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Understanding patient perceptions following a psycho-educational intervention for psychogenic nonepileptic seizures

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Abstract

This study formed part of an evaluation of a brief educational intervention for patients with psychogenic nonepileptic seizures (PNES). The sessions provide information, seizure control techniques and management planning. The qualitative component of the research reported here aimed to provide insight into the perceptions of participants following the intervention. Semi-structured interviews were conducted with twelve patients. Interviews were tape-recorded, transcribed and analysed using principles of thematic analysis. Six key themes were identified: 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 highlight considerable individual variation in response, with evidence of changed perceptions or enhanced understanding in some patients whilst others continued to seek answers or explanations about the cause of their seizures. There were no clear links between reported improved understanding or acceptance of the diagnosis, and a perceived improvement in the condition.

Keywords: Psychogenic nonepileptic seizures; Illness perceptions; Psychological treatment; Thematic analysis; Qualitative research

1. Introduction

Psychogenic nonepileptic seizures (PNES) are episodes of altered movement, sensation or experience that resemble epileptic seizures but are not associated with abnormal activity discharges in the brain. PNES are thought to have psychological causes [1]. It has been estimated that around 12-18% of patients newly presenting with seizures may have PNES [2]. Patients with PNES are a clinically heterogeneous group [3]. The differential diagnosis between epilepsy and PNES can be challenging and many patients are treated as epileptic for several years before receiving the correct diagnosis [4].

While the prevalence of PNES has been estimated to be as high as 33 per 100,000 of the population [5], there is little available evidence regarding effective interventions. Although there are unanswered questions regarding the effectiveness of psychological treatment, 93% of neurologists in the United Kingdom (UK) consider this the management of choice [6]. A randomised controlled study of cognitive behavioural therapy demonstrated the effectiveness of this therapeutic approach in the short-term, although the follow-up data six months after the end of treatment called into question whether benefits would be maintained

over a longer time [7]. Longer-term seizure-free rates in an uncontrolled study of Augmented Psychodynamic Interpersonal Therapy (PIT) were similar to remission rates in natural history studies [8 9 10 11], although in the short-term, therapy was associated with impressive improvements in distress and self-reported quality of life [12].

Unfortunately neurologists face a number of obstacles when they want to refer their patients for psychological treatment. At present access to this treatment is restricted in many areas. Only 65% of UK neurologists are able to refer all their patients [6]. Even when treatment is available, there may also be long waiting periods or intervals between treatment sessions [13]. Patients who have been referred may not understand the relevance of psychological treatment for symptoms they perceive as physical and fail to engage. Many remain upset and confused about the diagnosis after the neurologist has explained it to them [14 15 16] and about a quarter typically fail to come for their first session [17].

Ongoing research by our research group has focused on the development of an optimised management pathway for patients with PNES. Taking account of the condition and current treatment provisions in the UK, we have designed a stepped-care pathway. We have previously described step one (an acceptable communication of the diagnosis by the neurologist)[14]. Step three (individualised psychotherapy) is currently being developed and will build on the Augmented PIT approach we have outlined in prior publications [11 18]. The purpose of the current study was to explore patient perceptions regarding step two of our pathway. Step two is a brief (four session) psycho-educational intervention intended to be suitable for all patients newly diagnosed with PNES and delivered by a relatively junior healthcare professional (such as an epilepsy nurse or psychology assistant). It is designed to follow on from communication of the diagnosis by the neurologist. The research question we aimed to explore in this work was whether this brief intervention influenced patient perceptions, and if so whether changed perceptions might influence the severity of the condition.

2. Method

Three centres across the UK were involved in the study which used a mixed method design to evaluate a psycho-educational intervention for people with PNES. This paper reports the qualitative data.

All patients were recruited immediately after they had first been provided with a secure diagnosis of PNES by a neurologist specialising in the treatment of seizures and

offered a psycho-educational intervention. Patients were only asked to consider taking part in the study 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 previously reported [1]. Patients were only included in this trial if they were not thought to have any additional epileptic seizures for at least one year prior to the PNES diagnosis. Patients with a previous history of (possible) epilepsy were excluded. The psycho-educational intervention was delivered by health professionals with minimal training in psychological therapies (two epilepsy nurses and one clinical research assistant). These individuals had expressed an interest in being involved in the intervention and had attended a one-day training course in the delivery of the scripted psycho-educational intervention including a discussion of PNES, role play, and an exploration of the content of the intervention.

