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A feasibility study of a brief psycho-educational intervention for psychogenic nonepileptic seizures



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ABSTRACT

Purpose: We have previously reported that one in six patients stops experiencing psychogenic nonepileptic seizures (PNES) following our communication protocol. This prospective multicentre study describes a psycho-educational intervention for PNES building on the initial communication of the diagnosis and examines the feasibility of its delivery by healthcare professionals with minimal experience in psychological therapies.

Method: Three healthcare professionals with minimal training in psychological therapies took part in a one-day training course. 20 participants attended for a four-session manualised psycho-educational intervention delivered at three different clinical neuroscience centres. Participants completed self-report measures prior to the intervention at baseline (n = 29) and seven months after diagnosis (n = 13) measures included seizure frequency, health related quality of life, healthcare utilisation, activity levels, symptom attributions and levels of functioning. Therapy sessions were audiorecorded and manual adherence assessed.

Results: Of 29 patients enrolled into the study, 20 started and 13 completed the intervention and provided follow-up information. At follow-up, 4/13 of patients had achieved complete seizure control and a further 3/13 reported a greater than 50% improvement in seizure frequency. After training, epilepsy nurses and assistant psychologists demonstrated sufficient adherence to the manualised psycho-educational intervention in 80% of sessions.

Conclusion: The delivery of our brief manualised psycho-educational intervention for PNES by health professionals with minimal training in psychological treatment was feasible. The intervention was associated with higher rates of PNES cessation than those observed in our previous studies describing the short-term outcome of the communication of the diagnosis alone. An RCT of the intervention is justified but a significant proportion of drop-outs will have to be anticipated.

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1. Introduction

Recent surveys report considerable variation in the approach of neurologists to the diagnosis and management of patients with psychogenic non-epileptic seizures (PNES). Most consider psy-

E-mail addresses: r.j.mayor@sheffield.ac.uk (R. Mayor), r.j.brown@manchester.ac.uk (R.J. Brown), hannahrc@sgul.ac.uk (H. Cock), a.o.house@leeds.ac.uk (A. House), stephanie.howlett@sth.nhs.uk (S. Howlett), SmithPE@cf.ac.uk (P. Smith), markus.reuber@sth.nhs.uk (M. Reuber). chological therapy to be the treatment of choice^{1,2} and four different psychotherapeutic approaches have now been described in some detail.³⁻⁶ The short-term benefits of psychological treatment have been suggested by a single randomised controlled trial,⁷ and the subsequent benefits are supported by an uncontrolled long-term follow-up study.⁸ However, unlike neurologists, most patients with PNES consider "physical" causes more relevant to their disorder than "psychological" causes.⁹ Patients are commonly confused by their doctor's attempts to reframe their condition as something which psychological treatment could stop, ^{10,11} and nearly half of the patients diagnosed by neurologists find it difficult, or fail entirely, to engage with psychological treatment.¹²

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We have previously proposed a communication package to address some of the difficulties which neurologists face when they explain the diagnosis of PNES and recommend psychological treatment. 13,14 Communication using this package (consisting of a crib sheet for neurologists and a booklet for patients) left 86% of patients acknowledging that psychological factors were at least contributing to their seizures and was associated with seizures stopping in 14% of patients. A prospective multicentre study assessing the effectiveness of the package (and no additional treatment) six months after the communication of the diagnosis demonstrated that the improvements in seizure control were maintained. However, the high levels of impairment in measures of health related quality of life, work and social adjustment or activities of daily living observed at baseline persisted to the end of the follow-up period and demonstrate the need for more extensive therapeutic intervention.¹⁵

At present two thirds of neurologists in the United Kingdom (UK) are unable to offer all of the patients they diagnose with PNES access to psychological treatment and one in six neurologists has no access to psychological treatment services at all. Accepting the limited provision of psychotherapy resources in the UK, and aware of studies demonstrating that very modest and time-limited further interventions can have clinically relevant therapeutic effects in patients with unexplained neurological symptoms (including PNES)^{16,17} we have developed a stepped-care model in which the communication of the diagnosis of PNES (step 1) is followed by a fully manualised psycho-educational intervention (step 2). Following this model, only patients with more entrenched PNES disorders would proceed to more extensive individualised treatment delivered by expert psychotherapists (step 3). Psychoeducation is a well-recognised inexpensive treatment option for patients with mental health conditions, which involves educating patients about their condition with the aim to improve understanding and self-management. Psycho-education has previously been described as an effective treatment option for depression, anxiety and psychological distress.¹⁸

