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## Differences in relatives' and patients' illness perceptions in functional neurological symptom disorders compared to neurological disease

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## Keywords

Psychogenic nonepileptic seizures; Functional weakness; Conversion disorder; Epilepsy  
Illness perception; Neurology

## Abstract

### Objective

The illness perceptions of the relatives of patients with functional neurological symptom disorders (FNSD) and the relation to patients' illness perceptions have been little studied. We aimed to compare illness perceptions of relatives of patients with FNSD to those held by patients themselves. We used control pairs with neurological diseases (ND) to examine the specificity of the findings to FNSD.

### Material and methods

Patients with FNSD (functional limb weakness and psychogenic non-epileptic seizures) and patients with ND causing limb weakness and epilepsy, and their relatives, completed adapted versions of the Illness Perception Questionnaire Revised (IPQ-R).

### Results

We included 112 pairs of patients with FNSD and their relatives and 680 ND patient and relative pairs. Relatives of patients with FNSD were more likely to endorse psychological explanations and, in particular stress as a causal factor than patients with FNSD ( $p < .001$ ). Relatives of FNSD patients were also more pessimistic about the expected duration of the disorder and perceived a greater emotional impact than patients themselves ( $p < .001$ ). However, the latter two differences between patients and relatives were also found in ND pairs.

### Conclusion

The main difference in illness perceptions between relatives and patients with FNSD was a tendency for relatives to see psychological factors as more relevant than patients. Some other differences were observed between FNSD relatives and patients but the same differences were also seen in ND pairs. These other differences were therefore not -and are

~~therefore not~~ specific to FNSD. Discussion about possibly relevant psychological factors with patients suffering from FNSD may be helped by including relatives.

## Introduction

It has long been argued that illness perceptions have a central role in the aetiology of functional neurological symptom disorders (FNSD) [1]. Studies in psychogenic nonepileptic seizures (PNES) and functional weakness have demonstrated that patients generally have illness perceptions compatible with behaving and feeling as if they have the corresponding neurological disease [2-6]. Illness perceptions can arise or alter because ~~be seen both as a~~ patient has experienced ~~consequence of a~~ baffling, frightening and unexpected neurological symptom. However, by helping to ~~but also as a factor which may be relevant in the~~ processes which determine whether somatic sensations are noticed and recognised as symptoms illness perceptions may also be aetiologically relevant: attention to particular sensations is likely – at least in part - to be driven by people's prior beliefs about medical disorders and the functioning of the body.

Illness perceptions are also likely to be relevant for patients with recognised neurological disease (ND) and may help to explain clinically important features such as patients' level of disability or health related quality of life [7-10].

In ~~patients with~~ FNSD patients' illness perceptions are likely to have very significant effects on their acceptance of psychological treatments and on patients' outcome ~~be central to the provision of clinical care.~~ PPatients with PNES for instance are more likely than those with epilepsy to consider their problem "somatic" rather than "psychological", or to deny significant non-health stresses in their lives [3]. Similarly patients with functional weakness

are less likely to agree that stress was a cause of their symptoms than those with weakness caused by neurological disease (24% vs 56%) [4]. These ~~observations suggest that~~ illness perceptions are likely to be one of the reasons why patients with FNSD may find it difficult to ~~can stand in the way of successful~~ engagement in psychological treatment [11], although a number of studies have shown that such treatment can be effective [12-13].

In patients with FNSD, illness perceptions have also been linked to outcomes; Sharpe et al. [14] showed that FNSD illness perceptions, especially beliefs in non-recovery and a somatic cause of symptoms, played a more important role in poor prognosis than other variables such as anxiety, depression and even physical functioning.

