

This is a repository copy of *The frequency and management of seizures during* psychological treatment among patients with psychogenic nonepileptic seizures and epilepsy.

White Rose Research Online URL for this paper: http://eprints.whiterose.ac.uk/129714/

Version: Accepted Version

#### Article:

Kemp, S, Graham, CD, Chan, R et al. (3 more authors) (2018) The frequency and management of seizures during psychological treatment among patients with psychogenic nonepileptic seizures and epilepsy. Epilepsia, 59 (4). pp. 844-853. ISSN 0013-9580

https://doi.org/10.1111/epi.14040

(c) 2018 International League Against Epilepsy. This is the peer reviewed version of the following article: Kemp, S, Graham, CD, Chan, R et al. (3 more authors) (2018) The frequency and management of seizures during psychological treatment among patients with sychogenic nonepileptic seizures and epilepsy. Epilepsia, 59 (4). pp. 844-853., which has been published in final form at https://doi.org/10.1111/epi.14040. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

#### Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

#### **Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



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

Steven Kemp [1]\*, Christopher D. Graham [1, 2], Rebecca Chan [1],

Hayley Kitchingman [1], Kirsty Vickerman [3], Markus Reuber [3].

[1] Department of Clinical and Health Psychology, St James's University Hospital,

Leeds, UK

[2] Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

[3] Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital,

Sheffield, UK

\*Corresponding author

Dr Steven Kemp

Department of Clinical and Health Psychology

St James's University Hospital

Leeds (UK)

LS9 7TF

Fax: 0113 2064079

Email: <a href="mailto:stevenkemp@nhs.net">stevenkemp@nhs.net</a>

1

# <u>Abstract</u>

**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 about seizures disrupting treatment. 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 4.4, 95% CI 1.3-15.2). 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 insession 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.

# **Bullet points**

- Seizures do occur in psychological treatment sessions and are 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.
- Aspects of psychological treatment may trigger seizures in PNES.

# 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 <sup>[5,6,7,8]</sup>, and the complex and intimate nature of the links between seizures and psychiatric and cognitive morbidity is recognised in the ILAE definition of epilepsy <sup>[9]</sup>. 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 <sup>[5,6,7,8,10,11]</sup>. 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 <sup>[12]</sup>, and seizure control, HRQoL, and functioning in those with PNES <sup>[13,14,15]</sup>. 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 primary treatment of choice, access to psychological assessment and treatment remains patchy [12,16,17]. While this may be the result of a number of factors, one potential barrier to access may involve the extent to which, psychology services are equipped to manage the occurrence of seizures. 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) can cause significant practical problems.

To our knowledge, in-session seizures have not been the primary focus on any previous studies and their incidence in unselected populations of patients with epilepsy or PNES is not known. Although there is advice for therapists on how to respond to an in-session seizure [18], it is unclear to whether therapists are able to adhere to such guidance and to what extent seizures interfere with therapy. Such information can help guide the practice of psychological therapy services treating people with seizure disorders. Therefore, this study was designed to determine the incidence of seizures during outpatient psychological therapy sessions in consecutive, unselected patient populations. It also 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. Data at both centres were collected from contemporaneous notes based on clinical observation. In centre 1 data was collected prospectively after treatment sessions between February 2014 and April 2015. At centre 2, data for the data capture forms was extracted retrospectively from clinical records of patients 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 video-EEG recordings of typical seizures). Video EEG was not always feasible due to access limitations, waiting times or seizure frequency. Also, video EEG confirmation of diagnoses was not always considered clinically indicated. All diagnoses of PNES were sufficiently certain for neurologists to recommend psychological treatment and stop antiepileptic drug treatments (if previously prescribed). Patients in whom a dual diagnosis (epilepsy and PNES) was suspected were not included (centre 1 excluded three patients with a dual diagnosis and centre 2 excluded eight).

# Psychological therapies

In both centres, patients with epilepsy received psychological therapy aimed at addressing adjustment problems, distress, and/or seizure phobia. Managing possible emotional triggers was addressed in treatment, but with less emphasis than in the PNES treatment group. Depending on assessment and patient and clinician preference, patients received one of the following three therapies:

Cognitive behavioural therapy (CBT): This is the most widely applied evidence-based psychological treatment approach [19]. The focus is on distress and/or symptom reduction (depending on diagnosis: epilepsy or PNES) via the identification and modification of unhelpful beliefs and behaviours. Treatment methods include: credible communication of the diagnosis; symptom control methods, such as distraction or grounding; relaxation training; modification of unhelpful beliefs; and, exposure to avoided situations.

