Title: Experiences of Individuals with Functional/Dissociative Seizures with Healthcare Professionals: A Systematic Review and Thematic Synthesis

Category: Full Review

Authors: Lucy Eaves, Jane Simpson and Markus Reuber

Author Details:

- 1. Lucy Eaves, Clinical and Applied Psychology Unit, Cathedral Court, The University of Sheffield, 1 Vicar Ln, Sheffield City Centre, Sheffield S1 2LT. Email: <u>lucy.eaves@shsc.nhs.uk</u>.
- Jane Simpson, Division of Health Research, Health Innovation Campus, Lancaster University, Lancaster, LA1 4YT. Email: <u>j.simpson2@lancaster.ac.uk</u>; ORCID 0000-0001-5071-4077
- Markus Reuber, Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF. Email: <u>m.reuber@sheffield.ac.uk</u>; 0000-0002-4104-6705

Corresponding Author: Lucy Eaves, Clinical and Applied Psychology Unit, Cathedral Court, The University of Sheffield, 1 Vicar Ln, Sheffield City Centre, Sheffield S1 2LT. Email: <u>lucy.eaves@shsc.nhs.uk;</u> Phone: ; ORCID: 0009-0001-8924-1438

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Abstract

Objective: Research suggests people with functional/dissociative seizures (pwFDS) often experience challenging encounters with healthcare professionals (HCPs). PwFDS report communication problems, difficult relationships with HCPs and sub-standard care. However, no previous reviews have explored this issue from the perspective of pwFDS. Therefore, this systematic review aimed to explore pwFDS' experiences of their encounters with HCPs.

Methods: Four databases (Scopus, PsycINFO, CINAHL and MEDLINE) were systematically searched for peer-reviewed qualitative studies in February 2024. 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: The findings highlight a number of difficulties which pwFDS face in their encounters with HCPs. Three superordinate themes with five subthemes were developed: 'clinician uncertainty feeds patient uncertainty', 'not fitting into the model of medical illness', 'stigma fuelling negative experiences with HCPs'. Positive encounters were mentioned but these were reported in the minority of instances.

Conclusions: Findings highlight the difficult experiences pwFDS face in their encounters with HCPs. PwFDS experience uncertainty about their condition due to poor knowledge and stigmatising beliefs about FDS. Difficult encounters with HCPs are frequently experienced, which may lead pwFDS to avoid accessing medical support.

Practitioner Points

- Healthcare services must reduce patient uncertainty and provide training to address any discriminatory or stigmatising attitudes.
- Specialist services comprising multidisciplinary professionals are needed 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; psychogenic nonepileptic seizures

Introduction

Navigating healthcare systems and accessing medical treatments is a crucial part of living with a chronic health condition, 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).

Healthcare may be particularly difficult to access for patients with poorly understood health conditions, who may experience particularly high levels of stigma, discrimination and sub-standard care. Functional/Dissociative seizures (FDS) are one example of a condition of this nature (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 cognition, resembling a range of other neurological conditions but not associated with any structural or 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, for most experts, psychological interventions are the treatment of choice (Hingray et al., 2018). Recent reviews also suggest psychological therapy can reduce seizure frequency, severity and intensity, as well as

improve overall wellbeing and quality of life for pwFDS (Gaskell et al., 2023; Gaskell et al., 2024).

FDS typically have a significant impact on a person's life. 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). A history of trauma and adverse life experiences are also prevalent, with some studies reporting these to occur in over 90% of pwFDS (Jones & Rickards, 2021; Ludwig et al., 2018). 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 reflect these data, with participants describing 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); as well as there being a lack of awareness and understanding from others about their condition (Rawlings et al., 2016).

Previous systematic reviews have explored different issues and experiences of FDS. A review of participants' accounts of living with FDS, highlights 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 among 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 these were only explored as part of a wider synthesis. Consequently, there remain gaps in our knowledge of the studies to date exploring pwFDS' experiences with HCPs.

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 and 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' experiences with HCPs have been noted, they have 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. The present review seeks to answer the question: 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). The review applied a thematic synthesis of qualitative studies (Thomas & Harden, 2008).

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 pre-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 in February 2024 to identify literature published from 1st January 2000 until 1st February 2024. Date restrictions were applied in order to capture articles that reflect the more recent context of clinical practice and patient experiences. The full search strategy is available in Appendix A.

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 (members of the UKFNS emailing list). 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, grey literature was not consulted for this review.

Study Selection

Study selection was determined by the following inclusion criteria: peer reviewed journal articles written in English that explore people with FDS' encounters or interactions with healthcare professionals; studies that use a qualitative methodology for data collectionincluding interviews, focus groups and surveys with open ended/unstructured responses; studies that use a qualitative method of data analysis- including thematic analysis, interpretative phenomenological analysis, content analysis, narrative analysis, grounded

theory; mixed method studies that contain relevant and extractable qualitative data. Papers were excluded if: they were not written in English; a quantitative study; study or analysis of patients' experiences outside of healthcare services or evaluations of specific interventions; included people who did not experience functional seizures (i.e. FND without seizures, epilepsy or other neurological conditions); lacked quotes to support synthesis interpretation.

Screening

Following systematic searches, all studies were exported from each database and into a reference management system (EndNote) to identify duplicate entries and to perform a selection through systematic reading of titles and abstracts. Full-text articles of the titles that were not excluded were subsequently obtained and screened. Systematic searching and screening was conducted by the first author and a portion of the articles (50%) were ratified by an independent researcher 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 1). 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). 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. 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).

All studies were appraised by the lead researcher (LE), and two independent reviewers. 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 author (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 while 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). The nine additional papers were not picked up in the initial searches as the titles of the papers did not contain a key search term due to the studies having a broader focus on pwFDS' experiences, and therefore only containing a small amount of data relevant to the current research question.

