

1. Introduction

Functional seizures are defined as “episodic disturbances of normal functioning and reduced-self control associated with a range of motor, sensory, and mental manifestations that resemble epileptic attacks, but which are not caused by epileptic activity in the brain” [1]. Functional seizures fall within the broader categories of ‘Conversion Disorder (Functional Neurological Symptom Disorder)’ in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [2] and ‘Dissociative Disorders’ in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [3]. It is estimated that between 10 and 22% of patients presenting to epilepsy clinics have functional seizures [4]. There are many terms for the condition. For brevity's sake, and due to increasing preference for the broader category term of “functional neurological disorder”, “functional seizures” is the term used in this paper.

Having an accurate diagnosis and comprehensive explanation of functional seizures is a vital first step: the diagnosis itself can result in cessation or reduced frequency of functional seizures [5], and the process from diagnosis to treatment can be more streamlined [6], with psychological therapy typically being the treatment of choice [7–9]. To date, receiving the correct diagnosis is still a lengthy process, with research indicating that patients are diagnosed between 3-7 years after the first occurrence of an attack [10,11].

Research indicates that delivering the diagnosis can be challenging to both clinicians and patients; patients report feeling confused or angry after receiving a diagnosis [12,13], concerned that they are being accused of ‘faking it’, or that they are ‘crazy’ in some way [14]. While comorbid psychiatric disorders are common in this patient group and patients report a higher incidence of negative life events than those with epilepsy [15], and of sexual, physical and emotional abuse [16], patients are less likely to accept that stress or emotional factors may play a causal or maintaining role of seizures compared to patients with epilepsy [17]. Patients have reported doubting the diagnosis, and feeling left in ‘limbo land’ [18]. Patients may seek a second opinion in the hope that a neurological cause is found, and therefore the stigma of having a psychiatric diagnosis is avoided [18]. Indeed, in comparison to individuals with epilepsy, patients with functional seizures report experiencing higher stigma [19,20], and that the level of stigma is negatively associated with perceived quality of life [20]. It has been reported that 41% of patients diagnosed with functional seizures continue to take antiepileptic drugs for four years after receiving the diagnosis of functional seizures [21] and only three in five patients referred by a neurologist attend for psychological support [22].

The above-collated research has adopted a wide variety of diagnostic terms when investigating and discussing functional seizures (see [23] for a recent summary), most likely due to the difference in perspectives about the underlying mechanisms, and of equal if not greater importance, due to the diagnosis being only variably well received by patients [24]. There appears to be a trade-off: provide a psychological explanation, such as ‘pseudoseizures’ or ‘psychogenic seizures’ and risk being offensive [25–28] and/or exclude organic factors [18,29], or, provide a more neutrally accepting term, such as ‘functional seizures’ or ‘non-epileptic attack disorder (NEAD)’ and risk an ambiguous explanation for the symptoms and unclear suggestions for treatment [24,30].

This current inconsistency not only adds to the confusion felt by patients, it also plays a role in patients’ difficulties of accepting the diagnosis, which in turn may contribute to poorer uptake of treatments and outcomes [6]. Importantly, it may contribute to the relatively low public awareness and ongoing stigma patients report facing [6,20]

Supporting the request for a suitable diagnostic term to be adopted by patients, healthcare professionals and the public [6], this study expands upon Stone and colleagues work [29], and our most recent study [23], and aims to investigate patient preferences for, and offensiveness of, terminology used to describe functional seizures, including the terms used in current classification systems (‘dissociative seizures’ and ‘conversion disorder’). The study also seeks to explore the experience of being diagnosed and the explanation provided.

2. Method

2.1. Participants

Ethical approval was gained from the National Health Service Ethics Committee (IRAS 240777), and University College London Data Protection Office (Z6364106/2018/06/147).

