

What should we call pseudoseizures? The patient's perspective

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Background: There are numerous terms to describe seizure-like episodes not explained by disease—for example pseudoseizures, psychogenic seizures and non-epileptic attack disorder. Debates about which is best to use tend to centre around theoretical arguments and not scientific evaluation. In this study we examine the meanings of these labels for patients, which have the least potential to offend, and consequently to provide a more positive basis for further management.

Methods and results: We interviewed 102 consecutive general neurology outpatients who were asked to consider a scenario that they were being given a diagnosis by a doctor after experiencing a blackout with normal tests. We investigated 10 different diagnoses for blackouts with six different connotations. Three of these connotations—‘putting it on’, ‘mad’ and ‘imagining symptoms’—were used to derive an overall ‘offence score’. Using this score some labels were highly offensive, e.g. ‘symptoms all in the mind’ (89%) and ‘hysterical seizures’ (48%). There were no significant differences between the labels ‘pseudoseizures’, ‘psychogenic seizures’ and ‘non-epileptic attack disorder’. ‘Stress-related seizures’ and ‘functional seizures’ were significantly less offensive than these three diagnoses and were equivalent to ‘tonic-clonic’ and ‘grand mal’.

Conclusions: Many labels for seizures unexplained by disease are potentially offensive to patients. The search for labels that accurately describe the phenomenon, can be used by patients, doctors and researchers and enhance trust and recovery is worthwhile and amenable to scientific study.

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Key words: seizure; pseudoseizure; psychogenic seizure; conversion disorder; diagnosis; labels.

INTRODUCTION

Patients with attacks that look like epilepsy but are not due to a recognised physical disorder are common in neurological practice. As many as one third of patients attending specialist epilepsy clinics may have this problem¹.

One of the most vexed questions in the management of these patients is what diagnosis to use^{2–4} and how to deliver this diagnosis to the patient^{5,6}. Numerous labels have been applied over the years, ranging from ‘hystero-epilepsy’ in the 19th century to ‘non-epileptic attack disorder’ in the late 20th century. Unfortunately, in our experience many of these labels seem to convey to patients the idea that the doctor thinks that they are ‘mad’ or ‘putting on’ their symptoms. The final mean-

ing of a diagnosis is of course dependent on factors other than the label itself, such as the way in which it is delivered by the doctor and the way that society stigmatises mental disorders. In this study, however, we focus on the labels themselves and explore their acceptability and offensiveness to general neurology outpatients.

METHODS

We approached consecutive new patients attending general neurology out patient clinics in Edinburgh. Most patients are referred to these clinics from their primary care doctor. Patients were asked after their consultation: “If you had blackouts, your tests were

Table 1: "If you had blackouts, your tests were normal and a doctor said you had X would he be suggesting that you were Y (or had Y)": percent responses among 102 new neurology outpatients and overall offence score.

X diagnoses	Y connotations (% response, <i>n</i> = 102)					Offence score (% (95% CI)) ^a	
	Putting it on (Yes)	Doctor doesn't know what it is (Yes)	Mad (Yes)	Medical condition (No)	Imagining symptoms (Yes)		A good reason to be off sick from work (No)
Symptoms all in the mind	74	55	29	70	70	67	89 (82–94)
Hysterical seizures	38	34	12	32	30	55	48 (38–58)
Pseudoseizures	29	25	6	23	21	46	33 (24–43)
Psychogenic seizures	22	17	5	10	16	27	26 (18–36)
Non-epileptic attack disorder	17	21	2	15	17	38	22 (15–32)
Tonic-clonic seizures	8	10	3	8	6	31	12 (6–20)
Stress-related seizures	6	18	0	10	5	21	8 (3–15)
Functional seizures	3	7	0	5	4	30	6 (2–12)
Grand mal seizures	4	4	3	5	3	28	5 (2–11)
Epilepsy	0	0	0	1	0	31	0 (0–4)

^a The proportion of subjects who responded 'Yes' to one or more of: 'putting it on', 'mad' or 'imagining symptoms'. 95% confidence intervals calculated by exact Clapper–Pearson method.

normal and a doctor said you had (diagnosis X) would he be suggesting . . . (connotation)Y?" The 10 diagnostic labels for blackouts (X) and 6 connotations (Y) are shown in Table 1. Responses were coded as 'Yes', 'No' or 'Don't Know' for each of the 60 combinations of diagnosis and connotation. These were different patients to those interviewed for a similar study on patients views of diagnostic labels for weakness⁷.