It is likely that patients' illness perceptions are not only shaped and influenced by their knowledge of the body and its disorders and their encounters with doctors, but also by their interactions with family, friends and caregivers. The authors of this paper have encountered many clinical situations in which caregivers were characterised as ~~ians often recall~~ "overbearing", "over-involved" or "co-dependent", and ~~relatives~~ as enhancing patients' disabilities. As long ago as 1892 Gowers commented in his textbook of neurology, "The near relatives of the hysterical are often conspicuously deficient in judgment, and the little common sense they may possess is often rendered useless by their affection for the sufferers" [15]. However, these stereotypes of illness perceptions in relatives of patients with FNSD have been little studied empirically. Nor have they been compared to those found in relatives of patients with ND. Morgan et al. [16] examined how the parents of children with seizures perceived PNES terminology and how this would affect their trust in the doctor. Other studies have examined family functioning or determinants of the quality of life of

caregivers for people with epilepsy and PNES, but have not studied their perceptions about what was wrong [17-20]. Family members' perceptions of the causes of FNSD may be particularly relevant and may affect which treatments patients choose. For instance, in another field, Dardennes et al. [21] found that parental perceptions about the causes of autism affected their choice of therapy type.

The Illness Perception Questionnaire-Revised (IPQ-R) has been used to compare the illness perceptions of the relatives of, and patients with, a range of conditions [22]. The IPQ-R is based on the self-regulation model, which proposes that the way in which people behave in relation to illness depends on their perception or mental representation of their health problem. This model subdivides illness representations into five elements: identity (symptoms), cause, consequences (effects on life), timeline (duration) and controllability or cure [23]. The IPQ-R also assesses people's perceived understanding of the health problem (coherence) and the emotional impact of the health problem (emotional representations).

The illness perceptions of patients and their partners have been related to quality of life in Huntington's disease [24], coping and adaptive outcome in chronic fatigue syndrome and Addison's disease [25-26], recovery following myocardial infarction [27] and psychological adjustment in rheumatoid arthritis [28]. Overall, these studies have indicated that relatives' illness perceptions are relevant to patients' psychological outcomes. Depending on the clinical scenario, both contrasting and concordant perceptions in couples have been related to better patient adjustment [24]. Other studies have focused more on the relevance of relatives' illness perceptions to the experience of the relative. A study of family carers of individuals with eating disorders found that carers were less likely to view their caregiving

positively if they believed the illness was attributable to the patient's personality [29]. A recent paper comparing caregivers of patients with epilepsy with caregivers of patients with PNES found no difference in caregiver quality of life; however, differences in illness perceptions were not measured [19]. In fact, there have been no studies of relatives' illness perceptions in FNSD such as PNES or functional weakness. However, clinical experience suggests that it is of vital importance to engage not only patients with FNSD with the rationale for diagnosis and treatment, but also their relatives and friends [30].

The aim of this study was firstly to compare the illness perceptions of patients and their relatives and friends with FNSD and secondly to do the same in patients and their relatives and friends with ND, to determine the specificity of any differences found between the FNSD patient-relative pairs.

## **Method**

### *Recruitment of the weakness groups*

Patients with functional weakness and weakness due to ND were recruited prospectively by consultant neurologists working at the Department of Clinical Neurosciences, Western General Hospital in Edinburgh between 1999 and 2002. The study was promoted by means of personal contact and reminders and through regular newsletters. Patients with an unequivocal functional limb weakness with no neurological disease comorbidity and onset within two years were referred to the study by consultant neurologists who had made the diagnosis. Patients with weakness caused exclusively by a neurological disease, with symptom onset within two years were identified consecutively and prospectively from the inpatient and outpatient correspondence of three consultant neurologists. Patients aged

under 16 or with communication difficulties preventing the completion of the questionnaire were excluded. JS carried out a research assessment of participants following which they were asked to give the IPQ-R to a relative or friend who they thought had been involved in their illness. They were provided with a stamped addressed envelope to return it. Further details of recruitment and other clinical and self-report data from the weakness patient groups, including the patient IPQ-R results (but not their relatives), have been reported previously [4,31].