Between January 2019-March 2020, consultant neuropsychiatrists in a regional neuropsychiatry service discussed the research with patients diagnosed with functional seizures during routine appointments. Patients had a confirmed diagnosis of functional seizures made by a neurologist and confirmed by a neuropsychiatrist. Patients were diagnosed with FS by the referring epileptologist or neurologist. The diagnosis may have included video-EEG monitoring, but not all patients who receive the diagnosis of FS will have required video-EEG monitoring to confirm a diagnosis of FS. Patients with co-morbid epilepsy were not excluded from the study, which we consider more naturalistic as there are relatively high rates of comorbidity between epilepsy and FS. Patients who

took part in the research did so anonymously, in order to maximise engagement, so the proportion of patients who underwent video-EEG monitoring or who had a co-morbid epilepsy is unknown. However, only patients with a confirmed diagnosis of FS were included in the study, and if there was any doubt regarding diagnosis or if investigations were still taking place, they would not have been invited to take part. A paper survey, or a link to the online survey format on Qualtrics software, was given to patients expressing interest. Patients who completed the survey were asked whether they would also be interested in taking part in an interview. Those who consented to complete an individual interview were contacted by a research assistant via telephone/ email to arrange a suitable date and time.

Thirty-nine patients participated in this study. Exclusion criteria included non-fluency in English, those under 18; those experiencing active psychosis or mania; and those without a confirmed diagnosis of functional seizures.

Group A: 39 adults in a regional neuropsychiatry service diagnosed with functional seizures.

Group B: 13 Group A patients who participated in individual interviews

2.2. Design and procedure

The survey replicated Loewenberger et al. (2020) [23], consisting of a demographic questionnaire, followed by the Preferences For Terms (PFT) questionnaire where Group A participants were asked to preferentially rank the eight terms previously investigated and three additional terms ('somatoform disorder', 'medically unexplained symptoms', 'psychogenic non-epileptic seizures'). The Numbers Needed To Offend (NNTO) questionnaire [29] followed, in which participants ranked the implications of each term. Terms were randomly presented in both formats. Participants were able to include an email address if they wished to enter a prize draw (£50 Amazon voucher).

Group B completed a semi-structured interview with one of two research assistants. The interview schedule consisted of 5 open-style questions, exploring patients' experience(s) with health professionals when they received their diagnosis and was based upon Thompson and colleagues [31]. Questions explored thoughts and feelings of receiving the diagnosis and the explanation (if provided), experience of healthcare prior to being diagnosed, experience of healthcare following diagnosis, and participant disclosure of diagnosis. A further question exploring reasons for preference of terminology was added to the interview schedule. Interviews were conducted in the neuropsychiatry service, audio-recorded using a USB-recorder and saved in a password-protected file on a NHS-network computer.

2.3. Analysis

As data did not meet assumptions for normality, Wilcoxon Signed Ranks tests were employed to examine differences in ranked preferences. Offence scores were calculated from the number of participants who selected “yes” to at least one of the offensive connotations (“putting it on”, “mad”, imagining your symptoms”) per term [29].

A reflexive thematic analysis employing Braun and Clarke’s six-phase approach was conducted on the qualitative data, set within a realist approach [32]. In summary, this involved the first and second author familiarising with the data, initially reading the transcripts with no specific focus. Initial codes were generated manually, and then searching for themes, defining and naming themes, and co-producing the report. The second author led the analysis, and the first author reviewed each phase of the analysis with the second author in order to finalize the developing codes and themes and ensure inter-rater reliability. Themes and subthemes were mapped, revised and refined to ensure a good fit with the data. Supervision was used throughout data collection and analysis to increase researcher reflexivity [33].

3. Results

3.1. Demographics

Thirty-nine participants completed the survey. Seven males (18%) and 32 females (82%) completed the online survey. Participants ranged in age: eight participants were aged 18-25 (12%), ten aged 26-35 (26%), nine aged 36-45 (22%) and 12 aged 46+ (31%). Five participants (13%) were diagnosed with comorbid epilepsy, with a further four patients (10%) having a diagnosis of epilepsy investigated. Two data sets were incomplete, thus 37 responses were analysed.

Of the 39 participants in Group A, 13 participants (11 female, 2 male) opted to take part in a semi-structured interview on the experience of being diagnosed. The number of years since onset of functional seizures ranged between 1-8 years, with a mean average of 4 years since onset. Six participants stated that ‘Pseudoseizures’ was the original term used to describe the difficulties, four participants stated ‘Functional Neurological Disorder; and three stated ‘Non-epileptic attack disorder’.

3.2. Preferences For Terms

As displayed in Fig. 1, ‘NEAD’ was the most preferred term (mean rank: 2.65), with ‘FNEA’ (mean rank: 3.32), ‘functional seizures’ (mean rank: 3.62) and ‘dissociative seizures’ (4.35) closely following. ‘Pseudoseizures’ (8.05) and ‘hysteria’ (9.49) were the least preferred terms.

