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

Kimberley Whitehead BSc, Jon Stone PhD, Paul Norman PhD, Michael Sharpe MD, Markus Reuber PhD

Kimberley Whitehead[1]
Department of Clinical Neurophysiology
Royal Hallamshire Hospital
Sheffield, S10 2JF, UK

Dr Jon Stone
Consultant Neurologist and Honorary Senior Lecturer
Dept Clinical Neurosciences
Western General Hospital
Edinburgh, EH4 2XU, UK
T: +44 (0)131 5371167
E: Jon.Stone@ed.ac.uk

Professor Paul Norman
Professor of Health Psychology
Department of Psychology
University of Sheffield
Sheffield, S10 2TP, UK
T: +44 (0)114 2226505
E: p.norman@sheffield.ac.uk

Professor Michael Sharpe
Department of Psychiatry
University of Oxford
Oxford, OX3 7JX, UK
T: +44 (0)1865 226397
E: Michael.sharpe@psych.ox.ac.uk

Professor Markus Reuber
Academic Neurology Unit
University of Sheffield
Royal Hallamshire Hospital
Sheffield, S10 2JF, UK
T: +44 (0)114 2268763
E: m.reuber@sheffield.ac.uk

Corresponding author: Kimberley Whitehead[1]

[1]Present address:
Telemetry Unit
National Hospital for Neurology and Neurosurgery
London, WC1N 3BG, UK
T: +44 (0)20 34483339
E: Kimberley.Whitehead@uclh.nhs.uk

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 60 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 that appeared
specific to 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 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]. Such illness perceptions can arise or alter because a patient has experienced baffling, frightening and unexpected neurological symptoms. However, by helping to determine whether somatic sensations are noticed and recognised as symptoms, illness perceptions may also be aetiologically relevant. Abnormally focused 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 [5].

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 FNSD patients' illness perceptions are likely to have an important impact on their acceptance of psychological treatments and on treatment outcomes. Patients 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 illness perceptions are likely to be one of the reasons why patients with FNSD may find it

difficult to engage 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 "overbearing", "over-involved" or "co-dependent", and 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. A recent study found that caregivers were more likely to accept the PNES diagnosis than patients at initial presentation of the diagnosis, both patient and caregiver acceptance at 6-12 months was highly predictive of fewer attacks at that time point [needs to be sixteen]. Morgan et al. [17] examined how the parents of children with seizures perceived PNES terminology and how this affected 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 not

their perceptions about what was wrong [18-21]. 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. [22] 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 [23]. 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 core elements: identity (symptoms), cause, consequences (effects on life), timeline (duration) and controllability or cure [24]. 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 [25], coping and adaptive outcome in chronic fatigue syndrome and Addison's disease [26-27], recovery following myocardial infarction [28] and psychological adjustment in rheumatoid arthritis [29]. 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 [25]. 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 [30]. 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 [20]. 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 [31].

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 [4,32].

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 [23]. 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 [23]. The IPQ-R is an improved version of the Illness Perception Questionnaire (IPQ) [33]. The IPQ and IPQ-R have been used in a number of studies regarding epilepsy or PNES [2,9,8,34-35].

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 [36]. 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) [37], 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 [38]. Up to here references.

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 α scores. A Cronbach's α >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 whereas independent t-tests were used to compare the perceptions between groups of relatives in order to investigate the effect of gender. 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). '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 ≤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 subjects with a relative had a significantly shorter duration of symptoms than those without (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 (Table 1). The ND patients reported longer symptom duration and had lower depression scores than those in the FNSD group. (Table 1)

<u>*Patient-relative pair differences*</u>

The main results from the study are shown in Table 2 and Fig. 1. 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. 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).

Gender differences in patients and relatives

Independent t tests were used to compare the illness perceptions of the relatives of male patients and the relatives of female patients, within the FNSD and ND pairs separately. This found no significant differences.

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 [2,39]. 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 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 [31]. 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 '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' frustration or their anxiety about the patients' disorder. Potentially, negative beliefs could impact adversely on attempts at rehabilitation. 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.

This study did not find any statistically significant differences between the illness perceptions of relatives of male patients and the perceptions of relatives of female patients. An earlier study found that carers of women were three times less likely to reject a PNES diagnosis than carers of men [40].

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. However, 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 [35,41]. 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 and of course the approach should be individualised in treatment.

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 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.

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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