Our psycho-educational intervention consists of four weekly one-hour-sessions and is designed to be delivered by healthcare professionals with limited psychological training quickly after the communication of the diagnosis. By covering patients' most common concerns after receipt of the diagnosis (such as confusion and being left "in limbo"), 10,11 and by addressing the commonest psychological issues encountered at this stage (especially poorly recognised or acknowledged anxiety and avoidance), 19 it was intended to be meaningful for most patients diagnosed by neurologists with PNES. The intervention was designed to maximise patients' acceptance of this diagnosis, make them aware of simple seizure control techniques and provide strategies for reducing common maintaining factors such as anxiety and avoidance. Based on publications describing the effectiveness of slightly more elaborate explanations of the diagnosis. 17,20 we expected that PNES would stop in about one third of patients and that the remaining patients would be better prepared for individualised psychotherapy.

The present study describes the psycho-educational intervention and examines the feasibility of its delivery by healthcare professionals with minimal experience in psychological therapy and the completion of a randomised controlled trial (RCT) of the intervention.

2. Methods

2.1. Patients

Patients were prospectively recruited between December 2008 and June 2010 from seizure clinics based in three UK neuroscience

centres: the Royal Hallamshire Hospital, Sheffield, the University Hospital of Wales, Cardiff, and St George's Hospital, London (all UK). All patients recruited had just been provided with a clinically secure diagnosis of PNES by a neurologist specialising in the treatment of seizures. The PNES diagnosis was considered "clinically secure" if the neurologist was sufficiently certain of the diagnosis of PNES to recommend psychological treatment (for instance because seizures had been captured by video-EEG. observed by the neurologist or because clinical information available strongly suggested this diagnosis). The diagnosis was communicated using the communication protocol reported previously.²¹ None of the patients recruited into this study had taken part in any previous PNES-related studies. Participants were given information about the study after receiving the diagnosis of PNES and were subsequently contacted by a member of the research team to provide more information about the study. Patients were referred for standard medical care (including referral to psychotherapists, counselling or psychiatry). However, waiting lists for any further interventions meant that psychological treatment was unlikely to commence at the time of completion of the follow-up for this study. PNES patients with an additional possible history of epilepsy but no epileptic seizures in the last twelve months were also eligible to take part in the study. Patients with concurrent epilepsy and PNES were excluded from the study because it would have been difficult to assess the main outcome of this study (seizure frequency and seizure cessation).

Participants completed an initial set of questionnaires via post or telephone four weeks after receiving the diagnosis from the neurologist. Patients contact details were then passed on to the therapist in the appropriate centre who invited patients for the first session of the intervention. Follow-up questionnaires were sent to patients after completion of the intervention and three months later (approximately seven months after the communication of the diagnosis by the neurologist). Patients not responding to the postal questionnaires were contacted by telephone. If possible, they were asked to provide all data otherwise provided via the questionnaires. As a minimum, they were asked to provide information about their seizure frequency since the last contact from the research team.

Patients were classed as completing therapy if they attended for at least three of the four sessions and if the therapist deemed to have covered all essential part of the manual.

2.2. Therapists

Two epilepsy nurses (MS and JM) and one assistant psychologist (RM) with minimal experience in psychological therapies took part in a one-day training course. This involved learning more about PNES and psycho-education as well as about how to deliver the manualised intervention. Health professionals were encouraged to take part in role-plays to practise how to deliver the intervention and engage patients in this. All participants in the one-day course received Compact Disc compiled by the authors of the psychoeducational intervention with examples of good communication practices reflecting the spirit of the intervention.

2.3. Therapy

The psycho-educational intervention combines information provision with measures intended to change patients' illness perceptions (cognition) and self-management (behaviour). The one-to-one format offers patients the opportunity to discuss the diagnosis with a healthcare professional and ask questions.

The intervention is fully manualised. A detailed description of each session lists points to cover, examples of how to do this, and the estimated time needed to cover this effectively. Therapists are

Table 1Main areas to address in each of the four sessions of the psycho-educational intervention and essential criteria scored for adherence ratings.