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 were identified and highlighted during the coding stage of analysis to ensure that data were only coded once. One study also included HCPs' views (Read et al., 2020). Data provided by HCPs could easily be separated from patient data and excluded from the analysis. Three studies included people with epilepsy (Rawlings 2018a; Rawlings 2018b) and functional movement disorder (FMD) (Zeun et al., 2023). However, 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 1

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	United	Specialist	12	Psychogenic	Clinic	Semi-	Thematic	The relevant theme, 'Getting
al. (2012)	Kingdom	neurology	participants,	non-epileptic	consultations;	structured	analysis	answers' discussed participants'
		clinics across	aged 19-58. 8	seizures	HCPs not	interviews		endeavours to make sense of PNES
		3 centres	females, 4	(PNES)	specified			and managing unresolved questions
			males					and uncertainties
								Key quote: "Nobody seems to be
								able to put their finger on it. That's
								the frustrating bit."
Dickinson	Canada	Two major	5 participants-	Nonepileptic	Physicians	Semi-	Thematic	Relevant themes related to factors
et al.		hospitals	3 female, 2	seizures		structured	content	that had a beneficial or detrimental
(2011)			male; age 30-			interviews-	analysis	impact on illness experience, such
			50			adapted		as medical communication.
						McGill Illness		Key quote: "They just pretty much
						Narrative		write you off and say, 'You know
						Interview		you don't have epilepsy, go see
						Schedule		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	United	NHS clinical	9 women and	Psychogenic	Psychological	Semi-	'Data	Relevant themes: post-diagnostic
et al.	Kingdom	neuropsycholo	3 men, aged	nonepileptic	therapy	structured	driven'	limbo and uncertainty apprehension
(2014)		gy waiting list	17-64. 1-35	seizures		interviews	thematic	about therapy, and need for
			years seizure			and	analysis	validation.
			experiences			questionnaires		Key quote: "I feel I've been left in
								limbo."
Goldstein	United	27	21 females	Dissociative	Psychological	Semi-	Thematic	Four main themes related the
et al.	Kingdom	neurology/epil	and 9 males,	non-epileptic	therapy;	structured	framework	experience of receiving a diagnosis
(2021)		epsy services,	aged 18-80	seizures	Healthcare	interviews	analysis	and experiences of engaging in
		17 liaison	who had		professionals;			CBT as part of a large clinical trial.
		psychiatry/neu	participated in		neurologists;			Key quote: "I think because she'd
		ropsychiatry	the		CBT			[neurologist] seen part of one [a
		services and	randomised-		therapists			seizure] and she explained it in the
		18 cognitive-	controlled					way that we would talk. And she
		behavioural	trial					just really explained how it actually
		services						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	United	Neuropsychiat	9 participants,	Non-epileptic	Hospital;	Semi-	Interpretati	The relevant theme concerned
al. (2004)	Kingdom	ry outpatient	5 female, 4	seizures	doctors;	structured	ve	being accepted by others,
		clinics	male, aged		neurologist;	interviews	phenomen	particularly doctors.
								13

			30-65		consultant		ological	Key quote: "When I get taken to
					physician		analysis	hospital [] they 're very rude.[]I
								feel that they 're
								thinking that I put it all on"
Karterud	Norway	Specialist	10	Psychogenic	Health	Semi-	Systematic	Relevant themes related to 'transfer
et al.		hospital for	participants; 6	non-epileptic	personnel;	structured	text	of responsibility' from health
(2010)		epilepsy	female, 4	seizures	health	interviews	condensati	professionals to the participants due
			male aged 16-		providers;		on	to having a PNES diagnosis, not
			61		doctors			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	Norway	General	11	Non-epileptic	Health	Semi-	Systematic	Two relevant themes: Threatened
et al.		Hospital	participants,	seizures	professionals;	structured	text	self-image, being believed and
(2015)			aged 14-24		doctor;	interviews	condensati	belief in oneself and getting an
			7 female		healthcare		on	explanation that makes sense.
			participants		providers			Key quote: "As long as others
			aged 19-24					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	participants,	attack disorder	consultant;	Association	Associatio	legitimacy and medicalization of
un (2020)	C	clinics	aged 34-64	(NEAD)	doctor;	Narrative	n Narrative	NEAD: the plausibility of stress-
			-		neurologist	Interview	Interview	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	United	Routine	5 female	Non-epileptic	Doctors;	Free	Free	The relevant theme explored how
al. (2022)*	Kingdom	hospital	participants,	attack disorder	registrars	Association	Associatio	participants experienced their
		clinics	aged 34-64			Narrative	n Narrative	diagnostic journey.
						Interview	Interview	Key quote: "They do not
								understand NEAD – nobody I have
								met from even doctors, even at
								my surgery they've never seen it."
Pretorius	South	Epilepsy unit	10	Psychogenic	Hospital;	Semi-	Thematic	Two relevant themes; inexpert
	Africa	at a private	participants; 8	non-epileptic	doctor;	structured	analysis	health providers as a barrier to

(2016)		hospital	females, 2	seizures	paramedics;	interviews		diagnosis, and knowledgeable
			males; aged		psychologists;			healthcare providers as a facilitator
			between 19-		neurologist;			to diagnosis of PNES.
			51		healthcare			Key quote: "Once I went to Doctor
					providers;			B. He helped me through it, he was
					psychiatrist			a good doctor, always looked after
								<i>me.</i> "
Pretorius	South	Epilepsy unit	10	Psychogenic	Medical	Semi-	Thematic	Medical professionals were seen as
&	Africa	at a private	participants; 8	non-epileptic	professionals-	structured	analysis	a challenge and a resource
Sparrow		hospital	females, 2	seizures	neurologists,	interviews		following diagnosis on the mirco-
(2015)*			males; aged		psychologists,			and macrosystem level.
()			between 19-		psychologists			Key quote: "Some of them were
			51		and first			really rude and otherwise it's
					responders			just doctors that they almost
					(emergency			make you feel like you're the
					care			problem."
					technicians)			
Rawlings	United	Membership-	19	Psychogenic	Nurses;	Written	Thematic	Two relevant themes concerning
et al.	Kingdom	led	participants,	nonepileptic	healthcare	narratives	analysis	participant's perceptions of others'
(2017)		organisations	16 females	seizures	professionals;	based on		reactions to their diagnosis and lack
		for individuals	and 3 males,		paramedics	specific		of understanding amongst HCPs.
		experiencing	aged 20-69			prompts from		Key quote: "We have a participant
		seizures and				the researcher		who's mum has pseudo seizures
		outpatient				&		and the nurses always mock her or
		neurology				questionnaires		say she is weird and fakes seizures

