

# **Acceptability and effectiveness of a strategy for the communication of the diagnosis of non-epileptic attacks**

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**Running title:** A communication protocol for NEA

**Key words:** Psychogenic non-epileptic seizures, diagnosis, communication, illness perceptions, psychological treatment

**Statistics:** Manuscript including abstract: 26 pages, 4 tables, 1 box, 1 figure

## **Summary**

**Purpose:** Communicating the diagnosis of **psychogenic** non-epileptic seizures (**PNES**) is a challenging task. This study was carried out to assess the acceptability and effectiveness of a new communication procedure consisting of a patient information leaflet and a communication strategy for neurologists.

**Methods:** In a multicentre prospective study, 50 patients newly diagnosed with **PNES** were informed about the diagnosis by ten different neurologists using the communication procedure. Follow-up data were gathered by telephone interview and completion of a questionnaire about symptom attributions (psychological/physical) and illness cognitions (Illness Perception Questionnaire-Revised, IPQ-R).

**Results:** 94% of patients found the leaflet easy to understand. 94% stated their questions were answered by the doctor, 70% got what they wanted from the consultation, 94% stated their questions were answered by the doctor, only 4% reported feeling angry during the consultation. 86% of patients acknowledged that psychological factors were at least contributing to their seizures. On the IPQ-R, 'emotional' causes were endorsed more commonly than 'non-emotional' causes ( $p < 0.001$ ). After three months, 14% of patients were seizure-free 63% reported a >50% reduction in seizure frequency.

**Conclusion:** We conclude that our procedure is acceptable and effectively communicates a psychological etiological model for **PNES**.

**Keywords:**

Psychogenic non-epileptic seizures, diagnosis,  
communication, illness perceptions, communication,  
psychological treatment

# **Acceptability and effectiveness of a strategy for the communication of the diagnosis of Psychogenic non-epileptic seizures**

## **Introduction**

Psychogenic non-epileptic **seizures (PNES)** are episodes of altered movement, sensation or experience resembling epileptic seizures but not associated with **epileptic** discharges in the brain. They can be defined positively as episodes of loss of control which occur in response to distressing situations, sensations, emotions, conflicts or memories when alternative coping mechanisms are inadequate or have been overwhelmed (Reuber M., 2008). **PNES** are classified as a manifestation of dissociative or conversion disorder in the current nosologies (American Psychiatric Association, 1994; World Health Organization, 1992). Whilst many questions about their etiology remain unanswered, and there are presently no proven interventions for **PNES**, most neurologists consider psychological treatment the management of choice (LaFrance, Jr., Rusch & Machan, 2008).

**PNES are not uncommon.** The population prevalence of **PNES** has been estimated as 2-33 per 100,000 (Benbadis, Allen & Hauser W.A., 2000). **Two recent studies have shown that PNES make up 12 to 18% of patients newly presenting with seizures** (Angus-Leppan, 2008; Kotsopoulos et al., 2003). The same studies suggest that, in a first seizure clinic, physicians should expect to make one diagnosis of **PNES** for every three or four of epilepsy. However, most patients with **PNES** are initially misdiagnosed as

having epilepsy. In fact, the diagnosis of **PNES** is typically only made after patients have been treated inappropriately with antiepileptic drugs for several years (Reuber et al., 2002; de Timary, Fouchet et al., 2002).

Once the diagnosis has been made, neurologists face the challenge of explaining to patients that they do not have epilepsy, but that their seizures are a manifestation of psychological distress. This can be difficult as patients may be reluctant to accept that their seizures do not have a “physical” cause. Although they report more symptoms of psychopathology and more negative life events (Lawton, Baker & Brown, 2008; Binzer, Stone & Sharpe, 2004; Galimberti et al., 2003; Reuber et al., 2003; Prueter, Schulz-Venrath & Rimpau, 2002) , as a group, patients with PNES are paradoxically less likely to agree that stress or emotional factors could be a cause of seizures than patients with epilepsy (Stone, Binzer & Sharpe, 2004).

The question of how the diagnosis should be communicated has attracted considerable interest (Kanner, 2003; Harden & Ferrando, 2001). One reason why “good” communication is important at this point is that outcome is better in patients who accept the diagnosis (Ettinger et al., 1999). In fact, **PNES** can resolve when clinicians have explained the nature of the problem (Kanner et al., 1999; Aboukasm et al., 1998). What is more, effective communication at this point has the potential to change patients’ healthcare utilization behavior significantly and reduce healthcare costs (Martin et al., 1998).

At present, however, many patients report feeling confused or angry after receiving the diagnosis of **PNES** (Thompson, 2009; Thompson, Osorio & Hunter, 2005; Green, Payne & Barnitt, 2004; Carton, Thompson & Duncan, 2003). Only three in five patients referred by a neurologist attend for an assessment interview for psychological treatment (Howlett et al., 2007). “Unsuccessful” communication may also increase the risk of continuing inappropriate treatment with anticonvulsants. We have previously shown that 41% of patients diagnosed with **PNES** (and no additional epileptic seizures) were taking antiepileptic drugs a mean of four years after the diagnosis of **PNES** (Reuber et al., 2003).

