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**The frequency and management of seizures during psychological treatment
among patients with psychogenic non-epileptic seizures and epilepsy.**

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Abstract

Objective: Growing evidence suggests that psychological treatments are effective for improving outcomes in both epilepsy and psychogenic non-epileptic seizures (PNES). However, the risk of in-session seizures may cause concerns about safety and scope of psychological interventions. This study explores the risk of in-session seizures in patients with epilepsy and those with PNES, the timings of seizures during psychological therapy and therapists' responses to seizures.

Methods: Consecutive patients with epilepsy or PNES attending two neurology centres in the United Kingdom for psychological treatment to help with their seizure disorders were studied. Information about seizures during outpatient psychological therapy sessions was gathered using a 12-item pro-forma.

Results: 97 patients with epilepsy and 195 with PNES were captured. One in 32 patients with epilepsy and 1 in 8 with PNES had at least one in-session seizure. A seizure occurred in 1 in 136 treatment sessions provided to patients with epilepsy, and 1 in 36 sessions provided to those with PNES. The risk of in-session seizures was significantly greater in patients with PNES than epilepsy (odds ratio 4.42, 95% CI 1.29-15.15). Seizures tended to occur in the first half of treatment programs and individual sessions and only disrupted sessions briefly. Only one patient with PNES required in-patient observation not involving overnight admission.

Significance: In-session seizures do occur, and are much more common in patients with PNES than those with epilepsy. Seizures rarely caused major disruption to psychological treatment, and could almost invariably be managed by the treating therapist without help from additional medical staff. Nonetheless, this research suggests that psychological therapy providers should anticipate the occurrence of in-session seizures and have safe management plans in place. The greater frequency of in-session seizures in PNES adds to our understanding of the mechanisms triggering these seizures.

Current word count 290

Bullet points

- Seizures do occur in psychological treatment sessions
- In-session seizures are much more common in PNES (1 in 36 sessions) than in epilepsy (1 in 136 sessions)
- Seizures are more likely in the first few psychological therapy sessions.
- Most in-session seizures are readily managed by therapists without external medical assistance
- Psychological treatment providers should have seizure management plans in place when treating people with seizure disorders

1. Introduction

Epilepsy is a chronic disorder defined by an increased risk of recurrent, unprovoked epileptic seizures. Psychogenic non-epileptic seizure disorders (PNES) comprise paroxysms superficially resembling those seen in epilepsy but not associated with the abnormal electrical activity in the brain which characterises epilepsy. Most PNES are understood to occur as a manifestation of distress ^[1] or via attentional and belief-driven processes ^[2]. Both types of seizure disorders may remit, but become a chronic problem in many cases ^[3,4].

Neither epilepsy nor PNES disorders are characterised by seizures alone. Cognitive dysfunction and psychiatric comorbidities are more common in patients with both of these seizure disorders than in the general population ^[5,6,7,8], and the complex and intimate nature of the links between seizures and psychiatric and cognitive morbidity is recognised in the ILAE definition of epilepsy ^[9]. Indeed, when epileptic seizures or PNES are not fully controlled by treatment, neuropsychological and psychiatric problems have greater adverse effects on patients' quality of life than seizure-related variables ^[5,6,7,8,10,11]. There is accumulating evidence of the effectiveness of psychological therapy in patients with both types of seizure disorders: such treatments can improve health related quality of life (HRQoL) in patients with epilepsy ^[12], and seizure control, HRQoL, and functioning in those with PNES ^[13,14]. Consequently, in clinical practice a proportion of people with PNES and epilepsy may be referred for psychological therapy.

However, while there is a clear role for psychological treatment in patients with both seizure disorders, recent surveys in the United States, United Kingdom (UK) and globally suggest that even in the case of PNES, where psychological intervention is considered the treatment modality of choice, access to psychological assessment and treatment remains patchy ^[15,16,17]. While this may be the result of a number of factors, one potential barrier to access might involve the extent to which psychology services are equipped to manage the occurrence of seizures. For example, in many places psychological treatment services specialising in the treatment of patients with seizures are not available or accessible and generic services (such as primary care

or community mental health services) become involved. Less specialised services may lack immediate access to medical support, so the occurrence of seizures (or concerns about managing seizures) could cause significant practical problems.

It is presently not known how often seizures occur in the context of psychological therapy sessions, how they are managed by psychological therapists when they happen and the extent to which they interfere with therapy. Such information can help guide the practice of psychological therapy services that treat people with seizure disorders. Consequently, this study was designed to determine the prevalence of seizures during outpatient psychological therapy sessions. It explores: i) whether in-session seizures are more likely in PNES or epilepsy; ii) the characteristics of in-session seizures; and, (iii) how seizures are managed by psychological therapists.

