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Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures

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ABSTRACT

Epilepsy and psychogenic nonepileptic seizures (PNES) are associated with reduced health-related quality of life (HRQoL). The present study investigated the profile, relationship, and predictive power of illness perceptions, psychological distress (depression and anxiety), seizure activity, and demographic factors on HRQoL in these patient groups. Patients with epilepsy ($n = 62$) and PNES ($n = 45$) were recruited from a United Kingdom hospital and from membership-led organizations for individuals living with seizures. Patients completed a series of self-report questionnaires assessing: anxiety (GAD-7), depression (NDDI-E), illness perceptions (B-IPQ), HRQoL (NEWQOL-6D), and seizure frequency and severity (LSSS-3). Correlational and hierarchical multiple regression analyses were conducted. Patients with epilepsy reported higher HRQoL and scored lower on measures of depression and anxiety. Patients with PNES perceived their condition as more threatening overall. In both conditions, HRQoL was negatively correlated with more severe illness perceptions and psychological distress. In epilepsy and PNES, psychological distress (epilepsy: 27%; PNES: 24.8%) and illness perceptions (epilepsy: 23.1%; PNES: 23.3%) accounted for the largest amount of variance in HRQoL. Clinical factors were found not to be significant predictors, while demographic factors predicted HRQoL in epilepsy (12.6%), but not in PNES. Our findings support the notion that psychological factors are a stronger predictor of HRQoL in epilepsy and PNES than condition-related and demographic variables. Prior research suggests that anxiety and depression are key predictors of HRQoL; this study demonstrates that the relationship between illness perceptions and HRQoL is similarly close. These findings highlight the importance of addressing patients' beliefs about their condition.

1. Introduction

Epilepsy is a common neurological condition affecting between 5 and 10 per 1000 people in the United Kingdom (UK) [1]. It is a disorder of the brain characterized by recurrent seizures [2]. Psychogenic nonepileptic seizures (PNES) are one of the most important differential diagnoses of epilepsy. PNES superficially resemble epileptic seizures, but are not associated with epileptiform activity. Instead, most PNES are understood as a dissociative response to threatening internal or external stimuli [3]. PNES account for nearly 20% of presentations to seizure clinics [4].

Health-related quality of life (HRQoL) is reduced in epilepsy and PNES [5]. Both patient groups have to adjust to living with seizures and are at an increased risk of experiencing stigma [6,7] and developing psychiatric conditions, such as, mood, personality, and anxiety disorders [8,9]. Despite these commonalities, quantitative and qualitative research has indicated differences between patients' subjective accounts of living with epilepsy and PNES, perhaps reflecting the different etiologies of these disorders [10–12]. What is more, although findings in different studies are not completely consistent, patient groups with PNES tend to score higher than those with epilepsy on measures of anxiety, dissociation, and somatization and lower on measures of HRQoL [5,9]. There also tend to be clear demographic differences between cohorts with PNES or epilepsy which need to be taken into account in comparative studies; whereas epilepsy affects similar numbers of men and women, three quarters of patients with PNES are female, and the age at seizure onset is typically lower in epilepsy [13].

Systematic reviews have explored the most important factors contributing to the reduction in HRQoL in epilepsy and PNES. In epilepsy, Taylor et al. [14] reviewed 93 studies demonstrating that psychological variables (e.g. depression and anxiety) contributed 30–35% of the variance in HRQoL. Condition variables (e.g. seizure frequency and severity) accounted for up to 20% and demographics variables (e.g. age, gender) were "generally" found to have no significant relationship, while the association of educational level was inconsistent across studies. An

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equivalent systematic review of HRQoL in PNES by Jones et al. [15] based on 14 studies found that interpersonal and psychological factors (in particular, depression and anxiety) were negatively correlated with HRQoL, while condition and demographic variables were not significantly associated.

Neither of these systematic reviews considered the effect of illness perceptions on HRQoL although this psychological variable has been demonstrated to have an important influence on HRQoL in other medical conditions [16]. Illness perceptions are subjective emotional and cognitive representations about illness. Research into illness perceptions has predominately been based on the self-regulation model of health. This suggests that individuals are active problem solvers, and in response to a health threat, will generate a mental representation that can then be used as a framework to motivate coping behaviour and illness appraisal [17–19].

There are five components of illness perceptions that can be reliably investigated using the Illness Perception Questionnaire (IPQ) [20] or the Brief IPQ [21]. These are the perceived symptoms, consequences, probable cause, likely duration, and the extent to which the patient perceives that the condition can be cured or kept under control. Using the Brief IPQ, the components can be computed to create an overall perception reflecting how threatening or benign the illness is perceived to be. Illness perceptions have previously been explored in neurological symptom disorders including epilepsy and PNES, using the aforementioned questionnaires [22–28].

