## Title page

# Patients' and neurologists' perception of epilepsy and psychogenic nonepileptic seizures

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**Key words:**

Psychogenic nonepileptic seizures

Conversion disorder

Epilepsy

Illness perception

Illness representation

Neurology

Number of text pages: 23

Number of words: 4632

Number and proposed size (number of journal pages) of figures: 3 figures; 0.5 journal pages

Number and proposed size (number of journal pages) of tables: 4 tables (excluding the one designated as webcontent; 1 journal page)

## Summary

**Purpose:** Although differences in illness perceptions between neurologists and patients with epilepsy or psychogenic nonepileptic seizures (PNES) are likely to be clinically relevant, this

is the first study to attempt a direct comparison. In addition, this study was undertaken to compare the illness perceptions of patients with epilepsy with those of patients with PNES.

**Methods:** 34 patients with epilepsy, 40 patients with PNES and 45 neurologists were recruited. All patient participants completed versions of the illness perception questionnaire revised (IPQ-R) adapted for epileptic or nonepileptic seizure disorders, single-item symptom attribution question (SAQ), Hospital Anxiety and Depression Scale (HADS), Quality of Life in Epilepsy-31 (Quolie-31) and Liverpool Seizure Severity Scale (LSSS). Participating neurologists completed two versions of the IPQ-R and two SAQs for epileptic and nonepileptic seizure disorders.

**Key findings:** Differences in illness perceptions between patients with epilepsy and patients with PNES were minor compared to those between patients with either seizure disorder and neurologists. Neurologists considered both seizure disorders more treatable and more amenable to personal control than patients themselves. Neurologists had much more polarised views of the aetiology of both conditions: whereas patients mostly considered the causes of their seizure disorders as partially "physical" and partially "psychological", neurologists perceived epilepsy as an essentially "physical" and PNES as a clearly "psychological" problem.

**Significance:** There are considerable differences between the illness perceptions of patients with seizure disorders and their doctors, which could represent barriers to successful clinical management. In particular, a discrepancy between neurologists' and patients' beliefs about the personal control which a patients may be able to exert over PNES could contribute to the confusion or anger some patients report after the diagnosis has been explained to them. Further, patients' endorsement of "physical" causes for PNES may reflect an unrealistic faith in the effectiveness of "physical" treatments and could be a cause of tension in patients'

relationship with their doctor, for instance when the neurologist attempts to withdraw antiepileptic drug treatment or refers patients to psychological services.

## 1. Introduction

### *1.1 Illness perceptions of patients with epilepsy and PNES*

Ideas about illness are an essential part of the self-regulation model, which proposes that behaviour in relation to illness depends on people's perception or representation of their health problem. In this model, illness representations consist of five elements: identity (symptoms), cause, consequences (effects on life), timeline (duration) and controllability or cure (Leventhal et al, 1992). Studies in patients with epilepsy have demonstrated that illness perceptions are related to clinically important behaviours and explain a greater proportion of the variance of anxiety measures and people's ability to cope with their disorder than seizure-related variables (Kemp et al, 1999; Goldstein et al, 2005; Jones et al, 2006; Brown et al, 2009). A study in patients with PNES demonstrated that the model can be applied to nonepileptic seizure disorders as well (Green et al, 2004).

### *1.2 Illness perceptions of doctors*

The illness perceptions of healthcare professionals, particularly those of doctors in relation to PNES, have also been studied. O'Sullivan et al (2006) studied the attitudes of General Practitioners to PNES, Shneker & Elliott (2008) those of primary care and emergency physicians and Sahaya et al. (2012) those of a mixture of doctors and nurses from primary care and neurology. We have previously described the illness perceptions of emergency care

and neuroscience ward staff as well as those of psychiatrists and neurologists relating to PNES, and contrasted these illness perceptions with those relating to epilepsy (Worsley et al, 2011; Whitehead & Reuber, 2012). Doctors' illness perceptions about patients with medically unexplained somatic symptoms or patients with conversion disorders have been shown to reflect how difficult they find interactions with such patients (Jackson & Kroenke, 1999; Kanaan et al, 2011).

