



A multicenter evaluation of a brief manualized psychoeducation intervention for psychogenic nonepileptic seizures delivered by health professionals with limited experience in psychological treatment



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ABSTRACT

Rationale: The aim of this study was to add to our understanding of the impact of psychoeducation on patients' acceptance of the diagnosis of psychogenic nonepileptic seizures (PNESs), the frequency of their seizures, and their quality of life. The study also aimed to evaluate the effectiveness of brief manualized psychoeducation interventions for PNESs, delivered by a more diverse range of clinicians and in a wider range of treatment settings.

Method: The final sample consisted of 25 patients diagnosed with PNESs by a neurologist specializing in the treatment of seizure disorder and referred to the psychotherapy service. The study included patients from four centers, using a manualized psychoeducation intervention delivered over 4 sessions by specialist epilepsy nurses and assistant psychologists. All patients completed self-measure questionnaires for Seizure Frequency, Impaired Functioning (WSAS), Psychological Distress (CORE-OM), Illness Perception (BIPQ), Health-Related Quality of Life: general (ED-QOL) and epilepsy-specific (NewQOL-6D), Symptom Attribution, and patient's perception of usefulness and relevance of the intervention. All measures were collected at baseline and after the completion of the fourth session.

Results: All measures improved from baseline to postintervention, but this improvement was only significant for CORE-OM ($p < .05$) and BIPQ ($p < .01$). Out of the 25 patients who completed the intervention information, 6 out of 25 (24%) had been seizure-free for the past month, and an additional 6 out of 25 (24%) had achieved seizure frequency reduction. Consequently, upon completion of the intervention, 12 out of 25 patients (48%) were either seizure-free or experienced fewer seizures compared with the start of the intervention.

Conclusion: The evidence suggests that brief manualized psychoeducation intervention can reduce PNES frequency, improve the psychological distress, and have an effect on patients' illness perceptions that should help them engage with a more extended psychotherapy program if that was necessary. The intervention was carried out successfully by staff with relatively little training in delivering psychological interventions. Further controlled studies are required to provide proof of efficacy.

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1. Introduction

Psychogenic nonepileptic seizures (PNESs) are one of the most common differential diagnoses of epilepsy. The incidence of PNESs has been reported as 4.9 per 100,000 [1]; however, this may well be an underestimate, as this figure only includes cases referred and presenting to a specialist clinic [2]. Psychogenic nonepileptic seizures are often chronic, and the prevalence of the disorder may be as high as 33/100,000 [3]. Despite this high prevalence, there are no evidence-based standard care pathways for managing this condition [4,5]. A survey distributed to 130 practitioners in the UK who work with this patient population

showed that 93% of health professionals believe that these patients should be offered psychological treatment as the treatment of choice [4]. However, only 35% of practitioners were able to refer all of their patients for this treatment, and 15% were unable to provide this treatment option to any of their patients.

Recent, small-scale randomized controlled trials have demonstrated the benefits of psychological treatment for PNESs, including reduction in seizure frequency as well as improvement in psychosocial functioning [6,7], and an uncontrolled long-term study suggested that the positive effects of psychotherapy are likely to persist [8]. However, it has been shown that patients with PNESs preferentially endorse physical factors as being responsible for their seizures and are resistant to the sort of psychological explanations of their difficulties which may be provided by neurologists [9]. As a result, many patients find it hard to accept that psychological treatment would be beneficial to treating their condition [10], and nearly half of all patients diagnosed

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by neurologists with functional symptoms struggle, or entirely fail, to engage in a treatment program after they have been referred for psychotherapy [11].

We previously developed a communication strategy which provided guidelines for neurologists to deliver the diagnosis of PNEs and which included an information booklet intended to back up their verbal explanation in writing. The content of the information given to patients was based on reassurance of genuine symptoms, labeling of the condition, the cause and maintaining factors, and treatment and treatment expectations [12]. An evaluation showed that 86% of patients acknowledged that psychological symptoms contributed towards their symptoms when this protocol had been followed [12]. The explanation of the condition based on this strategy was also associated with a decrease in seizure frequency, with PNEs stopping altogether in 7 out of 44 patients (16%). However, in the absence of further intervention, impairment in quality-of-life measures persisted, indicating a need for a more active or persistent treatment approach not limited to the explanation of the diagnosis alone [12].

The communication strategy was conceived as Step 1 of a stepped care model for patients with PNEs. Step 2 of this stepped care model involves a brief manualized one-to-one psychoeducation intervention designed to help patients better understand their diagnosis and to improve their ability to self-manage their symptoms. This intervention was intended to be delivered by clinicians with very limited psychological treatment experience. Following this step, individuals needing more extensive psychological treatment can go on to receive individualized psychotherapy (Step 3).

The psychoeducation program designed for Step 2 of this approach was intended to be sufficient as a standalone treatment for some individuals. At the same time, the program was conceived to help other patients to engage in further psychotherapy and to understand the rationale for this treatment modality.

