The rate of misdiagnosis in epilepsy is high. As many as 20 per cent of patients may be initially misdiagnosed resulting in one in five patients taking anti-epileptic drugs (AEDs) when epilepsy is not the cause of their seizures. Meanwhile the real cause goes undetected. So why is the diagnosis of epilepsy so challenging and what are we doing about it?

There are more than 40 types of epilepsy and many different seizures. To complicate matters further seizures which may appear similar to an observer can have very different causes requiring different treatment. For instance, attacks with loss of awareness, collapse and shaking may have one of three causes. They may be caused by abnormal electrical activity in the brain, as in epileptic seizures; by a temporary reduction of the blood supply to the brain, as in faints; or by a sequence of events in which the brain ‘switches off’ because it is overwhelmed by distressing feelings, thoughts or memories as in non-epileptic attack disorder (NEAD).

The greatest difficulty is distinguishing between epilepsy and NEAD. Traditional tests such as electrical heart or brainwave recordings or brain scans are normal in most patients when they are not having one of their attacks and are therefore of limited use for diagnosis.

The limitations of these tests in achieving satisfactory outcomes have led us to think more innovatively about the process of making a diagnosis and to examine whether something as simple as the way a person describes their seizures could give us clues as to their origins.

Twenty years ago researchers from Bethel Epilepsy Centre in Bielefeld, Germany began to examine the language of patients describing their seizures to differentiate between epileptic and non-epileptic seizures. As well as looking at what patients said about their seizures, they focused on how patients talked to the doctor. They felt that although the visible symptoms of a seizure may be similar in both epileptic and non-epileptic patients, the person’s own experiences and the way they described them should be different and helpful in diagnosis.

To ensure they were tapping into the patient’s own seizure experience, unprompted by leading questions from the doctor, they devised a method of history-taking beginning with an open question making no mention of seizures. For example they might ask ‘what can I do for you today?’ before moving on to similarly open prompts about memorable seizure episodes – ‘can you tell me about your first/last/worst seizure?’

Using this sort of clinical interviewing, researchers showed that the way a patient described their seizures differed depending on whether they were epileptic and non-epileptic seizures. Language, it seemed, may well help doctors differentiate between epilepsy and NEAD.

Almost 10 years ago, we began to apply these methods in Sheffield. We also began our own studies looking at the language of seizures, using conversation analysis, the close examination of metaphors (or figures of speech patients use to describe seizures) and the diagnostic labels they attach to their seizures. Our studies were based on 20 interviews at our video-EEG unit to confirm epilepsy or NEAD.

Conversation analysis
This study focused on ‘interactional’ differences between patient and doctor, looking at how people talk and respond to each other in conversation. The most prominent interactional features suggesting a diagnosis of NEAD were called ‘detailing block’
and ‘focusing resistance.’

‘Detailing block’ refers to the small amount of information volunteered by patients with NEAD about their own seizure symptoms. ‘Focusing resistance’ describes their inability or unwillingness to focus on their seizure symptoms.

While people with epilepsy tended to describe subjective seizure symptoms in great detail, those with NEAD preferred to talk about the situations in which their seizures occurred or the consequences of their seizures.

‘Focusing resistance’ becomes particularly apparent when patients are prompted to speak about particular seizure episodes but don’t provide much information. They might say things such as ‘I can’t remember my first seizure’ or ‘they are all the same.’

In this study two linguists were asked independently to predict the diagnosis eventually proven by video-EEG. The linguists did not have any other information about the patient than video recordings and transcripts of the conversation between the neurologist and the patient. Both linguists correctly predicted the final medical diagnosis in 17 out of 20 patients. This is quite an achievement considering that only eight out of 20 patients had been given a correct clinical diagnosis prior to their admission.

**Metaphors**

We then examined the metaphors patients used to describe their seizures. All metaphors were separated into three groups with different meanings.

In the first group seizures were described as an agent or force. These metaphors imply that the seizure does something to the patient and the patient is the victim of the seizure. In the second group seizures were depicted as an event or situation. Here the seizure can act on its own but the patient is a witness of the seizure’s actions rather than a victim. The third group were metaphors where seizures were a space or place patients travel through. In these the patient was active and the seizure was quite passive.

The table below gives examples of the 383 metaphors we identified. Our study showed that patients with epilepsy preferred metaphors depicting the seizure as an agent/force or event/situation. By contrast, patients with NEAD more often used metaphors of space/place for their attacks.

**Seizure labels**

We also analysed patients’ use of diagnostic labels. Whereas ‘fit’ and ‘blackout’ were used as lay terms, the word ‘seizure’ was typically only used for attacks which had been diagnosed by a health professional.

Patients with NEAD used fewer symptom labels than patients with epilepsy and often resisted using the the word ‘seizure’.

Analysing how people speak not only helps with the diagnosis of the different seizure disorders but also helps us to understand these disorders better. For instance, the ‘detailing block’ and ‘focusing resistance’ seen in patients with NEAD may reflect the fact that these attacks have something to do with processing distress by blanking out difficult situations or memories.

Metaphors preferred by people with epilepsy may help doctors understand why epileptic seizures can cause quite disabling anxiety. Patients may feel better understood by physicians who pay attention to how they describe their seizures and who then use similar metaphors when they talk to them.

In the same way, patients’ resistance to the term ‘seizure’ is not only useful as a pointer to the diagnosis of NEAD but also communicates an important message to the doctor. Some patients may be in doubt about the medical nature of their problem and may be ready to accept a psychological explanation for their seizures. Further research into the language of seizures is now under way.

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www.nonepilepticattacks.info/
drifting off creep up on you not being there witnessed being off somewhere else run their course through seizures are straight there

Artists and epilepsy: Symphonia 5, Douglas Capron, Canada (one of the entries in the IBE Epilepsy without words photography competition)