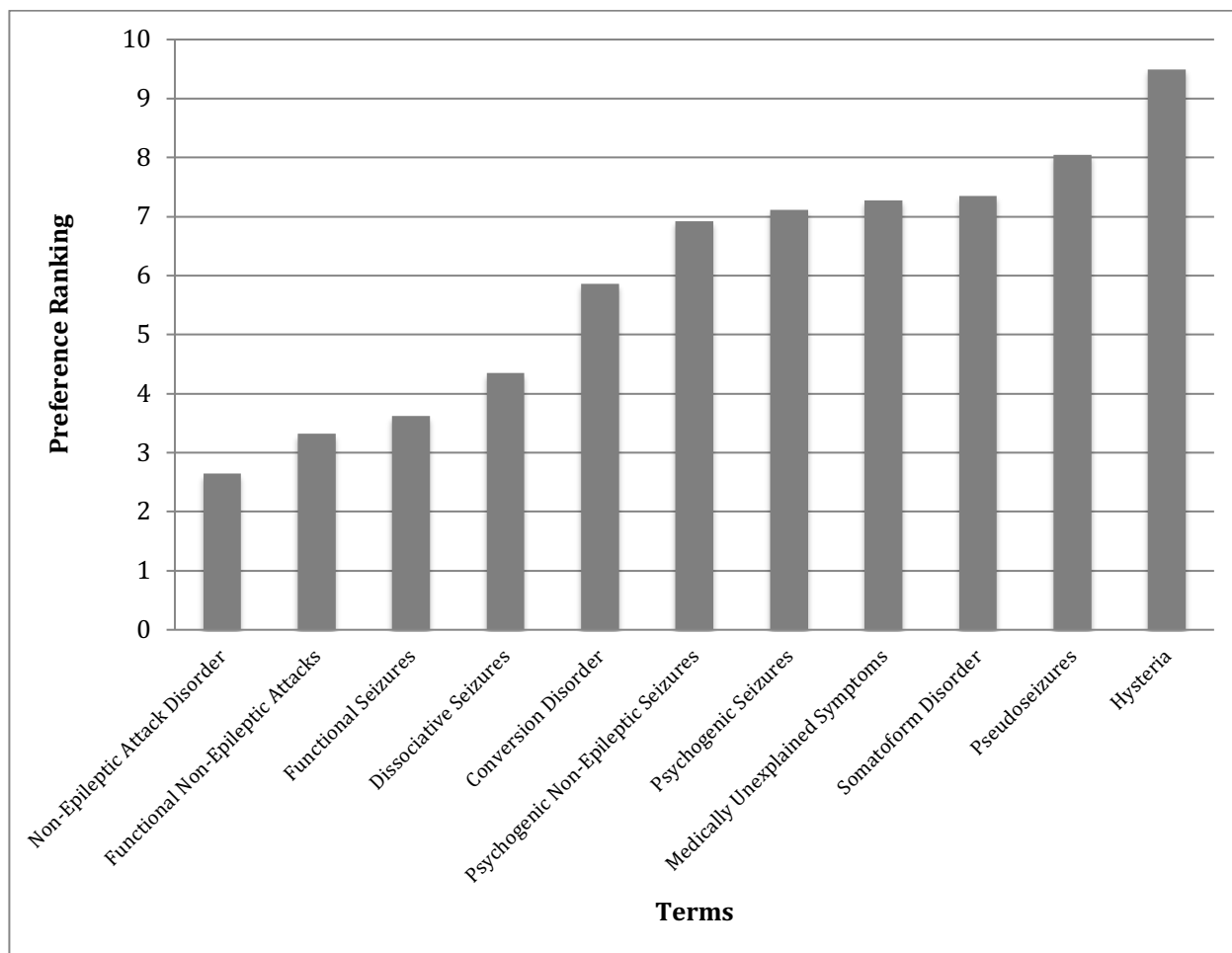


Fig 1. The mean rank of preferred terms

As displayed in Table 1, ‘FNEA’, ‘NEAD’, ‘functional seizures’ and ‘dissociative seizures’ were significantly more preferred than all other terms and did not significantly differ from one another ($p > .005$). The next six terms ranked in preference did not significantly differently from one another, excluding ‘conversion disorder’ which was significantly preferred over ‘pseudoseizures’ ($p = .002$). ‘Hysteria’ was significantly less preferred than all terms except ‘pseudoseizures’ ($p = .008$).