The intervention consists of four one-hour face to face sessions (in most cases once a week over four weeks) guided by a therapist's manual and patient work book developed for this study. The work-book includes activities to complete during the sessions and agreed goals and activities to be carried out in between sessions. Patients could attend on their own or with a carer. The content of the sessions has been designed to address all elements of patients' illness perceptions (identity, cause, consequences, time-line and controllability or cure). Session one of the intervention focuses on understanding the diagnosis and agreeing a management plan; session two on understanding seizures and learning seizure control techniques; session three on learning to address excessive avoidance; and session four on consolidation and future plans. Patients who had taken part in the intervention study and who expressed an interest in supporting additional research were contacted by a member of our team and were interviewed for this qualitative study after they had given their written informed consent. See Table 1 for characteristics of participants.

2.2 Procedure

Semi-structured interviews were carried out based around a pre-defined interview schedule (see Appendix). Interviews lasted 45 minutes to one hour and were undertaken by an experienced qualitative researcher (SB) in a location of the participant's choice (in all but one case the patient's home). A second researcher was present during the interviews in an observer role. In some cases participants indicated that they wished family members/a carer to

be present during the interview for support or to aid recall. The semi-structured nature of the method allowed the interviewees to lead the discussion, and enabled detailed exploration of any particular issues or views raised.

2.3 Data analysis

The interviews were audio-recorded and later transcribed verbatim. Data were analysed in parallel to collection, using techniques of thematic analysis [19]. The coding and retrieval of data during the analysis was supported by the NVivo 8 qualitative data analysis software. Each document was read line-by-line with ideas or themes within the data highlighted and assigned a name or code (free node). As each interview transcript was added, previous transcripts and coding were re-checked for consistency and emerging new themes. Following the coding of three transcripts, links between themes were identified and themes and sub-themes (tree nodes) were developed using principles similar to axial coding in grounded theory [20]. When all the interviews had been completed, the coding of each transcript was re-checked for consistency across the set. The final step in the process of analysis was to retrieve the data within each code and identify further subthemes, explore links and highlight negative instances.

Initial analysis of the data was carried out by the first author, with emerging themes and concepts discussed with the second researcher who had been present. The anonymised data was shared with the research team as the analysis progressed, and themes were discussed and refined.

3. Results

Twelve patients of white European origin were interviewed from the total of 39 who were offered the programme (24 began the intervention). See Table 1 for characteristics of the participants. One additional person had agreed to be interviewed but withdrew later for personal availability reasons. Family members or a carer were present for five of the interviews (two parents, three partners and one care assistant) and contributed a small amount of data. We endeavoured to recruit individuals who had either declined the psycho-educational intervention or the small number who had withdrawn part way through. However, we achieved only one interview with an individual who had chosen to discontinue the programme following the first session.

Analysis of the data provided insights into the effect that the intervention had on participant's understanding of the condition and their perceptions of the future. Six key themes were identified. These were: getting answers; understanding the link with emotion; seeking a physiological explanation; doubting the diagnosis; the role of medication; and finding a way forward. In the following section data has been selected to provide example quotes across the participants, with particular attention paid to outlying data or "negative instances." There has been minor editing of some quotes to preserve anonymity and ensure meaning of extracts.

3.1 Getting answers

Interviewees described a process of endeavouring to make sense of the condition since they had received the diagnosis. A theme of "getting answers" was identified in the data, with participants describing leaving a consultation with unresolved questions and uncertainties. While this theme has some overlap with following themes, it represents a general perception amongst participants of needing information. The intervention was reported to have enabled participants to have questions answered:

"Y was really good and went through things right down to where you did understand it and everything, so I'd ask the questions in the session anyway, I wouldn't come out with any like questions hanging over me" (pt12).

"at the end of the day it was giving me answers to questions that I needed answers to" (pt10).

