

FULL-LENGTH ORIGINAL RESEARCH

Acceptability and effectiveness of a strategy for the communication of the diagnosis of psychogenic nonepileptic seizures

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SUMMARY

Purpose: Communicating the diagnosis of psychogenic nonepileptic 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 multicenter prospective study, 50 patients newly diagnosed with PNES were informed about the diagnosis by 10 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: Ninety-four percent of patients found the leaflet easy to understand. Ninety-four percent

stated their questions were answered by the doctor; 70% got what they wanted from the consultation; only 4% reported feeling angry during the consultation. Eighty-six percent of patients acknowledged that psychological factors were at least contributing to their seizures. On the IPQ-R, “emotional” causes for the seizures were endorsed more commonly than “nonemotional” causes ($p < 0.001$). After 3 months, 14% of patients were seizure-free and 63% reported a >50% reduction in seizure frequency.

Discussion: We conclude that our procedure is acceptable and effectively communicates a psychological etiologic model for PNES.

KEY WORDS: Psychogenic nonepileptic seizures, Diagnosis, Communication, Illness perceptions, Psychological treatment.

Psychogenic nonepileptic 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 that occur in response to distressing situations, sensations, emotions, conflicts, or

memories when alternative coping mechanisms are inadequate or have been overwhelmed (Reuber, 2008). PNES are classified as a manifestation of dissociative or conversion disorder in the current nosologies (World Health Organization, 1992; American Psychiatric Association, 1994). Although 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 et al., 2008).

PNES are not uncommon. The population prevalence of PNES has been estimated as 2–33 per 100,000 (Benbadis et al., 2000). Two recent studies have shown that patients

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with PNES make up 12–18% of patients newly presenting with seizures (Kotsopoulos et al., 2003; Angus-Leppan, 2008). 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 made only after patients have been treated inappropriately with antiepileptic drugs for several years (Reuber et al., 2002; de Timary 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 (Prueter et al., 2002; Galimberti et al., 2003; Reuber et al., 2003a; Binzer et al., 2004; Lawton et al., 2008), 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 et al., 2004).

The question of how the diagnosis should be communicated has attracted considerable interest (Harden & Ferrando, 2001; Kanner, 2003). One reason that “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 (Aboukasm et al., 1998; Kanner et al., 1999). What is more, effective communication at this point has the potential to change patients’ healthcare utilization behavior significantly and to reduce healthcare costs (Martin et al., 1998).

At present, however, many patients report feeling confused or angry after receiving the diagnosis of PNES (Carton et al., 2003; Green et al., 2004; Thompson et al., 2005, 2009). Only three in five patients referred by a neurologist attend 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 4 years after the diagnosis of PNES (Reuber et al., 2003b).

A protocol for a more satisfactory communication of the diagnosis of PNES has been proposed (Shen et al., 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/non epileptic/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 lifestyle), time line (time to develop and duration), and controllability or cure (Leventhal et al., 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 toward 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 that covered and elaborated the 14 core points over 27 pages. The leaflet refers to PNES as “nonepileptic attacks” because this has become the most commonly used label in the United Kingdom. However, the authors consider the label of “nonepileptic attacks” as synonymous with the label 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 Table 1).

Table 1. Crib sheet with 14 core points of the strategy for the communication of the diagnosis of PNES

Genuine symptoms
<i>Real attacks</i> —can be frightening or disabling
Label
<i>Give a name</i> for the condition
<i>Give alternative names</i> they may hear
Reassure that this is a <i>common and recognized condition</i>
Cause and maintaining factors
<i>Not epilepsy</i>
Predisposing factors— <i>difficult to find out causes</i>
Precipitating factors— <i>can be related to stress/emotions</i>
Perpetuating factors— <i>vicious cycle – worry → stress → attacks → worry</i>
Provide a <i>model</i> for the attacks—e.g., brain becomes overloaded and shuts down
Treatment
<i>Antiepileptic drugs are not effective</i>
Evidence that <i>psychological treatment is effective</i>
Talk to the patient about <i>referral to a specialist</i>
Expectations
<i>Can resolve</i>
<i>Can expect improvement</i>
PNES, psychogenic nonepileptic seizures.

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 who met the criteria and who presented within a 6-months period. Recruitment began in the first center 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 via mail. 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-electroencephalography), or based on the direct observation of a seizure by an experienced healthcare professional (e.g., neurologist, experienced EEG technician, or specialist nurse). Patients with a history of possible epilepsy (but no epileptic seizures for at least 1 year) were eligible for participation. Patients were excluded if they did not speak English sufficiently 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 semistructured 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 2 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 categorized 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-retest reliability. It provides a quantitative assessment of patients' illness perceptions in the five major domains listed previously and has been used in a wide range of disorders and clinical scenarios (Moss-Morris et al., 2002; Moss-Morris & Chalder, 2003; Gray & Rutter, 2007; Stockford et al., 2007). In line with a previous study (Goldstein et al., 2004), the list of possible causes of seizures included in the IPQ-R was split into seven "emotional" causes (stress or worry; my own behavior; my mental attitude; family problems or worries; overwork; my emotional state; my personality) and 11 "nonemotional" causes (hereditary; a germ or virus; diet or eating habits; chance or bad luck; poor medical care in the past; pollution; aging; 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 categorized as “(potential) endorsement.” The responses “I strongly disagree” and “I disagree” were categorized as “nonendorsement.” The proportion of “(potentially) endorsed” and “nonendorsed” “emotional” and “non-emotional” causes was compared using chi-square statistics.

Patients were telephoned again approximately 11 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, United Kingdom. Approval was also secured separately from the Research Governance departments of all participating National Health Service Trusts.