A protocol for a more satisfactory communication of the diagnosis of **PNES** has been proposed (Shen, Bowman & Markand, 1990), but its effectiveness or acceptability has never been tested. A number of individuals and organizations have produced information leaflets for patients intended to help explain the diagnosis, but these have not been evaluated in clinical studies either (for examples see <http://hsc.usf.edu/COM/epilepsy/PNESbrochure.pdf> or <http://www.epilepsyfoundation.org/about/types/types/nonpileptic/index.cfm>).

The primary aim of the present study was to evaluate the acceptability and short-term effectiveness of a communication strategy consisting of a detailed patient information leaflet and doctors’ guide encouraging clinicians to emphasize the core points made in the leaflet. The communication strategy was designed to address all domains of patients’ illness representations.

Illness representations are an essential part of the self-regulation model which proposes that how people behave in relation to illness depends on their own perception or representation of the illness. 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 (Leventhal, Diefenbach & Leventhal, 1992). A recent review concluded that there was a clear relationship between illness cognitions, coping behavior and illness outcomes (Hagger & Orbell, 2003), and one study demonstrated that (with some minor modification) the self-regulation model was applicable to how patients think about **PNES** (Green et al., 2004).

This communication strategy was conceived as a first step towards the development of an evidence-based management pathway for patients with **PNES**. The secondary aim of this study was to explore the recruitment potential of the collaborating clinicians for future treatment studies and to describe the characteristics of the patients entering such studies.

## **Methods**

***Development of the communication strategy*** - Based on a review of the literature, available patient information leaflets and their own clinical practice, the collaborators identified 14 core points addressing all major domains of patients' illness representations. A patient leaflet was compiled which covered and elaborated the 14 core points over 27 pages. **The leaflet refers to PNES**

as ‘non-epileptic attacks’ because this has become the most commonly used label in the United Kingdom. However, the authors consider the label of ‘non-epileptic attacks’ as synonymous with the labels PNES (which has been used more frequently in recent research publications) and terms such as ‘pseudoseizures’, ‘dissociative seizures’ or ‘conversion seizures’. The leaflet is available for download at <http://www.shef.ac.uk/content/1/c6/08/82/45/NEST%20Patient%20Booklet.pdf>. A doctor’s guide was written to accompany the leaflet, offering further explanation of the reasons for including each point, references to relevant research, and advice on how to communicate the information to patients (<http://www.shef.ac.uk/content/1/c6/08/82/45/NEST%201%20Clinician%20Handbook.doc>). A crib sheet was also produced and neurologists were encouraged to use this as a checklist to try to ensure they covered all the points (see box 1).

**Insert Box 1 here**

***Collaborating clinicians*** – Fully trained neurologists with a clinical interest in seizure disorders from centers throughout the United Kingdom were invited to take part in the study. Each neurologist was encouraged to recruit all patients meeting the criteria who presented within a six months’ period. Recruitment began in the first centre in October 2006 and finished in the last in June 2008.

***Patients*** - Patients received the patient leaflet at the point of receiving the diagnosis of PNES. During the same consultation they were asked whether they would mind finding out more about a research study

**evaluating the communication of the diagnosis.** If they agreed to find out more about the project, their contact details were passed on to the research psychologist (LHP) who contacted them, offered information and obtained written informed consent by post. Patients were included if they had received the diagnosis of **PNES** from the neurologist for the first time and if the diagnosis was secure (confirmed by video-EEG, or based on the direct observation of a seizure by an **experienced healthcare professional**, eg. neurologist, experienced EEG technician or specialist nurse). Patients with a history of possible epilepsy (but no epileptic seizures for at least one year) were eligible for participation. Patients were excluded if they did not speak English sufficiently well to take part in a telephone interview or to complete the self-report questionnaires used in the study.

***Evaluating the communication strategy*** – Patients’ recollections of their encounter with the neurologist were assessed in a semi structured telephone interview which was conducted by the research psychologist **after patients had returned a form documenting their written informed consent.** This interview was conducted approximately two weeks after their consultation with the neurologist. The interview consisted of a series of cued questions. These were followed by closed (yes/no) questions if the patient had not given the expected answer to the initial question (e.g. ‘What kind of treatment did your doctor suggest for your attacks?’, expected answer : ‘Psychological treatment.’, follow-up question: ‘Did your doctor suggest psychological treatment?’). For the full telephone questionnaire see <http://www.shef.ac.uk/content/1/c6/08/82/45/NEST%201%20Telephone%20interview>

.doc. Patients were also asked to provide a self-report measure of their seizure frequency before they spoke to their neurologist about their diagnosis and at the time of the telephone interview. Responses were categorised into 'daily' (one seizure or more per day), 'weekly' (at least one seizure per week, but less than one per day), 'monthly' (at least one seizure per month but less than one per week), 'occasionally' (less than one seizure per month) and 'seizure free'.