The data highlight how patients may struggle to hear and understand information during the consultation where the diagnosis is first presented. Within this theme of getting answers were data describing how patients had an angry or disbelieving response to receiving the PNES diagnosis. This was perceived as an obstacle to them getting answers. Patients described how even though the consultation and communication of the diagnosis could be "done well" they needed a further opportunity to listen to explanations in order to gain an understanding:

"She kind of explained it as much as... I think it helps because I was so mad when I saw the consultant. I just wasn't listening to him. And he explained it well but I just didn't want, I didn't hear anything past it's psychological.....she went through it all again and it was almost easier that time because she says you know you're not mad" (pt3).

The importance of the intervention as providing further opportunities to get answers was also described in terms of providing written material that could be read and re-read, and achieving comfort from understanding that they “were not alone” in having the diagnosis:

“You get little doubts and you think oh I’m not sure and then I just read the book again and think actually no, this is normal. So the book’s been very helpful” (pt7)

“And what I found is, reading the information, it was quite useful to see I’m not the only person who suffers non-epileptic seizures. There’s quite a lot of people that do” (pt8).

While the intervention was reportedly beneficial in terms of answering questions, there were some individuals for whom the sessions had not provided sufficient answers or understanding for their needs. These respondents reported how they continued to search for an explanation, with the description of frustration at this inability to achieve an understanding:

“I got one little booklet but it doesn’t really explain much. Me and my mum, we’ve sat here and we’ve gone through it and through it and through it and its like well, what’s the point [laughs]. It doesn’t really tell you anything, so we’re like at a complete loss with it” (pt2).

“Nobody seems to be able to put their finger on it. That’s the frustrating bit. Nobody can say well yes, you know but that’s it” (pt4).

3.2 Understanding the link with emotion

Respondents described how the psychological nature of the condition was a particularly challenging aspect of the diagnosis, with some confusion regarding how a physical episode could be linked to an emotional cause:

“I’d never heard of it before and the, the fact that it was more classed as a psychological thing, to be honest, it did concern me” (pt11).

“I sat and I thought well if there’s nothing physically wrong in my brain, why, you know, what’s causing them” (pt2).

Six participants described how the intervention had been successful in facilitating their understanding of the link between emotions and the seizures:

“I mean it’s useful to get an understanding of what’s causing it, even if I don’t know the exact cause of it, to know that it’s the emotional side. I think that is really helpful because I can understand. I can see the logic in it and I can see where it’s coming from” (pt7).

Some described how the sessions had led them to a detailed self-examination of possible emotional causation and how they had been able to identify influential elements. Participants described how underpinning factors needed to make sense to them:

“She basically said “You’re not taking on board how much this has phys, emotionally affected you. You take everybody else’s problems on.....no-one’s fixing you” (pt4).

“So it must be playing on the back of me mind all the time. Cos me mum’s health, got a real big scare of cancer, you know” (pt8).

One described how the intervention had facilitated the difficult process of “taking responsibility” for managing the seizures:

“It’s quite hard to take responsibility that actually emotionally you might not have been looking after yourself the way that you should have been and that’s why this is happening” (pt10).

3.3 Seeking a physiological explanation for onset

For five participants in contrast, the explanation of emotional causation outlined during the sessions was perceived as insufficient, and they were unable or unwilling to recognise potential emotional factors:

“To me there didn’t seem to be any reason to why they started. There was no actual event that happened around that time, the actual time they started” (pt7).

“I still can’t believe it.... I just think how can something so far back, like forty years back, cause this now” (pt12).

For some of these patients the onset of the seizures had been immediately following surgery. This association with a medical rather than emotional event led to them continuing to describe physiological explanations for causation:

“It could have been related to your physiology, being under so much pressure... they can’t really sort of nail down as to what is the actual thing that’s causing the seizures” (pt8).

“They said it was something to do with neuro-signals from my brain being like misinterpreted and doing something differently” (pt6).

3.4 Doubting the diagnosis

Continued puzzlement about causative factors led six participants to describe an element of ongoing doubt regarding the diagnosis of PNES. The intervention had been unable to provide

a complete explanation regarding the onset and continued existence of the seizures for these individuals, and some expressed concerns that “something was being missed”:

“You know, are they missing something. Because I read these things all the time on the internet...if somebody goes to the doctor with a bad back, they find out they’ve got cancer, somebody else it’s just a bad back. So but I do find it hard to accept still, yes” (parent).