Table 1. Wilcoxon Signed Ranks tests (z and p value) comparing preferences for each term.

	FNEA	Functional seizures	Dissociative seizures	Conversion Disorder	Psychogenic Non-epileptic	Psychogenic seizures	Medical Unexplained Symptom	Somatoform Disorder	Pseudoseizures	Hysteria

					seizures		ms			
Non-epileptic attack disorder	-1.523 ^c .128	-1.940 ^c .052	-2.820 ^c .005	-4.284 ^c .000***	-5.050 ^b .000***	-4.886 ^b .000***	-4.679 ^c .000***	4.794 ^c .000***	-4.800 ^c .000***	-5.199 ^c .000***
Functional non-epileptic attacks (FNEA)		-1.004 ^b .315	-1.971 ^b .049	-3.335 ^b .001***	-4.430 ^c .000***	-4.219 ^c .000***	-4.444 ^c .000***	-4.754 ^c .000***	-4.515 ^c .000***	-4.981 ^b .000***
Functional seizures			-1.315 ^c .189	-3.261 ^c .001***	-43.937 ^c .000***	-4.069 ^c .000***	-4.705 ^c .000***	-4.698 ^c .000***	-4.693 ^b .000***	-4.869 ^c .000***
Dissociative seizures				-2.959 ^c .003***	-4.054 ^c .000***	-3.906 ^c .000***	3.749 ^c .000***	-4.075 ^c .000***	-4.144 ^c .000***	-4.640 ^b .000***
Conversion Disorder					-1.684 ^b .092	2.067 ^b .039	-2.295 ^b .022	-2.407 ^b .016	-3.131 ^b .002***	-4.888 ^c .000***
Psychogenic Non-epileptic seizures						-0.917 ^b .359	-0.568 ^b .570	-0.742 ^b .458	-1.749 ^b .080	-3.615 ^c .000***
Psychogenic seizures							-0.023 ^b .982	-0.488 ^b .625	-1.728 ^b .084	-3.658 ^c .000***
Medically Unexplained Symptoms								-0.288 ^c .773	-1.481 ^c .139	-3.4.88 ^b .000***
Somatoform Disorder									-1.300 ^c .194	-3.378 ^c .001***
Pseudoseizures										-2.649 ^c

a = based on negative ranks, *** indicates statistical significance with Bonferroni correction ($p < .005$).

3.3. Numbers Needed To Offend

As displayed in Table 2, 'NEAD' had the lowest offence score (16%) and the highest number needed to offend (NNTO = 7), meaning that seven people could be diagnosed with this term prior to one person being offended. 'Functional Seizures' (19%, NNTO = 6) and 'FNEA' (22%, NNTO = 5) were the next terms reported as least offensive, meaning that three of the four most preferred terms were also the least offensive. Notably, 'dissociative seizures' (38%, NNTO = 3) was reported as more offensive than the other highest preferred terms, as well as terms such 'somatoform disorder' (27%, NNTO = 4) which were significantly less favoured in rankings. Offence score generally match Fig. 1, with terms indicating a psychological cause being considered as more offensive.

There is extensive overlap in confidence intervals between terms that did not significantly differ from one another in terms of preference, and also between significantly differently preferred terms. Although confidence intervals are a crude measure subject to Type 2 error, the overlap suggests considerable heterogeneity in perceived offensiveness of the terms.

Table 2.