**Patients were sent a questionnaire immediately after this telephone interview** which was intended to reveal their thoughts about their disorder at a point at which they may start psychological treatment in future intervention studies. It included a forced choice question with five response options previously used to sample symptom attribution to physical or psychological causes in other patient groups with medically explained or unexplained physical symptoms (see results section for wording) (Wessely & Powell, 1989). It also contained a version of the Illness Perception Questionnaire-Revised (IPQ-R), which had been adapted for seizures in line with the instructions of its authors (Moss-Morris et al., 2002). The IPQ-R has been shown to have high internal and external validity and good test-re-test reliability. It provides a quantitative assessment of patients illness perceptions in the five major domains listed above and has been used in a wide range of disorders and clinical scenarios (Gray & Rutter, 2007; Stockford, Turner & Cooper, 2007; Moss-Morris & Chalder, 2003; Moss-Morris et al., 2002). In line with a previous study (Goldstein, Deale, Mitchell-O'Malley, Toone & Mellers, 2004), the list of possible causes of seizures included in the IPQ-R was split

into seven 'emotional' (stress or worry; my own behaviour; my mental attitude; family problems or worries; overwork; my emotional state; my personality) and eleven 'non-emotional' causes (hereditary; a germ or virus; diet or eating habits; chance or bad luck; poor medical care in the past; pollution; ageing; alcohol; smoking; accident or injury; altered immunity). Patients scored the self-perceived relevance of these potential causes on a scale from 1 (strongly disagree) to 5 (strongly agree). The responses 'I neither agree nor disagree', 'I agree' and 'I strongly agree' were categorised as '(potential) endorsement'. The responses 'I strongly disagree' and 'I disagree' were categorised as 'non-endorsement'. The proportion of '(potentially) endorsed' and 'non-endorsed' 'emotional' and 'non-emotional' causes was compared using Chi<sup>2</sup> statistics..

Patients were telephoned again approximately eleven weeks after receiving the diagnosis and asked to provide a further self-report estimate of seizure-frequency.

***Statutory permission*** – This study was approved by the Northern and Yorkshire Multicentre Research Ethics Committee, Leeds, UK. Approval was also secured separately from the Research Governance departments of all participating NHS Trusts.

## **RESULTS**

***Neurologists*** – The 23 neurologists who participated in this study worked for 15 different NHS Trusts across England, Wales and Scotland. 86% (19/23)

were male. The proportion of the neurologist's work time taken up by seizure disorders ranged from under 10% to 100% (median 55%). Ten of the 23 neurologists who took part in this study recruited patients.

**Patients** - A total of 56 eligible patients were identified. Five declined to participate after receiving the study information and one could not be contacted. 50 patients completed the telephone interview. 36 patients returned the postal questionnaires (72%), and 49 patients completed the telephone follow-up (98%).

90% of patients were female. The participants received the diagnosis of **PNES** a median of 5.2 years after seizure manifestation (range two months to 27 years), their median age was 29.5 (range 17-69). 20% (10/50) of patients not only saw the neurologist at the point of diagnosis but also met an Epilepsy Specialist Nurse. Of these patients 90% (9/10) stated that the nurse discussed the same things they had talked about with the neurologist. 40% (20/50) of patients received a letter from their neurologist following the consultation. Of these 90% (18/20) stated that the letter discussed what had been covered in the consultation.

54% (27/50) of the participants had taken anti-epileptic drugs prior to the diagnosis of **PNES**. Of these patients, 89% (24/27) were advised to stop their AEDs during the consultation. Two weeks after the clinic visit, 67% (18/27) had stopped the AED treatment, and 11% (3/27) were in the process of reducing the medication. Three patients had not been advised to reduce their

AEDs, and three decided not to reduce the AEDs despite being advised to do so. This means that 12% (6/50) of all patients in this group continued to take AEDs.

***Patients' experience of the communication strategy*** - 94% (47/50) of patients could recall being given the **PNES** booklet developed by the researchers. Of those, 94% (44/47) found it clear and easy to understand and 91% (43/47) particularly liked something about the booklet. 9% (4/47) disliked something, eg. parts not being personally relevant and finding parts of it confusing. 11% (5/47) had questions that were not covered. These questions related to memory, headaches, pregnancy, the possibility of concurrent epilepsy and the difficulty of finding the cause of the attacks.