“I still feel there is something causing these seizures” (pt9).

The complex nature of the diagnosis and lack of physiological indicators was also described by one person as requiring an element of “trust” in the diagnosis:

“So I think part of me thought there was something perhaps being missed here but you know how you just sort of trust people” (pt7).

Some patients described an acceptance of the diagnosis, however continued to perceive that it was an incomplete explanation:

“So yeah, it did fit in for some things but for a, for a lot of things it, it didn’t (pt11).

Even now we still say we think that some of them are epilepsy” (pt1).

The need to have trust in the diagnosis was particularly difficult for some, as they previously had an epilepsy diagnosis which had subsequently been changed. One person contrasted their current state of uncertainty with when they had an epilepsy diagnosis:

“I mean I accepted. Yes you are epileptic and I accepted it and I was given medication and I just got on with my life and nothing in my life changed, nothing. And then one day, for some unknown reason I don’t know what...all gone the opposite way” (pt9).

3.5 The role of medication

The difficulty in fully understanding and “trusting” the diagnosis seemed linked in four cases to the perceived effect that medication had on their condition. These patients described how they were continuing to be prescribed medication and this seemed to reduce the frequency of seizures. This then led to them having doubts regarding the psychological cause:

“I think it’s got a little bit of epilepsy there somewhere, because the way I feel is why is this Epilim working? But I have been told and I’ve read up on the computer and stuff if it’s non-epileptic then Epilim won’t touch it, you’ll carry on fitting” (pt1).

“To me it doesn’t fit because I respond to treatment so if medications help, you know, and I respond to migraine medications” (pt11).

One person described how continuing to take medication seemed to blur the boundary between an epilepsy and PNES diagnosis:

“I am still on epilepsy medication but I only take two and I only take them at night, which I did all the time when I thought I was epileptic as well” (pt9).

Another, while recognising that the drug intervention was only a partial treatment reported that it was effective:

“I don’t know, it’s only a 15mg, a once a day thing so it’s not like a massive amount ...but yeah, I think that’s kind of just helps” (pt6).

For one parent, the impact of the drug rather than psychological intervention was clear cut:

“To me I think that the sessions didn’t help. I think the tablet helped. That’s my opinion” (parent).

3.6 The way forward

Participants were asked what they perceived the current status of their condition to be. At the time of interview their condition was described as no change for seven patients, some improvement for four and of a worsening in severity for one person. Participants described how the seizures had led to an inability to work, loss of income, reduced school attendance, a negative impact on their families, loss of driving licence, loss of independence and social life, all causing a significant impact on their lives. While for just over half the interviewees there had been little change, three participants described how the intervention had led them to begin thinking about a more positive future. These patients described their current status as improving (one) and no change (two):

“We talked about moving on, as what we talked about the plan of where my life might go from now, getting my independence back” (pt10)

“It’s made me start thinking well now let’s see if I can get back to doing those things that I stopped doing” (pt7).

“So everybody has their own triggers and I think it’s a case for them personally is to have a look and see what’s going on for them personally, and then to move on from there and that, to find a way forward” (pt8).

Following the intervention around half the participants reported that they had been referred on for further input consisting of either a waiting list for psychiatry, or a waiting list for a specialist in-patient unit (two patients). The perception of this further input for one person was that it would “go deeper”:

“I think it will be helpful, because they go a little bit deeper into maybe what’s ... this is what she said” (pt3).

Participants described a hope that it would help to resolve continuing questions regarding causation as this continued to be a key concern for them:

“I’m hoping he will get more of an understanding of what I’m like and what might be causing them and sort of how to sort of” (pt7).

“She has referred me to another psychotherapist so we’re just waiting to hear from them now. I’m hoping, I’m really hoping they can tell me more of why because that’s the big issue with me” (pt2).