Session	Aims of session	Strategies to use	Homework	Essential criteria
Session 1: Understanding PNES	Engage the patient. Establish problems patients experiencing. Provide a simple biopsychosocial explanation of their attacks. Provide an opportunity to answer the patient's questions about their diagnosis.	Explanation of mind-body link. Devise a problem list Life events checklist.	Information sheets Case studies.	Asking about the diagnosis. Asking about the effects of the diagnosis. Discussing non-epileptic attacks disorder. Related to stress. Stressors in patient's life. Setting homework.
Session 2: Before and during attacks	Plot out the course of a typical attack, including build up and consequences. Identify any triggers for attacks. Train patient in seizure control techniques (if appropriate). Train anxious patients in imagery distraction technique.	List of physical symptoms. Relaxation seizure prevention technique. Distraction technique.	Practise techniques and relaxation.	Reviewing homework. Identify possible triggers and warning signs. Attack prevention techniques. Setting homework.
Session 3: Improving life	Identify the activities/places that the patient currently avoids. Provide an explanation of why avoidance is unhelpful and a rational for the reversal of avoidance. Construct a plan with the patient to gradually re-start avoided activities or going to avoided places.	Avoidance checklist. Advantages and Disadvantages Table. Homework plan.	Patient to begin to put the plan into action for homework.	Review homework. Areas of awareness. Tackling avoidance. Setting homework.
Session 4: Therapy blueprint	Summarise information about the illness. Develop a plan to manage symptoms based on previous sessions and homework tasks.	Therapy blueprint.		Review homework. Therapy blueprint.

encouraged to stick to the manual and timings as much as possible. Within the framework set out in the manual, therapists can adopt the intervention to individual patients' needs. For instance, only patients with seizure warnings are taught seizure control techniques. Otherwise patients learn about more generic stress self-management techniques. Table 1 summarises the main areas the therapist is asked to address in each of the four sessions.

2.4. Adherence measures

A measure of adherence to the manual was developed to establish to what extent the therapists were able to deliver the content of the manual. This was adapted from the CSPS-6 (Collaborative Study Psychotherapy Rating Scale-form 6) developed by Hollon, Waskow, Evans and Lowery to measure adherence to treatment protocols for depression.²² Our adapted measure asks raters to score each item as covered "fully or mostly", "partially" or "not at all". 16 essential criteria items across the 4 sessions were identified that must be addressed by the therapist in order for the therapy to be considered as adherent with the manual. The essential criteria for each session can be found in Table 1. Ten sessions were rated for adherence by two fully trained psychotherapists (RB and SH). Adherence of each item was rated dichotomously as present (fully/mostly and partially combined) vs. absent. An overall rating of manual adherence of each session (adherent vs. non-adherent) was also provided by each rater for each session (all essential criteria had to have been met for the session to be rated adherent).

2.5. Self-report measures

This study was not powered or intended to provide conclusive information on the effectiveness of the psycho-educational intervention. Nevertheless patients completed a number of self-report questionnaires at entry into the study and during follow-up to explore the acceptability and utility of these questionnaires in a future randomised trial of the intervention, and to provide information about baseline levels of impairment and disability.

2.5.1. Seizure frequency

Patients were asked to report how many seizures they had experienced in the last month at baseline and in the last 3 months at follow-up. Patients used diaries when available or estimated the seizure frequency at baseline. They were asked to keep seizure diaries during the study to base their report of seizure frequency at follow-up on the diaries. The numbers of patients who experienced a >50% improvement and >50% worsening in their PNES frequency at follow-up were calculated. Patients who experienced <50% improvement but <50% worsening were classed as "unchanged".

2.5.2. Health related quality of life

The SF-36 Health Survey²³ is a 36-item measure of eight health concepts that can be combined to produce a physical health component score (with four concept scores: Physical Functioning, Role Limitation Physical, Bodily Pain, General Health) and a mental health component score (with four concept scores: Vitality, Social Functioning, Role Limitations Emotional, Mental Health). The SF-36 raw data were transformed to 0–100 scores, with low scores indicating poor health and functioning.

2.5.3. Symptom attribution

A single symptom attribution question was used to establish attribution of seizures to physical factors, psychological factors, or a combination of the two. It has previously been used with patients with Chronic Fatigue Syndrome, epilepsy and PNES. 9.24

2.5.4. Activities of daily living

The Frenchay Activity Index (FAI) is a method of recording extended activities of daily living and has been found to be a successful measure in assessing functional status in stroke patients.²⁵ Three factors can be combined to a total score with a higher score indicating increased activity levels (indoor domestic activities; outdoor domestic activities; outdoor social activities).

2.5.5. Social adjustment

The Work and Social Adjustment Scale (WSAS) measures impairment in functioning in work, home management, social

leisure activities, private leisure activities, and family & relationships. ²⁶ A total score can be calculated, with high scores indicating poorer levels of functioning.