When asked 'did you get out of the consultation what you wanted?', 70% of patients said 'yes', 24% 'partly' and 6% 'no'. 94% of patients stated that they had their questions answered, 2% said questions had been partly answered and 4% not answered. 14% of patients found the consultation confusing, 30% partly confusing and 56% not confusing. Table 1 gives an overview of patients' feelings during the consultation. Initially cued to describe any positive or negative emotions during their meeting with the neurologist, patients were also prompted with a list of possible reactions generated by the authors on the basis of previous studies (Thompson, 2009; Thompson et al., 2005; Green et al., 2004; Carton et al., 2003).

Table 2 summarizes patients' cued and prompted reports of the factual information included in the information leaflet and crib sheet two weeks after receiving the diagnosis. The most important twelve points of the communication procedure were reportedly covered in a median of 82% of consultations (range 70-98%).

### **Insert tables 1 and 2 here**

When given the choice of five different physical or psychological attributions about their attacks previously put to patients with medically explained or unexplained fatigue (Wessely & Powell, 1989), 13.8% of patients endorsed 'my problem is a purely physical one', 11.1% 'my problem is mainly physical but some psychological factors are involved', 25% 'both physical and psychological factors are involved in my problem', 16.7% 'although there are some physical reasons for my problems, it is mainly psychological in nature' and 25% 'my problem is a psychological one'.

The results of the IPQ-R completed two to four weeks after the encounter with the neurologists are summarised in table 3. The mean response score on the 'emotional' causes for the seizures offered by the IPQ-R was 2.7 with a range of 2.1 (overwork) to 3.7 (stress/worry). The mean response score on the 'non-emotional' items was 1.9 with a range of 1.4 (alcohol) to 2.8 (accident/injury). Participants '(potentially) endorsed' 52.5% 'emotional' compared to 21.7% 'non-emotional' causes ( $\chi^2=55.74$ ,  $p<0.001$ ). The list of the three most important causes most commonly included stress/worry (61%), physical

injury/illness (50%), emotional state (50%), mental attitude (28%), family problems (25%) and poor medical care in the past (19%).

**Insert table 3 here**

***PNES frequency*** – Table 4 shows the distribution of **PNES** frequency before the diagnosis, two weeks (mean 15 days, sd 21.1) and eleven weeks (mean 77.9 days, sd 28.4) after patients received the diagnosis. Three patients could not be included because they were unable to estimate their seizure frequency before diagnosis; one patient was lost to follow-up. The seizure frequency improved by at least one category (i.e. by >50%) between diagnosis and follow-up in 63% (29/46) of patients, remained unchanged in 24% (11/46) and deteriorated in 14% (6/46).

**Insert table 4 here.**

## **DISCUSSION**

Patients with **PNES** are a clinically heterogeneous group (Reuber M., 2008; Lesser, 1996). Nevertheless the occasion when a seizure expert (usually a neurologist) informs the patient of the diagnosis of **PNES** is a relatively stereotyped encounter. Because of this we devised a standardized procedure consisting of a detailed patient information leaflet, a more extensive booklet for neurologists and a crib sheet covering the core aspects of the communication. The communication strategy was conceived as the starting point of future intervention studies. This preliminary study evaluates the acceptability and effectiveness of this strategy in a **real life** clinic setting. The high levels of reported adherence to the communication strategy suggest that the communication strategy was acceptable to the participating clinicians and that the core points were communicated in most encounters.

Our approach differs from the only previously published proposal of how to communicate the diagnosis of **PNES** in a number of important details (Shen et al., 1990). The communication protocol suggested by Shen et al. begins with a demonstration of the recorded **PNES**. However, **23-30% of patients with PNES never have a seizure during video-EEG tests** (even when seizure provocation is used) (McGonigal et al., 2004; Benbadis et al., 2004). What is more, most diagnoses in the UK are given in an outpatient setting with limited access to seizure recordings. Another important difference between the procedures is that our strategy uses a medical label ('non-epileptic attacks') and provides patients with a psychological model of the etiology of the seizures whereas the older proposal emphasizes that it is not known what the attacks are and uses the non-specific term "spell". There is ample evidence that patients (especially patients with medically unexplained symptoms) (Madden & Sim, 2006) are keen to understand what is causing their symptoms and to receive a diagnostic label (Green et al., 2004). They are more likely to achieve mastery over their health problems or cope with ongoing symptoms if they have a better understanding of their nature (Peters et al. 1998). There is no convincing evidence that the use of labels is harmful. We felt that a comprehensible and acceptable etiological model and a clear label were likely to reduce confusion, increase confidence in the clinician and acceptance of the treatment or referral plan.

Further, Shen et al. suggest that patients should be questioned specifically about the possibility of sexual abuse. Whilst sexual trauma is obviously an important risk factor for **PNES** (Sharpe & Faye, 2006), it is only relevant in a minority of patients (Reuber et al., 2007). We do not think that it needs to be addressed in this particular setting. In fact, it might be unsafe to discuss this issue in a clinic without rapid follow-up or suitable support systems. Disclosure of traumatic events (without any further intervention) was found not to have a beneficial effect on outcome in a similar patient group (Schilte et al., 2001).