2. Method

2.1 Setting

Data for this study were collected from two clinical neuroscience centres in the UK: The Specialised Neuropsychotherapy Service based within the Department of Neurology of the Sheffield Teaching Hospitals NHS Foundation Trust (centre 1) and the Department of Clinical Neuropsychology at the Leeds Teaching Hospitals NHS Trust (centre 2). Patients were seen by one of eight therapists. Consecutive recruitment was prospective at centre 1 (February 2014 to April 2015) and retrospective at centre 2 (data retrieved from records of patient seen between April 2010 and March 2015). This study was approved as a Service Evaluation by the Clinical Effectiveness Units of the participating hospitals.

2.2 Patients

All patients had diagnoses of epilepsy or PNES and had been referred to the participating psychological therapy services for psychological assessment and treatment. All seizure disorders were diagnosed by fully-trained neurologists. Diagnoses were based on all available clinical information (including seizure description, brain imaging and EEG findings, but not always including the video-EEG

recording of typical seizures). All diagnoses of PNES were sufficiently certain for neurologists to recommend psychological treatment and stop antiepileptic drug treatments (if previously prescribed). Patients with uncertain diagnoses or mixed (epileptic / non-epileptic) seizure disorders were not included. In both centres, patients with epilepsy receive psychological therapy aimed at addressing adjustment problems, depression, anxiety, seizure phobia and posttraumatic symptoms relating to the epilepsy, with less urgency on managing specific emotional triggers which do not generally lead to 'epileptic' seizures. Patients with PNES on the other hand engage in various forms of psychological therapy including integrative, cognitive behavioural (CBT), sensori-motor, Gestalt, psychodynamic and various trauma based paradigms, with an additional initial focus on grounding and stabilisation techniques in centre 1. The therapeutic work focuses on processing trauma and loss, with the ultimate aim of improving emotional processing and psychological self-care.

2.3 Measures and Procedure

This study comprised an audit of routinely collected data. Data for this study was collected on a pro-forma (provided as supplementary online information, appendix A). The pro-forma was used to collect information about the nature, precise timing, clinical context, treatment and consequences of in-session seizures. At centre 1 this pro-forma was completed immediately after treatment sessions in which a seizure had been observed by the therapist providing the psychological intervention. At centre 2, the pro-forma was completed retrospectively from the detailed contemporaneous treatment records by two assistant psychologists and one research assistant, working under the supervision of a Consultant Clinical Neuropsychologist. Data about the number of treatment sessions provided to patients with seizures in both centres, the total number of patients seen and treatment sessions provided during the study period were obtained from the participating hospitals' patient administration systems.

2.4 Data Analysis

Data were analysed using SPSS (version 17). Between-group differences were analysed using chi-square test. The association between diagnosis and occurrence

of in-session seizures was analysed using chi-square test. In a logistic regression analysis comparing seizures in patients with epilepsy and PNES, baseline seizure frequency was entered as block 1 and in-session seizure occurrence as block 2.

3. Results

A total of 292 patients with seizures attended psychological therapy at the two centres during the recruitment period, 97 with epilepsy and 195 with PNES. Descriptive data on all 292 patients is set out in Table 1. Descriptive data on patients who had in-session seizures is set out in Table 2. There was a gender difference between the groups, with more female patients in the PNES group. PNES patients also reported a higher seizure frequency compared to those with epilepsy (i.e. median = 10 and 4 seizures per month respectively). The median number of psychological treatment sessions attended was 6 for epilepsy patients and 5 for PNES patients.

Insert Table 1: about here

Insert Table 2: about here

The total number of treatment sessions provided to patients with epilepsy during the whole recruitment period at the two centres was 678. The total number of treatment sessions provided to patients with PNES during the data collection period was 1,356.

Three patients with epilepsy experienced at least one seizure during psychological therapy. Among these three participants there were seven seizures in total. In comparison, 26 patients with PNES experienced at least one in-session seizure, with 48 in-session seizures in total. This means that one in 32 patients with epilepsy and one in eight with PNES had at least one in-session seizure. One or more seizures occurred in one in 136 treatment sessions provided to patients with epilepsy, and in one in 36 sessions involving patients with PNES.