Acceptance & Commitment Therapy (ACT): Acceptance and Commitment Therapy (ACT) is a newer type of CBT <sup>[20]</sup>. It involves the use of mindfulness and perspective-taking techniques, alongside functional analysis, and metaphor. The aim is to help people interact with their thoughts and feelings in ways that enable them to behave more in line with their over-arching goals <sup>[21,22]</sup>, as opposed to focusing on distress control or symptom reduction alone.

Brief integrative psychodynamic psychotherapy: is grounded in psychodynamic interpersonal therapy <sup>[23]</sup> but augmented with elements from several other therapies (e.g. somatic trauma therapy <sup>[24,25]</sup>, CBT and ACT) <sup>[26]</sup>. The underlying model assumes that the patient's emotional and interpersonal problems will be re-enacted in the relationship with the therapist, and seeks to use this relationship to understand and address these problems. PNES specific additional techniques that may be used, dependent on presentation, include: seizure management and prevention techniques; exploration of hyper-and/or hypo-arousal (often in the context of a trauma history); and techniques aiming to maintain an optimal level of arousal.

#### 2.3 Measures and Procedure

This study was a service evaluation using routinely collected data. The data capture pro-forma was used to collect information about the nature, precise timing, clinical context, treatment and consequences of in-session seizures (see appendix A for the proforma). 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, two assistant psychologists and one research assistant, working under the supervision of a Consultant Clinical Neuropsychologist, extracted data for the pro-forma retrospectively from the detailed contemporaneous clinical records produced by the therapist after treatment sessions. The pro-forma captured rudimentary data and we did not establish inter-rater reliability. Patients at both centres were identified using the hospitals' patient administration systems.

# 2.4 Data Analysis

Data were analysed using SPSS (version 17). Between-group differences were analysed using chi-square tests. The association between diagnosis and occurrence of in-session seizures was analysed using chi-square tests. In a logistic regression analysis comparing seizures in patients with epilepsy and patients with 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 patients 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. Patients with PNES 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 patients with PNES.

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. These three participants had a total of seven seizures. 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 patients 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 4.4 (95% CI 1.3-15.2). Therefore, patients who had in-session seizures were four times more likely to have PNES than epilepsy.

#### Insert Table 3: about here

In the PNES group, seizures occurred more commonly in the first half of the psychological treatment as a whole, and in the first half of individual sessions. For the epilepsy group, the pattern was similar for individual treatment sessions. However, in terms of the overall course of treatment, 29 per cent of the epilepsy patients had in-session seizures in the last quarter of treatment. For the PNES group, the most commonly identified trigger was a traumatic reminder (e.g. talking about loss - 33%). Twenty seven per cent of PNES were judged to have been triggered by anxiety or other emotions evoked during psychological treatment. Seventeen per cent of PNES were thought to be triggered by 'other' features of the psychological treatment, such as talking about daily functioning, engagement with treatment or relaxation training. For the remaining PNES, therapists were unable to identify a trigger (Table 4). Epileptic seizures tended to be shorter than PNES, but three quarters of PNES resolved in less than five minutes. Therapists typically responded to in-session seizures by ensuring safety, removing any potentially dangerous objects, talking calmly to the patient, but generally not talking other than stating that the therapist will sit quietly, and not touching the patient. The vast majority of seizures stopped with this approach. Therapists arranged temporary observation (without admission overnight) on a neurology ward for one patient because of three consecutive PNES. 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).

#### Insert Table 4: about here

### **Discussion**

Our study demonstrates that in-session seizures occur during psychological treatment for patients with seizure disorders. In-session seizures are significantly more common among 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. Just over one half of the seven epileptic seizures presented as episodes of altered awareness ("absences"), just under one half involved limb / body shaking. The semiology of the 48 PNES observed in therapy was more variable (Table 4). Interestingly, 13 per cent of the PNES were described as involving complete unresponsiveness, compared to none of the epileptic seizures.

This difference in the incidence of seizures 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, it suggests that aspects of psychological therapy sessions can trigger in-session PNES. Given that the exploration of seizure triggers and patients' understanding of their seizures was a more significant part of the psychological treatment for PNES than that for epilepsy, our observations are consistent with the idea that PNES are triggered by the activation of seizure representations, by the modulation of mood, level of arousal or the mentalisation of specific triggers including trauma reminders [5,29]. This interpretation would be consistent with the Integrative Cognitive Model (ICM), which argues that PNES represent the activation of a 'seizure scaffold', as a conditioned reflex-like response to internal or external cues in the context of impaired inhibition [27,29]. In the ICM the seizure scaffold is conceptualized as a learned script (similar to a computer program) comprising a sequence of perceptions and motor activities. The seizure scaffold is originally formed via inherent automatic responses (eg. freeze, startle), physical symptoms (eg. dissociation / hyperventilation / head injury), but also shaped by personal knowledge or modeling.