		clinics						– these are professionals and even
								they don't understand it."
Rawlings	United	Membership-	38	Psychogenic	Healthcare	Written	Thematic	Findings compared the experience
et al.	Kingdom	led	participants,	nonepileptic	professionals	narratives	compariso	of participants with epileptic and
(2018a)*		organisations	of which 19	seizures		based on	n	PNES. There was one key relevant
		for individuals	had PNES, 16			specific		theme: 'treatment' which included
		experiencing	females and 3			prompts from		participants' experience with HCPs
		seizures and	males, median			the researcher		and perceptions of treatment.
		outpatient	age 42			&		Key quote: "I came across a
		neurology				questionnaires		psychologist though, yesterday to
		clinics						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	United	Membership-	49	Psychogenic	Healthcare	Written	Narrative	Two narrative typologies included
et al.	Kingdom	led	participants,	nonepileptic	professionals;	narratives	analysis	participants' experience of HCPs:
(2018b)*		organisations	of which 20	seizures	doctors;	based on		'losses from illness', 'feeling lost'.
× ,		for individuals	had PNES, 17		hospital;	specific		
		experiencing	females and 3		psychologist	prompts from		Key quote: "it's frustrating as no
		seizures and	males, median			the researcher		health professional has given me
		outpatient	age 39			&		any ideas or support"
		neurology				questionnaires		
		clinics						

Read et al	United	CODES	21 females	Dissociative	CODES (trial)	Semi-	Thematic	Themes related to participants'
(2020)*	Kingdom	randomised	and 9 males,	seizures	health	structured	framework	experience of participating the
		controlled	aged 18-80		professionals;	interviews	analysis	CODES trial. Themes relating to
		trial			research			their experience with HCPs: 1)
					workers;			participating in a treatment trial-
					psychiatrist;			'the only thing out there', 2)
					CBT therapist			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 &	United	Specialist	8 female	Psychogenic	Doctors;	Video	Critical	Three main themes are discussed:
Lian	Kingdom	outpatient	participants,	non-epileptic	clinical	recordings of	discourse	1) explaining the diagnosis- how
(2016)		neurology	aged 18-65,	seizures	consultations	consultations	analysis	the diagnosis of PNES is delivered;
		clinics	12.5 years			with		2) explaining the cause-
			median			consultant		investigation of the reasons doctors
			seizure			neurologists		give to explain the causes of their
			experience					seizures, 3) explaining treatment
								options- examination of treatment
								options recommended to patients.
								Patients' responses to doctors'
								explanations are highlighted.

								make sure I, it's not me doing it to
								myself because it's, um."
Robson &	Internatio	Patient and	135	Non-epileptic	General and	Free-text	Thematic	Six themes relating to participants'
Lian	nal online	practitioner-	participants,	seizures (NES)	specialist	surveys	discourse	'single worst healthcare interaction
(2017)	recruitme	led online	118 females,		neurologists;		analysis	relating to NES' arose: negative
	nt- United	support	14 males and		specialist and			and disrespectful encounters, lack
	Kingdom	groups for	3 transgender		non-specialist			of knowledge and awareness,
	and	people with	people, aged		psychotherapi			illegitimate patients, disregard of
	Ireland,	non-epileptic	18-60+		sts; doctors			patients' perspective, voluntary
	United	seizures			and nurses in			control and consequences.
	States and				the emergency			Key quote: "The doctor told me I
	Canada,				department			was faking. He stabbed my arms
	Australia,				and general			with a needle whilst I was
	New				hospital			paralyzed to prove I was faking
	Zealand				settings;			[] He kept telling me I was faking
	and				paramedics;			and there is nothing wrong with
	Norway				general			me"
					practitioners/			
					family			
					physicians			
Thompson	United	NHS	8 female	Nonepileptic	Medical	Semi-	Interpretati	Three relevant themes related to the
et al.	Kingdom	psychotherapy	participants,	seizures	professionals;	structured	ve	impact of receiving the diagnosis of
(2009)		waiting lists	aged between		psychiatrist;	interviews	phenomen	NES: being left in limbo, doubts
·			their 20s and		GP		ological	and uncertainty and feeling like a
								19

Key quote: "Lilly: "I just had to

			60s with 1-21		counsellor;		analysis	human being again.
			years since		neurologist			Key quote: 'Just left in limbo land
			seizure onset					wondering what's gonna happen."
Wyatt et	United	Adult	6 participants,	Non-epileptic	Healthcare	Semi-	Thematic	Three relevant themes are reported
al. (2014)	Kingdom	neuropsycholo	4 female and	attack disorder	professionals;	structured	analysis	on: understanding NEAD,
		gy NHS	1 male, aged	(NEAD);	ambulance	interviews		relationships with professionals and
		service	29-55	Non-epileptic	crew; doctors;			experience of psychological therapy
				seizures	neurologists;			Key quote: "Everybody is trying to
					psychologists			convince me that I am faking an
								epileptic seizure."
Zeun et al.	United	FND charity	7 participants	Not specified	Physiotherapis	Semi-	Interpretati	Three relevant themes were
(2023)	Kingdom	websites and	with	-	ts	structured	ve	identified: 1) my brain, mind and
()		social media	functional			interview	phenomen	body are all me, 2) Physiotherapy;
		pages	movement				ological	what helps and what doesn't, 3)
			disorder, of				analysis	barriers to treatment.
			which 1					Key quote: "My physio has taken it
			reported					upon herself to learn about FMD
			experiencing					and she's very graciously allowed
			seizures. This					me to help educate her and she's
			participant					done it herself and this is meant our
			was male,					sessions have been most
			aged 67					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

Appendix E 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. Half the 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.

