Seizure, Fit or Attack? The Use of Diagnostic Labels by Patients with Epileptic or Non-epileptic Seizures

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We present an analysis of the use of diagnostic labels such as *seizure*, *attack*, *fit*, and *blackout* by patients who experience seizures. While previous research on patients' preferences for diagnostic terminology has relied on questionnaires, we assess patients' own preferences and their responses to a doctor's use of different labels through the qualitative and quantitative analysis of doctor–patient interactions in a realistic clinical setting. We also examine whether two sub-groups of patients—those with epileptic seizures and those with (psychogenic) non-epileptic seizures—show different behaviours in this respect. Our findings suggest first that patients make fine lexical distinctions between the various diagnostic labels they use to describe their seizure experiences; secondly, that patients play an active role in the development and application of labels for their medical complaint; and thirdly, that attention to patients' lexical choices and interactive use or avoidance of labels can be relevant for the differential diagnosis of seizures.

INTRODUCTION

It is widely acknowledged that while lexical choice plays a crucial role in human verbal interaction (Hakulinen and Selting 2005), establishing the meaning of alternative lexical items is far from straightforward, especially if contextual factors are taken into account (Fischer 1998; Xiao and McEnery 2006; Norén and Linell 2007). In this article, we explore the function of lexical choice and the meanings of a number of related lexical items in the context of a specific type of medical interaction. We focus on the use of diagnostic labels—that is, lexical items that refer to an illness or the symptom of an illness—in interactions between a doctor and patients with recurrent seizures.

The choice of diagnostic labels is significant for many reasons. For patients, the labels which describe their illness are a core aspect of their 'illness representations' (Leventhal *et al.* 1992; Horne 1999; Hagger and Orbell 2003). A range of studies have confirmed that 'the manner in which individuals perceive their illnesses is likely to impact on many aspects of their experience, including the likelihood of seeking help, the particular nature of the help being sought, the degree of adherence to the treatment prescribed, and the

likelihood of response to such treatment' (Manber *et al*. 2003: 335). For example, patients who view their depression as caused by a 'chemical imbalance' are unlikely to engage in or respond to psychotherapy, even if this treatment is the most suitable from the physician's point of view (Manber *et al*. 2003: 336). Associations between patients' illness representations and treatment outcomes have been found in diverse clinical scenarios including Irritable Bowel Syndrome and Chronic Fatigue Syndrome (Edwards *et al*. 2001; Rutter and Rutter 2007), cardiac events (Petrie *et al*. 2002; Lau-Walker 2004), and epileptic and non-epileptic seizures (NES) (Kemp *et al*. 1999; Goldstein *et al*. 2004; Green *et al*. 2004).

For the doctor, it is important to adopt diagnostic labels which are clear, but which do not carry unwanted connotations. Misunderstandings are particularly likely in the area of medically unexplained symptoms, or 'psychosomatic disorders', which include NES. NES superficially resemble epileptic seizures, but are not caused by abnormal electrical activity in the brain. NES are an involuntary response to distressing situations, physical, or emotional stimuli (Reuber and Elger 2003). Most patients with NES have a previous history of traumatic experiences or face difficult dilemmas in their current lives. However, they typically fail to recognize the relevance of psychological or emotional factors for their seizures (Reuber and Grünewald 2007). They may therefore resist labels that associate their disorder more closely with a psychological problem and prefer labels which imply a physical aetiology, such as *epilepsy*. However, the clear differentiation of epilepsy and NES is very important to doctors because the two seizure disorders are treated differently. Whereas the first line of treatment for epileptic seizures involves the use of antiepileptic drugs, the treatment of choice for NES is psychotherapy (Reuber and Elger 2003; Reuber *et al*. 2005). Patients with NES who are inappropriately labelled as having epilepsy, or who fail to understand that they do not have epilepsy, are at risk of receiving unnecessary and potentially harmful medical treatments, and are unlikely to improve.

Unfortunately, there is considerable uncertainty amongst doctors about the most appropriate diagnostic label for NES. One paper identified 19 different terms in the recent medical literature (Scull 1997). Whereas some terms give patients the impression that the doctor does not understand the cause of the attacks, others suggest that seizures are 'put on' or 'all in the mind': in fact, it has been shown that terms such as 'hysterical seizure' and 'pseudoseizure' are likely to offend patients (Stone *et al*. 2003). The implications for compliance with proposed treatment are obvious. For the doctor–patient relationship to work effectively, 'diagnostic labels have to be not only helpful to doctors but also acceptable to patients' (Stone *et al*. 2002: 1449; see also Page and Wessely 2003).

Whereas the medical literature on diagnostic labels tends to discuss the advantages and drawbacks of particular terms from the doctor's point of view, this article will focus on patients' use of labels for their condition or their main symptom. Our study is based on one-to-one conversations between

a doctor and 21 patients with epileptic or NES. The study is a part of the project *Listening to people with seizures* at the University of Sheffield, UK, which set out to improve the differential diagnosis of seizure disorders by analysing the communicative behaviour of patients with epileptic and NES (Schwabe *et al.* 2007). This project was inspired by a range of sociolinguistic studies carried out at the Bethel Epilepsy Centre and the University of Bielefeld in Germany (Schwabe *et al.* 2008).

Our article seeks to answer two questions. First, we wanted to determine how patients use diagnostic labels for their seizures and which labels they prefer. Stone *et al.* (2003) employed a questionnaire to address the second half of this question. They asked neurology outpatients a range of variants of the question 'If you had blackouts, your tests were normal and the doctor said you had *pseudoseizures*, would that be suggesting that you *were putting it on*?' In contrast, our study takes a corpus-based approach (Biber *et al.* 1994), relying solely on the analysis of actual doctor–patient interactions. This methodology allows us to assess patients' preferences directly: that is, we can gain insight into patients' actual preferred use of diagnostic labels, rather than their reported preference in hypothetical scenarios. The sociolinguistic methods applied in *Listening to people with seizures* are strongly informed by work in Conversation Analysis (Drew *et al.* 2001; Schegloff *et al.* 2002), which has a long history of investigating issues of lexical choice and labelling in realistic interactional settings: see for example the work on membership categorization by Sacks (1972, 1992) and Schegloff (2007a, 2007b).