We previously showed that three healthcare professionals with minimal experience in psychological treatment were able to deliver this psychoeducation intervention following a brief one-day training [13]. Thirteen out of twenty participants completed the postintervention in our pilot study, and the program seemed to have a greater effect in terms of PNE reduction than patients receiving the communication strategy alone [12]: 4 out of the 13 participants (31%) became seizure-free after receiving the psychoeducation intervention, and a further 3 out of 13 (23%) reported a significant reduction in their seizure frequency [13].

Given the positive outcome of this pilot project, further evaluation of the intervention was justified. The present multicenter service evaluation of our psychoeducation intervention was conducted to add to our understanding of the impact of this intervention on patients' acceptance of the diagnosis of PNEs, the frequency of their seizures, and their quality of life. We also wanted to assess whether the intervention can be rolled out successfully to be delivered by a more diverse range of clinicians and in a wider range of treatment settings.

2. Method

2.1. Patients

Adult patients were recruited consecutively from December 2013 to February 2016 in four hospital trusts in the UK: Sheffield Teaching Hospitals (STH), Nottingham University Hospital, Huddersfield and Calderdale NHS Foundation Trust, and Derby Hospitals Foundation Trust. In Fig. 1, the patient recruitment pathway is shown, and Table 1 further shows patient numbers and demographics. In total, nine health professionals were involved in delivering the intervention. Four were based in Sheffield, two in Nottingham, two in Huddersfield, and one in Derby. Three of the ten practitioners involved were assistant psychologists (which meant that they had an undergraduate degree in psychology and some basic understanding of psychotherapy), one

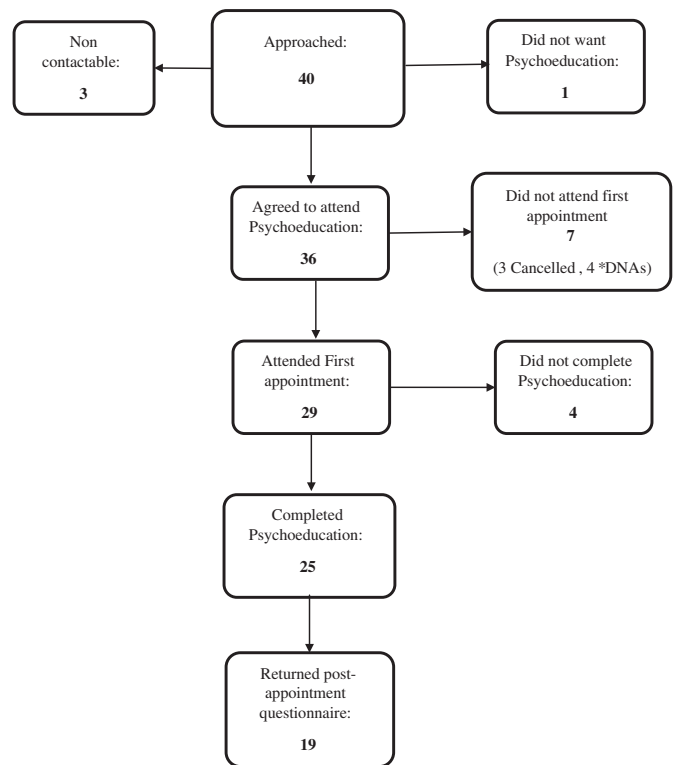


Fig. 1. Participants' pathway. *DNA: Did not attend appointment without contacting the service.

was an occupational therapist, and the remaining six were specialist epilepsy nurses. Only one of the practitioners was male.

Although not all professionals were based in neurology services, all patients were referred for psychoeducation after the diagnosis of PNEs had been made and communicated by neurologists. Referral procedures varied. The majority of the patients involved were treated at STH. This hospital has a specialist neurology psychotherapy service, which is not widely available in other parts of the UK. As a matter of routine, most patients diagnosed with PNEs at STH would be offered a stepped care approach. Following the explanation of the diagnosis by the neurologist, they would be provided with access to psychoeducation if seizures persisted. Patients still symptomatic after psychoeducation would be referred for psychotherapy. However, exceptions from this routine care pathway are made if possible. Patients at STH are triaged on the basis of the referral letter from the neurologist to the psychotherapy service and self-report data provided in their response to a postal screening questionnaire, the Clinical Outcome Routine Evaluation (CORE-OM) measure. The CORE-OM was used routinely as part of the opt-in process of the psychotherapy service, and patients whose existing health records show serious and complex mental health problems, or patients who highlighted on the CORE-10 that they were at risk of suicide, were not selected for the psychoeducation but were referred straight to psychotherapy.

In Nottingham, a clinical psychologist assessed all patients referred with PNEs. Following this assessment, patients were selected for psychoeducation if they were considered to be low-risk (based on responses to the CORE-OM and to clinical interview questions) and if they were thought to be engaged and motivated to complete the program. The psychologist tried to include patients whom she felt were not resistant to the psychological explanation of seizures by assessing how they felt about receiving the diagnosis of PNEs. In Derby, the patients were seen by an occupational therapist who only accepts referrals for individuals with comorbid chronic fatigue and PNEs. Following the four sessions of psychoeducation, three of the four centers were

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