By consensus we decided that three of the connotations, 'putting it on', being 'mad' or 'imagining symptoms' could reasonably be considered as offensive. For each diagnosis, the proportion of subjects who said 'Yes' to one or more of these categories was called the 'offence score'. Local research ethics approval was obtained.

RESULTS

Two medical students (K.C. and N.S.) approached 127 consecutive new patients attending a general neurology out patient clinic. Twenty-one patients declined to take part and four further interviews were incomplete, leaving 102 patients included in the study. The mean age of the sample was 42 years (range of 18–62). Sixty percent of the patients were female.

Responses were consistent across categories for each diagnostic label (Table 1); 'epilepsy' always had fewest negative connotations whereas 'symptoms all in the mind' always had most. The 'offence score' was similar for the commonly used terms 'non-epileptic attack disorder', 'pseudoseizures' and 'psychogenic seizure' (Fig. 1). There were no significant differ-

ences between these categories (Fisher's exact test). 'Stress-related seizures' and 'functional seizures' were significantly less offensive than 'non-epileptic attack disorder', 'pseudoseizure' and 'psychogenic' ($P < 0.0001$, Fisher's exact test).

DISCUSSION

Commonly used diagnoses for pseudoseizures may be offensive to patients

The results confirm the clinical suspicion that many of the labels used for pseudoseizures have offensive connotations for patients. Most importantly many of the labels seem to communicate the possibility that the doctor thinks the symptoms are being 'put on' or deliberately manufactured.

Obtaining a diagnosis is a major reason why patients see doctors. While it may be possible to manage a patient without being explicit about the diagnosis, the question 'So what have I got then?' will inevitably arise if not from the patient, from their friends and family or from social agencies.

A considerable amount of debate has already taken place about what to call pseudoseizures²⁻⁴. The word *pseudoseizure* implies what the attack mimics, rather than what it is and the prefix 'pseudo' implies falsehood. Implying that the attacks are purely psychological in origin with the label *psychogenic seizures*⁸ ignores important physiological aspects (such as the autonomic disturbance of panic) and socially determined aspects of these