*1.3 Comparing illness perceptions of doctors and patients*

Previous studies suggest that the difficulties which doctors may experience with the explanation of PNES or functional neurological symptoms may specifically relate to the differences between their own and their patients' illness perceptions rather than their own illness perceptions per se (Kanaan et al, 2009b; Monzoni et al, 2011a & b). Links between differences in the illness perceptions of doctors and patients have also been shown to explain adverse treatment outcomes and increased healthcare utilisation in other conditions (Heijmans et al, 2001). A number of studies suggest that there are clear differences between the illness perceptions of doctors and patients with PNES. For instance, two surveys suggest that most neurologists consider PNES a disorder related to psychological difficulties or "stress" for which psychotherapy is the most appropriate treatment (LaFrance et al, 2008; Mayor et al, 2011). In contrast, patients with PNES were more likely than those with epilepsy to consider their problem "somatic" rather than "psychological", and to deny significant non-health stresses in their lives (Stone, 2004). This may explain why patients often fail to engage with available psychological treatment services (Howlett et al, 2007), although a number of studies have shown that psychotherapy can be effective for PNES (Goldstein et al, 2010; Mayor et al, 2010).

*1.4 Comparing illness perceptions about PNES and epilepsy*

We have recently demonstrated that an adapted version of the Illness Perception Questionnaire - Revised (IPQ-R) and the single-item symptom attribution question can be used to investigate the illness perceptions of doctors and healthcare workers about epilepsy and PNES (Worsley et al, 2011; Whitehead & Reuber, 2012). Slightly different versions of the same IPQ had been used previously in studies involving patients with epilepsy and patients with PNES (Jones et al, 2006; Goldstein et al, 2005; Hall-Patch et al, 2010). Our study comparing illness perceptions about PNES and epilepsy showed that neurologists thought that patients with PNES had greater personal control over their condition than those with epilepsy. They professed a greater understanding of epilepsy than of PNES (Whitehead & Reuber, 2012).

*1.5 Aims of this study*

The present study was designed to build on this work and to compare the illness perceptions of patients with epilepsy and patients with PNES with each other and with those of neurologists to both disorders.

## 2. Methods

*2.1 Participants*

*2.1.1 Patients*

Between May 2009 and December 2011, we reviewed all EEG request forms submitted to the Clinical Neurophysiology department of the Royal Hallamshire Hospital in Sheffield, UK. We prospectively identified all patients aged 16 years or older who had been referred for video-EEG (outpatient routine or two to five day videotelemetry) with a differential diagnosis of epilepsy or PNES, and who appeared able to complete self-report questionnaires based on the information provided on the request form. Two weeks prior to their attendance for the test we sent potential participants information about the study. Patients were asked whether they wanted to participate and provide informed consent when they came to the hospital for their EEG.

Patients' questionnaire responses were only included if a "gold standard" diagnosis had been made, i.e. if an attack considered typical by the patient and family members / friends (if available) was recorded, if the recorded attack was judged to be clearly epileptic or non-epileptic by a Consultant Neurophysiologist, and if the referring neurologist confirmed that the recorded seizure matched the final diagnosis of epilepsy or PNES based on the video-EEG report and all other available clinical data. There were two exceptions – we included one patient who did not have a typical attack but whose EEG showed generalised spike and wave and in whom a clinical diagnosis of idiopathic generalised epilepsy was made after the EEG recording. Secondly, we included one patient whose attack did not have EEG changes but whose clinical history, seizure semiology and brain imaging findings were consistent with a diagnosis of focal epilepsy and who subsequently underwent epilepsy surgery. Patients with mixed epilepsy and PNES were excluded.

*2.1.2 Neurologists*

Between February and April 2011, over 1,000 members of the United Kingdom Chapter of the International League Against Epilepsy were approached by e-mail. The email invited neurologists to take part in the study by following a SurveyMonkey link. In addition, neurologists known to the researchers were approached directly and asked to encourage colleagues to complete the survey. Each participating neurologist had to complete two sets of questionnaires - one about epilepsy and one about PNES.

*2.2 Questionnaires*

All patient participants completed the questionnaires for this study after they had come to the hospital for their in- or outpatient video-EEG test and before any seizures had been captured in the hospital. Patients were only recruited to this study if they had been referred for clarification of the epileptic or non-epileptic aetiology of their seizure disorder (rather than, for instance, evaluation of suitability for epilepsy surgery). They were not aware of the outcome of test (or indeed whether a seizure would be captured during the test) when they completed the questionnaires.