#### *Recruitment of the seizure disorder groups*

Between May 2009 and December 2011, KW reviewed all EEG request forms submitted to the Clinical Neurophysiology department of the Royal Hallamshire Hospital in Sheffield. We prospectively identified all patients referred for video-EEG (outpatient routine or two to five day videotelemetry) with a differential diagnosis of epilepsy or PNES. Patients aged under 16 or with communication difficulties preventing completion of the questionnaire were excluded. Two weeks prior to their attendance for the test we sent potential participants information about the study. This included a relative study pack containing the adapted IPQ-R and a self-addressed envelope which the patient could choose to pass on to a relative or friend if they wished to take part in the study. Patients were asked whether they wanted to participate and completed their questionnaires at the hospital when they attended for their EEG appointment.

Patients' and their relative's questionnaire responses were only included in the analysis if a "gold standard" diagnosis had been made, i.e. if an attack considered typical by the patient and family members (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. Patients with mixed epilepsy and PNES were excluded. We have used the data provided by this patient group (but not their relatives) in a previous study comparing the perceptions of seizure patients with those of neurologists [2].

### *Illness perception questionnaire-revised (IPQ-R)*

The IPQ-R is a 38-item self-report questionnaire designed to capture the nature of patients' illness perceptions [22]. 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 (subscales used within this study listed with the Cronbach's alpha coefficient for the patients and relatives/friends respectively): Timeline (acute/chronic) (.878 and .908); Consequences (.784 and .769); Personal control (.812 and .790); Treatment control (.746 and .828); Timeline (cyclical) (.809 and .804); Emotional representations (.862 and .870). Two subscales from the IPQ-R were not used. The coherence subscale was excluded because perceptions about understanding of a condition will be affected by what stage of diagnosis patients are at so it did not make sense to use this with combined groups. The identity subscale was excluded because it is a list of general symptoms which are not particularly relevant to the conditions of our patient groups. 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) (See Table 2). The psychological grouping of the causal data is used within this study and has a Cronbach's

alpha coefficient of .864 for patients and .846 for relatives. 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 [22]. The IPQ-R is an improved version of the Illness Perception Questionnaire (IPQ) [32]. The IPQ and IPQ-R have been used in a number of studies regarding epilepsy or PNES [2,9,8,33-34,].

A relative's version of the IPQ-R followed exactly the same structure but with a slightly altered wording so that the respondent is being asked about their "relative or friend's illness" rather than their own. Since this study's data was collected, a spouse version of the IPQ-R (excluding the cause subscale) for husbands of women with rheumatoid arthritis has been developed and shown to be reliable and have a predictive validity over a four-month period [35]. Within this study, the scoring system for each subscale was normalised so that each score ranged from 0-100 as described in Table 2.

#### *Hospital Anxiety and Depression Scale (HADS)*

All patient groups also completed the Hospital Anxiety and Depression Scale (HADS) [36], 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 and 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 of the mood disorder ('caseness'). It has been widely used in studies of patients with neurological diseases and in functional disorders [37].

#### *Statistical analysis*

For this study the functional weakness and nonepileptic seizure patients and their relatives were combined to form one Functional Neurological Symptom Disorder (FNSD) group and a FNSD relative group. Likewise, the patient groups with epilepsy and weakness explained by neurological disease were combined to form one ND group and a paired ND relative group.

We sought to investigate the differences or similarities of the perceptions of the patient-relative pairs only. In this analysis we did not compare patient group means with each other or the relative groups with each other. The internal consistency of the IPQ-R subscales used was analysed by calculating Cronbach's  $\alpha$  scores. A Cronbach's  $\alpha > 0.6$  was considered acceptable. Means and standard deviations were calculated for each subscale score and paired t-tests were used to make comparisons between patients with the disorder and their relatives. We wished to compare the FNSD and ND pairings directly so we conducted additional ANCOVA analyses to look at interaction between the key issues: patients vs.

relatives and FNSD vs. ND (controlling for patient group, seizure vs. weakness). ~~Two subscales from the IPQ-R were not used. The coherence subscale was excluded because perceptions about understanding of a condition will be affected by what stage of diagnosis patients are at so it did not make sense to use this with combined groups. The identity subscale was excluded because it is a list of general symptoms which are not particularly relevant to the conditions of our patient groups.~~ 'Stress or worry' was provided as one of the possible causes for the condition within the IPQ-R and this was analysed as a single item.