Table 3 shows the logistic regression analysis with diagnostic group (epilepsy vs. PNES) as the dependent variable. First, we controlled for seizure frequency, which was not an independent predictor of diagnostic group ($p < .141$). Secondly, we controlled for gender, which was an independent predictor of diagnostic group ($p < .042$). The addition of in-session seizure (present vs. absent) showed this to be an independent predictor ($p < .018$) with an odds ratio of 4.42 (95% CI 1.29-15.15). Therefore patients who had in-session seizures were four times more likely to have PNES than epilepsy.

Insert Table 3: about here

Seizures occurred more commonly in the first half of the psychological treatment programme and of individual treatment sessions than the second. Epileptic seizures tended to be shorter than PNES but three quarters of PNES resolved in less than five minutes. The vast majority of seizures stopped with “just waiting”. Therapists arranged temporary observation (without admission overnight) on a neurology ward because of three consecutive PNES in one case. These measures were never considered necessary for any of the observed epileptic seizures, although epileptic seizures prompted therapists more often than PNES to make patients safe or ask a relative or carer to help manage the seizure (see Table 4 for descriptive data of observed seizures).

Discussion

Our study demonstrates that the occurrence in-session seizures is a feature of psychological therapy sessions with patients with seizure disorders. They are significantly more common in sessions with patients with PNES than those with epilepsy - occurring in 1 in 136 sessions with patients with epilepsy and 1 in 36 sessions involving those with PNES.

This difference between the groups was not explained by the greater seizure frequency reported by patients with PNES, with the group difference remaining

significant after controlling for this variable. Thus, while our dataset does not allow us to disentangle the exact reasons for the greater frequency of in-session seizures in those with PNES, these observations suggest that aspects of psychological therapy sessions can trigger these seizures. Given that these sessions explore seizure triggers, mood and a person's understanding of their seizures, it may be that PNES are triggered by the activations of seizure representations, by the modulation of mood or the level of arousal [5,18]. This interpretation would be consistent with the integrative cognitive model which argues that PNES represent the activation of a seizure scaffold as a dissociative response to internal or external cues in the context of impaired inhibition [18].

Previous studies have demonstrated that about 50% of patients receiving psychotherapy for PNES become seizure-free with treatment and about 80% experience an >50% reduction in the frequency of their attacks [13]. Our finding that in-session seizures in PNES are less likely to occur in latter psychological therapy sessions resonates with these observations and suggests that patients may become better able to tolerate emotionally challenging situations as their treatment progresses.

Although there is some evidence suggesting that, like PNES, epileptic seizures can also be triggered by emotional states (and controlled by a modulation of such states) [19], our dataset suggests that, generally speaking, psychological therapy is unlikely to comprise such a trigger for this patient group.

The between-group difference in in-session seizure frequency may also be explained by therapists pursuing a different treatment focus in epilepsy compared to PNES. For example, treatments for PNES may have more often focused on improving patients' tolerance of seizure triggers, or on antecedent psychological trauma; whereas psychological therapy for epilepsy may have focused on finding ways to live well with a chronic disease.

Neither epileptic seizures nor PNES were likely to cause a major disruption of psychological therapy. Almost invariably, seizures were successfully managed by the treating therapist without help from physicians or emergency care staff within the normal time frame of the therapy session. None of the seizures observed caused any injuries. Only one patient with PNES (and none with epilepsy) failed to recover

sufficiently from their seizures within the time allocated for the therapy session to go home.

Despite the fact that seizures were relatively infrequent in our patient cohort, psychological therapy providers should anticipate the occurrence of in-session seizures in the patient groups described here, and to have safe management plans in place. Both epileptic and non-epileptic seizures can cause serious injuries ^[20, 21]. Although studies exploring the injury risk in these two seizures disorders have failed to identify clear differences in the reported frequency of injuries ^[22], the injury risk per seizure is likely to be much lower in PNES. In patients with epilepsy, psychological therapy service providers should also consider the risk of status epilepticus, a potentially life-threatening emergency. In our consecutive cohort medical support was only needed once - for a patient with recurrent PNES. Support was not required because of a life-threatening emergency but rather because PNES were recurrent and appeared unresponsive to the seizure control techniques applied by the therapist. The patient was given extra time within the contained environment of a neurology ward to recover from the prolonged seizure. The patient returned to a normal level of consciousness within half an hour of being brought onto the ward. Although medical support was, therefore, rarely called upon, psychological therapists in both centres had access to this support and could arrange further observation of patients. The ability to call for help when needed, and without exposing patients to the risk of traumatisation by the involvement of emergency services ^[23], may have helped therapists to feel more confident about tackling potentially distressing aspects of therapy.