Individual connotations, offence scores and numbers needed to offend per term

Diagnoses (X)	Number who said yes (% of participants)			Offence score (%) ^a (95% CI) ^b	Numbers needed to offend (95% CI) ^b
	Putting it on	Mad	Imagining of symptoms		
<i>Non-Epileptic Attack Disorder</i>	5 (13)	2 (5)	3 (8)	16 (10-26)	7 (4-10)
<i>Functional Non- Epileptic Attacks</i>	7 (19)	5 (13)	7 (19)	22 (14-31)	5 (3-7)
<i>Functional Seizures</i>	5 (13)	2 (5)	4 (11)	19 (12-28)	6 (4-9)

<i>Dissociative Seizures</i>	6 (16)	10 (27)	13 (35)	38 (28-48)	3 (2-4)
<i>Conversion Disorder</i>	8 (22)	9 (24)	11 (30)	32 (24-43)	4 (3-5)
<i>Psychogenic Non-Epileptic Seizures</i>	15 (40)	17 (46)	15 (40)	60 (50-70)	2 (2-2)
<i>Psychogenic Seizures</i>	12 (32)	12 (32)	13 (35)	46 (36-56)	3 (2-3)
<i>Medically Unexplained Symptoms</i>	17 (46)	9 (24)	18 (49)	54 (45-65)	2 (2-3)
<i>Somatoform Disorder</i>	9 (24)	7 (19)	8 (22)	27 (18-37)	4 (3-6)
<i>Pseudoseizures</i>	22 (60)	20 (54)	22 (60)	65 (55-74)	2 (2-2)
<i>Hysteria</i>	31 (84)	30 (81)	30 (81)	89 (82-95)	2 (1-2)

^a The proportion of subjects who responded ‘Yes’ to one or more of: ‘putting it on’, ‘mad’ or ‘imagining symptoms’.

^b 95% confidence intervals calculated by exact Clopper–Pearson method

3.4. Qualitative Analysis

Thematic analysis of 13 semi-structured interviews revealed three themes surrounding the experience of being diagnosed: the importance of a shared understanding; feeling alone; and a sense of hope (Table 3). Findings are discussed in order of prominence.

Table 3.
Themes and sub-themes

Theme	Sub-themes
Shared understanding	Provision of an explanation
	Individuality
	Being taken seriously
	Not epilepsy
Feeling alone	Not knowing

	Faking it/ to blame (inc. terms)
	Feeling dismissed
	Self-initiated research
Sense of hope	Importance of hope

3.4.1. Shared understanding

All 13 patients desired knowledge of the causes and symptoms of functional seizures, and to be able to share this knowledge with others. Terms facilitating understanding were deemed useful, however the exact terms seen as helpful varied by individuals. For three, the explanation and understanding of functional seizures provided by a term was more crucial than the term itself.

PATIENT 2: "I think [a good term] is something that tells you what [the condition] is"

PATIENT 13: "I'm not overly fussy what it's called providing there's an understanding about what it is"

PATIENT 1: "I would have preferred it if [the 999 operator and GP] had enough knowledge to be able to say "this is what we think it is, and there's going to be no benefit to having the ambulance team because they can't do anything, but we are going to refer you onto...""

Individuality was clear with heterogeneity of causes, symptoms and experiences, and preferences for terminology varied across individuals. For example, the present participants who described experiences of depersonalisation and derealisation found 'dissociative seizures' useful in aiding theirs (and others) understanding of the condition, whilst some preferred 'FNEA' or 'NEAD' as these explain the non-organic nature, although the latter term was also criticised for explaining what the seizure was not, rather than what it is. Amongst nine participants, there was a strong desire for health care professionals to recognise this and consider each patient as an individual rather than provide generalised explanations/ treatment. The variation in preferred terms linked to this individuality.

PATIENT 1: "I personally experience them as seizures and that's why I use 'dissociative seizures', I was getting a lot of depersonalisation and derealisation along with those symptoms"

PATIENT 12: "To tell me it's stress-related? I didn't feel stressed so I found that difficult to understand at first. But to tell me it's trauma-related? Barking up completely the wrong tree"

All described the importance of being taken seriously, being reassured and supported. Many knew that both specialist and non-specialist health care professionals (HCPs) lacked answers themselves,

however this uncertainty was mitigated where empathy and validation occurred. ‘FNEA’ and ‘NEAD’ terms were favoured in this regard, although, again, preferences for which terms facilitated this differed.

PATIENT 5: “[I prefer ‘NEAD’] because the others terms imply that I actually made [the seizures] up, and they’re not a real condition, and I’m in control of them”

Ten patients described a long, arduous journey to diagnosis, and the relief this provided in gaining some certainty and feeling taken seriously. Many expressed gratitude at finding out it was not epilepsy, or a fatal condition.

