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Catastrophising and normalising in patient's accounts of their seizure experiences☆

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ABSTRACT

Purpose: To extend our previous research demonstrating that linguistic/interactional features in patients' talk can assist the challenging differential diagnosis of epilepsy and psychogenic nonepileptic seizures (PNES) by exploring the differential diagnostic potential of references to non co-present persons (third parties).
Method: Initial encounters were recorded between 20 seizure patients (13 with PNES, seven with epilepsy) who were subsequently diagnosed by the recording of typical seizures with video-EEG. An analyst blinded to the medical diagnoses coded and analysed transcripts.
Results: There were no significant differences between the two diagnostic groups in terms of the total number of third party references or references made spontaneously by patients without prompting from the doctor. However, patients with PNES made significantly more prompted references to third parties ($p = 0.022$). 'Castrophising' third party references were made in 12/13 (92.3%) of encounters with PNES patients and 1/7 (14.3%) of encounters with epilepsy patients ($p = 0.001$, OR 72, 95% CI = 3.8–1361.9). Normalising references were identified in 2/13 (15.4%) of encounters in the PNES and 6/7 (85.7%) of encounters in the epilepsy groups ($p = 0.004$, OR 33, 95% CI = 2.5–443.6).
Conclusion: There are significant differences in how patients with epilepsy or patients with PNES refer to third parties. Patients with PNES are more likely to be prompted to tell doctors what others have told them about their seizures. Patients using third party references to catastrophise their seizure experiences are more likely to have PNES, whilst patients who use third party references to normalise their life with seizures are more likely to have epilepsy.

1. Introduction

Psychogenic non-epileptic seizures (PNES) are defined by their superficial resemblance to epileptic seizures. However, unlike epileptic seizures, PNES are not the result of abnormal electrical discharges in the brain, but are generally interpreted as physical manifestations of psychological distress or as the result of dissociative processes.[1] Given the similarities in the visible manifestations of epileptic seizures and PNES, the differentiation between these two seizure disorders can be difficult, even for the most experienced clinicians. However, it is crucial to get the diagnosis right because the choice of treatment critically depends on the cause and nature of the seizures.

History-taking from patients and, if available, seizure witnesses is a key part of the diagnostic process.[2] Interictal tests such as brain MRI and EEG can show nonspecific changes or appear normal in over two-thirds of patients presenting after an unprovoked epileptic seizure.[2,3] The same tests can show (unexpected) abnormalities in more than one-fifth of patients with PNES.[4] Video-EEG telemetry captures typical events in only one-half to two-thirds of patients referred for testing.[5–8]

To date, only a very modest number of studies have focused on the diagnostic value of different aspects of history-taking when patients present with transient loss of consciousness. For instance, it has been shown that clusters of factual items (such as the presence of presyncopal symptoms or postictal confusion) can differentiate well between epileptic seizures and syncope [3,9,10]. However, it is not clear that this approach works reliably for the differentiation of epilepsy and PNES. A number of studies have demonstrated that some clinical features traditionally used by doctors to inform their diagnosis (such as seizures from sleep or pelvic thrusting) have no prognostic value.[11,12]

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In view of this, it is perhaps not surprising that studies in different clinical settings have identified misdiagnosis rates ranging from 5 to 50%,[5,13–15] with an average estimated as ranging between 20% and 30%.[16] Most patients with PNES are initially thought to have epilepsy, and it typically takes several years for the correct diagnosis of PNES to be made.[17,18] This means that many patients are exposed to inappropriate, ineffective and potentially dangerous drug treatments that may actually exacerbate their condition, cause iatrogenic injury or even death.[19–21]

It is also important to consider the cost implications of misdiagnoses. The total medical treatment cost attributable to erroneous diagnoses of epilepsy to has recently been estimated to amount to £138 million (€162 million or $216 million) per year in England and Wales alone.[22]

The present study is part of a multidisciplinary programme of research involving sociologists, linguists and neurologists at the Universities of Sheffield and York (UK). Building on previous work using an approach derived from conversation analysis and carried out in Bielefeld, Germany,[23–27] the programme aims to improve the effectiveness of the history-taking process for the purpose of distinguishing between epileptic seizures and PNES. So far we have demonstrated that the observations made in conversations with German patients can be replicated in English clinical encounters,[28] that patients with epilepsy and PNES use different metaphoric conceptualisations for their seizure experiences,[29,30] that they prefer different labels for their seizures,[31] and that patients with epilepsy are more likely to volunteer subjective accounts of seizure symptoms than patients with PNES.[32] Furthermore, a prospective multi-rater study has confirmed the diagnostic potential of linguistic, topical and interactional observations in the seizure clinic setting: Two linguists analysed transcripts of clinical encounters without having access to any other medical information about the patients. All diagnoses were ultimately proven by the video-EEG recording of typical attacks. By clustering the non-factual features identified in previous studies and using a diagnostic scoring aid (DSA) to convert qualitative assessments into a numeric score, linguists blinded to diagnosis predicted 85% of diagnoses correctly. The differences in the mean DSA scores were significant for both raters (rater 1: $p = 0.017$, rater 2: $p = 0.047$). The procedure had a sensitivity of 85.7% (71.4%), a specificity of 84.6% (92.3%) and an acceptable inter-rater reliability (Kappa = 0.59).[33]