Secondly, we set out to explore whether patients with epilepsy and patients with NES differ in their preferences or use of diagnostic labels. Although epileptic and NES look similar to an external observer, the results of the German studies as well as the preliminary findings of the *Listening to people with seizures* project show that patients with these aetiologically distinct seizure disorders describe their seizures very differently (Schwabe *et al.* 2007; Plug *et al.* in press). Broadly speaking, patients with epilepsy readily focus on the seizure experience and on the description of individual episodes, and volunteer a lot of information about how they feel during their seizures. Patients with NES, on the other hand, are more likely to talk about the impact of the seizures on their lives and about the failure of previous treatment; they need to be prompted to focus on how they feel *during* seizures, and generally provide less detailed information about individual seizure episodes than patients with epilepsy.

In view of the superficial similarities between the manifestations of epileptic and NES it is perhaps not surprising that the differential diagnosis represents a serious challenge for doctors, who have to base their diagnosis on seizure descriptions in most cases. Tests carried out in between seizures are only modestly useful in this setting. Seizure recordings are impossible if seizures are infrequent. These difficulties may explain why most patients eventually diagnosed with NES on the basis of the 'gold standard' investigation (the synchronous recording of a typical seizure with video and EEG

(electroencephalography)) have carried an inaccurate diagnosis of epilepsy for several years (Reuber *et al.* 2002). Any additional differential diagnostic pointers, for instance from patients' interactive use or selection of labels, could therefore be very useful in clinical practice.

METHODOLOGY

This study is based on the analysis of 21 first clinical encounters between a doctor (M. R., a consultant neurologist) and patients with seizures. The clinical interviews were conducted between August 2005 and July 2007. All patients had been admitted to the neurology ward at the Royal Hallamshire Hospital in Sheffield, UK, for 48 hours of video-EEG monitoring because their admitting neurologist was uncertain whether they had epileptic or NES. All patients had seizures with impairment of consciousness while being monitored. All diagnoses were confirmed by the video-EEG recording of a seizure which was considered typical of the habitual attacks by the patient and a seizure witness. Eight patients were found to have epilepsy, 13 NES. Pseudonyms were used to protect participants' identity. The study was approved by the South Sheffield Ethics Review Committee and all patients gave written informed consent for their consultations to be recorded and analysed.

The consultations were audio- and video-recorded using pre-installed monitoring equipment. Each consultation lasted between 20 and 35 minutes and followed a semi-standardized interview procedure which encourages the doctor to adopt an unusually passive but very attentive role, and which allows patients to develop their own communication agenda (Schwabe *et al.* 2007; Plug and Reuber in press). One aspect of the interview procedure of particular importance for this study is that the doctor opens the consultation by asking the patient about his/her expectations of the current hospital visit— with no mention of *seizures* or any other diagnostic label. At the beginning of the interview, it is therefore left to the patient how he/she refers to the seizure episodes. Moreover, the doctor does not present a diagnosis during the consultation. Therefore, while the doctor's lexical choices may influence the patient's, the doctor cannot be said to impose a terminological frame of reference: this is largely left to the patient.

All 21 consultations were transcribed following standard conversation-analytic conventions. All nouns referring to the patients' seizures—such as *seizure*, *fit*, *attack*, *blackout*—were identified and subjected to further qualitative and quantitative analysis. In particular, we were interested in establishing whether different labels were used synonymously or whether differences in meaning could be observed. We were also interested in how the doctor's use of a particular label affects the patient's lexical choice in the immediately subsequent speaking turns. Quantitative differences in usage between the doctor, patients with epilepsy and patients with NES were analysed using the Mann–Whitney *U*-test for independent groups (ordinal variables) and

Pearson's Chi-square test (categorical variables). Two-tailed p-values <0.05 are reported as significant.

It is worth highlighting that a number of factors that may be expected to influence patients' communicative behaviour, including lexical choice, were controlled for in this study. As indicated above, all consultations were led by the same doctor, who did not have an established relationship with any of the patients and followed the same interview procedure in each case. Therefore, for the purpose of our analysis 'the doctor' can be treated as a relatively homogeneous category. Personal details were taken for each patient, so that any effects of gender, age, and duration of medical treatment could be investigated. In addition, all patients were assessed for their general linguistic competence using the Graded Naming Test (McKenna and Warrington 1983; Warrington 1997) for vocabulary and the Test for Reception of Grammar Version 2 (Bishop 2003) for grammar. On the other hand, we did not classify our patients in terms of social, geographical, or educational background, so that 'the patient' remains a relatively heterogeneous category.

DIAGNOSTIC LABELS AND OVERALL USAGE PATTERNS

Table 1 provides an overview of the diagnostic labels identified in the 21 consultations. The diagnostic label *seizure* was used most frequently, both by patients and by the doctor (255 instances in total). The term *seizure* was also used by the greatest number of patients (16 out of 21) and it was used by the doctor in most interviews (16 of 21).