4. DISCUSSION

Research has suggested that a patients’ perception (or representation) of their illness affects adjustment, acceptance of treatment and treatment outcomes [21 22]. For instance, studies in epilepsy have demonstrated that illness perceptions are related to clinically important behaviours (such as medical adherence) and explain a greater proportion of the variance of anxiety measures and people’s ability to cope with their disorder than seizure-related variables [23 24 25 26]. Illness beliefs have also been shown to predict outcome in patients with medically unexplained neurological symptoms [27]. Patients' illness perceptions are a key feature of the self-regulation model. This assumes that people are active problem solvers and are motivated to treat illness in accordance with their understanding of the problem. In this model, illness representations consist of five elements: identity (symptoms or label), cause, consequences (effects on life or life-style), time-line (time to develop and duration) and controllability or cure [28]. A study in patients with PNES has demonstrated that the model can be applied to non-epileptic seizures [29]. The psychoeducational intervention used here was designed to address all elements of patients' illness perceptions and to enable them to deal more effectively with the diagnosis of PNES.

The previous study of people with PNES using this model found that confusion regarding their condition (illness identity) and its cause was particularly evident [29]. Other studies have confirmed this observation [14 16]. These findings provide a strong rationale for interventions aimed at reducing confusion and providing patients with a clear and credible explanation for their symptoms. Although our programme starts with an elaboration of the explanation of PNES already provided by the neurologist and repeated in a detailed information booklet about PNES (available as a download from

www.shef.ac.uk/nest/downloads.html), the findings of this study show that that confusion about the diagnosis persisted in a substantial group of patients. However, a similarly large group of patients seemed to appreciate the extra time with a health professional and written materials provided during the course of the intervention.

Our interviews provided some confirmation of the finding of a previous qualitative study that patients with an external locus of control for their seizures find it more difficult to accept the diagnosis of PNES and to engage in psychological treatment [16]. Patients are unlikely to get better or accept the rationale for psychological treatment if they have not accepted a model of the disorder, which at least provides them with the potential to control their seizures.

The participants in our study formed a heterogeneous group, with eight females and four males, with an age range of 18 to 51, and seizure histories ranging in duration from one to eight years, mirroring the typical demographic details of patients diagnosed with PNES in secondary care [30]. The heterogeneity of our patient group was not limited to these clinical and demographic features but also comprised a range of different illness perceptions. This means that it is perhaps not surprising that we found considerable variation in participant views about the helpfulness of the intervention.

While qualitative data provides description and is not intended to explore cause-effect associations it is interesting to note the lack of any clear link between the participants' reported understandings of the condition following the intervention, and perceived outcome. For example, of the interviewees who described how the intervention had positively impacted on their understanding, one reported that they were improving, one worsening and the others thought that little had changed. The two individuals who described that the intervention did not provide answers were both improving. Similarly, of the five participants who were unable to identify psychological causative factors, three were improving and two reported no change.

It is not entirely surprising that there is no clear link between patients' understanding of their condition and short term seizure control: The link between seizures and emotional distress may be obvious to a severely traumatised individual but seizures may continue without further intervention. In contrast, an association between emotional distress and PNES may be more difficult to understand for someone whose PNES develop out of the misinterpretation of physical symptoms (such as presyncope associated with orthostatic intolerance) but the seizures may stop when the patient has been reassured that there is no serious or progressive neurological disease. Nevertheless, the heterogeneity evident from the

interviews described here highlight the challenges for establishing effective interventions. This variation in responses suggests a need for further intervention packages (such as longer courses of psychotherapy) to be carefully tailored to individual needs, with perhaps multiple options being required rather than one specified management pathway. Our findings also suggest that individualized psychotherapeutic interventions may not be appropriate, acceptable or effective if they target seizures alone.

Along similar lines, future intervention studies may not reflect relationships between illness perceptions and outcomes fully if the observed outcomes are limited to seizure counts. We have previously demonstrated the modest statistical relationships between PNES counts and other important outcomes such as health-related quality of life, psychological distress or other physical symptoms [31 32]. Our data clearly showed that previous healthcare experiences had been an important influence on patients' ability to accept the explanations for their symptoms offered by the intervention, and the idea of psychological treatment. This was particularly evident in those cases in whom anti-epileptic drugs had been used in the past. The ongoing prescription of anti-epileptic medication caused particular confusion and contributed to doubts regarding a psychological rather than physiological causation. A study of Dutch patients reported that while all anti-epileptic medication was withdrawn by a specialist centre at time of diagnosis, by the time of follow up (23-67 months) nearly a third of patients were receiving medication again [33]. The authors of this work described this as illustrating "an implicit reversion" to an epilepsy diagnosis. The risk of this may be reduced by reinforcing the "diagnostic message" to patients with written information describing the diagnosis of PNES, although the comments made by participants in this and one previous study suggest that a leaflet about PNES is unlikely to answer all of the patients' questions [16]. To some extent, patients' information needs may be met by more in-depth websites (for instance www.nonepilepticattacks.info), but our findings suggest that it is advisable to offer patients follow-up appointments after the initial diagnosis of PNES to allow them to ask further questions.