Thematic Synthesis

Two-hundred and seventy codes were produced through line-by-line coding of studies' text and original quotes by participants. Fourteen descriptive themes were developed (Appendix F). Three key theme were generated capturing pwFDS' experiences with HCPs: *Clinician uncertainty feeds patient uncertainty* (Table 3), *Not fitting into the model of medical illness* (Table 4), *Stigma fuelling negative experiences with HCPs* (Table 4). 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.



Diagrammatic representation of themes



Theme 1: 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', 'anger in uncertainty' and 'clear communication creates clarity'.

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 participants receiving conflicting messages (Quote 1, Table 2).

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), which damaged their confidence in the diagnosis (Quote 2, Table 2).

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 (Quote 3, Table 2).

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 (Quote 4, Table 2).

Mutual difficulty understanding FDS

PwFDS attributed difficulties with understanding their condition to HCPs' struggles to explain FDS (Quote 5, Table 2). 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).

Anger in uncertainty

Repeated encounters with HCPs lacking knowledge or certainty about FDS were experienced as deeply frustrating and destabilising. The perceived "*chronic ignorance*" (Robson & Lian, 2017, p.7) resulted in a sense of loneliness (Quote 6, Table 2).

Additionally, pwFDS felt that HCPs were oblivious to their concerns. The ensuing frustration suggests this was threatening to them (Quote 7, Table 2). 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.

Clear communication creates clarity

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).

PwFDS also 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).

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).

Table 2

Illustrative quotes for theme 1

The	eme	1: Clinician uncertainty feeds patient uncertainty
Sub-themes		
Uncertainty about	1.	"they'll think it's something else and send you off in that direction
diagnosis		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).
	2.	"In two or three years' time they might tell me it's a different one"
		(Fairclough et al., 2014, p.298).
	3.	"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)
	4.	"What if nobody can help me?" (Karterud et al., 2010, p.42)
Mutual difficulty	5.	"So now I must say I have PNES and I don't know how I can
understanding		explain this to anybody else when I don't even understand it

FDS		<i>myself</i> " (Karterud et al., 2010, p.42).
Anger in	6.	"nobody realises what it's like to be like this" (Dickinson, 2011,
uncertainty		p.456).
	7.	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
		<i>you?</i> " (Read et al., 2020, p.6).

Theme 2: 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 de-legitimisation', 'dismissed and rejected' and 'acceptance promotes empowerment'.

Experiences of de-legitimisation

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 (Quote 1, Table 3). Some HCPs even refused to acknowledge their seizures (Rawlings et al., 2017), which made pwFDS feel HCPs did not believe they experienced seizures (Quote 2, Table 3).

Others noted they encountered HCPs who did not believe in the existence of FDS (Quote 3, Table 3), which paved the way for pwFDS' symptoms being doubted (Quote 4, Table 3). Some believed that pwFDS could control their seizures (Quote 5, Table 3). 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 selfcriticism, fear of abandonment and hopelessness (Quote 6, Table 3).

Repeated experiences of invalidation by HCPs resulted in participants anticipating further negative responses and fearing abandonment (Quote 7, Table 3). 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).

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 (Quote 8, Table 3). 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 (Quote 9, Table, 3)

The lack of positive biomarkers heightened pwFDS' fear of abandonment as it could be used to reject them (Quote 10, Table, 3). Ostracisation (Rawlings et al., 2017) created deep shame for their condition (Quote 11, Table 3) and anger in knowing they would have been taken seriously had they had epilepsy (Karterud et al., 2010). Ultimately, pwFDS felt abandoned by services (Quote 12, Table 3), 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). 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) (Quote 13, Table 3). 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.

Table 3

Illustrative quotes for theme 2

Th	ieme	e 2: Not fitting into the model of medical illness
Sub-themes		
Experiences of de-	1.	"Cause you're not physically ill, they don't think you're ill"
legitimisation		(Wyatt et al., 2014 p.803).
	2.	"I was told I had 'attacks' and that what I was experiencing were
		NOT seizures at all" (Robson & Lian, 2017, p.6
	3.	"I haven't met a single one who believes this is an illness"
		(Robson & Lian, 2017, p.7).
	4.	"people treat PNES as if it were an imaginary friend. Fake,
		irrational, and made up" (Robson & Lian, 2017, p.7).
	5.	"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).
	6.	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)

	7. "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).
Dismissed and	8. "my situation was a hopeless one as far as his medical expertise
rejected	was concerned" (Robson & Lian, 2017, p. 6).
	9. 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)
	10. "You know you don't have epilepsy, go see somebody else"
	(Dickinson et al., 2011, p.456).
	11. "I felt very ashamed walking out of his office, because I wasn't a
	real epilepsy patient" (Robson & Lian, 2017, p.9)
	12. "You just feel like you've been dumped" (Thompson et al., 2009,
	p.511).
Acceptance	13. (the Professor) wrote me a letter So, I took it into hospital and I give
promotes	it'em and I said and the Professor wrote: 'This lady does not do this
empowerment	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).

Theme 3: Stigma fuelling negative experiences with HCPs

Many pwFDS reported having negative 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 negative 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 (Quote 1, Table 4). PwFDS reported encountering HCPs who regarded them with little respect and spoke derogatively about them, as if invisible (Quote 2, Table 4).

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) (Quote 3, Table, 4). 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 (Quote 4, Table, 4). 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 (Quote 5, Table 4). 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).

Compassion enables coping

Conversely, 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).