2.5.6. Health service utilisation

A health service utilisation measure asked participants to identify all health service attendances (including GP, practise nurse, outpatient appointments, inpatient stays and emergency room visits). Patients were also asked the number of medications they were currently prescribed and whether they had attended for any psychological treatment in the last 3 months.

Patients were considered 'Economically active' if they were either in full-time or part-time employment, full time education or aged over 55 and retired.

2.6. Statistical analysis

As the aim of the study was to assess the feasibility of the psycho-educational intervention and assessment measures we only used descriptive statistics to present the self-report measures and did not compare baseline with follow-up values. We also report the completeness of follow-up information available. For comparative purposes we refer to data from a previous study in which patients were informed about their diagnosis of PNES, recruited and followed up in the same way as they were in this study (although they did not receive the psychoeducational intervention).¹⁵

3. Results

3.1. Baseline data

Fig. 1 shows the recruitment and retention rates for the study. 29/38 patients were recruited in to the study a median of four weeks after diagnosis. The baseline seizure frequency of the whole group (n = 29) at time of recruitment was ten per month (IQR 4.5–75). Two patients, although experiencing seizures at time of diagnosis, had become seizure free at the time of consenting to take part in the study. 20/29 (69%) of the patients recruited into the study began and 17/29 (59%) of all patients recruited completed the psycho-educational intervention.

3.1.1. Manual adherence

38 critical items were rated across 10 therapy sessions. Two raters agreed that the therapists were adherent with the therapy on 34 of these (89.5% agreement). Treating therapy sessions as a whole, the two raters agreed that 8 out of 10 (80%) of the sessions were adherent with the therapy.

3.1.2. PNES outcome

Follow-up information was received from 13 patients (45% of those enrolled) a median of seven months after diagnosis (IQR 5.5–9 months). For completers, the median seizure frequency at time of recruitment (median 4 weeks after diagnosis) was 8 per month (n = 13, IQR 2–15). At follow-up this was unchanged (median 8, IQR 0–16). However, 4/13 patients were seizure free at follow-up (of these one patient had remained seizure free throughout the study and three had become seizure free), an additional 3 patients showed a greater than 50% reduction in their seizures, 5 patients were unchanged, a further 1 patient experienced a worsening of seizures. Table 2 reports questionnaire data at baseline and follow-up for this study and a previous study in which patients were recruited in the same way but offered no further intervention. ¹⁵ Medians and inter-quartile ranges are reported.

4. Discussion

We have previously reported that one in six patients stops experiencing PNES following our communication protocol and demonstrated that the same number of patients remains PNES free six months later without any additional treatment. 15,21 This feasibility study suggests that about one in three patients could become PNES-free with a relatively brief and simple intervention. The self-report measures shown above (Table 2) demonstrate that the participants of this study had levels of seizure frequency, disability, HRQoL and functioning which were comparable to those of the patients who took part in our previous studies. The 45% completer rate appears low but is likely to be a realistic reflection of the potential for treatment in this population who often fail to engage with psychological treatment or drop out of treatment programmes. This figure is also in line with a previous study in which 44% of patients did not attend or later dropped out of a psychotherapy intervention for PNES. 12

The results of this study are in keeping with other studies reporting a similar short-term outcome of procedures which involve a somewhat elaborated explanation of the diagnosis of PNES and no individualised psychotherapy. 17,27,28 Having said that, the majority of participants in this study continued to experience PNES at the end of the follow-up period. This and the high levels of impairment demonstrate that a simple intervention such as the manualised psycho-education programme described here will not be sufficient for most patients diagnosed with PNES.

The examination of the manual adherence of the therapists revealed that epilepsy nurses or psychology assistants with minimal experience in the delivery of psycho-educational or psychotherapeutic interventions can be trained to deliver a simple manualised intervention. However, we suspect that manual adherence would have been better if the therapist had undergone

Table 2Demographic and clinical characteristics of group at baseline and follow-up for current study and control study.