4.1 Limitations

During the study we endeavoured to recruit participants for telephone interviews from amongst those who had refused the offer of the intervention. These potential respondents were either not contactable or not interested in taking part. Given the spontaneous recovery rates reported by other studies it is likely that some of these individuals may no longer have

seizures. Other work however has highlighted the challenges in recruiting and retaining patients with PNES to research studies, with approach/avoidance patterns, rejection of diagnosis, frequent crises and transportation issues described [34]. Data we have reported represents the views of a small sample of patients with PNES who accepted the intervention, and may therefore have an emphasis on more positive perceptions or particular responses to the diagnosis. It would be important to seek views and perceptions from those refusing the intervention in order to gain a complete understanding of PNES patient perceptions. The findings may also be influenced by the time lag between the intervention and the interview being carried out. Patients were interviewed between one and seven months following completion of the intervention. The recollection required for some may have adversely impacted on their ability to provide detailed perceptions. This slight interim period however, may have had a positive impact on the study, by providing a window of time for further reflection and evaluation by participants leading to deeper insights.

The intervention provided for participants was relatively brief, consisting of four individual sessions. It was designed to stop seizures in a number of patients but it was always expected that the majority of patients would need further individualised and more in-depth treatment. Some participants who were waiting for psychotherapy appointments perceived that this further input would be beneficial in achieving enhanced understanding. Given that the literature highlights that patients diagnosed with PNES are often reluctant to accept psychiatric input [6], the intervention may have been successful in acting as a bridge between the diagnosis and attending psychiatric services.

5. Conclusion

The findings of this study emphasise the heterogeneity of this patient group and the differential response to the intervention. The results suggest that the greatest area where patients with PNES require intervention is around getting satisfactory answers. In order to be perceived as beneficial, an intervention should enable improved understanding of the link with emotions, and provide sufficient explanation regarding a psychological rather than physical causation. However, the explanatory model must be constructed carefully if it is to achieve maximum acceptability: an explanation predominantly based on recent or ongoing trauma or conflict is likely to leave a substantial subgroup of patients confused and unconvinced. The continuation of antiepileptic drugs can cause additional confusion and “send different signals” regarding the diagnosis.

The results suggest that a brief educational intervention can assist in finding a way forward for some patients. Whilst this study has prompted us to make some minor changes to our explanation of the nature of PNES in the psycho-education programme we think that the findings justify a randomised controlled trial of this intervention.

REFERENCES

- [1] Hall-Patch L, Brown R, House A, Howlett S, Kemp S, Lawton G, Mayor R, Smith P, Reuber M. Acceptability and effectiveness of a strategy for communication of the diagnosis of psychogenic nonepileptic seizures. *Epilepsia* 2010; 51: 70-78.
- [2] Kotsopolous IA, de Krom MC, Kessels FG, Lodder J, Troost J, Twellar M, van Merode T, Knottnerus AJ. The diagnosis of epileptic and non-epileptic seizures. *Epilepsy Res* 57; 59-67.
- [3] Reuber M. Psychogenic nonepileptic seizures: questions and answers. *Epilepsy Behav* 2008; 12: 622-635.
- [4] de Timary P, Fouchet P, Sylin M, Indriets JP, de Barsy T, Lefebvre A, van Rijckevorsel K. Non-epileptic seizures: delayed diagnosis in patients presenting with electroencephalographic (EEG) or clinical signs of epileptic seizures. *Seizure* 2002; 11: 193-197.
- [5] Benbadis SR, Hauser WA. An estimate of the prevalence of psychogenic non-epileptic seizures. *Seizure* 2000; 9: 280-281.
- [6] Mayor R, Reuber M. Management of patients with nonepileptic attack disorder in the United Kingdom; a survey of healthcare professionals. *Epilepsy Behav* In Press.
- [7] Goldstein LH, Deale AC, Mitchell-O'Malley SJ, Toone BK, Mellers JD. An evaluation of cognitive behavioural therapy as a treatment for dissociative seizures. *Cogn Behav Neurol* 2004; 17: 41-49.
- [8] Kanner AM, Parra J, Frey M, Stebbins G, Pierre-Louis S, Iriarte J. Psychiatric and neurologic predictors of psychogenic pseudoseizure outcome. *Neurology* 2003; 53: 933-938.
- [9] So NK, Bennett C, Smith B. Prospective outcome after diagnosis of nonepileptic seizures. *Epilepsia* 2004; 45 (Suppl 7): 266-267.
- [10] Reuber M, Pukrop R, Bauer J, Helmstaedter C, Tessendorf N, Elger CE. Outcome in psychogenic nonepileptic seizures: one to 10 year follow-up in 164 patients. *Ann Neurol* 2003; 53: 305-311.