*2.2.1 Illness Perception Questionnaire-Revised (IPQ-R)*

The IPQ-R is a 38-item self-report questionnaire designed to capture the five domains of thinking about illness (Leventhal et al, 1992). The questionnaire asks respondents to rate each item on a 5-point Likert scale (ranging from "I strongly agree" to "I strongly disagree"). It generates eight different subscales. For the purpose of this study we did not collect data for the first of the eight subscales (Illness Identity). This subscale asks respondents to attribute

symptoms from a list to their disorder, and therefore was considered inappropriate to a study of illness perceptions of neurologists rather than patients.

The IPQ-R also encourages respondents to rate items from a list of 18 possible causes for the described disorder on the same Likert scale. These causes can be grouped into psychological/emotional (cause items 1, 9–12, 17) and non-psychological (cause items 2–8, 13–16, 18). There is an additional part of the IPQ-R that asks respondents freely to list the three most important causes of their condition.

The IPQ-R has been shown to have good levels of both internal consistency and test–retest reliability in patients with a wide range of different conditions (Moss-Morris et al, 2002). The IPQ-R is an improved version of the Illness Perception Questionnaire (IPQ) (Weinman et al, 1996). The IPQ and IPQ-R have been used in a number of studies regarding epilepsy or PNES (Jones et al, 2006; Goldstein et al, 2005; Hall-Patch et al, 2010; Worsley et al, 2011; Whitehead & Reuber, 2012).

Taking up the authors' invitation to adapt the IPQ-R for different conditions, we made minor changes to its wording. We replaced the word illness in the neurologists' questionnaires with the terms 'epileptic seizure disorder' or 'non-epileptic seizure disorder'. This was to ensure that participants answered the questions about the disorder as a whole and its underlying pathology (rather than individual seizures and proximal triggers). This wording also mirrored the 'your seizure disorder' wording used in the adapted IPQ-R for patients.

**Table 1**

*2.2.2 Symptom Attribution Question (SAQ)*

This is a single item asking respondents to choose one of five response options (ranging from "my problem is an entirely physical one," to "my problem is an entirely psychological one") (Wessely & Powell, 1989). For the purpose of this study "my" was replaced by "the" on the questionnaire for neurologists. This question has been used previously to sample symptom attribution to physical or psychological causes in patients with PNES (Hall-Patch et al, 2010), but had not been used in connection with epilepsy until we used it in our studies of healthcare workers, neurologists and psychiatrists (Worsley et al, 2011; Whitehead & Reuber, 2012). The SAQ responses were scored in order to perform a statistical analysis with entirely physical equal to 1 and entirely psychological equal to 5.

*2.2.3 Liverpool Seizure Severity Scale (LSSS)*

Patients (but not neurologists) also completed the Liverpool Seizure Severity Scale (LSSS) (Baker et al, 1998; Scott-Lennox et al, 2001). This 12-item self-report seizure scale has been shown to be a reliable and valid measure of patients' own perceptions of seizure severity and is scored from 0-100. Higher scores reflect a greater seizure severity.

*2.2.4 Hospital Anxiety and Depression Scale (HADS)*

Both patient groups also completed the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983), which is an established, valid and reliable measure of severity of depression and anxiety in non-psychiatric clinical environments. It consists of 14 items, seven of which measure depression, the other seven anxiety. Scores range from 0 to 21 for anxiety and 0 to 21 for depression. A score of 11 or higher indicates probable presence ('caseness') of

the mood disorder. It has previously been used in patients with epilepsy (Goldstein et al, 2005).

*2.2.5 Quality of Life in Epilepsy-31 (Quolie-31)*

Patients self-reported health related quality of life (HRQoL) using the Quolie-31 (Cramer et al, 1998). This is a 31-item measure which has been well validated in patients with seizures and which has been widely used in patients with epilepsy and patients with PNES (Van Merode et al, 2004). Scores range from 0-100; lower scores reflect a poorer HRQoL).

*2.3 Statistical analysis*

Data was collected from patients in person and from neurologists using the online software SurveyMonkey. Individual item scores were entered onto an Excel 2007 spreadsheet (Microsoft Corp., Mountain View, CA, USA) and subscale scores were calculated. Statistical comparisons were made using PASW Version 18 for Windows (IBM Corp., Somers, NY, USA). The reliability of our IPQ-R adaptation data for seizures was analysed separately for the neurologists and for the combined patient group by calculating Cronbach's α scores. A Cronbach's $\alpha < 0.5$ was considered unacceptable. Medians and interquartile ranges were calculated for each subscale score and used to make comparisons between responses relating to epilepsy and PNES from the neurologists and patients with the seizure disorder. Pearson's $Chi^2$ or Mann–Whitney U test were used for between group comparisons. We only interpreted two-sided P values of $\leq 0.02$ as significant to reduce the risk of type 2 errors.