Perhaps the most significant difference between the communication protocol suggested by Shen et al. and the approach described here is the central role

apportioned to the detailed patient information leaflet in this study. The older proposal does not involve the use of written information. Our leaflet was devised because previous studies identified “confusion” as the most common sentiment after receipt of the diagnosis of **PNES** (Thompson, 2009; Carton et al., 2003). The leaflet was also used as a means of ensuring that all patients in this study were equipped with the same basic information about **PNES** at the point of diagnosis. This would obviously be of great benefit in future intervention studies. The leaflet was very well received by the patients, only 11% of whom found that they had questions which had not been sufficiently well covered. Most of these questions would not have been applicable to the majority of readers.

Patients’ reported feelings about the consultation with the neurologist were more positive than previous studies would suggest (Thompson, 2009; Thompson et al., 2005; Carton et al., 2003). Although patients volunteered more negative than positive feelings, with prompting, positive feelings were reported more frequently than negative sentiments. What is more, most negative feelings (like being “upset”, “anxious” or “confused”) may have been attributable to the nature of the problem rather than the quality of the interaction with the neurologist. This interpretation is supported by the fact that 94% of patients stated that they had their questions answered by the neurologist, 90% of patients felt they had been “listened to”, and only 14% of patients found the consultation confusing. The number of patients who claimed to have been angry during the consultation (4%) was much lower than the 18% reporting anger after receiving the diagnosis in a previous study (Carton et al., 2003). **The marked differences of participants responses to open or prompted questions raises important questions about the validity of self-report questionnaires in this patient group. The discrepancies observed here suggest that in future outcome studies, self-report questionnaires should be combined with other methods of observation (such as qualitative approaches, the use of objective behavioral data or additional questioning of healthcare staff or care givers).**

In marked contrast to patients presenting to neurologists with unexplained fatigue of whom 94% attributed their symptoms to physical causes (Wessely & Powell, 1989), only 11% of the patients in this study thought that their seizures had a purely physical etiology after they had received the information leaflet and seen the doctor. On the IPQ-R patients endorsed emotional causes more strongly and frequently than non-emotional causes for their symptoms. Four of the commonest six causes listed as most important by the participants in this study can be classed as 'emotional' (stress/worry, emotional state, mental attitude, family problems). These findings suggest that only a small minority of patients failed to take on board core aspects of the psychological etiological model which the communication was meant to convey.

Patients' illness perceptions after receipt of the diagnosis of **PNES** were characterized by much higher IPQ-R 'Illness Identity' and 'Timeline Cyclical' scores than reported in previous studies of patients with rheumatoid arthritis, chronic fatigue syndrome or chronic pain (Moss-Morris et al., 2002; Moss-Morris & Chalder, 2003). The 'Illness Identity' score measures the number of symptoms which patients attribute to their condition, the high 'Timeline Cyclical' score reflects the unpredictability of their condition. Perhaps these two factors explain why the 'Illness Coherence' score in our study (reflecting patients' subjective understanding of their problem) was lower than in the conditions listed above, although patients reported less confusion about the diagnosis here than in previous studies (Green et al., 2004; Carton et al., 2003). A low 'Illness Coherence' score is not necessarily a negative finding. One study in patients with eating disorders found that patients are less likely to resist change and more likely to embrace treatment if they have low 'Illness Coherence' and high 'Emotional Representation' scores (Stockford et al., 2007).

Our finding that 6% of patients were seizure free two weeks after diagnosis and 14% after six weeks, fits in well with a range of previous studies which show that the short term outcome of **PNES** after diagnosis (at least in terms of achieving seizure control) is better than naturalistic long-term outcome studies

suggest (Reuber et al., 2003). One prospective investigation found that six months after diagnosis, **PNES** had stopped in 29% of patients (Kanner et al., 1999). A second demonstrated that 42% of patients had become seizure-free after one year (So, Bennett & Smith, 2004). Two studies showed that **PNES** had stopped in half the patients at 18 months (Ettinger et al., 1999), or after two years of follow-up (Thompson et al., 2005). In fact the 'spontaneous' improvements in terms of seizure cessation or reduction seen here are no worse than the treatment outcomes reported in the only controlled (pilot) study of a Cognitive Behavioral Therapy treatment for patients with **PNES** (Goldstein et al., 2004), indicating the urgent need for larger controlled studies of the management modality currently favored by most clinicians.