In Greek children with epilepsy (10–18 years), Rizou et al. [29] demonstrated that, when age and seizure severity were controlled for, the different components of illness perceptions accounted for 36.6% ($p < 0.001$) of the variance in HRQoL. Shallcross et al. [29] found in patients with epilepsy that the perception of how threatening the illness is overall mediated the relationship between depression and HRQoL, even if demographic and condition variables were controlled for. Similarly, in a study of 50 patients with PNES, Novakova et al. [30] reported that a more threatening view of the illness was associated with lower mental ($rho = 0.7$, $p = 0.001$) and physical ($rho = 0.44$, $p = 0.001$) HRQoL components.

In summary, there is evidence to suggest illness perceptions have a significant relationship with HRQoL in individuals with medical disorders including epilepsy and PNES. However, the relationship or predictive value of the individual components of illness perceptions on HRQoL has not been studied extensively or compared directly in adult samples of patients with epilepsy or PNES. Factors determining HRQoL in chronic disorders, such as epilepsy and PNES, can provide insight into patients' subjective illness experience and the nature of the disorder [31].

The first aim of the present study was to explore and compare the condition and psychological profile of patients with epilepsy on the one hand, and those with PNES on the other. Understanding the differences between the two conditions can highlight potential targets for treatment, as well as offer implications for making a differential diagnosis and prognosis. We hypothesized that patients with PNES would report higher scores on anxiety and depression and a lower HRQoL. Patients would also hold different beliefs about their condition including the perceived threat.

The second aim was more specifically to investigate the relationship and determine the predictive power of a range of factors on HRQoL: psychological factors (illness perceptions and psychological distress) and condition-related features (seizure duration, frequency, and severity). In light of the fact that prior research has reported inconsistencies between the association of demographic factors (age, gender and education) and HRQoL, we also investigated this as a potential factor.

Our study tested the hypothesis that there is a significant correlation between HRQoL and psychological variables in patients with epilepsy and those with PNES. Secondly, we expected that psychological variables would account for the largest variance in HRQoL in both conditions.

2. Methods

2.1. Patients

Patients were recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield (UK). To maximize recruitment, patients were also recruited from membership-led organizations for individuals who experience seizures (see acknowledgements for the list of organizations). Recruitment took place between October 2015 and July 2016. All patients were either from the UK (89.7%) or the United States (10.3%). This dataset was collected in the context of a randomized control trial investigating the effects of a writing intervention for patients with seizure disorders. The data presented in this study have been extracted from patients' baseline measures. The North of Scotland Research Ethics Committee granted ethical approval for this study.

Patients were included in the present study if they: were over the age of 18 years; had experienced at least one seizure in the last twelve months; had a diagnosis of epilepsy or PNES (patients with comorbid epilepsy and PNES were excluded); were able to provide informed consent and complete a demographic and clinical questionnaire without help (i.e. have a sufficient understanding of English and no recognized learning difficulties). Patients recruited through membership-led organizations were asked to self-report their diagnosis: epilepsy or PNES (patients were not eligible if they were currently undergoing clinical investigations to obtain a seizure diagnosis or if there was any doubt about the diagnosis).

All self-reported diagnoses of patients recruited at the Royal Hallamshire Hospital were confirmed by review of the hospital records. Patients were only included if they had a clear diagnosis of either epilepsy or PNES formulated by a Consultant Neurologist on the basis of all available clinical evidence (sometimes but not always including video-EEG recorded habitual seizures). When possible, confirmation of the self-reported diagnoses of patients recruited through membership-led organizations was sought from their General Practitioner (GP). However, patients were not excluded if GPs failed to respond to our requests for diagnostic confirmation.

A sample size calculation revealed that using the alpha level ($p = 0.05$), with 90% power, and a correlation of at least 0.5, that a sample size of 31 was required (>0.5 is classified as a strong relationship). The data from 45 patients with PNES and 62 patients with epilepsy were analysed.

2.2. Recruitment

This was a cross-sectional study. Patients recruited from outpatient neurology clinics were sent a participant information sheet at least 48 h before their appointment with a Consultant Neurologist. On the day of their appointment, the patient was approached in the waiting room by G.R. and invited to take part in the study. Patients who agreed to take part were asked to complete a set of self-report measures. Patients recruited from membership-led organizations replied to an advert for a study of a writing intervention designed to help patients with seizure disorders. The patient then contacted G.R. who gained written informed consent and provided access to an online form where patients could complete the self-report measures.

2.3. Measures

2.3.1. Demographic and medical information

This included age, gender, years in education, current diagnosis (PNES, epilepsy), duration since seizure onset, and the date of their last seizure.

2.3.2. Anxiety

The Generalized Anxiety Disorder (GAD-7) instrument is a seven-item scale used as a screening tool and severity measure of mild