*2.4 Statutory approval*

Ethical approval was provided by the Sheffield Research Ethics Committee and Research Governance approval was given by Sheffield Teaching Hospitals NHS Foundation Trust.

## 3. Results

*3.1 Respondents*

**Figure 1**

117 of the patients initially informed about this study by letter prior to their EEG test took part in the study. These patients completed their questionnaire packs before undergoing the video-EEG study. After excluding patients who failed to have a typical seizure during the test, 34 patients with epilepsy and 40 patients with PNES (63.2% of all initial recruits) were included in the analyses (for details of selection and exclusions see figure 1). In addition 45 neurologists were recruited. See table 2 for demographic and clinical details. The two patient groups did not differ in terms of age, gender ratio, self-reported seizure severity, anxiety or depression. Patients with PNES reported a poorer HRQoL than did those with epilepsy. More patients with epilepsy had been exposed to antiepileptic drug treatment. Neurologists had a median post-qualification experience of 22 years (range 6-39). 76% of participants worked in England, 11% in Scotland, the rest in Wales and Northern Ireland. Fourteen of the participating health professionals described themselves as general neurologists, 31 as specialising in epilepsy. The median estimated share of the clinical workload dedicated to seeing patients with seizures was 40% (range 10-100%). Participants estimated that they saw

a median of 45 patients with epilepsy and 10 with PNES per month (range 5-187 and 1-25 respectively).

**Table 2**

*3.2 Reliability of our adaptation of the Illness Perception Questionnaire-Revised*

All Cronbach's α scores with the exception of the neurologists' timeline (cyclical) subscale were acceptable (see table 3 in additional web content). This subscale was excluded from further analysis.

*3.3 IPQ-R: patients with epilepsy versus patients with PNES*

There were no significant differences between the illness perceptions of patients with epilepsy and PNES on the majority of subscales. Patients with PNES believed more strongly in the potential of treatment to control their condition that did patients with epilepsy. There was also a trend towards patients with epilepsy professing a greater understanding of their condition when compared to patients with PNES but this did not reach the level of statistical significance demanded by this study.

**Table 4**

*3.4 IPQ-R: neurologists versus patients with epilepsy*

Patients considered epilepsy a more chronic condition than did the neurologists. Neurologists thought that epilepsy had greater negative consequences and emotional representations than did the patients themselves. Neurologists saw a greater potential for personal and treatment-related control of epilepsy than did patients. Neurologists claimed a greater understanding of epilepsy than did patients (see table 5).

*3.5 IPQ-R: neurologists versus patients with PNES*

Neurologists attributed greater consequences (e.g. social and financial) to PNES than did the patients themselves although the two groups did not differ in their appraisal of the emotional impact of the condition. As with epilepsy, the neurologists thought patients had higher levels of personal and treatment-related control of PNES than did the patients themselves. Neurologists claimed a greater understanding of PNES than patients with the condition (see table 5).

**Table 5**

*3.6 IPQ-R: Causes*

*3.6.1 Causes: patients with epilepsy versus patients with PNES*

There were no significant differences between the degree of endorsement of psychological or of non-psychological causes suggested in the IPQ-R between patients with epilepsy and patients with PNES. Respondents were also asked to state the first, second and third most important cause for the seizure disorder (they could choose freely and did not have to choose

these most important causes from a list). Of the 27 patients with epilepsy whose freely chosen "most important cause" for their disorder could be categorised in this fashion, 15/27 (55%) identified some sort of physical cause or stressor (e.g. head injury), 5/27 (19%) listed some form of bad luck (e.g. 'there is no reason, it just happened to me'), and 7/27 (26%) stated a psychological stressor of some sort (e.g. stress about family). Of the 27 patients with PNES whose freely chosen "most important cause" for their condition could be categorised in this way, 12/27 (44%) gave a physical cause or stressor, 1/27 (4%) bad luck and 14/27 (52%) a psychological stressor.