Limitations

This study has two salient limitations. First, the retrospective recording of seizures in one of the two centres may have affected the accuracy of some collected data. Second, given that we recorded only a few variables, we were unable to disentangle the reasons why seizures were more frequent in people with PNES. We also had limited information about the timings of seizures within sessions in relation to session content, which might have identified the aspects of the therapeutic interaction serving as seizure triggers. As mentioned previously, another limitation regarding the

comparisons between the PNES and epilepsy groups is that, given the differing aetiology of the two conditions, the psychological intervention methods utilised by therapists may have differed between these groups. Last but not least, psychiatric comorbidities may have had an effect on the risk of in-session seizures, and psychiatric comorbidity profiles are likely to have differed between the patients with epilepsy and PNES ^[5], but relevant data was not collected in a structured fashion in all cases and therefore not available for analysis.

Conclusion

This study showed that the presence of in-session seizures is a feature of working with patients with seizure disorders, and these are much more common in those with PNES compared to those with epilepsy. Although PNES could almost invariably be managed by the psychological therapist without help from physicians or emergency care staff, we recommend that psychological therapy providers should anticipate the occurrence of in-session seizures and to have safe management plans in place. The fact that PNES occur more commonly than epileptic seizures during psychological therapy sessions adds to our understanding of the mechanisms triggering PNES.

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Table 1: Descriptive data for all patients: Clinical characteristics and seizure incidence:

	PNES	Epilepsy	Total
N	195	97	292
Age at first session (median years; range)	40 (18-87)	39 (15-63)	40 (15-87)
Gender (% women/men)	67/33	55/45	63/37
Learning disabilities (%)	3	5	4
Seizure frequency per month (median; range)	10 (0-1500)	4 (0-600)	8 (0-1500)
Number of sessions (median; range)	5 (1-26)	6 (1-21)	6 (1-26)
Number of patients that had in-session seizures (%)	26 (13)	3 (3)	
Number of patients that did not have seizures (%)	169 (87)	94 (97)	

Table 2: Descriptive data for patients who had in-session seizures: Incidence of in-session seizures:

	PNES	Epilepsy	Total
N			
Number of patients who had seizures	26	3	29
Number of seizures captured	48	7	55
Incidence of seizures in these patients (median; range)	1 (1-10)	3 (1-3)	
Number of patients that had more than one seizure (%)	7 (27)	2 (67)	

Table 3: Logistic regression:

Variable	B	SE	Wald test	Sig	Odds ratio	95% CI	
						Lower	Upper
Constant	0.708	0.174	16.592	0.000	2.029		
Seizure Frequency	0.002	0.002	2.162	0.141	1.002	0.999	1.006
Gender	-0.528	0.260	4.132	0.042	0.590	0.355	0.981
Presence/Absence of Seizure	1.485	0.629	5.573	0.018	4.416	1.287	15.151

Table 4: Clinical characteristics and management of in-session seizures:

	PNES n=46	Epilepsy n=7
Place of attack (% of seizures)		
In hospital transport	0	0
In the waiting area	17	14
In therapy room	17	86
Ambulance waiting area	0	0
Elsewhere in the hospital	6	0
Not known	0	0
Timing of seizure in course of treatment (%)		
First quarter	39	43
Second quarter	39	29
Third quarter	7	0
Last quarter	7	29
During the only session attended	9	0
Timing of attack in session (%)		
Before the session	15	14
First quarter of session	17	43
2nd quarter	27	29
3rd quarter	21	0
Last quarter	6	14
Immediately after session	10	0
Not known	4	0
Duration of attack (%)		
Less than a minute	31	57
1 minute	4	0
2 minutes	17	0
3 minutes	8	14
4 minutes	4	0
5 minutes	10	14
10 minutes	13	0
15-30 minutes	13	14
Description of attack (%)*		
Seizure warning	29	29
Absence	33	57
Drop attack	10	0
Shaking of limbs	35	29
Shaking of body	40	14
Some consciousness retained	29	14
Consciousness lost completely	15	0
Some responsiveness during seizure	31	43
Completely unresponsive	13	0
Speech during episode	6	0
Crying during/after episode	0	0
Patient looked fearful	0	0
Incontinent of urine	0	0
Incontinent of faeces	0	0
Injuries incurred	0	0
Single episode	15	0
Multiple episodes	0	0
Not known	17	0
Possible trigger (%)*		
Traumatic reminder	33	0
Anxiety/panic	10	29
Other emotion	17	14
Sounds	0	0
Other	17	0
No trigger apparent or Unknown	29	57