The present study was intended to add to this work by exploring the differential diagnostic potential of observations relating to a further feature in doctor–patient talk in clinical encounters about seizures, namely references to individuals not present during the encounter (third parties). People with seizures who talk to their doctor often refer to others who are not present. Previous work has alerted researchers (and neurologists) to the important role that references to people who are not present during the conversation can play, and suggested that a focus on third party references could uncover further linguistic observations which could help with the differential diagnosis of epilepsy and PNES. However, previous studies have not examined or described the use of third party references in detail. The aim of the research reported here was to describe the nature of such references and to discover differences in how and when patients with epilepsy and those with PNES refer to third parties not present during first encounters with a neurologist.

2. Method

2.1. Patients

Between May 2005 and January 2008 unselected adults (aged over 18 years) with refractory seizures who had been referred for 48 h of video-EEG observation to the Department of Neurology at the Royal Hallamshire Hospital (Sheffield, UK) by a Consultant Neurologist because of diagnostic uncertainty were invited to take part in this study. Patients admitted for epilepsy surgery evaluation were not approached. Patients were only included if a diagnosis of epilepsy or PNES was eventually proven during the period of admission. Diagnoses were confirmed by assessment of clinical history, video-EEG recording of a typical seizure involving impairment of consciousness, confirmation of the recorded seizure as typical by patients and witnesses, and scrutiny of ictal electro-clinical appearances by fully trained neurophysiologists. Participants were excluded from the study if a dual diagnosis of epilepsy and PNES was demonstrated by video-EEG or considered possible on clinical grounds, if they were not fluent in English, or had learning disabilities. All patients completed the Hospital Anxiety and Depression Scale (HADS)[34] and Trauma History Questionnaire (THQ).[35] The Graded Naming Test[36] and the Test for Reception of Grammar (Version 2)[37] were used to assess linguistic competence.

Clinical assessment by neurologists not involved in this study (including the analysis of the video-EEG recording of typical seizures in all cases) revealed that seven of the 20 patients who had given written informed consent to participate in the study had epilepsy and 13 had PNES. The clinical interviews analysed here were included in previous studies.[29,31,33] The patients (and the ratio of epilepsy and PNES diagnoses) are representative of patients admitted to this unit for diagnostic video-EEG monitoring. Patients with epilepsy were significantly older than patients with PNES and the proportion of females was significantly greater in the PNES group.

2.2. Interview method

Participants were interviewed on their own by a neurologist blinded to the video-EEG findings. Participants and neurologist had not met previously. Interviews were conducted following guidelines initially developed by the EpiLing project in Bielefeld, Germany.[23–26] Prior to this study we demonstrated that the semi-standardised interview procedure could be replicated in English with similar sociolinguistic findings.[27,28] The most significant differences between this interview procedure and 'traditional' history taking are that doctor's contributions are restricted to encourage the patient to develop their own communicative agenda and to maximise their participation in the conversation. This involves the use of open questions, which give the floor to the patient and can be addressed in a range of ways. Interruptions and direct questions about clinical features (such as ictal injuries, tongue biting, incontinence, etc.) and previous treatments are deliberately discouraged. The interviews began with an open question, which makes no direct mention of seizures ("what was your expectation when you came here?"). Accounts of individual seizure episodes were then elicited by asking: "Could you tell me about your first/worst/last seizure?" Finally, the patient was encouraged to elaborate something that s/he had already described earlier on in the conversation (e.g. "You say that you black out in this seizure. Are you completely unconscious when this happens or can you still hear or see what is going on around you?"). This phase is referred to as the challenge phase in previous publications based on the same interview method.[23–26] The use of this semi-standardised approach increases opportunities to identify diagnostically differential linguistic responses to the same interactional challenges and allows researchers to relate findings to previous work in this area. The interviews took place in the video-EEG suite and lasted a median of 25 min each (range 16–46 min), with no statistical difference between PNES and epilepsy samples (p 0.895).