- [11] Mayor R, Grunewald R, Reuber M. Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: seizure control and healthcare utilization. *Epilepsia* 2010; 51: 1169-1176.
- [12] Reuber M, Burness C, Howlett S, Brazier J, Grunewald R. Tailored psychotherapy for patients with functional neurological symptoms: results of a pilot study. *J Psychosom Res* 2007; 63: 625-632.
- [13] Carton S, Thompson P, Duncan S. Non-epileptic seizures patients' understanding and reaction to the diagnosis and impact on understanding. *Seizure* 2003; 12: 287-294.
- [14] Thompson R, Isaac C, Rowse G, Tooth CL, Reuber M. What is it like to receive a diagnosis of nonepileptic seizures? *Epilepsy Behav* 2009; 14: 508-515.
- [15] Thompson R. *What is it like to receive a diagnosis of nonepileptic seizures?* Sheffield: University of Sheffield, 2007.
- [16] Karterud HN, Knizek BL, Nakken KO. Changing the diagnosis from epilepsy to PNES: patients' experiences and understanding of their new diagnosis. *Seizure* 2010; 19: 40-46.
- [17] Howlett S, Grunewald R, Khan A, Reuber M. Engagement in psychological treatment for functional neurological symptoms – barriers and solutions. *Psychotherapy Theory, Res, Pract, Train* 2007; 44: 354-360.
- [18] Howlett S, Reuber M. An augmented model of brief psychodynamic interpersonal therapy for patients with nonepileptic seizures. *Psychother Theory Res Pract Train* 2009; 46: 125-138.
- [19] Mason J. *Qualitative Researching* (Second Edition) London: Sage, 2002.
- [20] Glaser B, Strauss A. *The Discovery of Grounded Theory*. New York: Aldine De Gruyter, 1967.
- [21] Hagger MS, Orbell S. A meta-analytic review of the common-sense model of illness representations. *Psychol. Health* 2003; 18: 141–184.
- [22] Horne R. Patients' beliefs about treatment: the hidden determinant of treatment outcome? *J Psychosom Res* 1999; 47: 491–495.
- [23] Brown I, Sheeran P, Reuber M. Enhancing antiepileptic drug adherence: A randomized controlled trial. *Epilepsy Behav* 2009; 16: 34-39.
- [24] Jones RM, Butler JA, Thomas VA, Peveler RC, Prevett M. Adherence to treatment in patients with epilepsy: associations with seizure control and illness beliefs. *Seizure* 2006; 15: 504-508.