The most commonly used alternative labels were *fit*, *attack*, and *blackout*; together, these occurred 240 times in our data. A similar number of patients used the terms *fit* and *attack* (12 versus 11, difference not significant); and considering that 40 of the 66 usages of *attack* were attributable to a single

Table 1: *Overview of diagnostic labels used by patients and doctor*

Diagnostic label	Patients' usage		Doctor's usage	
	N	$N_{patients}$	N	$N_{consultations}$
Seizure	132	16	123	16
Fit	41	12	6	3
Attack	66	11	99	17
Blackout	22	4	6	5
Absence, Grand mal, Petit mal, Partial seizure, Tonic clonic (seizure), Dizzy do, Funny do, (Funny) turn, Reaction, Chin thing, (Chin) episode, Blank spell, Collapse	≤ 10	≤ 3	≤ 2	≤ 1

patient, the number of instances in which patients used the terms *fit* and *attack* were also rather similar.

In the cases of *fit* and *attack*, there were interesting differences in usage between doctor and patients. Patients used *fit* much more commonly than the doctor. The doctor on the other hand showed a marked preference for the label *attack*. Whereas he used *attack* 99 times in 17 consultations, he only used *fit* 6 times in 3 consultations. This means that there were several consultations in which a patient used the label *fit* repeatedly, but the doctor chose not to adopt the label. Conversely, there were a number of encounters in which the doctor used *attack* repeatedly, but the patient persisted in their use of alternative labels. The differences between patients' and doctor's usage were statistically significant, both for *fit* (usage: 41 versus 6, $p = 0.006$; number of patients/consultations: 12 versus 3, $p = 0.004$) and *attack* (usage: 66 versus 99, $p = 0.02$; number of patients/consultations: 11 versus 17, $p = 0.05$). *Blackout* was used sparingly by doctor and patients alike, and additional diagnostic labels, including epilepsy-specific terms such as *grand mal* or *partial seizure*, as well as relatively colloquial labels such *dizzy do* or *funny turn*, were used 10 or fewer times by patients and/or doctor.

To explore to what extent the described patterns of usage reflect patients' own preferences, rather than alignment with the doctor, we checked in how many consultations each of the diagnostic labels was first used by the patient (patient-initiated usage) and in how many the patient only used a label after the doctor had introduced it (doctor-initiated usage). We only found a small number of examples (six patients, two labels) in which patients altered their terminology after the doctor had first used a particular term. One of the 16 patients who used the label *seizure* only did so after it was first mentioned by the doctor, whereas 15 out of our 21 patients self-initiated the use of *seizure* as a diagnostic label. All 12 patients who used *fit* self-initiated its usage. However, five out of the 11 patients who used *attack* did so only after the doctor had introduced the term.

This offers further support for the suggestion that *seizure* is the most popular diagnostic label in this patient group; that *fit* is relatively popular among patients although it is used sparingly by the doctor; and that *attack* is used frequently by the doctor while only a small number of patients use the label without prompting.

DIFFERENCES IN MEANING BETWEEN DIAGNOSTIC LABELS

The quantitative differences reported above were replicated when we focused on those encounters in which the patient used at least two different labels. For example, 10 patients used both *seizure* and *fit*. In these 10 encounters, *fit* was used a mean of three times per consultation, while *seizure* was used eight times. Taken together, these quantitative observations suggest that while at first sight the terms listed in Table 1 would appear to be synonymous, they may in fact have different meanings in the context of the interactions we are dealing

with—if not at the level of denotation, perhaps in terms of their connotations or the collocational patterns in which they participate. To assess whether this is the case, we investigated the contexts in which the labels were employed in our consultations in greater detail.

This qualitative investigation revealed patterns of usage which suggest that there are indeed differences in meaning between individual labels. In what follows, we outline the crucial patterns and propose an account along two lines. First, we suggest that there are differences in the degree of specificity of reference between certain labels. Secondly, we suggest that the patients' lexical choice is governed at least in part by the perceived appropriateness of certain labels in medical versus lay registers. We discuss the former differences in meaning in terms of differences at the level of denotation, and the latter in terms of differences at the level of connotation.

Differences at the level of denotation

Many of the patients' usages of *fit* and *blackout* suggest that these labels refer to a specific type of paroxysmal event, or a phase within a wider event trajectory, while the most popular diagnostic label, *seizure*, has a more general and inclusive denotation. Relevant examples of the use of *fit* are given below.

(1)   a. 'and then I fell down with the fit' (Carl).
      b. 'that's about fifteen minutes before I go into the really deep fit, you know' (Sue).
      c. 'others go into a more, er a bigger fit kind of thing' (David).
      d. 'I kept having these like fits, just collapsing and having fits, like grand mal symptoms, jerking and losing consciousness' (Chris).
      e. 'as I say I thought epilepsy was someone thrashing about having a fit on the floor' (Samantha).

Carl and Sue both use *seizure* repeatedly to refer to events that involve a period of altered consciousness, followed by a period of complete unconsciousness and loss of physical control, and finally a gradual return to normality. Their uses of *fit* in (1a) and (1b) suggest that Carl reserves this label for the period of complete unconsciousness, while Sue uses it to refer to the middle phase of her more serious seizures. Similarly, David describes several types of paroxysm—with repeated use of *seizure*—including episodes in which he loses control of his body, but remains conscious throughout. He uses *fit* to refer to seizures in which he loses consciousness completely, as seen in (1c). Chris' use of *fit* in (1c) suggests that in addition to loss of consciousness, 'fits' involve involuntary movement—or 'jerking'. Chris distinguishes his 'fits' from 'blackouts', to which we turn below. The same is apparent from Samantha's description of someone 'thrashing about having a fit'. In Samantha's case, she does not describe her own seizures as 'fits', and she does not mention involuntary movement as a prominent symptom.

The clearest evidence that (like *fit*) *blackout* is a more specific diagnostic label than *seizure* is provided by Chris; in particular in the fragment given in (2).