*3.6.2 Causes: neurologists versus patients with epilepsy*

Neurologists were significantly less likely to endorse the psychological causes offered in the IPQ-R and more likely to endorse non-psychological causes for epilepsy when compared to patients themselves. When asked to freely list the most important cause of epilepsy, 93% of neurologists endorsed a physical cause whereas 7% listed some form of bad luck, the latter more commonly endorsed by patients. Unlike patients with epilepsy, no neurologists cited any kind of psychological stressor as a first, second or third most important cause of epilepsy. These findings are not at variance with the fact that neurologists reported greater "emotional representations" associated with epilepsy than the patients: the questions relating to the emotional representations subscale ask about the emotional *consequences* of the disorder, not its cause.

*3.6.3 Causes: neurologists versus patients with PNES*

Neurologists were significantly more likely to endorse the psychological causes listed in the IPQ-R and less likely to endorse non-psychological causes for PNES. Of the 38 neurologists whose freely chosen "most important cause" could be easily categorised, 42% of neurologists identified some kind of "abuse". Of the 32 PNES patients who listed a most important cause for their PNES, only one listed abuse (physical, resulting in a head injury). No neurologists gave a physical reason as the most important cause of PNES whereas 44% of patients gave a physical reason for their PNES. 50% neurologists provided a psychological cause or stressor as the most important cause of PNES (of these, 8% specified poor coping skills and 13% the patient's personality). An additional 8% of neurologists gave a form of panic attack as their most important cause of PNES.

*3.7 Symptom Attribution Question: Causes*

The majority of neurologists attributed epilepsy to mostly or entirely physical causes whereas patients were significantly more likely to endorse a psychological component or a wholly psychological aetiology of the condition (see figure 2a). All of the neurologists attributed PNES to mostly or entirely psychological causes whereas patients were significantly more likely to endorse a physical component or a wholly physical cause of the condition (see figure 2b). The response distributions in the PNES and epilepsy groups did not differ significantly.

**Figure 2a**

**Figure 2b**

## 4. Discussion

Despite the likely relevance of differences in the illness perceptions of neurologists and patients in relation to seizure disorders for the clinical management of these conditions, relatively few studies have addressed this topic and even fewer have demonstrated the validity of their approach. A number of surveys about the management of PNES have included some questions relating to illness perceptions of health professionals (Harden et al, 2003; O'Sullivan et al, 2006; LaFrance et al, 2008; Shneker & Elliott, 2008; Mayor et al, 2011) . One study has used a grounded theory approach to explore psychotherapists' understanding of PNES (Quinn et al, 2012). Some surveys or interview studies focussing on neurologists' attitudes towards medically unexplained symptoms or conversion disorder have touched on thoughts about PNES (Kanaan et al, 2009a; Kanaan et al, 2009b; Kanaan et al, 2011; Kanaan et al, 2012). The illness perceptions of patients with PNES and patients with epilepsy have been described separately (Hall-Patch et al, 2010; Stone et al, 2004; Goldstein et al, 2005; Kemp et al, 1999). Previous studies have looked at the concordance of views of the effectiveness of neuropsychiatry inpatient treatment between referring doctors and patients with neuropsychiatric illness including epilepsy (Goldstein et al, 1997). The perceptions of paediatricians and paediatric neurologists regarding epilepsy have been compared with those of the parents of patients (Ryan, et al 2003). A Korean study has compared the opinions of doctors and nurses working in neurology on what people with epilepsy need to know about their condition with those of patients (Choi-Kwon et al, 2001). The literature on the illness perceptions of patients, caregivers and medical staff has been reviewed (Scambler, 1994; Elliott & Shneker, 2008). Our study is the first to contrast the illness perceptions of patients with epilepsy, patients with PNES and neurologists.

*Comparison of patients with epilepsy and PNES*

The similarities in the illness perceptions of the two patient groups may reflect the fact that most of the patients with PNES are likely to have been misdiagnosed initially as having epilepsy or to have considered a diagnosis of epilepsy likely themselves. Even those patients aware of the diagnosis of PNES may have modelled their cognitions relating to this diagnosis on those relating to epilepsy. Despite not reaching the level of statistical significance required by this study, there was a trend towards patients with epilepsy claiming a greater understanding of their condition when compared to those with PNES, reflecting the previously documented potential of the diagnosis of PNES to cause confusion (Carton et al, 2003; Thompson et al, 2009; Hall-Patch et al, 2010).