Measure	Control study		Current study	
	Baseline (n = 36)	Follow-up (<i>n</i> = 36)	Baseline $(n = 29)$	Follow-up (<i>n</i> = 13)
Age (years)	38 (26-46)	=	37 (23–38)	=
Gender (% female)	83%	_	76%	_
Duration (months)	16.5 (6.5-48)	_	20 (11.5-66.5)	_
Economic activity status (% active)	44%	_	38%	_
SF36 physical health component score	39.2 (27.2-50)	38.6 (26.5-50.2)	38.6 (31.2-47.6)	44.8 (31.6-53.9)
SF36 mental health component score	28.9 (22.9-43.5)	29.3 (24.5-35.4)	28.6 (20.2-46.0)	44.6 (21.0-51.5)
Health service utilisation (contacts in last 3 months)	5 (3-12)	5 (2-10)	7 (1.5-10)	6 (4–12)
Number of emergency room visits (% attended in last 3 months)	25%	6%	35%	10%
Psychological treatment (% received in last 3 months)	11%	25%	0%	15%
Number of current medications	1 (0-2)	1 (0-2)	1 (0-2.5)	1 (0-2.5)
Frenchay Activity Index	31 (18-41)	33.5 (14-39)	39 (34–46.5)	40 (32.5-44.5)
Work and Social Adjustment Scale	25 (17–31)	24.5 (16–32)	26 (7.5–34)	13 (16–32.5)

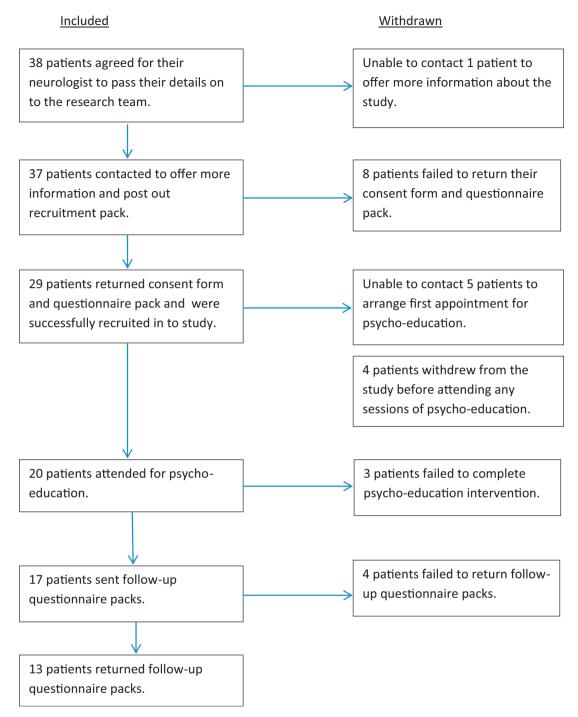


Fig. 1. Flow diagram of patient retention.

more extensive training than we were able to deliver in one day. Furthermore, the interactions between the therapists in the different centres and the research team suggested that therapists need a degree of on-going support - even if they are "only" tasked with delivering a fully manualised intervention of this nature.

We have previously reported the results of a study based on interviews between a qualitative researcher (who had not been involved in the development or delivery of the psycho-educational intervention) and twelve of the participants in this study. ²⁹ Six themes were identified in this study: getting answers; understanding the link with emotions; seeking a physiological explanation; doubting the diagnosis; the role of medication; and finding a

way forward. The findings highlighted the considerable individual variation in response to the psycho-educational intervention. There was evidence of changed perceptions or enhanced understanding in some patients while others continued to seek answers or explanations about the cause of their seizures. The improvement of the understanding and acceptance of the diagnosis has previously been linked to better medium term outcomes. The heterogeneity of patients' responses to the intervention clearly demonstrated the limitations of a "one size fits all" approach to treatment and suggested that longer psychotherapeutic interventions would have to be tailored to individual patients' needs to be optimally effective.

Our study has a number of important limitations. The most important limitation of this study is the small sample size. The project was designed as a feasibility study and the lack of statistical power means that the results of this study should not be generalised at this point. A future, much larger trial will need to demonstrate the effectiveness of our manualised psycho-education intervention in terms of seizure control, quality of life, functioning and healthcare cost.

Secondly, we included patients with a clinical diagnosis of PNES, as well as those with a "gold-standard" video-EEG-documented diagnosis. Although we excluded all cases where there was any clinical doubt on the part of the assessing neurologist, and although all participating neurologists were experienced epileptologists, it is possible that some patients in this study were misdiagnosed. However, we were keen for our study to reflect the clinical reality of patients with PNES presenting to neurology clinics, and felt that the exclusion of the 30% or so of patients with clinically likely PNES in whom no seizures can be recorded with video-EEG would have skewed our results more than the inclusion of a much smaller number of patients given an incorrect diagnosis of PNES.

Despite its limitations, this study shows that the provision of a simple psycho-educational intervention by healthcare professionals with limited experience in the delivery of such interventions or of more extensive psychotherapy is feasible. This and the fact that more patients seem able to achieve complete seizure control with this intervention than with the communication of the diagnosis alone suggest that a randomised controlled trial of the intervention is now justified.

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