Table 4

Illustrative quotes for theme 3

Theme 3: Stigma fuelling negative experiences with HCPs

- 1. "they went on to degrade me as a person" (Robson & Lian, 2017, p.5).
- 2. "...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).

- "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).
- 4. "They see 'pseudoseizures' on my chart and avoid me like I am an axe murderer" (Robson & Lian, 2017, p.7).
- 5. "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).

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: (1) clinician uncertainty feeds patient uncertainty, (2) not fitting into the model of medical illness, and (3) stigma fuelling negative experiences with HCPs. A lack of knowledge and understanding of FDS underpinned many of pwFDS' experiences in this review. While some pwFDS also had positive experiences with HCPs, these were less prominent in the papers. These findings reflect those of previous reviews regarding the effects of stigma in both FDS and FND, where pwFDS felt 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 experienced 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).

In qualitative studies, pwFDS 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) - presents a major barrier to diagnosis and appropriate treatment, as well as having a profound impact on the lives of pwFDS. A survey of people with FND found that 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). Importantly, stigma has been found to interact in a mutually reinforcing way with shame, demonstrating both the intra- and interpersonal impacts of stigma (Reuber et al., 2022).

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). Additionally, this bias towards medical explanations in healthcare may encourage pwFDS to feel the need to medicalise their problem in order to get any degree of social recognition of their needs and disabilities (Peacock et al., 2023).

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). Perceived stigmatisation can also negatively impact on patient outcomes (Taft et al., 2009). In other practitioner studies, HCPs have expressed a desire to help pwFDS, but were 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).

The negative attitudes of HCPs could possibly be due to a sense of helplessness and inadequacy provoked by FDS. In one study, nearly 90% of surveyed doctors admitted their training did not equip them to manage functional conditions (de Liège et al., 2022). Negative attitudes among 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 (Peackock et al., 2023).

The negative experiences with HCPs, detailed in theme three, could be an enactment of the stigmatising beliefs held by HCPs (Worsley et al., 2011). 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, we found multiple quotes in which pwFDS expressed hopelessness, 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). This is problematic in view of the high rates of medical comorbidities and premature mortality observed in pwFDS and the premature mortality associated with these comorbidities (Jennum et al., 2019; Tan et al., 2023; Zhang et al., 2022). 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 associated with 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.

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 in patients' experiences with HCPs over this time period.

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). Mental health professionals could support this by offering reflective practice groups, informed by psychological approaches such as the Power Threat Meaning Framework. This is a traumainformed 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. Adequate psychoeducation of FDS using explanatory models that bridge the mind-brain barrier is paramount to patients to gain knowledge and learn how to live with their condition. Importantly, this can help patients perceive their condition as legitimate and reduce stigma. This, in turn, promotes understanding and acceptance, and supports patients to make informed decisions relating to a range of activities, preventing the condition becoming too much of an impairment on their quality of life (McLoughlin et al., 2024; Roddis et al., 2016). HCPs are well positioned to provide accurate and helpful information, providing they have adequate knowledge themselves, with Roddis et al.'s (2016) findings suggesting the long-term benefits of this.

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 clinical guidelines (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 (Gaskell et al., 2023; Gaskell et al., 2024), supporting the need for more specialist support and updated clinical guidelines.

Lack of engagement and poor clinic attendance is common among pwFDS (Howlett et al., 2007). 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 specifically exploring pwFDS' experience of their encounters with HCPs. Findings highlighted that pwFDS experience difficult and negative 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.

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Appendix A

Search terms corresponding to the SPICE framework

Search Terms	
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	
"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	
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"	
N/A	
AND	
experience* OR perception* OR view* OR attitude* OR perspective* OR	
reflection* OR opinion* OR explor* OR thought* OR belie* OR feel* OR	
qualitativa	

<mark>Appendix B</mark>

PRISMA 2020 Checklist

	Item #	Checklist item	Location where item is reported
TITLE	1		
Title	1	Identify the report as a systematic review.	1
ABSTRACT	1		
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTIO	DN		
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	4-5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	6-7
Information sources	ormation6Specify 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.		6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	57
Selection process	Selection process8Specify 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.		6-7
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.	7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were	6-9

	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.	<mark>7-9</mark>
Study risk of bias assessment	ent 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.		<mark>7-8</mark>
Effect measures	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)).	6-9; 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.	<mark>8-9</mark>
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 1 & Appendix E
	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.	<mark>8-9</mark>
	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.	<mark>7-8</mark>
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	7-8; Appendix G

	Item #	Checklist item	Location where item is reported
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	<mark>7-8</mark>
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.	<mark>9-10; Figure</mark> 1
	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	17 Cite each included study and present its characteristics.	
Risk of bias in studies18Present assessments of risk of bias for each included study.		21; Appendix G	
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 1
Results of syntheses	Results of syntheses 20a For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.		21; Appendix G
	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

	Item #	Checklist item	Location where item is reported
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	<mark>32-37</mark>
	23b	Discuss any limitations of the evidence included in the review.	<mark>37-38</mark>
	23c	Discuss any limitations of the review processes used.	<mark>37-38</mark>
	23d	Discuss implications of the results for practice, policy, and future research.	<mark>38-39</mark>
OTHER INFOR	MATIC	DN	
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	<mark>6</mark>
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	<mark>6</mark>
	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.	N/A
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

<mark>Appendix C</mark>

ENTREQ Checklist

Number	Item	Guide and Description	Location	Checked by independent reviewer (EE)
1	Aim	State the research question the synthesis addresses.	<mark>5</mark>	✓
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology.	<mark>5, 8-9</mark>	1
3	Approach to searching	Indicate whether the search was pre-planned or iterative.	<mark>6</mark>	1
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	<mark>6-7</mark>	1
5	Data sources	Describe the information sources used and when the searches conducted; provide the rationale for using the data sources.	<mark>6</mark>	1
6	Electronic search strategy	Describe the literature search.	<mark>6</mark>	1
7	Study screening methods	Describe the process of study screening and sifting	<mark>7-8</mark>	1
8	Study characteristics	Present the characteristics of the included studies	<mark>12-20;</mark> Table 1	1
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion.	9-11; Figure 1	1