Were seizure prevention techniques employed by clinician? (% yes)	63	29
Were seizure prevention techniques considered successful? (% yes; % partly)	47 (43)	100 (0)
Types of seizure prevention techniques used (% of seizures)*		
Talking to the patient	58	29
Breathing	19	14
Grounding	33	14
Other somatic techniques	0	0
Distraction	0	0
Smelling salts	0	0
Rose oil or other perfume	4	0
Other	0	14
Other actions employed (% of seizures, several responses possible)*		
Just waited	75	100
Patient kept safe	33	86
Family member/friend asked for help	8	43
Service protocol for lengthy in-session seizures used	4	0
Emergency assistance called for	0	0
Other	13	0
Consequence of seizure (% of seizures)*		
Able to go home normally	88	57
Had to call relative or friend	4	43
Went on neurology ward for observation	6	0
Admitted with overnight stay	0	0
Other	2	0
Number of patients requiring help from relatives or other professionals following a seizure	2	1
Number of patients requiring medical help/emergency services following a seizure	1	0

* Several answers possible

Pro-forma used

Pilot study - Seizures in the therapy context in epilepsy and non-epileptic attack disorder

Sheffield teaching Hospitals and St James University Hospital, Leeds

Front sheet – Therapist to complete one for each patient

Name of Therapist

1 Patient details

1.1 ID no.:

1.2 Age:

1.3 Gender

M/F

1.4 The patient is diagnosed with:

Epilepsy/NEAD/epilepsy **and** NEAD

1.5 Duration of seizure disorder

_____ years

1.6 Is patient on anti-epileptic medication?

Yes/No

1.7 Does the patient have learning difficulties?

Yes/No

1.8 Do you work with the patient through an interpreter?

Yes/No

Pilot study - Seizures in the therapy context in epilepsy and non-epileptic attack disorder

Episode sheet

To be completed by therapist for each session of therapy in which patient experiences an actual or threatened seizure.

Name of therapist:

Patient ID no.

Age

Session no.

Date

Number of seizures patient has had in the last week

1. Context of the episode

1.1 Was the patient accompanied to session? Yes/No

1.2 Where did the seizure occur?

- a) In hospital transport
- b) In the waiting area
- c) In therapy room
- d) Ambulance waiting area
- e) Elsewhere in the hospital
- f) Not Known

1.3 Who was present at the time? (tick all that apply)

- a) Therapist
- b) Family or friend
- c) Reception staff
- d) Other patients in waiting room
- e) General public
- f) Other (please specify)
- g) Not Known

1.4 When did the episode occur?

- a) Before the session
- b) 1st quarter
- c) 2nd quarter
- d) 3rd quarter
- e) Last quarter
- f) Immediately after session

2. Nature of episode

2.1 What best describes the episode? Tick any that apply.

- a) Seizure warning
- b) Absence
- c) Drop attack
- d) Shaking of limbs
- e) Shaking of body

- f) Some consciousness retained
- g) Consciousness lost completely
- h) Some responsiveness during seizure
- i) Completely unresponsive
- j) Speech during episode
- k) Crying during/after episode
- l) Patient looked fearful
- m) Incontinent of urine
- n) Incontinent of faeces
- o) Injuries incurred
- p) Single episode/multiple episodes
- q) Not known

2.2 Episode trigger

- a) Traumatic reminder
- b) Anxiety/panic
- c) Other emotion
- d) Sounds
- e) Other (please specify)
- f) No trigger apparent
- g) Not known

2.3 Duration of total episode minutes

2.4 Was the episode over by the end of the session? Yes/No

2.5 What happened afterwards?

- a) Able to go home normally
- b) Had to call relative or friend
- c) Went on neurology ward for observation
- d) Admitted with overnight stay
- e) Other

3. Actions taken by therapist

3.1 Were seizure prevention techniques used Yes/No

3.1.1 If yes, which techniques were used?

- a) Talking to patient
- b) Breathing
- c) Grounding
- d) Other somatic techniques
- e) Distraction
- f) Smelling salts
- g) Rose oil or other perfumes
- h) Other

3.1.2. Were the techniques successful? Yes/No/Partly

3.2 What other action was taken by the therapist? Tick all that apply.

- a) Just waited
- b) Patient kept safe

- c) Family member/friend asked for help
- d) Service protocol for lengthy in-session seizures used
- e) Emergency assistance called for
- f) Other (please specify)