PATIENT 11: “I was over the moon because I’d been going on for about 7 years with this [and] then I had an actual diagnosis”

PATIENT 3: “When she told me it was non-epileptic, I was relieved just for the pure fact that I may not be suffering from this for the rest of my life”

3.4.2. Feeling alone and confused

Much of feeling alone resulted from not knowing. For all patients, there were significant periods of insufficient answers, often with difficult diagnostic journeys and long waiting lists. Non-specialist HCPs and the layperson were a further aspect of not knowing; patients described that most others had not heard of functional seizures and could not provide an explanation of the cause, or what would be helpful next steps. All expressed frustration and distress at this uncertainty.

PATIENT 4: “It’s overwhelming...there’s a lot of unknowns with [the condition]... I found it quite frustrating and scary to think how I’ll deal with this”

Despite this, four appeared accepting of this uncertainty, acknowledging the lack of answers and awareness from others.

PATIENT 11: “[If] you specialise in a certain [healthcare] field, you’re not necessarily going to have heard of it”

Confusion was apparent regarding the abundance of terms and their individual meanings. Six criticised terms that include ‘non-epileptic’ as solely explaining what the seizure is not, rather than what it is, and that it “incorporates a condition that is not [their] own”. Terms including ‘psycho-’ provided little clear meaning for those with non-medical backgrounds. The combined uncertainty caused fear and surprise of functional seizures.

PATIENT 9: "I found it more difficult to get my head around 'non-epileptic' ... if it's not epileptic why would you put 'epileptic' in the name?"

PATIENT 5: "[Diagnosis of 'pseudoseizures'] left loads of questions flying around my head because nothing seemed to make any sense... I was like "it doesn't tell me what it is, I don't understand how you've come to the conclusion""

Experiences in which patients were subjected to significant stigma from health care professionals and/or the public were common. Accusations of "faking it" were described; those unaware of functional seizures judged patients when they involuntarily showed or explained symptoms. Specific terminology was deemed incredibly offensive in this regard, notably "pseudoseizures" and "hysteria".

PATIENT 7: People think I'm faking it so a lot of people in A&E thought maybe it's not real"

PATIENT 5: "I wasn't happy [with 'pseudoseizures' term] because I knew that I wasn't making them up... it really upset me because it made me very frustrated and I started to question myself, like, 'am I crazy? Have I gone insane?'"

PATIENT 10: "The worst term I've heard was when a nurse was telling another nurse that I was 'faking it', and I thought, 'yes, because I love to be [in hospitals] in my free time'"

All described feeling dismissed/ abandoned by healthcare professionals, primarily pre- but also post-diagnosis. Poor communication and a lack of follow-up was commonly reported, with patients feeling angry, lost, let down, unsupported and neglected.

PATIENT 2: "I was angry... I couldn't understand why these people weren't getting me the help I need... it was like everyone was washing their hands of me and weren't doing anything to help"

PATIENT 10: "It's really frustrating because first you want to get diagnosed... but after being diagnosed, [other health conditions] go under the [functional seizure] umbrella and they stop listening to you and you start to feel like no one really cares"

Feeling dismissed by non-specialist HCPs prior to receiving a diagnosis led 10 patients to engage in self-initiated research in a search for answers. Online resources were utilised, with many mentioning "neurosymptoms.org" as a key platform for gaining answers. Frustration was described when clinicians provided no further information than that online.

PATIENT 4: "It was sort of having to almost suggest or fight to get treatments for myself...neurosymptoms.org. [is where] we were able to get all of that other information"

Patients described the responsibility of explaining functional seizures to non-specialist HCPs, family, friends, work colleagues etc. Some explained this as a tiresome and isolating burden, whilst others viewed this as a positive opportunity to educate others.

PATIENT 13: "where people don't understand [functional seizures] or haven't heard of it, and there's a lot of questions that come with it, I just sometimes feel like a robot like 'yeah this is what happens, but it's fine, don't call an ambulance etc'"

*PATIENT 8: "*Relative* is part of the Royal College of Nursing and I've offered to go and talk about my experiences and raise awareness about it"*

3.4.3. Sense of hope

Seven patients stressed the importance of hope and not giving up in order to continue with their daily life after receiving a diagnosis, irrespective of the term. Hope also occurred by gaining knowledge and being heard by healthcare professionals and loved ones, with small goals being noted as especially important in retaining a sense of normality.