Due to making multiple comparisons, we conservatively interpreted two-sided P values of  $\leq 0.01$  as significant.

*Ethical approval*

Ethical approval for the weakness part of the study was provided by the Lothian Research Ethics committee. Ethical approval for the seizure disorder arm of the study was provided by the Sheffield Research Ethics Committee.

## Results

### *Participants*

We recruited 107 patients with functional weakness (and 92 of their relatives and friends) and 46 patients with weakness caused by neurological disease (and 40 of their relatives and friends). We recruited 40 patients with PNES (and 20 of their relatives and friends) and 34 patients with epilepsy (and 20 of their relatives and friends) (Table 1). Because there were only 11 'friends' among the 172 'relatives and friends' we refer to them from this point on as 'relatives' for the sake of simplicity. In the FNSD patient group there were no significant differences between the gender, age, duration of symptoms and anxiety and depression score of patients with relative IPQ data (n=172) and those without (n=55). In the ND patients there were no significant differences except that [participants who had recruited as a relative](#) had a significantly shorter duration of symptoms than [those who had not](#)~~non-recruiters~~ (median 19 months vs. 78 months respectively; Mann-Whitney U test gives  $p = .015$ ;  $U = 414.5$ ).

The paired data from the four subgroups was investigated separately to ensure that creating combined FNSD and ND groups was appropriate. Data from the subgroups were combined into one FNSD and one ND group when we had established that all significant dyadic differences on the IPQ-R subscales in the functional weakness plus PNES and in the neurological weakness plus epilepsy groups were in the same direction.

### *Internal reliability of the IPQ-R subscales*

The internal reliability of all IPQ-R subscales was satisfactory or good. All Cronbach's alpha coefficients were greater than 0.7 (i.e. well above our acceptability cut-off of 0.6).

### *Demographic differences*

There were no significant differences between the age, gender or anxiety scores of the patients with FNSD or ND or the gender of their relatives. The ND patients reported longer symptom duration and had lower depression scores than those in the FNSD group.

### *Patient-relative pair differences*

The main results from the study are shown in Table 2. The most striking finding was that relatives of patients with FNSD were significantly more likely to endorse psychological causal factors such as "stress" than patients. This difference was not found among patients with ND and their relatives.

The absolute values in the FNSD patients, however, show that, the relatives of FNSD patients as a group still generally disagreed with the idea of a psychological causation (mean score 30 out of 100).

There were four subscales which differed in the same direction for both FNSD and ND patients suggesting these may be generic effects of asking someone's relative about any illness, regardless of its cause. Relatives of both FNSD and ND patients reported that the condition caused a greater emotional impact than the patients themselves. There was a

trend towards both sets of relatives believing in a worse outlook (timeline) and greater negative consequences but this only reached statistical significance for FNSD pairs. There was also a trend towards both FNSD and ND relatives believing patients had less personal control over symptoms than the patients themselves believed but this did not reach significance. There were two domains where there were no differences between patients and relatives regardless of disorder (treatment control and cyclical nature of the symptoms).

A more detailed analysis of these differences using ANCOVA was conducted to examine the interaction between cause (FNSD vs ND) and rater (patient vs relative) on illness perceptions, controlling for patient group (seizure vs weakness). Two cause x rater interactions were observed for psychological causes ( $F = 6.040$ ,  $p = .015$ ), and stress cause ( $F = 10.609$ ,  $p = .001$ ) showing that only in FNSD pairs did relatives endorse psychological or stress causes for the disorder more than patients (see fig. 1 & 2). This was consistent with the observations made from the two separate paired t test comparisons. As shown in table 2, for both psychological causes and the stress cause, the difference between patients' and relatives' ratings was significant for FNSD ( $t = -4.314$  and  $-3.944$  respectively,  $p < .001$  for both), but non-significant for ND ( $t = .194$  and  $1.075$  respectively,  $p > .05$  for both).