*Comparison of patients with epilepsy and neurologists*

Neurologists considered epilepsy a much more "physical" problem than patients. We reported previously that neurologists self-report a better understanding of epileptic than nonepileptic seizure disorders (Whitehead & Reuber, 2012). They thought that patients had a greater degree of personal and treatment-related control over epilepsy than did the patients themselves. It is interesting to note that patients endorsed more "psychological" causes for epilepsy than the neurologists, although neurologists perceived epilepsy as having greater negative emotional consequences than patients.

*Comparison of patients with PNES and neurologists*

Mirroring the differences between neurologists and patients in relation to epilepsy, neurologists thought that patients with PNES had more personal and treatment control over their seizures than did the patients with this condition. Given that their views on the aetiology of epilepsy and PNES differed very markedly, it is, however, likely that there were different reasons why neurologists thought that patients with epilepsy and patients with PNES have more control over their seizure disorders than the patients themselves. Patients' self-reported 'illness control' in this study was as low as that in a previous study in which 50 patients with PNES who had just received their diagnosis completed the IPQ-R (Hall-Patch et al, 2010). These results are consistent with those of another study which used a different self-report instrument, and in which patients with recently developed PNES claimed an even more external locus of control than those who had just developed epilepsy (Stone, 2004). At a similar stage in their illness trajectory patients with PNES told us in a qualitative study that they felt helpless or 'in limbo' because of their disorder (Thompson et al, 2009). Like with epilepsy, neurologists thought that PNES had greater negative consequences than patients themselves. The questions within this subscale ask about the seriousness of the condition, general effects on the patient's life as well as, more specifically, about social stigma, financial consequences and difficulties for those close to the patient. Neurologists also perceived greater negative 'emotional representations' (i.e. emotional impact) associated with PNES than did the patients themselves. These findings are surprising: Previous conversation analytic studies have shown that patients with PNES particularly focus on the consequences (rather than the symptoms) of their seizures when they talk to a neurologist about their seizure disorder (Reuber et al, 2009). Perhaps patients underestimate the likely longer-term

consequences of their condition at the relatively early stage in the disorder at which they were captured for the present study.

In line with previous studies using a conversation analytic approach to explore conversations in which neurologists explain the diagnosis of PNES (Monzoni et al, 2011a & b), neurologists were much more likely to endorse psychological causes for PNES than the patients themselves. Whilst most patients with PNES thought that their condition was more likely to have "physical" rather than "psychological" causes, around one half also included psychosocial factors in their list of causes. A number of studies have previously demonstrated that patients with PNES often report or endorse psychosocial stressors before the development of PNES although they do not accept the aetiological relevance of these stressors and continue to use a ("physical") epilepsy 'prototype' to understand their condition (Binzer et al, 2004; Stone et al, 2004; Dickinson et al, 2011). The difference in patients' and neurologists' beliefs about the relevance of psychosocial factors is likely to be one reason why it can be so difficult to engage patients in psychological treatment for PNES (Howlett et al, 2007).

This study has a number of limitations. Although each patient self-reported their perceptions about their own individual seizure disorder, the neurologists were asked to think about the seizure disorders as a whole. It is not clear how the results would have differed if the perceptions of patients had been contrasted with the 'paired' perceptions of their own neurologists. Studies using this methodology in other patient groups have shown an association with clinical outcome (Heijmans et al, 2001). The patients were recruited from a tertiary referral centre, mostly from the telemetry unit which generally admits patients with frequent and/or intractable seizures. This patient group may not be typical of the patients