PATIENT 10: "It's functional seizures, that's it, like I've got brown hair...it's a part of me...I think it's important to let people know to not feel sorry for yourself... you're gonna live with this for your whole life, you've got to try to do your best to enjoy your life"

4. Discussion

The present investigation built upon previous research by including terms yet to be researched from patients' perspective. Findings are discussed in the context of existing literature, followed by limitations and directions for future research.

4.1. Preference and Offensiveness

Our previous research on healthy participants indicated that the most preferred and least offensive terms from a choice of eight terms were FNEA and Functional Seizures [23]. This study explored *patients' perspectives*, and included three additional terms 'somatoform disorder', 'medically unexplained symptoms', 'psychogenic non-epileptic seizures'. The findings were similar: 'NEAD', 'FNEA', 'functional seizures' and 'dissociative seizures' were significantly more preferred than all other terms. The terms did not rank significantly differently from one another, which may indicate heterogeneity in preferences, or result from the strict Bonferroni corrections/small sample. Of note,

conversion disorder, a term currently adopted by the DSM-5 [2] was significantly less preferred than these four terms.

Three of the most preferred terms were also the least offensive ('NEAD', 'FNEA', 'functional seizures'). The terms 'dissociative seizures' and 'conversion disorder', currently utilised by the DSM-5 and ICD-10 classification systems [2,3] were viewed as more offensive than these three terms, pulling into question the utility and acceptability of the terms used in current classification systems. Consistent with the literature, 'hysteria' and 'pseudoseizures' were overwhelmingly ranked lowest and considered most offensive [23,29,34]. As we discussed in our previous paper, terms that are relatively more aetiologically neutral were preferred and viewed as less offensive by patients than terms that indicate a psychological explanation [23]. The large range in the preferred terms may also reflect the heterogeneity in the condition and preference for certain terms over others may mirror a patient's view on aetiology, e.g. rejecting the term dissociative seizures if the idea of a dissociative mechanism playing a part does not fit with their experiences of having functional seizures.

4.2. Shared understanding

The qualitative part of the project highlighted that for some patients, the term itself was of less importance than the understanding and explanation provided. This echoes previous research in that whilst the diagnostic term used may help determine the successful delivery and acceptance of a diagnosis, other factors such as the attitude of the clinician [35] and the explanation used [29] are of importance. Patients desire an understanding of causes, symptoms and treatment of functional seizures for themselves and others [31,36]. Research has reported that patients with functional seizures feel a 'static quality' to their lives and feel isolated and unable to move on until gaining an understanding of causation [36]. Whilst this disruption to daily life was described in present findings, it seemed more closely linked to a desire to be taken seriously given the disruption caused. Young people and children with functional seizures have too described being understood and taken seriously as most helpful in moving forward [37] and receiving this understanding and reassurance from healthcare professionals (HCPs) in particular has been noted in both current and previous findings [31]. Present patients explained that the terms utilised by HCPs played a role in feeling taken seriously, with the less offensive terms ('NEAD', 'FNEA', 'functional seizures') generally being favoured in this regard, although some criticised the use of "non-epileptic" as offensive.

Current results strongly depict patients' desire to be seen as an individual, with many feeling frustrated or distressed at the generalised explanation of functional seizures given at diagnosis, even

by specialist HCPs. To date, this appears unique to the current study. It can be hypothesised that this desire arises from the heterogeneity of the causes of functional seizures.

4.3. Feeling alone

Patients described feeling alone, partially resulting from a sense of not knowing. Coping with symptoms, the distress of not knowing what precisely was wrong and the perceived lack of support from non-specialist HCPs caused significant emotional burden amongst many patients, also described by patients with functional movement disorders [38]. The majority of patients reported speaking to multiple doctors from various specialties over several months or years, yet still felt they lacked desired answers, reassurance and empathy. Many described frustration at feeling “palmed off” and that doctors made them feel they were “wasting their time”. Negative experiences with HCPs are frequently reported [36], such as questions around the validity of the condition [39], and accusations of the patient being in control of the seizures [37] or attention seeking [13]. Terminology plays a significant role in this; ‘pseudoseizures’ and ‘hysteria’ were overwhelmingly disliked presently due to the implied accusation of “faking it”.