(2) Doctor: well can I (.) take you back to your first (1.0) seizure (1.6)
     Chris: which one
     Doctor: well you know you've come here because of these blackouts (0.3) what about the first one you can remember (0.3) what can you tell me about that (1.6)
     Chris: the blackout or the (.) fit cos i'm having like (.) two different types at the moment

Chris' subsequent usage of *blackout* suggests that both 'fits' and 'blackouts' involve complete loss of consciousness and possibly a limp collapse, but only 'fits' involve involuntary movements. This observation is confirmed by several other uses of *blackout*. Additional relevant examples are given in (3).

(3) a. 'the blackouts started being different [. . .] you know, just dropping' (Chris).
     b. 'it was more like a blackout than anything else that one [. . .] nothing happened to me while I was gone if you like, I was just gone' (Alastair).
     c. 'because when I'm having the blackouts I could just be stood there' (Alastair).
     d. 'to me they were just blackouts, but not to everybody else [. . .] I just thought, one minute I can remember something, next minute I can't' (Sue).

In (3a), Chris indicates that what he calls 'blackouts' are seizures that involve him 'just dropping'—but not 'jerking'. While Alastair also describes seizures in which he loses control over his body, he suggests that in some 'nothing happens', and he remains stationary while his mind has 'gone' (3b and c). Sue's use of *blackouts* in (3d) highlights a possible mismatch between the diagnostic label that the patient may assign to a seizure-related event on the basis of his/her own experience, and that of onlookers. Sue indicates that she started experiencing brief periods of unconsciousness and loss of memory. She was not aware of her physical state during these periods; therefore she classified as 'blackouts' what to those around her looked like 'fits'.

The usage of *attack* by the patients (as well as the doctor) suggests that it is synonymous with *seizure*; that is, it is a diagnostic label with a more general denotation than *fit* and *blackout*. Relevant examples are given in (4).

(4) a. 'it's been ver- very – they've been very disruptive to my life, the, the er, the seizures, the attacks I've been having' (Zack)
     b. 'I had another, erm, I had another, er, seizure, but there again, I d- I don't know what happened with these attacks' (Jack)
     c. 'I was having a fit at the time [. . .] everything was going off-scale in that attack' (Betty)
     d. 'it must be difficult to remember individual seizures when it's – they're such long way back, but maybe, maybe you can tell me about the last attack, what – just explain exactly what, what, what happened in, in the last seizure that you had' (Doctor to Sandra)

> e. 'so you, you said you're scared after seizures [...] and how do you feel *in* the attack?' (Doctor to Laura)

Both Zack and Jack use *seizure* and *attack* within one speaking turn, with no indication that the two labels differ in meaning (4a and b). Betty's use of both *fit* and *attack* in (4c) is consistent with the idea that the former is a sub-type of the latter: she describes one particular 'attack' as involving her 'having a fit'. The doctor uses *attack* and *seizure* interchangeably on several occasions, as seen in (4d and e).

Most of the less frequent diagnostic labels, in particular the epilepsy-specific terms such as *absence*, *partial seizure*, *grand mal*, and *petit mal* refer to particular types of seizures, but we have too few occurrences of these labels in our data to be able to report significant generalizations regarding their contexts of use. Our observations with regard to *seizure*, *fit*, *blackout*, and *attack* can be summarized as in (5): our patients recurrently use *fit* and *blackout* to refer to a specific sub-type of seizure or to a specific phase in a wider seizure trajectory, while reserving *seizure* and, sparingly, *attack* to refer more generically and inclusively to seizure-related events.

(5)   *seizure, attack*   GENERAL DENOTATION

         fit   *blackout*   SPECIFIC DENOTATION
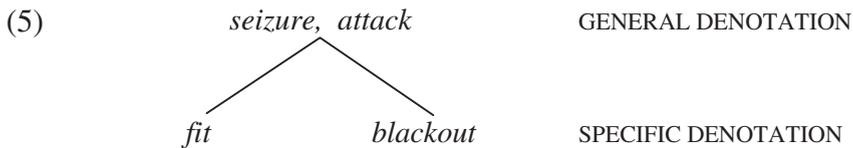
Differences at the level of connotation

In addition, we observed usage patterns which can be understood in terms of a register-related difference between *seizure* on the one hand and *fit* and *blackout* on the other. In particular, while *seizure* appears to have a more general denotation than *fit* and *blackout*, its usage by some of our patients suggests that it also has the connotation of 'medical term', while the more specific *fit* and *blackout* are at the same time more 'colloquial', representing the patient's personal experience rather than a medical diagnosis. Again, we illustrate the crucial usage patterns below.

First, we note the occurrence of instances of self-repair from *fit* to *seizure*. Examples are given in (6).

(6)   a. 'in one respect the fi- seizures were better' (Barbara)
      b. 'I could have it, have a fit – seizure whatever you will call them' (Peter)

In (6a) Barbara starts saying 'fits', but cuts off its production in favour of 'seizures'. She uses *seizure* as a diagnostic label throughout the rest of her consultation, and does not use *fit* or *blackout*. Peter does produce 'fit', but repairs it to 'seizure' immediately (6b). His accompanying remark 'whatever you will call them' is suggestive of a concern with what is the 'correct'

terminology to use in the setting of the consultation. In fact, one way of understanding examples such as those in (6) is in terms of an orientation by the patient to *seizure* as a medical term which can be used freely in interactions with a doctor, and to *fit* as a term that is potentially inappropriate. The fact that the doctor uses *fit* only six times in the 21 consultations is indeed consistent with it being a dispreferred diagnostic label from the doctor's point of view.

Perhaps more strikingly, over half of the instances of *fit* and *blackout* in our data occur either in the context of reported speech by or directed at a lay person, or in the context of explicit reporting of personal experience, rather than general description or diagnosis. Examples of these two contexts are given in (7) and (8) below.