This view is speculative, but worthy of further investigation. This conjecture is similar to how Myers et al. <sup>[28]</sup> viewed seizure triggers. Although not their primary research question, they reported in-session seizures among a group of 16 patients treated for a dual diagnosis of post-traumatic stress disorder (PTSD) and PNES. Nine of their 16 patients experienced at least one seizure during the course of 12-15 weekly psychological treatment sessions.

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 <sup>[13]</sup>. 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) [29], these data suggest that, generally speaking, psychological therapy is unlikely to trigger epileptic seizures.

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 [30,31]. Although studies exploring the injury risk in these two seizures disorders have failed to identify clear differences in the reported frequency of injuries [32], 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 [33], may have helped therapists to feel more confident about tackling potentially distressing aspects of therapy.

We present these findings of differential incidence of seizures during psychological treatment as an important contribution to understanding the psychological aspects of seizure disorders. These data have important patient safety implications. It is clear that in-session seizures do occur among both patient groups and that patients could potentially come to harm in treatment. We have several suggestions for future work. First, further work is required to develop our understanding of triggers. Second, we propose developing and using a checklist to establish the in-session seizure risk. This could include questions such as typical triggers and could form part of the clinical assessment and the typical diary-keeping exercise as part of assessment for treatment. At the end of the assessment or engagement phase of psychological treatment, the risk of seizures should be discussed with patients and an in-session seizure plan agreed. We propose this approach as a clinical protocol to establish

risk, develop our understanding of triggers, promote transparency of clinical response and to ensure high standards of care and patient safety.

#### 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. Further, 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. Finally, these data relate to psychological treatment sessions and it is unclear to what extent the findings generalise to other medical settings.

#### Conclusion

This study showed that the presence of in-session seizures is a feature of treating 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 and our preliminary findings regarding triggers, adds to the understanding of PNES mechanisms.

#### References

- 1) Wiseman H, Reuber M. New insights into psychogenic nonepileptic seizures 2011–2014. Seizure. 2015;29:69-80.
- 2) Edwards MJ, Adams RA, Brown H, et al. A Bayesian account of 'hysteria'. Brain. 2012;135:3495-512.
- 3) Kwan P, Arzimanoglou A, Berg AT, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. Epilepsia. 2010;51:1069-77.
- 4) Reuber M, Pukrop R, Bauer J, et al. Outcome in psychogenic nonepileptic seizures: 1 to 10-year follow-up in 164 patients. Ann neurol. 2003;53:305-11.
- 5) Brown RJ, Reuber M. Psychological and psychiatric aspects of psychogenic nonepileptic seizures (PNES): a systematic review. Clin psychol rev. 2016;45:157-82.
- 6) Mula M. Cognitive dysfunction in patients with epilepsy: focus on clinical variables. Future Neurol. 2015;10:41-8.
- 7) Reuber M. Are psychogenic non-epileptic seizures an expression of "neurologic" pathology?". Psychiatric controversies in epilepsy. 2008:153-77.
- 8) Tellez-Zenteno JF, Patten SB, Jetté N, et al. Psychiatric comorbidity in epilepsy: a population-based analysis. Epilepsia. 2007;48:2336-44.
- 9) Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. Epilepsia. 2014;1:55:475-82.
- 10) Jacoby A, Snape D, Baker GA. Determinants of quality of life in people with epilepsy. Neurol clin. 2009;27:843-63.
- 11) Jones B, Reuber M, Norman P. Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: A systematic review. Epilepsia. 2016;57:171-81.
- 12) Michaelis R, Tang V, Wagner JL, et al. Psychological treatment for people with epilepsy. The Cochrane Library. 2016. Under review.
- 13) Carlson P, Perry KN. Psychological interventions for psychogenic non-epileptic seizures: A meta-analysis. Seizure. 2017;45:142-50.
- 14)LaFrance WC, Reuber M, Goldstein LH. Management of psychogenic nonepileptic seizures. Epilepsia. 2013;54(s1):53-67.

