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Differences in relatives' and patients' illness perceptions in functional neurological symptom disorders compared with neurological diseases

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ABSTRACT

Objective: The illness perceptions of the relatives of patients with functional neurological symptom disorders (FNSDs) and their relation to the illness perceptions of the patients have been little studied. We aimed to compare illness perceptions of relatives of patients with FNSDs with those held by patients themselves. We used control pairs with neurological diseases (NDs) to examine the specificity of the findings to FNSDs.
Material and methods: Patients with FNSDs (functional limb weakness and psychogenic nonepileptic seizures) and patients with NDs causing limb weakness and epilepsy, as well as their relatives, completed adapted versions of the Illness Perception Questionnaire — Revised (IPQ-R).
Results: We included 112 pairs of patients with FNSDs and their relatives and 60 pairs of patients with NDs and their relatives. Relatives of patients with FNSDs were more likely to endorse psychological explanations and, in particular, stress as causal factors than patients with FNSDs ($p < .001$). Relatives of patients with FNSDs were also more pessimistic about the expected duration of the disorder and perceived a greater emotional impact compared with patients themselves ($p < .001$). However, the latter two differences between patients and relatives were also found in pairs of patients with NDs and their relatives.
Conclusion: The main difference in illness perceptions between relatives and patients that appeared specific to FNSDs was a tendency for relatives to see psychological factors as more relevant compared with patients. Some other differences were observed between pairs of patients with FNSDs and their relatives, but the same differences were also seen in pairs of patients with NDs and their relatives. These other differences were, therefore, not specific to FNSDs. Discussion about possibly relevant psychological factors with patients suffering from FNSDs may be helped by including relatives.

1. Introduction

It has long been argued that illness perceptions have a central role in the etiology of functional neurological symptom disorders (FNSDs) [1]. Studies in psychogenic nonepileptic seizures (PNESs) 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 be altered because a patient has experienced baffling, frightening, and unexpected neurological symptoms. However, by helping in determining whether somatic sensations are noticed and recognized as symptoms, illness perceptions may also be etiologically 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 recognized neurological disease (ND) and may help in explaining clinically important features such as patients' level of disability or health-related quality of life [7–10].

In patients with FNSDs, illness perceptions are likely to have an important impact on their acceptance of psychological treatments and on treatment outcomes. Patients with PNESs, for instance, are more likely to consider their problem "somatic" rather than "psychological" or to deny significant nonhealth-related stresses in their lives than those with epilepsy [3]. Similarly, patients with functional weakness

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

It is likely that patients' illness perceptions are shaped and influenced not only 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 characterized as "overbearing", "overinvolved", or "codependent" 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 FNSDs have been little studied empirically and they have not been compared with those found in relatives of patients with NDs. A recent study found that caregivers were more likely to accept the PNES diagnosis than patients at initial presentation of the diagnosis, and that both patient acceptance and caregiver acceptance at 6–12 months were highly predictive of fewer attacks at that time point [16]. 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 PNESs, but not their perceptions about what was wrong [18–21]. Family members' perceptions of the causes of FNSDs 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 patients with a range of conditions with those of their relatives [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 relatives. A study of family carers of individuals with eating disorders found that carers were less likely to view their caregiving positively if they believed that the illness was attributable to the patients' personality [30]. A recent paper comparing caregivers of patients with epilepsy with caregivers of patients with PNESs found no difference in caregiver quality of life; however, differences in illness perceptions were not measured [20]. In fact, there have been no published studies of relatives' illness perceptions in FNSDs such as PNESs or functional weakness. However, clinical experience suggests that it is of vital importance to engage not only patients with FNSDs with the rationale for diagnosis and treatment but also their relatives and friends [31].

The aims of this study were, firstly, to compare the illness perceptions of patients and their relatives and friends with FNSDs and, secondly, to do the same in patients and their relatives and friends with NDs to determine the specificity of any differences found between the pairs of patients with FNSDs and their relatives.

2. Method

2.1. Recruitment of the weakness groups

Patients with functional weakness and weakness due to NDs 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 under 16 years of age or with communication difficulties preventing the completion of the questionnaire were excluded. Jon Stone carried out a research assessment of participants, following which they were asked to give the IPQ-R to a relative or a 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 patient groups with weakness, including the patient IPQ-R results (but not their relatives), have been reported previously [4,32].

2.2. 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 PNESs. Patients under 16 years of age or with communication difficulties preventing the 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 a 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 relatives' questionnaire responses were only included in the analysis if a "gold standard" diagnosis had been made, i.e., if an seizure considered typical by the patients and family members (if available) was recorded, if the recorded seizure was judged to be clearly epileptic or nonepileptic by a consultant neurophysiologist, and if the referring neurologist confirmed that the recorded seizure matched the final diagnosis of epilepsy or PNESs based on the video-EEG report and all other available clinical data. Patients with mixed epilepsy and PNESs were excluded. We have used the data provided by this patient group (but not their relatives) in a previous study comparing the perceptions of patients with seizures with those of neurologists [2].

2.3. 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