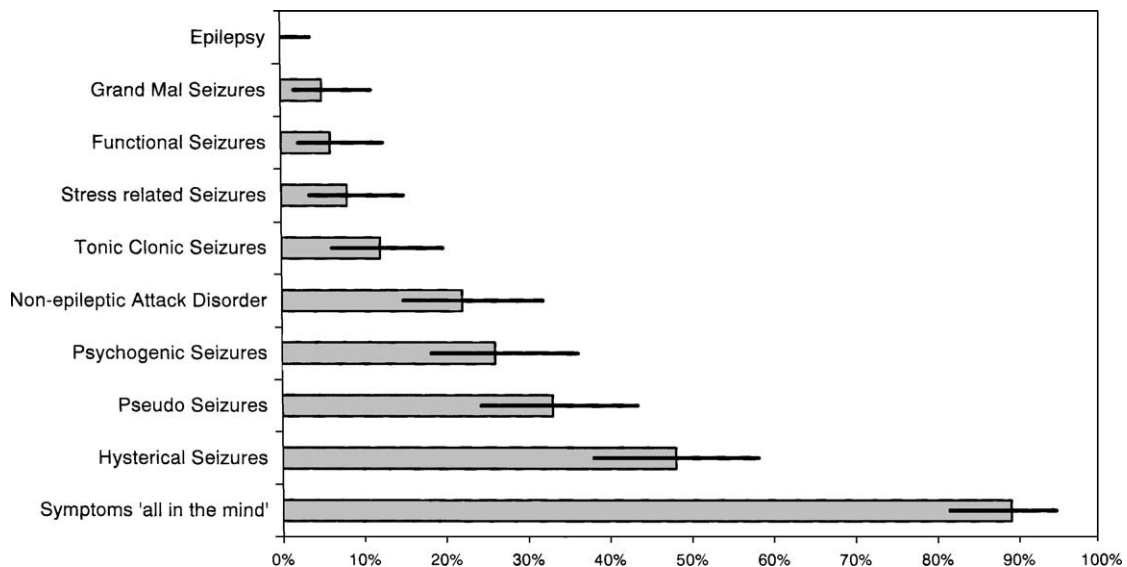


Fig. 1: Overall offensiveness of labels for blackouts—doctor would be suggesting I was 'putting it on', 'mad' or 'imagining symptoms' if I had blackouts and they gave me this diagnosis (%) (102 neurology patients). Bars represent 95% confidence intervals.

symptoms. In addition, to many people, the prefix 'psycho' brings up associations with words like 'psychopath' and 'psychotic'. *Non-epileptic attack disorder*⁹ is a neutral term but is a 'non-diagnosis' like 'non-cardiac' chest pain. It tells the patient what they don't have rather than what they do. The word *hysteria* carries substantial negative baggage¹⁰ but refuses to lie down¹¹ perhaps because it is the only word that specifically excludes malingering in its definition.

On the basis of this study, we find that the diagnoses *non-epileptic attack disorder*, *psychogenic and pseudoseizure* are similar in their capacity to offend around one third of neurology patients. Can we do better? The term *stress-related seizures* was less offensive. However, labelling attacks as stress-related might suggest to the patient that their external environment is wholly to blame and thus the attacks are outwith their control¹². This could represent an obstacle to recovery¹².

Labels are not as important as the explanations and physician attitude that accompany them

The successful delivery of a diagnosis of pseudoseizures is a skilled exercise. It relies on a number of factors including the attitude of the doctor, the confidence with which the diagnosis is made and the explanation used. Authors have consistently emphasised the importance of winning the trust of the patient and making it explicit that you believe their attacks are real^{5,6}. It could be argued that whether the doctor chooses a physiological explanation ('Your attacks are like an electrical short circuit') or a more psychological explanation ('Your attacks are emotional in origin') is less important than this underlying message of belief in the reality of the symptoms. Additionally, Jackson and Kroenke have shown how a doctor's negative attitude to patients with symptoms unexplained by disease can be an independent risk factor for poor outcome¹³.

Functional seizures?

'Functional seizures' was the least offensive 'non-organic' term assessed in this study. Although theoretically epilepsy is also a functional neurological disorder only 2% of neurologists regard it as such¹⁴. At some level, there must be a disturbance of the function of the nervous system in patients with pseudoseizures. Perhaps 'functional seizures' or better still, 'functional non-epileptic seizures', could be a useful diagnosis that circumvents an unhelpful physical versus psychological debate with the patient, avoids a

'non-diagnosis' but continues to emphasise that the problem is not epilepsy.

Limitations

We acknowledge a number of limitations to this exploratory study: it is based on a hypothetical situation; the subjects do not themselves have pseudoseizures; the interviewing procedure could have biased the results; and real-life usage of these terms would usually, one hopes, entail additional clarification and explanation. Other labels such as dissociative seizures, conversion disorder, non-organic seizures and psychological attacks could be usefully examined in further studies.

CONCLUSIONS

This study is the first time that patients have, to our knowledge, been asked what they think about labels for pseudoseizures and has highlighted the degree to which they may be viewed as offensive if not clarified. We need labels that can be used transparently between doctors and patients, in the clinic room and in research publications¹⁵. The ideal label is one which conveys a positive diagnosis but does not risk having a negative effect on the patients' ability to cope, either by suggesting they have no control over their symptoms (such as epilepsy) or that they have too much control ('putting it on'). We wish to argue that the implications of diagnostic labels to patients are an important and a researchable topic worth pursuing.

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