- 15) Kanemoto K, LaFrance WC, Duncan R, et al. PNES around the world: where we are now and how we can close the diagnosis and treatment gaps. An ILAE PNES Task Force report. Epilepsia Open. 2017;1–10. doi: 10.1002/epi4.12060.
- 16)LaFrance WC, Rusch MD, Machan JT. What is "treatment as usual" for nonepileptic seizures?. Epilepsy Behav. 2008;12:388-94.
- 17) Mayor R, Smith PE, Reuber M. Management of patients with nonepileptic attack disorder in the United Kingdom: a survey of health care professionals. Epilepsy Behav. 2011;21:402-6.
- 18)LaFrance Jr WC, Wincze JP. Treating nonepileptic seizures: therapist guide. Oxford University Press. 2015.
- 19) Butler AC, Chapman JE, Forman EM et al. The empirical status of cognitive-behavioral therapy: a review of meta-analyses. Clin psychol rev. 2006;31;26(1):17-31.
- 20) Hayes SC, Luoma JB, Bond FW et al. Acceptance and commitment therapy: Model, processes and outcomes. Behaviour research and therapy. 2006;31;44(1):1-25.
- 21) Graham CD, Gouick J, Krahé C et al. A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. Clin psychol rev. 2016;30;46:46-58.
- 22) Dewhurst E, Novakova B, Reuber M. A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy. Epilepsy Behav. 2015;31;46:234-41.
- 23) Hobson RF. Forms of feeling: The heart of psychotherapy. London: Tavistock, 1985.
- 24)Ogden P, Pain C, Fisher J. A sensorimotor approach to the treatment of trauma and dissociation. Psychiatric Clinics. 2006;1;29(1):263-79.
- 25)Rothschild B. Trauma Essentials: The Go-To Guide (Go-To Guides for Mental Health). WW Norton & Company. 2011.
- 26) Howlett S, Reuber M. An augmented model of brief psychodynamic interpersonal therapy for patients with nonepileptic seizures. Psychotherapy: Theory, Research, Practice, Training. 2009;46(1):125-138.
- 27)Reuber M, Brown RJ. Understanding psychogenic nonepileptic seizures— Phenomenology, semiology and the Integrative Cognitive Model. Seizure. 2017;31:44:199-205.
- 28) Myers L, Vaidya-Mathur U, Lancman M. Prolonged exposure therapy for the treatment of patients diagnosed with psychogenic non-epileptic seizures (PNES) and post-traumatic stress disorder (PTSD). Epilepsy Behav. 2017;31;66:86-92.

- 29)Brown RJ, Reuber M. Towards an integrative theory of psychogenic non-epileptic seizures (PNES). Clin psychol rev. 2016;47:55-70.
- 30) Asadi-Pooya AA, Emami M, Emami Y. Ictal injury in psychogenic non-epileptic seizures. Seizure. 2014;23:363-6.
- 31) Nguyen R, Zenteno JF. Injuries in epilepsy: a review of its prevalence, risk factors, type of injuries and prevention. Neurol int. 2009;1.
- 32)Peguero E, Abou-Khalil B, Fakhoury T, et al. Self-Injury and Incontinence in Psychogenic Seizures. Epilepsia. 1995;36:586-91.
- 33) Worsely C, Whitehead K, Kandler R, et al. Illness perceptions of health care workers in relation to epileptic and psychogenic nonepileptic seizures. Epilepsy Behav. 2011;20:668-73.

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

	PNES	Epilepsy	Total
N Age at first session (median years; range) Gender (% women/men) Learning disabilities (%) Seizure frequency per month (median;	195 40 (18-87) 67/33 3 10 (0-1500)	97 39 (15-63) 55/45 5 4 (0-600)	292 40 (15-87) 63/37 4 8 (0-1500)
range) 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	В	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=48	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 14	
Last quarter Immediately after session	6 10	0	
Not known	4	0	
NOUNIOWII	7	O .	
Duration of attack (%)	0.4		
Less than a minute	31	57	
1 minute	4 17	0	
2 minutes 3 minutes	8	0 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 Patient looked fearful	0 0	0 0	
Incontinent of urine	0	0	
Incontinent of dame	0	Ö	
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)*		20
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		0
	6	0
Admitted with overnight stay	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

<sup>\*</sup> 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.

Nlomo	٥f	tha	coni	<b>~</b> +•
Name	ΟI	mei	apı	St.

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) 1<sup>st</sup> quarterc) 2<sup>nd</sup> quarter
  - d) 3<sup>rd</sup> 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
- I) 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)