(7)   a. 'and he said I were, like, having, like, a fit, in my bed, jerking and everything' (Chris)
      b. 'right mate, you had a fit' (Peter)
      c. 'he's scared I'm going to have a fit in the middle of the street' (Betty)
      d. 'I just say hold on, I'm gonna have a fit' (Sandra)
      e. 'he says, you've got a – have you – do you suffer from seizures, I says yeah' (Tallulah)
      f. 'they said that the erm, seizures I'm having aren't as bad while I've been on medication' (Betty)

In (7a) Chris reports the observations of his brother using *fit*. The fragment both confirms that for Chris, 'fits' involve involuntary movement, and suggests that *fit* is a label that a lay person would use. This is confirmed by Peter and Betty's reports of a third person's use of *fit* (7b and c); on both occasions the third person is an acquaintance, not a doctor. Sandra's formulation of her habitual warning to friends before a seizure (7d) is consistent with an orientation to *fit* as an appropriate term to use in interaction with non-experts. Interestingly, Sandra self-initiates the use of *seizure* and uses it consistently throughout the rest of the interview, in which the context of reported speech does not reoccur. In our data, *seizure* is found in the context of reported speech only when the speech is that of a doctor, as is the cases in (7e and f) in which Tallulah and Betty describe particular hospital visits.

We have already seen the example of Sue indicating that when she first started having seizures, she thought she was having 'blackouts', while other people used alternative labels (3d). It is in this context—that of the patient's reporting of first 'realising the illness' (Halkowski 2006)—that we find more uses of *fit* and *blackout* than *seizure*. Here, patients are explicitly reporting their own experience before they received a medical diagnosis. Additional examples of instances of *fit* and *blackout* in this context are given in (8).

(8)   a. 'when I first started having fits' (Betty)
      b. 'and that's when the blackouts started' (Chris)
      c. 'and I'd maybe have a cluster of seizures, but I didn't know they were seizures at the time' (Samantha)

d. 'and I went into a seizure, but I didn't know' (Tallulah)

In (8a) Betty uses the label *fit* when referring to her very first seizures, while in the rest of the interview she repeatedly uses *seizure*. Chris similarly uses *blackout*—as well as *fit*—when referring to his first experience. The fragments in (8c and d) illustrate the recurrent retrospective application of the diagnostic label *seizure* to early, pre-diagnosis episodes: that is, the patient reports having had a seizure but not knowing that it was one at the time. This strongly suggests that the label *seizure* is one whose use is licensed by a medical diagnosis; not one that is readily used outside a medical context or in narratives of patients' first symptom discovery. *Fit* and *blackout*, on the other hand, are used in exactly these contexts.

The usage patterns illustrated in this section confirm that *seizure* on the one hand and *fit* and *blackout* on the other have different contextual distributions. One possible explanation for this is that there are register-related differences in meaning between these diagnostic labels. In the context of our interviews, patients appear to orient to *seizure* as a medical diagnostic label, whose use is appropriate in interaction with doctors and licensed by a medical diagnosis. They orient to *fit* and *blackout* as labels whose use is more appropriate in lay registers and which can be used to describe personal, pre-diagnosis experiences of seizure-related events. This account is summarized in (9).

(9)   *seizure*   MEDICAL REGISTER

        fit   *blackout*   LAY REGISTER
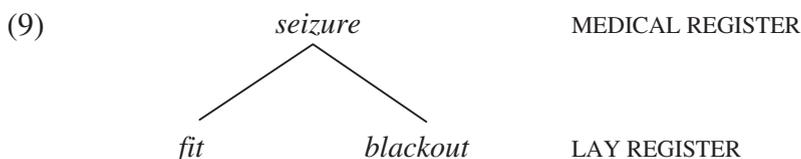
RESISTANCE TO THE USE OF DIAGNOSTIC LABELS

Having described which diagnostic labels patients use most commonly and explored a number of usage patterns which suggest meaning differences between some of these, we now focus on those diagnostic labels which patients do *not* commonly use, or which they adopt with evidence of a certain amount of hesitation or resistance. First of all, several patients seemed to show a *general* resistance to the use of diagnostic labels for their seizures. This was evident, in particular in the opening phases of the consultations. As indicated above, the doctor started each consultation with an open inquiry regarding the patient's expectations of the current hospital visit, without overt reference to seizures. All patients referred to seizures in their response to this inquiry, but eight out of 21 initially used a pronoun rather than any of the diagnostic labels we have discussed so far. A clear example is given in (10).

(10)   Doctor: what were your expectations when you (0.3) when you came here
                      (0.3)

Alastair:	erm (0.3) I was just hoping that we could find (1.0) what it was (0.3) that was causing **them**?
Doctor:	mmm
Alastair:	hopefully lead to something that would stop me having **them** so I could continue having a normal life
Doctor:	mmm
Alastair:	you know cos er (.) it's been very disrupted since **it** started
Doctor:	it's been very disrupted
Alastair:	yeah (.) well cos I've been off (.) of work on (.) at work off work (*several lines omitted; no diagnostic label*) **they** come and go so I can't really (2.2) risk being in a car
Doctor:	mmm
Alastair:	which is a shame so as soon as er (2.2) something's found out (.) I can go back to being er (0.3) normal
Doctor:	mmm
	(3.6)
Alastair:	yeah (0.3) so that's where **they**'re up to (1.4) well that's my expectation
Doctor:	mmm

Here, Alastair formulates an elaborate response to the doctor's opening inquiry in which he refers to his seizures several times using *they/them* (in bold), and to his disorder using *it* (in bold). It is only after a further inquiry by the doctor that he reverts to a diagnostic label—in this case *blackout*.

Evidence for general resistance against the use of diagnostic labels can also be found at other points during the consultation. Some patients attempt to avoid using labels in the description of particular episodes, even if several labels have already been mentioned earlier on in the consultation. Others accompany their use of labels with comments that downplay their commitment to them. We have already seen an example of the latter in (6b), in which Peter accompanies his self-repair from *fit* to *seizure* with the comment 'whatever you will call them'. Additional examples are given in (11).