The data indicated a responsibility on patients to explain functional seizures to others. There appeared to be a distinction between those who were tired/frustrated at explaining themselves to others, and others who viewed it as their duty to educate people. In both regards, having one diagnostic term may be helpful in improving public awareness [6].

4.4. Sense of hope

Several patients discussed the value gained from continuing with their lives, and how setting small goals during treatment facilitated this process. Indeed, there is a tendency for patients to discuss getting on with life despite functional seizures [13], and theoretical accounts point towards the importance of acceptance in prognosis [40]. This finding did not appear to be related to the specific terms used.

4.5. Limitations and future considerations

The quantitative part of the study did not explore if the diagnostic term the patient had received influenced the preference and offensiveness ratings of the terms. It is possible that the wide range of terms preferred may relate to the wide range of terms initially received. It would be of interest to firstly have controlled for this, and secondly to explore if patients whom have all received the same diagnosis differ in preferences of terminology. In the event of having access to a larger sample size, it

may also be of interest to examine correlations with other clinical and demographic variables, such as psychiatric comorbidity, disease severity/duration, who delivered the diagnosis and what kind of follow-up was offered, to help understand the heterogeneity of results.

In addition, the sample itself is gynocentrically biased (4:1), thus inconsistent with the 3:1 ratio of female to male diagnoses [41] and unrepresentative of the patient population. Participants' experiences were within the NHS and therefore ethnocentrically biased, potentially hindering generalisations to other healthcare systems. For example, the debate of the word "seizure" may be specific to the English language; an equivalent word is lacking in many languages and a more general word is utilised (French = epilepsy "crisis") [42].

Research has suggested that patients diagnosed with functional seizures may decline participation in research studies [43], with some hypothesising that the same personality and emotional features observed in patients with functional seizures may also be related to nonengagement in research[44]. To promote engagement, we made the first part of the project completely anonymous. As a consequence of this, we are unable to pair findings between Group A and Group B participants. It also means that we do not have the details of those patients that chose not to engage in the study, or those that chose to engage solely in the quantitative part of the project. The study is potentially limited by volunteer bias [45], although it has been recently argued that results can be generalised to the population as a whole as volunteer bias in the population group is not a concern [44].

Terms that emphasise the 'pseudo' or 'psychogenic' nature of functional seizures are commonly used terms by healthcare professionals [26,46,47]. It would be of interest to explore terminology preferences from a healthcare professional population, and to examine if preferences differ to our findings from both a patient and healthy population. It would also be of further interest to examine if healthcare professional preferences change in light of our current findings.

4.6. Conclusion

Consistent with previous literature, 'NEAD', 'functional seizures', 'FNEA' and 'dissociative seizures' were significantly preferred by patients, with the former three terms considered least offensive. 'Hysteria' and 'psuedoseizures' were overwhelmingly the most offensive and least preferred, with participants explaining that the terms imply an accusation of 'faking it'. This echoes our previous

findings that terms that are relatively more aetiologically neutral are preferred and viewed as less offensive by patients than terms that indicate a psychological explanation [23].

Qualitative analysis revealed the importance of being heard and having a shared understanding of functional seizures. Terms that facilitated understanding were preferred, and these terms differed across the sample, which may reflect the heterogeneity in the condition and patient's view on aetiology. A theme that all participants discussed was the experience of distress and frustration from being dismissed and stigmatised by non-specialist HCPs, with patients often being placed in the educational role as a result. The difficult experiences described by patients often result from an inadequate knowledge on a systemic scale [36], and in agreement with Tolchin and colleagues [6], there is a need for a single 'not perfect, but reasonable' term for this disorder.

From the point of view of avoiding iatrogenic harm, through the use of unnecessary medications and interventions appropriate for the treatment of epileptic seizures, the term needs to reflect clearly that the seizures are not epileptic. Our study found that 3 terms were most preferred and considered least offensive by patients: NEAD, FNEA, and 'functional seizures'. The use of the word "functional" in a diagnosis can enable a clinician to describe how the symptoms represent a loss of access or control over the body, and are not due to damage or abnormal electrical activity in the brain. It allows for both organic and psychological factors and has no seemingly pejorative connotations. In our view, given the additional benefit of connecting the condition to the broader category of functional neurological disorder, we are in support of one of the following two preferred terms being adopted: Functional Non-Epileptic Attacks or Functional Seizures.

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Declarations of interest

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