neurologists see in outpatient clinics. The views of the neurologists taking part in this study may also not have been representative of neurologists in the UK or elsewhere. However, the fact that 31/45 neurologists who took part in this study described themselves as having a special interest in epilepsy means that the respondents to this study were particularly likely to encounter patients with epilepsy or PNES in their routine clinical work. The demographic information from the neurologists and both patient groups showed statistically significant differences. However, the characteristics of each participant group broadly reflect the expected make-up of that group, other than the unexpectedly high number of women in the epilepsy group. This may reflect participation bias with more women than men willing to take part in a study examining psychosocial issues. Given that some of the comparisons in this paper are between patients with epilepsy and those with PNES, the potential influence of difference in demographic or clinical characteristics between the two patient groups may have had an effect on patients' illness perception. The significant differences in self-reported health related quality of life (worse in the PNES group) and in the median duration of the seizure disorders prior to the video-EEG test (108 months in the epilepsy group, 24 months in the epilepsy group) may be relevant. Whilst both groups had had a similar experience around the time of the video-EEG test (a neurologist referring them because of uncertainty about the diagnosis), the difference in the duration of the seizure disorders means that patients would have had different degrees of exposure to the illness perceptions of significant others including their doctors (although the marked differences between the illness perceptions of both patient groups and the neurologists suggest that patients had not taken over doctors' illness perception over time). These considerations do not call our findings into doubt, but they do mean that they should not be generalised to potentially quite different groups of patients (for instance those who have just developed their seizure disorder). The internal reliability of the neurologists' timeline cyclical subscale was unacceptably poor. The

questions of this subscale ask about the degree to which a disorder is cyclical, changing and unpredictable.

Despite these drawbacks, this study provides interesting insights into neurologists' and patients' understanding of epilepsy and PNES. Whereas both patients groups have a very similar understanding of their seizure disorders, neurologists hold much more dualistic views, perceiving epilepsy as a "physical" and PNES as a "psychological" disorder. The fact that neurologists and their patients have very different views about epilepsy and PNES highlights the potential for problems with communication and treatment. This may be particularly relevant for patients with PNES, many of whom have poor longer term outcomes (Reuber et al, 2003). In this context the timing of our study is particularly relevant, because it means that illness perceptions were captured shortly before patients met the neurologist to learn about the result of the video-EEG recording. The degree of difference in the illness perceptions of neurologists and patients with PNES found here is likely to be one of the reasons why the explanation of the diagnosis of PNES can be so challenging (Monzoni et al. 2011a; Monzoni et al. 2011b). In many cases it may not be possible to change the illness perception of patients sufficiently to enable them to engage in psychological treatment by means of a single conversation even if neurologists follow a previously validated approach (Hall-Patch 2010). More extensive psychoeducation programs have been developed but require further evaluation (Baxter et al. 2012).

None of the authors has any conflict of interest to disclose.

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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**Table 1**
Definition and scoring of IPQ-R subscales

| IPQ-R subscale | Score range | Definition | Interpretation of high scores |
|---|---|---|---|
| Timeline (acute/chronic) | 6-30 | Evaluates longevity of condition | Condition will have long duration |
| Timeline (cyclical) | 4-20 | Evaluates views on cyclical nature of condition | Condition is cyclical |
| Consequences | 6-30 | Evaluates views on negative consequences for patient and family | Condition has great effect on patient and family |
| Personal control | 6-30 | Evaluates views on the effect of personal control by the patient of the condition | Patient has high level of control over condition |
| Treatment control | 5-25 | Evaluates views on the effectiveness of treatments available for the condition | Treatment is effective for condition |
| Illness coherence | 5-25 | Evaluates the understanding of the condition | Greater understanding of condition |
| Emotional representations | 6-30 | Evaluates how the condition affects the patient emotionally | Greater emotional impact on patient |
| Psychological causal attributions | 6-30 | Evaluates how far psychological causes for the disorder are endorsed | Greater endorsement of psychological causes |
| Nonpsychological causal attributions | 12-60 | Evaluates how far non-psychological causes for the disorder are endorsed | Greater endorsement of nonpsychological causes |

**Table 2**
Demographic and clinical information

| | | Patients with epilepsy (n=34) | Patients with PNES (n=40) | Neurologists (n=45) | 2-sided P value | | |
|---|---|---|---|---|---|---|---|
| | | | | | Patients with epilepsy vs. patients with PNES | Patients with epilepsy vs. neurologists | Patients with PNES vs. neurologists |
| Age[a] | | 32.5 (17-64) | 36 (18-66) | 45 (32-59) | ns (.073) | <.001 | <.001 |
| % female[b] | | 79.4% female | 62.5% female | 35.6% female | ns (.133) | <.001 | .017 |
| Median length of education (years)[a] | | 12 | 13 | | ns (.267) | | |
| Median seizure disorder duration (months)[a] | | 108 (12-456) | 24 (5-504) | | .004 | | |
| AED use[b] | Taking AEDs | 30 | 22 | | .004 | | |
| | Used to take AEDs | 1 | 4 | | | | |
| | Never taken AEDs | 3 | 14 | | | | |
| Liverpool Seizure Severity Scale score (median) [a] | | 42.5 (31.3) | 55 (26.9) | | .246 | | |
| Hospital Anxiety and Depression Scale – Anxiety score (median) [a] | | 7.5 (4.3) | 10 (10.0) | | .163 | | |
| Hospital Anxiety and Depression Scale – Depression score (median) [a] | | 5.5 (5.3) | 7 (7.0) | | .113 | | |
| Quality of Life in Epilepsy-31 score (median) [a] | | 50.7 (28.0) | 41.9 (20.6) | | .019 | | |