(Adapted from Tong et al., 2007)

10	Rationale for	Describe the rationale and approach used to appraise the included	<mark>8</mark>	1
	appraisal	studies or selected findings		
11	Appraisal	State the tools, frameworks and criteria used to appraise the studies or	<mark>8</mark>	\checkmark
	items	selected findings		
12	Appraisal	Indicate whether the appraisal was conducted independently by more	<mark>8</mark>	\checkmark
	process	than one reviewer and if consensus was required.		
13	Appraisal	Present results of the quality assessment and indicate which articles, if	<mark>8, 21,</mark>	\checkmark
	results	any, were weighted/excluded based on the assessment and give the rationale.	Appendix E	
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies?	7	\checkmark
15	Software	State the computer software used, if any.	<mark>7 & 8</mark>	1
16	Number of reviewers	Identify who was involved in coding and analysis.	9	1
17	Coding	Describe the process for coding of data.	<mark>9</mark>	1
18	Study comparison	Describe how comparisons were made within and across studies.	<mark>9</mark>	1
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	<mark>9</mark>	\checkmark
20	Quotations	Provide quotations from the primary studies to illustrate	<mark>22-32</mark>	\checkmark
	-	themes/constructs, and identify whether the quotations were participant		
		quotations of the author's interpretation.		
21	Synthesis	Present rich, compelling and useful results that go beyond a summary of	<mark>22-32</mark>	1
	output	the primary studies		

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	Lack of awareness prevalent			
They've never seen NEAD	Lack of experience			
Did not understand their condition	Lack of knowledge			
Chronic ignorance	Lack of understanding			
didn't know what he was on about	Don't listen			
Difficulty establishing a joint understanding				
Difficulty reaching a common understanding	of NEAD			
Patient doesn't understand how treatments wi	ll help seizures			
Jargon and power imbalance during consultat	ions			
Difficulty on part of patient to absorb and ret	ain information			
Can't remember the explanations				
Difficulty understanding diagnosis				
struggled to retain information				
Difficulty understanding diagnosis				
Hard to make sense of info during consultation	ons			
Lack of information and support provided				
Needed more explanation	Need for explanation			
Wanting guidance	Desperate for information			
treatment options not well discussed	Limited information			
Lack of information provided	Information given not pitched at right level			
Not provided resources for how to cope				
Not given any information				
HCP encounters fail to address or reduce und	certainty			
Unresolved questions and uncertainty				
Uncertainty				
anger from lack of certainty led to disengager	nent 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 service	es .			
Negative experiences with HCPS affected access to specialist care				
Emotional impact of difficult encounters				
Anger	helplessness			
Angry at Dr who diagnosed NES	Hopeless			
Did not feel validated	Terrifying			
Frustration	Stressed			
Hopelessness and frustration drives desperation for treatment				
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 ioneliness and isolation				
Explanation can be helpful highly skills, asking the right questions				
Ingrity Skills, askilly the right questions				
nrofessional educating themselves henefits 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 amongs	Lack of knowledge and understanding amongst HCPs			
Enigma for professionals HCPs unwilling to learn about NEAD				
treatment without knowing what's going on Dr unwilling to compromise				
Patients recognise difficulties for HCPs Lack of experience				
Dr refusal to admit knowing less than pt				
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	NES not explained			
Nobody tells you anything	not given ideas or support			
No help or information given	Limited information			
No help or advice				
HCP encounters fail to address or reduce unc	ertainty			
Discharged without answers				
Unresolved questions and uncertainty				
Uncertainty				
No treatment offered- sent home				
anger from lack of certainty led to disengagen	nent from services			
Reliance on medical models results in ambigu	ity			
Communication breakdown				
Drs become frustrated	Frustrated by too many questions			
Bad communication	Defensive about psychological explanation			
Miscommunication	Anger at psychological explanation			
Disconnect between patient and HCP	defensive			
Lack of trust	Not feeling understood			
Not included in care	Paternalistic			
Source of tension				
Not believed or taken seriously				
Illegitimate seizures	less legitimate			
viewed as a fraud	made to feel I was wasting their time			
HCPs don't believe NEAD exists	making up sotries			
Told there is nothing wrong with them	Not enilensy so believe they can control it			
accused of being hysterical	Not believed			
Dr believed condition voluntary due to lack of	f Not taken seriously			
biomarkers	seen as unimportant			
treated as a fake	severity fo condition discounted			
Blamed	Made me feel like it was my fault			
seen as faking	Worry they will be accused of faking			
PNES treated as imaginary	worry ency will be accused of laking			
Lack of biomarkers leads to belief NEAD ille	oit			
legitimacy questioned by professionals				
Demeaning/helittling/abusive interactions				
rejected and blamed				
Made to feel worthless				
HCPs did not listen				
unsupportive and unempathetic				
no compassion or understanding	no compassion or understanding			
Patient wishes not respected				
made to feel guilty				
Not listened to				
Rejected and abandoned				
Abandoned by professionals	Dismissive			
Abandoned by services	Rejection			
alienated	Wouldn't assess injuries due to NEAD			
let down and ostracized	ashamed to not have epilepsy (rejection)			
Nobody seems to care	eel rejected			

Lack of biomarkers leads to dismissal	Feeling alienated			
Lack of knowledge fuels rejection	felt excluded from medical care			
disinterested	felt like I was wasting their time			
dumped	difficulty getting diagnosis resulted in feeling			
Cessation of investigations frustrating, felt	rejected			
rejected	Disregard leads to feeling alienated			
Written off	left in limbo			
Been failed by doctors	Getting help is impossible			
I feel I'm on my own				
Dismissed				
Distrust and avoidance of healthcare due to d	ifficult 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 FICP helped to not reel judged				
reassuring				
Patient used Drs power to their advantage				
offered help for the future				