Our study has a number of limitations. First and foremost, we did not standardize the communication procedure completely. Although the leaflet and crib sheet were core parts of the communication package, some patients also spoke to an epilepsy specialist nurse and some received a personalized clinic letter from their neurologist. It would be desirable, especially for comparative studies, to standardize the communication procedure more rigorously. **Next, there has to be a degree of uncertainty about the self-reported seizure frequency data. Confirmation of frequency estimates was sought from care givers, friends or relatives if possible, but ideally seizure frequency data would be collected prospective using diaries.** Furthermore, we cannot say how well the communication strategy fared compared to neurologists' historical performance or other possible strategies. However, the authors have made all the communication materials and evaluation procedures used here available on the Internet and are happy for these materials to be used in comparative studies. The neurologists contributing to this study all had extensive experience with **PNES** patients. It is possible that this experience contributed to the effectiveness of their communication behavior and patients' perception of their encounter with the doctor. This study was carried out by neurologists who were established in this clinical area to aid patient recruitment, but it would be desirable to confirm the effectiveness and acceptability of the communication strategy in the hands of **physicians who face the challenge of explaining the diagnosis of**

**PNES less frequently.** The fact that the patient leaflet is a core aspect of our communication strategy should facilitate this. Finally, we cannot say how our communication procedure would have performed in a group of patients with recent onset **PNES**. Although we were keen to recruit patients for this study who had only had seizures for weeks or months, the patients described here received the diagnosis a median of 5.2 years after seizure manifestation. However, one might expect that it would be easier to explain a psychological etiological model to someone who has just developed seizures than to someone who has received medication for an incorrect diagnosis for several years.

Taking account of these limitations our results suggest that the information booklet and communication strategy we have devised for patients newly diagnosed with **PNES** is acceptable to patients, and communicates a psychological model for **PNES** effectively. **Our findings suggest that giving a psychological explanation for PNES rarely results in patients becoming angry or being dissatisfied with their doctor.** A substantial number of patients become free of seizures after the diagnosis of **PNES** has been communicated to them.

## **Acknowledgements**

This study was supported by the Ryder Briggs Trust. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines. None of the authors has any conflict of interest to disclose.

**Box 1:** Crib sheet with 14 core points of the strategy for the communication of the diagnosis of **PNES**

### ***Genuine symptoms***

- **Real attacks** – can be frightening or disabling

### ***Label***

- **Give a name** for the condition
- **Give alternative names** they may hear
- Reassure this is a **common and recognised condition**

### ***Cause and maintaining factors***

- **Not epilepsy**
- Predisposing factors – **difficult to find out causes**
- Precipitating factors – **can be related to stress/emotions**
- Perpetuating factors – vicious cycle – **worry ⇒ stress ⇒ attacks ⇒ worry**
- Provide a **model** for the attacks – e.g. brain becomes overloaded and shuts down

### ***Treatment***

- **Anti-epileptic drugs are not effective**
- Evidence that **psychological treatment is effective**
- Talk to the patient about **referral to a specialist**

### ***Expectations***

- **Can resolve**
- **Can expect improvement**

**Table 1:** Patients' feelings during the consultation in which they were given the diagnosis of **PNES**.

<b>Feelings during the consultation</b>		<b>Cued recall</b>	<b>Cued and prompted</b>
Negative (Any: 86%)	Upset	48%	48%
	Anxious	38%	40%
	Confused	24%	26%
	Down/depressed	14%	16%
	Angry/frustrated	4%	6%
Positive (Any: 98%)	Felt listened to	2%	90%
	Relieved	14%	86%
	Felt understood	0%	86%
	Happy	18%	60%

**Table 2:** Patients' reports of factual information contained in the communication strategy.

Item	Cued reports	Cued and prompted reports
Name of the condition ( <b>'Non-epileptic attacks'</b> )	78%	98%
Alternative names	32%	N/A
<b>PNES</b> are common	54%	70%
<b>PNES</b> are not due to epilepsy	28%	92%
Difficult to know why attacks first started	0%	74%
Stress could be a maintaining factor	20%	94%
Understanding how stress leads to attacks	8%	76%
Some understanding of psychological etiology	72%	72%
Antiepileptic drugs are not effective	54%	72%
Psychological treatment suggested	58%	92%
Attacks are likely to improve	42%	84%
Attacks are likely to stop	50%	82%

**Table 3:** Illness perceptions after the consultation with the neurologist and receipt of the information leaflet, as revealed by the IPQ-R (Moss-Morris et al., 2002).

IPQ-R Scale	Explanation	Possible range	Median (n=36)	IQR
Illness identity	High scores represent strongly held beliefs about the number of symptoms attributed to the illness.	0-29	10	+/-7
Timeline acute/chronic	High scores represent strongly held beliefs about the chronicity of the condition.	6-30	19	+/-7
Timeline cyclical	High scores represent strongly held beliefs about the cyclical nature of the condition.	4-20	15	+/-3
Consequences	High scores represent strongly held beliefs about the negative consequences of the illness.	6-30	22	+/-7
Personal control	High scores represent positive beliefs about the controllability of the illness.	6-30	18	+/-5
Treatment control	High scores represent positive beliefs about the controllability of the illness.	5-25	16	+/-3
Emotional representation	High scores represent negative emotional representations of the illness.	6-30	22	+/-7
Illness coherence	High scores represent a personal understanding of the condition.	5-25	11	+/-5