[a]Mann-Whitney U test
[b]Pearson Chi-Square

**Table 3 (additional web content).**
Internal reliability of IPQ-R subscales for patients and neurologists

| Subscale | Cronbach's alpha | |
|---|---|---|
| | Patients | Neurologists |
| Timeline (acute/chronic) | .782 | .769 |
| Consequences | .764 | .750 |
| Personal control | .796 | .772 |
| Treatment control | .718 | .619 |
| Illness coherence | .926 | .862 |
| Timeline cyclical | .555 | .465[a] |
| Emotional representations | .903 | .801 |
| Psychological causal attributions | .814 | .935 |
| Non-psychological causal attributions | .750 | .784 |

[a] Unacceptable alpha score of <0.5: Timeline cyclical subscale from neurologists excluded from further analysis

**Table 4**

Comparison of IPQ-R adapted scores of patients with epilepsy and patients with PNES

| Subscale | IPQ-R or SAQ score, median (interquartile range) | | |
|---|---|---|---|
| | Patients | | |
| | Epilepsy | PNES | *P* value |
| Timeline (acute/chronic) | 21 (6.0) | 19.5 (4.0) | .221 |
| Consequences | 23 (8.3) | 23.5 (5.0) | .522 |
| Personal control | 15 (7.3) | 17 (7.5) | .091 |
| Treatment control | 15 (4.0) | 18 (5.0) | .015 |
| Illness coherence | 14 (7.0) | 10 (6.0) | .033 |
| Timeline (cyclical) | 14 (4.3) | 14 (3.3) | .448 |
| Emotional representations | 21.5 (9.0) | 21 (8.0) | .934 |
| Psychological causal attributions | 15 (5.0) | 14 (9.0) | .837 |

| | | | |
|---|---|---|---|
| Non-psychological causal attributions | 24 (8.0) | 26 (10.0) | .962 |
| SAQ | 3 (2.5) | 2 (2.0) | .239 |

**Table 5**

Comparison of IPQ-R adapted scores of neurologists and patients

| Subscale | IPQ-R or SAQ score, median (interquartile range) | | | | | |
|---|---|---|---|---|---|---|
| | Epilepsy | | | PNES | | |
| | Neurologists | Patients | *P* value | Neurologists | Patients | *P* value |
| Timeline (acute/chronic) | 19 (4.0) | 21 (6.0) | .018 | 18 (3.0) | 19.5 (4.0) | .071 |
| Consequences | 25 (2.0) | 23 (8.3) | .002 | 26 (4.0) | 23.5 (5.0) | .002 |
| Personal control | 22 (4.0) | 15 (7.3) | <.001 | 24 (3.5) | 17 (5.5) | <.001 |
| Treatment control | 20 (4.0) | 15 (4.0) | <.001 | 19 (3.0) | 18 (5.0) | .001 |
| Illness coherence | 20 (4.0) | 14 (7.0) | <.001 | 19 (4.0) | 10 (6.0) | <.001 |
| Timeline (cyclical)[a] | | | | | | |
| Emotional representations | 24 (4.0) | 21.5 (9.0) | .019 | 23 (4.0) | 21 (8.0) | .186 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Psychological causal attributions | 26 (14.0) | 15 (5.0) | <.001 | 59 (8.5) | 14 (9.0) | <.001 |
| Non-psychological causal attributions | 43 (6) | 24 (8.0) | <.001 | 33 (9.0) | 26 (10.0) | <.001 |
| SAQ | 2 (1) | 3 (2.5) | <.001 | 4 (1) | 2 (2.0) | <.001 |

[a] Comparison not performed because the timeline cyclical subscale from the neurologists had an unacceptable alpha score of <0.5