Stigma fuelling traumatic experiences with HCPs						
Lack of knowledge and understanding amongs	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	Drs can be blaming					
accused of faking	Accused of time wasting					
Made to feel like they're faking	accused of wasting NHS resource					
accused of attention-seeking	Blamed					

accused of being hysterical	They think I put it all on					
accused of having voluntary control	made to feel I was wasting their time					
accused of making it up	Not taken seriously					
Accused of malingering	its only psychiatric					
treated as a fake	515					
Demeaning/belittling/abusive interactions						
abusive treatment in hospital	Not heard					
abusive treatment in hospital was traumatic	Made to feel invisible					
be grateful its not epilepsy	hospital staff very rude					
all interactions have been negative	Hostility					
Degrading	was shouted at by nurse					
Degrading interaction	Traumatic hospital treatment					
Disrepectful behaviours	Told to just leave her					
Inappropriate treatment by HCP (mean)	mocked, called weird					
encountered dr who were rude	More negative expereinces than positive					
shocking encounters	Neg interactions with HCPs typical, the norm					
Shared disrespect between professions	Negative experiences with HCPs very					
towards pt	common					
Rude and offensive	Treated as a joke					
Poor treatment in hospital	Discriminated against					
Laughed in my face	Disrespectful attitudes					
Parameds speaking about patient infront of	Lack of awareness feed disrespect					
them	Looked at me like I was crazy					
Paramedics made rude comments	HCPs not wanting to listen					
Paramedics and ER HCPs worst offenders						
Not listened to						
Rejected and abandoned						
Nobody seems to care						
Dismissed						
Wouldn't assess injuries due to NEAD						
Distrust and avoidance of healthcare due to d	ifficult 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	Trusting therapist helpful to therapy					
Finally listened to	Taken seriously- attentive and validating					
He is just that kind of person, not just a	Taking an interest					

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

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

Appendix E

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)	1	?	1	1	1	Х	1	1	1	1	8.5	High
Dickinson et al. (2011)	1	1	?	1	\checkmark	Х	\checkmark	✓	?	1	8	Moderate
Fairclough et al. (2014)	1	1	1	1	\checkmark	?	1	1	1	1	9.5	High
Goldstein et al. (2021)	1	1	Х	1	1	✓	1	1	?	?	8	Moderate
Green et al. (2004)	1	1	1	1	1	Х	1	1	1	1	9	High
Karterud et al. (2010)	1	1	?	1	1	Х	1	1	1	1	8.5	High
Karterud et al. (2015)	1	1	1	1	1	1	1	1	1	1	10	High
Peacock et al. (2023)	1	1	1	1	\checkmark	1	1	1	1	1	10	High

Peacock et al. (2022)	1	1	1	?	1	\checkmark	1	1	1	1	9.5	High
Pretorius (2016)	1	1	1	1	1	Х	1	1	1	1	9	High
Pretorius & Sparrow (2015)	1	1	1	1	1	1	1	1	1	1	10	High
Rawlings et al. (2017)	1	1	1	1	1	1	1	1	1	1	10	High
Rawlings et al. (2018a)	1	1	1	1	1	Х	1	1	1	1	9	High
Rawlings et al. (2018b)	1	1	1	1	1	Х	1	1	1	?	8.5	High
Read et al (2020)	1	1	1	1	1	?	1	1	1	1	9.5	High
Robson & Lian (2016)	1	1	Х	1	1	Х	1	1	1	1	8	Moderate
Robson & Lian (2017)	1	1	1	1	1	Х	1	1	1	?	8.5	High
Thompson et al. (2009)	1	Х	1	1	1	1	1	1	1	1	9	High
Wyatt et al. (2014)	1	1	Х	1	?	Х	1	1	1	1	7.5	Moderate
Zeun et al. (2023)	1	1	?	1	1	1	1	1	1	1	9.5	High

Appendix F

Descriptive Themes with Codes

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	Reliance on medical models results in ambiguity
Unresolved questions and uncertainty	Worry about treatment working
Uncertainty	bewilderment
No treatment offered- sent home	
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	communicating with professions active struggle
Bad communication	stigmatising communication with doctor
Miscommunication	Frustrated by too many questions
--	---
Disconnect between patient and HCP	Defensive about psychological explanation
Lack of trust	Anger at psychological explanation
Lack of understanding leads to dissatisfactory	defensive
interactions	Dealing with HCPs barrier to
misunderstood	Not feeling understood
being lectured- inherent power imbalance	Paternalistic
Not included in care	
Source of tension	

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 r	ot discussed with them, adding to their felt					
uncertainty of their condition. Participants express	ed wanting and needing guidance to support their					
coping with their diagnosis, and some						
Needed more explanation	Not provided resources for how to cope					
Nobody tells you anything	not given ideas or support					
No help or information given	Not given any information					
No help or advice	Need for explanation					
Wanting guidance	Desperate for information					
treatment options not well discussed	Limited information					
Lack of information provided	Information given not pitched at right level					
NES not explained						
-						

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 accuse	d of faking them or having voluntary control of				
them. Participants felt that because their seizures we	ere not epilepsy, or they were "only psychiatric",				
they were not taken seriously or viewed as importan	nt.				
Illegitimate seizures	Took a long time to be taken seriously				
viewed as a fraud	They think I put it all on				
HCPs don't believe NEAD exists	seen as faking				
Told there is nothing wrong with them	PNES treated as imaginary				
accused of faking	Lack of biomarkers leads to belief NEAD illegit				
Made to feel like they're faking	legitimacy questioned by professionals				
accused of attention-seeking	less legitimate				
accused of being hysterical	made to feel I was wasting their time				
accused of having voluntary control	making up sotries				
accused of making it up	Not epilepsy so believe they can control it				
Accused of malingering	Not believed				
Dr believed condition voluntary due to lack of	Not taken seriously				
biomarkers	seen as unimportant				
treated as a fake	severity fo condition discounted				
Drs can be blaming	Made me feel like it was my fault				
Accused of time wasting	Worry they will be accused of faking				
accused of wasting NHS resource	Needing proof of legitimacy				
Blamed	its only psychiatric				
Nobody knows what its like					

