouldn't be disabled?..So what would make me think that I possibly I'm gonna live a life and not be hurt, you know? And not experience, physical pain? So I'm very aware of how arrogant that thought process is. I give myself a hard time for the arrogance* (Rachel) - *You had a life, and now its gone… I suppose I am still grieving for the life that I had. I'm still grieving that* (Rachel) - *Yeah I do feel a hindrance, I feel like erm, yeah I feel like I'm in the way all the time and erm, I can't do things anywhere near where like I used to, so I think that does lead you to feel really bad about yourself* (Steve) - *I feel like I've lost myself and I've just become an illness and erm like a sponger of society*. (Kelly) - *you don't accept who you are and what you are now…so why should they accept you?* (Steve).

Suppression and seclusion- attempting to cope with self-disgust	Avoiding exposure through social withdrawal	- *I didn’t want people to see me having a seizure, erm just the thought of how I look when I’m in one* (Kelly). - *Like I don’t want to really be out there and where people don’t understand* (Grace) - *I used to avoid like going out to like social things… I always like try and keep it to myself because I was embarrassed in case it happens.* (Lauren) - *it was because of me that we split up but that’s because, because of me basically because I think I was no good for her because I wasn’t able to do what I could do and I just felt like I was in the way all the time…I felt I needed to protect her from me* (Steve)
	Emotionally suppressing the unbearable self-disgust	- *I feel I’m trying to protect myself and other people around me from the disgust…it’s the emotion that’s so deep* (Steve). - *you want to curl up into a ball and just, I think that’s more of a protective thing though … it’s like you try to protect yourself from harm but you know that harm’s not there, it’s really complicated* (Steve) - *Yes and that’s what I’ve been doing for a long time and like I said I think that’s why the seizures, I honestly do feel like that’s why I have the seizures now, but then they bring, like I said they bring it to the forefront and then it’s, it’s like a cycle, a constant cycle.* (Lauren) - *now my body’s like ‘I’ve had enough, my brain can’t take it no more’* (Lauren) - *Just. Oh gosh. I tend not to (laughs) [refer to her seizures]. I don’t refer to them. I don’t talk about them. I don’t tend to tell people much about this anyway.* (Rachel) - *Oh I used to bottle up so much; I mean I reckon I’ve had two nervous breakdowns before in my life… I sort of blocked everything and all of that… I feel numb, it was like I felt numb, I don’t know what to do* (Jane) - *It’s just not easy to acknowledge because we're always taught. We have to be all positive. We have to be all happy and laughy and jokey and smiley* (Sarah)

		- *I think if I'd have gone into the feeling too much it would've been too much… I had no connection with my body whatsoever when we began. I wouldn't go near it.* (Grace)
	Hiding oneself to deny reality of self-disgust	- *There are days where I physically cover the mirrors in my home. With sheets, so I don't have to* [look at myself] *because I just get so annoyed, so frustrated, and so upset that I physically end up nearly throwing up* (Sarah). - *I'd wear clothes that were three or four times too big or too small… cos I didn't want people looking at me. I'd always wear trousers and Id always wear black cos it was like they couldn't, I thought wearing black didn't show the size of me and then I actually realised well that's actually wrong* (Jane) - *Sorry, I'm wearing a hat. I'm having a bad hair day.* [wearing bucket hat, sunglasses and baggy clothes] (Grace) - *There are days I can't do those things because I can't stand to look in the mirror because it makes me feel sick of the way I've ended up with seizures and the way they're affecting me every day* [tearful] (Sarah) - *Well we don't have any mirrors, well we have mirrors in the house, the ones that are in the house are covered erm because I just couldn't look at myself anymore, it wasn't just, it wasn't just like the inner shame and how I'd felt before, it was like how physically my body was changing too… seeing my body made me feel disgusting* (Kelly) - *when I started not liking the mirrors, the full length one in the bedroom was the one that got covered first, erm and then it was slowly like 'oh I cant look into that one', or 'I cant look into that one'.* (Kelly)