**Table 4:** Change in **PNES** frequency after communication of the diagnosis.

	<b>Before diagnosis</b>		<b>2 weeks after diagnosis</b>		<b>11 weeks after diagnosis</b>	
N=	50		50		49	
	Number	Percentage	Number	Percentage	Number	Percentage
Daily	21	42%	8	16%	9	18%
Weekly	20	40%	23	46%	22	45%
Monthly	6	12%	12	24%	8	16%
Occasionally	0	0%	4	8%	3	6%
None	0	0%	3	6%	7	14%
Not classified	3	6%	0	0%	0	0%

## REFERENCES

- Aboukasm, A, Mahr, G, Gahry, BR, Thomas, A & Barkley, GL (1998) Retrospective analysis of the effects of psychotherapeutic interventions on outcomes of psychogenic nonepileptic seizures. *Epilepsia*. 39: 470-473.
- American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorders*. APA, Washington, DC
- Angus-Leppan, H (2008) Diagnosing epilepsy in neurology clinics: A prospective study. *Seizure*. 17: 431-436.
- Benbadis, SR, Allen, HW & Hauser W.A. (2000) An estimate of the prevalence of psychogenic non-epileptic seizures. *Seizure*. 9: 280-281.
- Benbadis, SR, O'Neill, E, Tatum, WO & Heriaud, L (2004) Outcome of prolonged video-EEG monitoring at a typical referral epilepsy center. *Epilepsia*. 45: 1150-1153.
- Binzer, M, Stone, J & Sharpe, M (2004) Recent onset pseudoseizures - clues to aetiology. *Seizure*. 13: 146-155.
- Carton, S, Thompson, PJ & Duncan, JS (2003) Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure*. 12: 287-294.
- de Timary, P, Fouchet, P, Sylin, M, Indriets, JP, de Barys, T, Lefebvre, A & van Rijckevorsel, K (2002) Non-epileptic seizures: delayed diagnosis in patients presenting with electroencephalographic (EEG) or clinical signs of epileptic seizures. *Seizure*. 11: 193-197.
- Ettinger, AB, Devinsky, O, Weisbrot, DM, Ramakrishna, RK & Goyal, A (1999) A comprehensive profile of clinical, psychiatric, and psychosocial characteristics of patients with psychogenic nonepileptic seizures. *Epilepsia*. 40: 1292-1298.
- Galimberti, CA, Ratti, MT, Murelli, R, Marchioni, E, Manni, R & Tartara, A (2003) Patients with psychogenic nonepileptic seizures, alone or epilepsy associated, share a psychological profile distinct of epilepsy patients. *J Neurology*. 250: 338-346.
- Goldstein, LH, Deale, A, Mitchell-O'Malley, S, Toone, BK & Mellers, JDC (2004) An evaluation of cognitive behavioral therapy as a treatment for dissociative seizures. *Cogn Behav Neurol*. 17: 41-49.
- Gray, SE & Rutter, DR (2007) Illness representations in young people with Chronic Fatigue Syndrome. *Psychol Health*. 22: 159-174.
- Green, A, Payne, S & Barnitt, R (2004) Illness representations among people with non-epileptic seizures attending a neuropsychiatry clinic: a qualitative study based on the self-regulation model. *Seizure*. 13: 331-339.
- Hagger, MS & Orbell, S (2003) A meta-analytic review of the common-sense model of illness representations. *Psychol Health*. 18: 141-184.
- Harden, CL & Ferrando, S (2001) Controversies in epilepsy and behavior: delivering the diagnosis of psychogenic pseudoseizures, should the neurologist or psychiatrist be responsible. *Epilepsy Behav*. 2: 519-523.