(11) a. 'and then one of these (0.6) things started' (Trudie)
      b. 'I just want the fits to s- whatever they are to stop completely' (Betty)
      c. 'during the seizure or whatever it is I've had' (Betty)

In (11a), Trudie hesitates at the point when the use of a diagnostic label is relevant. After a pause, she opts for 'things'—avoiding the use of a specific label. In (11b and c), Betty uses both *fit* and *seizure* with the indication that she does not know what types of seizures she's having—and, by extension, that she does not know whether her use of diagnostic labels is 'correct'. The examples in (10) and (11) suggest that patients may feel they lack the authority to provide a diagnostic label for their experiences. One strategy is, then, to avoid using any label, at least until the doctor suggests one; another is to make it clear to the doctor that the use of a given diagnostic label is open to correction.

We have already mentioned patients' resistance to the use of the label *attack*, which the doctor used frequently as a synonym of *seizure*: only 11 out of our 21 patients used it. While one of these eleven patients used the label more than 40 times during the consultation, most others used it sparingly. As seen above, six patients chose not to adopt the label despite the doctor's repeated use. Illustrative fragments are given in (12) and (13). In both, the doctor's inquiry contains *attack*, but in their responses the patients choose to use an alternative label.

(12)   Doctor: so you (.) came in here to learn about the small
       Ken: yeah
       Doctor: attacks
                      (0.2)
       Ken: I've had one while I've been here
                      (1.7)
       Doctor: [mmm
       Ken: [but they're just (0.9) they only last for a couple of seconds (.)
                      there's a slight sort of partial seizure (0.3) it's er (1.3) it sort of
                      doesn't develop into a full seizure

(13)   Doctor: so that's in the attacks you had that feeling
       Samantha: yeah (.) yeah
       Doctor: mmm
       Samantha: erm (.) but up until this point I'd never ever had a full blown
                      seizure where I sort of lost consciousness (.) I could carry on
                      going about my business whilstever this were going on in my
                      head

It is perhaps surprising that the most popular label overall, *seizure*, was also the one that was most frequently and overtly resisted. First of all, recall that 16 out of 21 patients used this label at some point during the consultation. This means that five patients did not, although the doctor used the label repeatedly in two of these cases. We have already seen Chris' use of *fit* and *blackout* in direct response to the doctor's inquiry about his first 'seizure' in (2) above. In fact, Chris avoids the use of *seizure* throughout the consultation, while he uses *fit* and *blackout* repeatedly. Similarly, Steve avoids *seizure* despite the doctor's repeated usage, in this case in favour of several labels including *funny turn* and *funny do*.

Several other patients use *seizure* only in the context of reporting a previous medical diagnosis, rather than their own experience of seizures—using alternative labels in all other contexts. For example, we have seen two such uses of *seizure* by Tallulah in (7e) and (8d) above. Elsewhere in the consultation, she overtly resists the adoption of seizure, despite its use by the doctor, as seen in (14).

(14)   Doctor: is this related to (.) to the seizures er er not waking up from a
                      seizure or just not (.) waking up
       Tallulah: not waking up from (0.3) a sei- er having a fit

Here, Tallulah's response to the doctor's inquiry takes the form of a repetition of part of the inquiry: 'not waking up from a seizure'. However, Tallulah hesitates before 'a seizure' and subsequently cuts off its production in favour of 'having a fit'. Her self-repair, which constitutes a marked deviation from the part-turn repetition format and a marked refusal to align with the doctor in terms of lexical choice, makes it very clear that the adoption of the diagnostic label *seizure* is problematic for her.

In addition, the hesitations and hedging remarks illustrated in (11) above most frequently involve the use of the label *seizure*. Some more examples are given in (15).

(15) a. 'I've never had any problem with er (0.8) seizures or anything' (Trudie)
      b. 'because there's – I seem to have erm two different sorts of (0.9) seizures happening' (Pat)
      c. 'just really to find out what the problem is or what's causing (.).hhh erm (0.3) the seizures' (Sandra)

If patients' general resistance to using diagnostic labels is due to their perceived lack of authority on the issue of what their seizures should be called, then their specific resistance to the use of *seizure* may be explained in terms of the 'medical' connotations of this particular label. We have suggested above that while *fit* and *blackout* are lay terms which a patient can use freely without implications of self-diagnosis, *seizure* is a more formal medical diagnostic label. As such, its use may imply a degree of command and understanding of seizure-related medical terminology. While about half of our patients use *seizure* without evidence of hesitation or resistance—and in fact a few appear to adopt the term precisely because they feel the context of the medical consultation occasions it, as seen in (6) above—some display an orientation to *seizure* as medical vocabulary to which they themselves do not have straightforward right of access. The latter patients leave it to the doctor to decide on an 'official' diagnostic label that best covers what they describe as their experience.

RELEVANCE FOR THE DIFFERENTIAL DIAGNOSIS OF PATIENTS WITH SEIZURES

At this point, we turn to our second research question: do patients with epilepsy and patients with NES differ in their usage preferences or responses to certain diagnostic labels used by the doctor? So far we have discussed our patient group as a whole; however, when we compare the two clinical sub-groups striking differences emerge.