## **Discussion**

Although most relatives tended to disagree that FNSD could be due to psychological factors, they were significantly less averse to psychological explanations for FNSD (and, in particular, stress as a causal factor) than patients with FNSD themselves. This finding was not present in the ND pairs. This has important practical implications for clinicians who wish to discuss potentially relevant psychological factors- with patients with FNSD [2,38]. Our findings

suggest that, whilst potentially still requiring persuasion, relatives are more likely to accept that FNSD could be linked to stress, emotional problems or coping difficulties. This finding goes against the ~~usual~~ stereotype of the 'unhelpful' relative.

Our findings are consistent with a study of 100 patient and 84 witness accounts of non-epileptic seizures recorded by questionnaire [30]. Although not directly comparable, this study found that PNES witnesses perceived a closer link between stress and seizures, as well as seizure triggers, than patients themselves.

In both FNSD and ND, within several domains, relatives' illness perceptions tended to be more negative than patients'. This observation could reflect that relatives have a natural tendency to be ~~'concerned' and~~ 'caring'. Thus clinicians who pick up on 'overcaring' relatives may be doing so primarily because of their own negative cognitive bias and "suspicion" of patients with FNSD rather than because of any significant differences to the relatives of patients with neurological disease. Alternatively, the more negative illness perceptions of relatives could also reflect caregivers' annoyance and frustration or their anxiety about the patients' disorder. Potentially, caregivers with such negative attitudes could discourage patients from achieving maximum independence despite their health problems. However, given that caregivers in both groups (FNSD and ND) had more negative illness perceptions than patients this observation cannot readily explain any observations specific to the FNSD patient group.

*Limitations/future studies*

The above conclusions are tempered by a number of study limitations. First, we combined patients with two different “functional” and two different “neurological” symptoms for the analyses in this study. Weakness and seizures are different problems – weakness is more persistent, seizures come and go – analysis of the subgroups separately showed that significant paired differences were common to both of the subgroups making up an overall condition. It is uncertain how much heterogeneity this may be disguising and whether the data can be generalized to patients with milder FNSD or other functional symptoms.

Second, we did not have much information about the relatives who took part in the study. It may be that further data about them such as the nature of their relationship with the patient or how long they had known the individual may influence their views. Third, when presenting illness perceptions of patients in isolation it is also important to consider the context of those perceptions and where some of them may have originated from. For example, studies of neurologists, nurses and physiotherapists show that a minority harbour very negative views about patients with functional disorders which may significantly affect the views of patients and relatives [34,39]. Fourth, the cross-sectional design of our study does not allow us to distinguish between illness perceptions resulting from the experience of the symptoms and illness perceptions predating their onset and, perhaps, contributing to their development. Finally, the use of statistical averaging may hide clinically relevant heterogeneity among the patients and their relatives. For example, although on average relatives are more willing to consider psychological explanations in FNSD it may be that there are subgroups that are much less willing to do this than the patient. This would be clinically relevant for a particular patient-relative pair.

Notwithstanding these limitations, we found that the relatives of patients with FNSD are more likely to contemplate an aetiological role of psychological factors or stress than patients themselves, implying that they may have a positive role to play when encouraging patients to accept that psychological factors are relevant to their symptoms. Other potential differences in illness perceptions between patients and their relatives appear to be generic and not specific to FNSD calling the relevance of phenomena such as ‘the over-caring relative’ into question. Future longitudinal studies could focus on whether differences in perceptions of patients and their relatives and have effects on medical or social outcomes and whether the effect of differences in illness perceptions is the same in patients with FNSD and patients with ND.

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### **Author declaration**

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

We further confirm that the work covered in this manuscript has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript. We understand that the Corresponding Author is the sole contact for the Editorial process (including Editorial Manager and direct communications with the office). She is responsible for communicating with the other authors about progress, submissions of revisions and final approval of proofs. We confirm that we have provided a current, correct email address which is accessible by the Corresponding Author.

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