- Howlett, S, Grünewald, R, Khan, A & Reuber, M (2007) Engagement in psychological treatment for functional neurological symptoms - barriers and solutions. *Psychother Theory Res Pract Train*. 44: 354-360.
- Kanner, AM (2003) More controversies on the treatment of psychogenic pseudoseizures: an addendum. *Epilepsy Behav*. 4: 360-364.
- Kanner, AM, Parra, J, Frey, M, Stebbins, G, Pierre-Louis, S & Iriarte, J (1999) Psychiatric and neurologic predictors of psychogenic pseudoseizure outcome. *Neurology*. 53: 933-938.
- Kotsopoulos, IA, de Krom, MC, Kessels, FG, Lodder, J, Troost, J, Twellaar, M, van, MT & Knottnerus, AJ (2003) The diagnosis of epileptic and non-epileptic seizures. *Epilepsy Res*. 57: 59-67.
- LaFrance, WC, Jr., Rusch, MD & Machan, JT (2008) What is "treatment as usual" for nonepileptic seizures? *Epilepsy Behav*. 12: 388-394.
- Lawton, G, Baker, GA & Brown, RJ (2008) Comparison of two types of dissociation in epileptic and nonepileptic seizures. *Epilepsy Behav*. 13: 333-336.
- Lesser, RP (1996) Psychogenic seizures. *Neurology*. 46: 1499-1507.
- Leventhal, H, Diefenbach, M & Leventhal, EA (1992) Illness cognitions: using common sense to understand treatment adherence and affect cognition interactions. *Cogn Ther Res*. 16: 143-163.
- Madden, S & Sim, J (2006) Creating meaning in fibromyalgia syndrome. *Soc Sci Med*. 63: 2962-2973.
- Martin, RC, Gilliam, FG, Kilgore, M, Faught, E & Kuzniecky, R (1998) Improved health care resource utilization following video-EEG-confirmed diagnosis of nonepileptic psychogenic seizures. *Seizure*. 7: 385-390.
- McGonigal, A, Russell, AJ, Mallik, AK, Oto, M & Duncan, R (2004) Use of short term video EEG in the diagnosis of attack disorders. *J Neurol Neurosurg Psychiatry*. 75: 771-772.
- Moss-Morris, R & Chalder, T (2003) Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *J Psychosom Res*. 55: 305-308.
- Moss-Morris, R, Weinman, J, Petrie, KJ, Horne, R, Cameron, LD & Buick, D (2002) The Revised Illness Perception Questionnaire (IPQ-R). *Psychol Health*. 17: 1-16.
- Peters, S, Stanley, I, Rose, M & Salmon, P (1998) Patients with medically unexplained symptoms: sources of patients' authority and implications for demand on medical care. *Soc Sci Med*. 46: 559-565.
- Prueter, C, Schulz-Venrath, U & Rimpau, W (2002) Dissociative and associated psychopathological symptoms in patients with epilepsy, pseudoseizures and both seizure forms. *Epilepsia*. 43: 188-192.
- Reuber M. (2008) Psychogenic nonepileptic seizures: answers and questions. *Epilepsy Behav*. 12: 622-635.
- Reuber, M, Fernández, G, Bauer, J, Helmstaedter, C & Elger, CE (2002) Diagnostic delay in psychogenic nonepileptic seizures. *Neurology*. 58: 493-495.
- Reuber, M, House, AO, Pukrop, R, Bauer, J & Elger, CE (2003) Somatization, dissociation and psychopathology in patients with psychogenic nonepileptic seizures. *Epilepsy Res*. 57: 159-167.

- Reuber, M, Howlett, S, Khan, A & Grünewald, R (2007) Non-epileptic seizures and other functional neurological symptoms: predisposing, precipitating and perpetuating factors. *Psychosomatics*. 48: 230-238.
- Reuber, M, Pukrop, R, Bauer, J, Helmstaedter, C, Tessendorf, N & Elger, CE (2003) Outcome in psychogenic nonepileptic seizures: 1 to 10 year follow-up in 164 patients. *Ann Neurol*. 53: 305-311.
- Schilte, AF, Portegijs, PJ, Blankenstein, AH, Der Horst, HE, Latour, MB, van Eijk, JT & Knottnerus, JA (2001) Randomised controlled trial of disclosure of emotionally important events in somatisation in primary care. *Brit Med J*. 323: 86.
- Sharpe, D & Faye, C (2006) Non-epileptic seizures and child sexual abuse: A critical review of the literature. *Clin Psychol Rev*. 26: 1020-1040.
- Shen, W, Bowman, ES & Markand, ON (1990) Presenting the diagnosis of pseudoseizure. *Neurology*. 40: 756-759.
- So, NK, Bennett, C & Smith, B (2004) Prospective outcome after diagnosis of nonepileptic seizures. *Epilepsia*. 45 (Suppl. 7): 266-267.
- Stockford, K, Turner, H & Cooper, M (2007) Illness perception and its relationship to readiness to change in the eating disorders: a preliminary investigation. *Br J Clin Psychol*. 46: 139-154.
- Stone, J, Binzer, M & Sharpe, M (2004) Illness beliefs and locus of control: a comparison of patients with pseudoseizures and epilepsy. *J Psychosom Res*. 57: 541-547.
- Thompson, NC, Osorio, I & Hunter, EE (2005) Nonepileptic seizures: reframing the diagnosis. *Perspect Psych Care*. 41: 71-78.
- Thompson, R, Isaac, CL, Shakes, G, Tooth, C, Reuber, M (2009) What is it like to receive a diagnosis of non-epileptic seizures? *Epilepsy Behav*. In press.
- Wessely, S & Powell, R (1989) Fatigue syndromes: a comparison of chronic "postviral" fatigue with neuromuscular and affective disorders. *J Neurol Neurosurg Psychiatry*. 52: 940-948.
- World Health Organization (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. WHO, Geneva