The clearest difference relates to the usage of *seizure* as a diagnostic label— or the resistance to using *seizure* described in the previous section. When we compare the frequency of usage between the two sub-groups, we see that 76 out of the 132 instances of *seizure* were produced by patients with epilepsy

and 56 by patients with NES. This means that the mean number of instances per patient was 9.5 for the epilepsy sub-group and 4.3 for the NES sub-group. First, we can therefore state that patients with epilepsy used *seizure* more frequently than patients with NES. When we do the same comparison for *fit* and *blackout* we find the reverse pattern. Of the 41 instances of *fit*, 31 were produced by patients with NES (2.4 instances per patient) and 10 by patients with epilepsy (1.3 instances per patient). All 22 instances of *blackout* were produced by patients with NES. That is, patients with epilepsy preferred *seizure* over *fit* and *blackout*, and patients with NES used *fit* and *blackout* but appeared to disprefer the use of *seizure*. The pattern is summarized in Figure 1. A Mann–Whitney *U*-test reveals that the difference for *seizure* is statistically significant (mean 9.5 versus 4.3, $p = 0.034$), although the differences for *fit* and *blackout* are not.

Table 2 provides a more detailed view of the usage of and resistance to the label *seizure* among patients in the two sub-groups. Of the eight patients with epilepsy, all used *seizure* in the course of the consultation, and all self-initiated its usage. Of the 13 patients with NES, five did not use seizure at all, and six did not self-initiate its usage. Chi-square tests reveal that in both cases the difference between the two sub-groups is significant (no use of *seizure*: $\chi^2 = 4.04$, $p = 0.04$; no self-initiation: $\chi^2 = 5.17$, $p = 0.02$). Of the five patients who use *seizure* with evidence of resistance to the label, four have NES and one has epilepsy (difference not statistically significant). Together, these figures mean that only three out of 13 patients with NES use the label *seizure* without priming and without reservation, as opposed to all but one of eight patients with epilepsy. A Chi-square test confirms that this overall difference between the two sub-groups is significant ($\chi^2 = 8.24$, $p = 0.004$).

Of course, given the relatively small numbers on which our comparisons are based, we cannot at this point conclude that the observed differences between the two sub-groups of patients are robust and generalizable beyond our patient group. Nevertheless, the statistical significance of several of our comparisons does suggest that the differential patterns we observe are unlikely to be due to chance alone. It may be noted that the factors sex, age, and duration of medical treatment showed no significant effects in the same comparisons. Moreover, there is no observable difference between the two patient groups in terms of general linguistic competence: all patients scored average or above in both the Graded Naming Test and the Test for Reception of Grammar Version 2.

While our second research question focuses on the patients' rather than the doctor's lexical choices and communicative behaviour, it is worth noting that in our data, the doctor used the label *attack* more often in consultations with patients eventually found to have NES than in those diagnosed as having epilepsy (6.5 times per conversation versus 2.0 times, $p = 0.019$). Given the findings we have just reported, we may now have an explanation for this: the doctor may have resorted to the use of *attack* when he observed a degree of resistance to the label *seizure* on the patient's part. This would
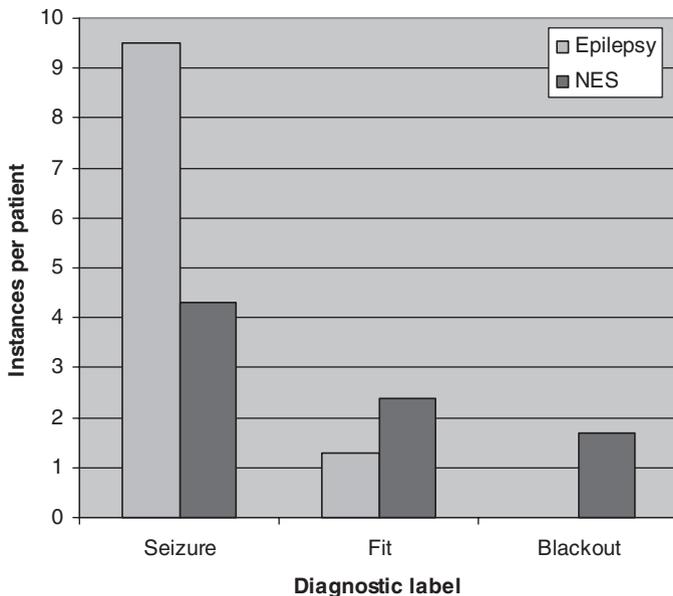
Figure 1: Bar chart showing mean instances per patient for seizure, fit, *and* blackout *in epilepsy and NES sub-groups*

Table 2: Resistance to the diagnostic label seizure, *comparing the epilepsy and NES sub-groups*

Disorder	N	No use of seizure (%)	No self-initiation of use of seizure (%)	Use of seizure with evidence of resistance (%)	Any evidence of resistance to seizure (%)
Epilepsy	8	0 (0)	0 (0)	1 (13)	1 (13)
NES	13	5 (38)	6 (46)	4 (31)	10 (77)

mean that patients' terminological preferences directly influence the doctor's choice of labels.

Finally, while patients with epilepsy were less likely to show resistance to the label *seizure* and to use *fit* and *blackout* instead, they were also more likely to adopt epilepsy-specific terminology when describing their seizure experience. The diagnostic labels *absence*, *partial seizure*, *tonic clonic* (*seizure*), *grand mal*, and *petit mal* occur almost exclusively in consultations with patients with epilepsy. This may seem a trivial observation, but it is not: each of our patients' diagnosis was unclear at the time of the consultation we recorded, and all patients who turned out to have NES had previously been diagnosed

with epilepsy—and had therefore been exposed to epilepsy-related diagnostic terminology. Nevertheless, the patient groups behaved differently in terms of their willingness to adopt this terminology. Patients with epilepsy readily adopted diagnostic labels which patients with NES may have seen as medical vocabulary items which were somehow less appropriate for them to use than the lay terms *fit* and *blackout*.