Rejected and abandoned					
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 t	o 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.				
Abandoned by professionals	HCPs uninterested in hearing their story				
Abandoned by services	Dismissed				
alienated	Dismissive				
let down and ostracized	Rejection				
Nobody seems to care	Wouldn't assess injuries due to NEAD				
Lack of biomarkers leads to dismissal	ashamed to not have epilepsy (rejection)				
Lack of knowledge fuels rejection	Feel rejected				
disinterested	Feeling alienated				
dumped	felt excluded from medical care				
Cessation of investigations frustrating, felt	felt like I was wasting their time				
rejected	difficulty getting diagnosis resulted in feeling				
Written off	rejected				
Been failed by doctors	Disregard leads to feeling alienated				
At a loss for what to do	worry that no one can help				
I feel I'm on my own	left in limbo				
Passed around professionals	Getting help is impossible				

Demeaning/belittling/abusive interactions						
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 fa	king when they thought the patient could not hear,					
being mocked, shouted at and physically assaulted	l(?) by staff.					
abusive treatment in hospital	Made to feel worthless					
abusive treatment in hospital was traumatic	HCPs did not listen					
be grateful its not epilepsy	hospital staff very rude					
all interactions have been negative	Hostility					
Degrading	was shouted at by nurse					
Degrading interaction	unsupportive and unempathetic					
Disrepectful behaviours	Traumatic hospital treatment					
Inappropriate treatment by HCP (mean)	Told to just leave her					
encountered dr who were rude	mocked, called weird					
shocking encounters	More negative expereinces than positive					
Shared disrespect between professions towards	Neg interactions with HCPs typical, the norm					
pt	no compassion or understanding					
rejected and blamed	Negative experiences with HCPs very common					
Rude and offensive	Treated as a joke					
Poor treatment in hospital	Discriminated against					
Laughed in my face	Disrespectful attitudes					
Parameds speaking about patient infront of them	Lack of awareness feed disrespect					
Paramedics made rude comments	Patient wishes not respected					
Paramedics and ER HCPs worst offenders	Looked at me like I was crazy					
Not listened to	made to feel guilty					
Not heard	HCPs not wanting to listen					
Made to feel invisible						
	1					

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	helplessness						
Angry at Dr who diagnosed NES	Hopeless						
Did not feel validated	Humiliated						
Experiences invalidated	Terrifying						
fed up of fighting	terrifying						
Feel like a failure	Stressed						
Frustration	offended						
Hopelessness and frustration drives desperation	attempted suicide due to treatment						
for 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 help	pful and helped them to feel validated, reassured					
and looked after						
helpful and beneficial	Positive relationship with one HCP supported					
Dr pleasant and approachable	engagement with therapy					
Drs helpful in advocating the legitimacy of PNES	Psychiatrist positive and non-judgemental					
to others	Psychologist willing to help them understand					
Felt looked after by Dr- good Dr	psychologists spend time with you, patience					
Finally listened to	Trusting therapist helpful to therapy					
good therapeutic relationship key to improvement	Taken seriously- attentive and validating					
He is just that kind of person, not just a doctor	Taking an interest					
helpful and felt listened to	She sat back and listen, hopes were raised					
Helpful drs in the minority	Reassurance in Dr's advocacy					
Helpful physicians listen	reassuring					
Helpful to be believed	Relief for being believed					
Positive relationship with HCP helped to not feel	Repeated explanation helped understanding					
judged	Right HCPs good source of coping and resilience					
Positive relationship with Dr unexpected	People who treat them well are in the minority					
Positive interactions at specialist services	Kindness and empathy important					
Positive dr attitude helped her feel looked after	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

	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			1	1		\checkmark		\checkmark		\checkmark	\checkmark	\checkmark			\checkmark		\checkmark	\checkmark	\checkmark	
Mutual difficulty understanding FDS		1	1	1		1	1				1		1		1		1		1	1
Anger in uncertainty	1	1												1	1		1			
Not fitting into the model of medical illness																				
Experiences of delegitimisation			1		1	1	1	1			1	1				1	1		1	
Dismissed and rejected		1				✓		1		1		1		1			1	1		
Stigma fuelling traumatic experiences with HCPs	1	1				1				1	1	1	1				1	1	1	

Appendix G

Study representation in themes

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Appendix H

Selection of additional illustrative quotes

Theme	Sub-theme	Quote
Clinician	Uncertainty about	I struggled for a long timeit felt like I was going from one doctor to another and nobody had a clue.
uncertainty feeds	diagnosis	(Pretorius & Sparrow 2015, p.36)
uncertainty		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 of 30 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	My physio very graciously allowed me to help educate her and she's done it herself and this is meant our
	understanding FDS	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
		<i>breath)</i> (Rawlings et al., 2018, p. 956)
	Anger in	None of them listen [] or can even tell you what a nonepileptic seizure is (Robson & Lian, 2017, p.7)
	uncertainty	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	Experiences of	when tests showed that I did not have epilepsy she was totally dismissive and rude she said there is nothing I
the model of medical illness	delegitimisation	can do to help you (Robson & Lian, 2017, p. 7)
meurear miness		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 attentionnot 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	I was discharged again without any explanation and just left it was frustration, it was anger, it was well,				
rejected		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		Such hostility [] I always feel guilty, ghastly, 'failing to get better', etc. I had a (minor) head injury, just				
traumatic		glued. I felt so humiliated by her antagonism when I was already emotionally really vulnerable (Robson &				
HCPs		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)