- [25] Goldstein LH, Holland L, Soteriou H, Mellers JD. Illness representations, coping styles and mood in adults with epilepsy. *Epilepsy Res* 2005;67: 1-11.
- [26] Kemp S, Morley S, Anderson E. Coping with epilepsy: Do illness representations play a role? *Br J Clin Psychol* 1999; 38: 43-58.
- [27] Sharpe M, Stone J, Hibberd C, Warlow C, Duncan C, Duncan R, Coleman R, Roberts R, Cull R, Pelosi A, Cavanagh J, Mathews K, Goldbeck R, Smyth R, Walker A, Walker J, MacMahon A, Murray G, Carson A. Neurology out-patients with symptoms unexplained by disease: illness beliefs and financial benefits predict 1-year outcome. *Psychol Med* 2010; 40: 689-98.
- [28] Leventhal H, Diefenbach M, Leventhal EA. Illness cognitions: using common sense to understand treatment adherence and affect cognition interactions. *Cogn Ther Res* 1992;16: 143-163.
- [29] Green A, Payne S, Barnitt R. Illness representations among people with non-epileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model. *Seizure* 2004; 13: 331-339.
- [30] Reuber M. Psychogenic nonepileptic seizures: answers and questions. *Epilepsy Behav* 2008; 12: 622-635.
- [31] G Lawton, R Mayor, S Howlett, M Reuber. Psychogenic non-epileptic seizures and Health Related Quality of Life: the relationship with psychological distress and other physical symptoms. *Epilepsy Behav* 2009; 14: 167-171.
- [32] M Reuber, Mitchell A, Elger CE. Measuring outcome in patients with psychogenic nonepileptic seizures: the relevance of seizure remission. *Epilepsia* 2005; 46: 1788-1795.
- [33] Gudmundsson O, Prendergast M, Foreman D, Cowley S. Outcome of pseudo-seizures in children and adolescents: a 6 year symptom survival analysis. *Develop Med Child Neurology* 2001; 43: 547-551.
- [34] LaFrance WC, Blum AS, Miller IW, Ryan CE, Keitner GI. Methodological issues in conducting treatment trials for psychological nonepileptic seizures. *J Neuropsychiatry Clin Neurosci* 2007; 19: 391-398.

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We confirm that this study was approved by an appropriate ethics committee and was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

Table 1 Characteristics of study participants

	Gender	Age	Reported time since onset	Study site	Current perceived status	Time since completion of intervention
Pt 1	Male	50	1-2 years	C	No change	Did not complete
Pt 2	Female	32	1-2 years	C	Improving	3 months
Pt 3	Female	23	1-2 years	C	Worsening	3 months
Pt 4	Female	26	10 years	C	Improving	4 months
Pt 5	Male	19	1-2 years	C	No change	8 months
Pt 6	Male	19	3 years	B	Improving	6 months
Pt 7	Female	48	1-2 years	B	No change	6 months
Pt 8	Male	41	18 years	A	No change	1 month
Pt 9	Female	54	8 years	A	No change	7 months
Pt 10	Female	34	1-2 years	C	Improving	3 months
Pt 11	Female	29	2-3 years	C	No change	3 months
Pt 12	Female	51	1-2 years	C	No change	2 months

Appendix Patient interview schedule

1. Brief background about NES and current situation

How long ago / when did your seizures start?

What happens / what are they like / how often do they happen? Has there been any change in how often you have seizures? Do you still have seizures?

What do you think is going on / causing them? Is that how you've always thought? [If not, did it change as a result of the educational intervention?]

When / how long ago were you told that your seizures aren't due to epilepsy?

What was said at that consultation / how did the consultation go / what did you think about that?

What happened after that? [I.e. in between receiving the diagnosis and starting the intervention]

2. Perspectives on the brief educational intervention for NES

When did you start the brief educational intervention / how did that come about?

What happened / what were you told / what did you do / what did it involve?

How did you find it / what was it like? [Looking for examples of what was good / not good, what was helpful and how. Also try to gauge whether the patient was doubtful / cynical or enthusiastic / keen about it before starting it. Prompt if necessary to distinguish between views about the therapist and the format / content of the sessions]

Did a carer / family member come along to the sessions with you? If so, what do you think they made of it?

How are things for you now / has the educational intervention been helpful? Has it changed anything in your life?

What do you think about the future in relation to your seizures? [Can also ask what they now think about taking up a longer intervention e.g. psychotherapy, if they still have seizures]

3. Perspectives on the study design / outcome measures

How have you found being part of a research study?

What did you make of the information you were given about the study? [E.g. sufficient / not sufficient]

Did you have any questions about it and, if so, who did you ask / were they answered sufficiently?

How did you find / what was it like completing the questionnaires? [Timing of them, ease of completion etc. Include (if necessary): How did you complete them (Internet, postal or telephone) and how did you find that?]

Was there anything that you think should be changed?

Is there anything else you think might be helpful for me to know / is there anything you want to ask? Thank you