DISCUSSION AND CONCLUSION

We set out to address two questions: first, which diagnostic labels do patients prefer to refer to their seizures; and secondly, do patients with epilepsy and patients with NES differ in their usage preferences or responses to the choice of certain diagnostic labels by the doctor? With respect to the first question, our study shows that *seizure* is a particularly popular diagnostic label, while *attack* is dispreferred and resisted by many patients. Further studies are necessary to establish whether this resistance is a general feature of patients with seizures, or whether it is particular to our sample of patients. Unfortunately, the label was not included in the set evaluated by Stone *et al.* (2003), and we have little insight into patients' interpretations of this label from other sources. In addition, it remains to be established how common the relative preference of the label *attack* is amongst doctors. The label occurs in the context of the medical term *Non-Epileptic Attack Disorder (NEAD)*, which is certainly widely used in the professional literature. If our findings are replicated by studies in larger patient populations, doctors may need to reconsider whether it is beneficial to use a term in this setting which is not readily acceptable to patients.

We also found that *fit* and *blackout* are relatively popular, but that they are not synonymous with *seizure*: patients recurrently use *fit* and *blackout* to refer to particular sub-types of seizure or phases within a wider seizure trajectory, and use the terms in the context of lay description of their experience. In contrast, *seizure* is used in contexts that favour established medical vocabulary. We have suggested that it is particularly the register difference between *seizure* on the one hand and *fit* and *blackout* on the other that explains why some patients show resistance to the use of *seizure*, while such resistance is much less common for *fit* and *blackout*. Especially when talking about their own experience, patients may feel they do not have access to medical vocabulary—or at least that their access must be licensed by the doctor in the course of the consultation. They may also feel that by using medical vocabulary, they would be claiming a degree of authority over their disorder with which they do not feel comfortable. Again, further studies are needed to confirm whether the differential use and treatment of *seizure* on the one hand and *fit* and *blackout* on the other is generalizable beyond our sample of patients.

As it stands, our proposed meanings of these labels account for a number of observed usage patterns in our consultations. Further studies on a wider

patient population may reveal patterns for which our proposals cannot account, and will provide a stronger empirical basis for the statement of the lexical meanings of the various diagnostic labels used by doctors and patients. Moreover, our analysis somewhat undervalues the fact that parameters of lexical choice may shift during the course of an interaction (Hakulinen and Selting 2005; Norén and Linell 2007). While we have discussed in some detail several contexts in which individual labels are recurrently used and have commented on the extent to which the doctor's usage of terminology influences the patient's and vice versa, our observations only scratch the surface of the sequential-interactional dimension of lexical choice. We must leave this dimension as an area for further research.

With respect to the second question, we noted several differences in the way patients with epilepsy and patients with NES use diagnostic labels. Patients with NES showed a tendency to avoid the use of labels such as *seizure* or *attack*, and to prefer labels such as *fit* and *blackout*. Patients with epilepsy did not show significant resistance to *seizure*, and several used epilepsy-specific medical terminology themselves. We have indicated that the factors sex, age, duration of treatment, and general linguistic competence do not help to explain this difference between the two patient groups. Other factors may be significant, however: as pointed out above, we did not control for the social, geographical, and educational background of the patients, let alone their sociolinguistic competence, sensitivity to register or state of mind at the time of the consultation. Again, more research is needed to assess the robustness of our current findings.

Notwithstanding these reservations, it is interesting to consider the possibility that the observed difference between the two patient groups is related to the distinct ways in which patients with epilepsy and NES communicate about their seizures. As suggested above, sociolinguistic research on a large sample of German patients has shown that while patients with epilepsy readily volunteer information about subjective seizure symptoms and particular seizure episodes, the communication behaviour of patients with NES in relation to their seizures is characterized by 'focusing resistance'. They tend to offer brief and superficial seizure accounts and put more emphasis on the situations in which seizures occur or on the negative impact seizures have had on their lives. When asked about specific seizure episodes, such as their first, last or worst seizure, they often say that they cannot remember, or produce general accounts of their seizures rather than descriptions of particular events (Schwabe *et al.* 2008).

At first sight, it is difficult to make sense of the relationship between the usage patterns reported in this article and the wider communicative differences between patients with epilepsy and NES. If patients with epilepsy spend more of their consultations talking about their personal seizure experiences, one would expect them to use *fit* and *blackout* more frequently than *seizure*. Similarly, if patients use the less generic and inclusive *fit* and *blackout* as part of an attempt to downgrade the seriousness of their disorder in communicating

with the doctor, one would not expect patients with NES to use these terms more frequently than patients with epilepsy: it is patients with NES who tend to stress the negative impact of the seizures on their lives. Patients with epilepsy are more likely to communicate that they are actively engaged in minimizing the impact of the seizures on their daily lives, and that they are coping as well as they can. We suggest that it may be this higher level of engagement with the process of diagnosis and treatment which makes patients with epilepsy more likely to adopt vocabulary which we have characterized as 'medical' in consultations than patients with NES. The latter patients' general resistance to engaging in a detailed discussion of their seizure experience would seem compatible with a resistance to the use of this type of vocabulary, and a tendency instead to resort to more colloquial formulations. Provided that our findings are generalizable to a larger patient population, this would be an interesting hypothesis for further research.

While the clinical relevance of our findings remains to be established, especially given their basis in careful *post hoc* analysis rather on-line observation during consultations, they confirm that while healthcare professionals play a significant role in shaping patients' views, patients take an active part in the negotiation of diagnoses and the use of diagnostic labels (Gerhardt 1989). Patients are capable of translating differences in seizure manifestations into lexical distinctions, and may resist the use of certain labels or actively encourage the doctor to apply particular labels to their experiences. Despite suggestions in early labelling theory (Hagan 1973; Mercer 1973), labelling is therefore not a one-way process from doctor to patient, but a complex, interactional negotiation with doctors and patients as participants with equal stakes (Maynard 1992; Gill and Maynard 1995; Peräkylä 1998).

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