RESULTS

Neurologists

The 23 neurologists who participated in this study worked for 15 different NHS Trusts across England, Wales, and Scotland. Eighty-six percent (19 of 23) were male. The proportion of the neurologist’s work time taken up by seizure disorders ranged from less than 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. Fifty patients completed the telephone interview. Thirty-six patients returned the postal questionnaires (72%), and 49 patients completed the telephone follow-up (98%).

Ninety percent of patients were female. The participants received the diagnosis of PNES a median of 5.2 years after seizure manifestation (range 2 months to 27 years); their median age was 29.5 years (range 17–69 years). Twenty percent of patients (10 of 50) not only saw the neurologist at the point of diagnosis but also met an Epilepsy Specialist Nurse. Of these patients 90% (9 of 10) stated that the nurse discussed the same things they had talked about with the neurologist. Forty percent of patients (20 of 50) received a letter from their neurologist following the consultation. Of these 90% (18 of 20) stated that the letter discussed what had been covered in the consultation.

Fifty percent of the participants (27 of 50) had taken antiepileptic drugs (AEDs) prior to the diagnosis of PNES. Of these patients, 89% (24 of 27) were advised to stop their AEDs during the consultation. Two weeks after the clinic visit, 67% (18 of 27) had stopped the AED

treatment, and 11% (3 of 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% of all patients (6 of 50) in this group continued to take AEDs.

Patients' experience with the communication strategy

Ninety-four percent of patients (47 of 50) could recall being given the PNES booklet developed by the researchers. Of those, 94% (44 of 47) found it clear and easy to understand and 91% (43 of 47) particularly liked something about the booklet. Nine percent (4 of 47) disliked something, for example, parts not being personally relevant and finding parts of it confusing. Eleven percent (5 of 47) had questions that were not covered. These questions related to memory, headaches, pregnancy, the possibility of concurrent epilepsy, and the difficulty in 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.” Ninety-four percent of patients stated that they had their questions answered, 2% said questions had been partly answered, and 4% not answered. Fourteen percent of patients found the consultation confusing, 30% partly confusing, and 56% not confusing. Table 2 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 (Carton et al., 2003; Green et al., 2004; Thompson et al., 2005, 2009).

Table 3 summarizes patients’ cued and prompted reports of the factual information included in the information leaflet and crib sheet 2 weeks after receiving the diagnosis. The most important 12 points of the communication

Table 2. Patients’ feelings during the consultation in which they were given the diagnosis of PNES

Feelings during the consultation		Cued recall (%)	Cued and prompted (%)
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

PNES, psychogenic nonepileptic seizures.

Table 3. Patients' reports of factual information contained in the communication strategy

Item	Cued reports (%)	Cued and prompted reports (%)
Name of the condition ("nonepileptic attacks")	78	98
Alternative names	32	N/A
PNES are common	54	70
PNES 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

PNES, psychogenic nonepileptic seizures.

procedure were reportedly covered in a median of 82% of consultations (range 70–98%).

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 2–4 weeks after the encounters with the neurologists are summarized in Table 4. 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 "nonemotional" 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% "nonemotional" 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%).

PNES frequency

Table 5 shows the distribution of PNES frequency before the diagnosis, 2 weeks [mean 15 days, standard deviation (SD) 21.1] and 11 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% of patients (29 of 46), remained unchanged in 24% (11 of 46), and deteriorated in 14% (6 of 46).

DISCUSSION

Patients with PNES are a clinically heterogeneous group (Lesser, 1996; Reuber, 2008). 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

Table 4. 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

IPQ-R, Illness Perception Questionnaire-Revised.

Table 5. Change in PNES frequency after communication of the diagnosis

	Before diagnosis (n = 50)	2 weeks after diagnosis (n = 50)	11 weeks after diagnosis (n = 49)
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)

Values are expressed as n (%).
PNES, psychogenic nonepileptic seizures.

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) (Benbadis et al., 2004; McGonigal et al., 2004). What is more, most diagnoses in the United Kingdom 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 nonspecific 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 etiologic model and a clear label were likely to reduce confusion, and increase confidence in the clinician and acceptance of the treatment or referral plan.

Furthermore, Shen et al. suggest that patients should be questioned specifically about the possibility of sexual abuse. Childhood sexual abuse is likely to be reported in a significant proportion of clinic cases of PNES (Sharpe & Faye, 2006), but it is probably centrally important in only a minority (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 (Carton et al., 2003; Thompson et al., 2009). 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 that 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 (Carton et al., 2003; Thompson et al., 2005, 2009). 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).

Open inquiries were followed by prompts in this study because we wanted to ensure that participants had understood the question fully and were given an opportunity to consider all possible answers. The use of prompts made it easier to compare responses of different participants. At this point it is not known whether the marked differences of responses to open or prompted questions is characteristic of this particular patient group. The difference certainly raises important questions about the validity of self-report questionnaires in this clinical area. 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 who present 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 nonemotional causes for their symptoms. Four of the most common 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 etiologic model that 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 that 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 previously, although patients reported less confusion about the diagnosis here than in previous studies (Carton et al., 2003; Green et al., 2004). 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 2 weeks after diagnosis and 14% after 11 weeks, fits 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., 2003b). One prospective investigation found that 6 months after diagnosis, PNES had stopped in 29% of patients (Kanner et al., 1999). A second study demonstrated that 42% of patients had become seizure-free after 1 year (So et al., 2004). Two studies showed that PNES had stopped in half of the patients at 18 months (Ettinger et al., 1999), or after 2 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 caregivers, friends, or relatives, if possible, but ideally seizure frequency data would be collected prospectively 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’ perceptions of their encounters 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 had seizures for only 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 etiologic 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 who are newly diagnosed with PNES is acceptable to patients, and communicates effectively a psychological model for PNES. 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 had been communicated to them.

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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.

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APPENDIX

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