

ANALYSING PATIENTS' TALK IN THE DIFFERENTIAL DIAGNOSIS OF SEIZURE DISORDERS: A CASE COMPARISON

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Abstract

Despite technological advances, 'taking the history' remains the doctor's most important tool in the diagnosis of seizures. In this paper we focus on the differential diagnosis of epileptic and psychogenic non-epileptic seizures (NES). Misdiagnosis rates are high, and diagnostic errors often result from poor history taking, including suboptimal questioning and inaccurate interpretation of the patient's responses. We describe a novel procedure for history taking and a method of analysis which appears to be superior to the conventional fact-oriented approach in the differential diagnosis of patients with seizures. The procedure is designed to leave the patient free to direct the course of the conversation, as opposed to the doctor asking a series of questions. The analytic method takes cues from linguistics and Conversation Analysis, and focuses as much on how patients talk about their seizures as on what precise symptoms they list. We illustrate the procedure and method through a case comparison of two of our patients, one of whom has epilepsy and one of whom has NES.

1. Introduction

While neuroimaging technology and access to tests such as video-EEG monitoring have improved dramatically over the last few decades, the interaction between doctor and patient is still the most important tool in the differential diagnosis of seizures. In many cases, the doctor must diagnose the patient's seizure disorder on the basis of the patient's description of his or her seizures alone. That is, the diagnosis is based entirely on the history, since physical tests remain inconclusive. Given that the act of taking the history is so important for the accurate diagnosis of epilepsy, and for distinguishing epileptic seizures from psychogenic non-epileptic seizures, faints and rarer causes of blackouts, it is surprising how little attention researchers have paid to this particular communication.

A number of studies have suggested that epilepsy and fainting can be distinguished reliably on the basis of symptom clusters which can be straightforwardly elicited from the patient (Hoefnagels, Padberg, Overweg, van der Velde and Roos 1991; Sheldon, Rose, Ritchie, Connolly, Koshman, Lee, Frenneaux, Fisher and Murphy 2002). The differentiation of epilepsy syndromes—which are caused by abnormal electrical activity in the brain—and psychogenic non-epileptic seizure disorders—which are generally rooted in some form of psychological distress (Reuber, Howlett, Khan and Grünwald in press)—is more challenging. Several recent studies have shown that symptoms traditionally elicited by doctors to inform the diagnosis, such as the presence or absence of ictal injury, or the onset of seizures during sleep, have no predictive value (Geyer, Payne and Drury 2000; Reuber and Elger 2003; Duncan, Russell and Conway 2004). The rate of misdiagnosis is high, ranging from 5 to 50% in different clinical settings (Howell, Owen and Chadwick 1989; Scheepers, Clough and Pickles 1998; Benbadis, O'Neill, Tatum and Heriaud 2004). As a result, many patients with NES are wrongly—and dangerously—treated with antiepileptic drugs. Research has shown that one of the commonest reasons for diagnostic errors is poor history taking or the misinterpretation of facts gathered in the history (Smith, Dafalla and Chadwick 1999). In this paper, we describe a novel procedure for history taking and a method of analysis which appears to be superior to the conventional

fact-oriented approach in the differential diagnosis of patients with epilepsy and patients with NES. We begin by sketching the background to the current project.

1.1. Listening to People with Seizures

In the 1990s a multidisciplinary team of neurologists, linguists, psychiatrists, sociologists, psychotherapists and psychologists based in Bielefeld, Germany, set out to study systematically how people with seizures talk to doctors, conscious of the need to improve the accuracy of diagnoses and inspired by the informal observation that patients with epilepsy and patients with NES seem to communicate differently with their doctors. The team used conversation analytic and linguistic methods to analyse clinical encounters in which patients talk to doctors about their seizures. Conversation Analysis—or, more broadly, ‘sociolinguistic micro-interactional analysis’ (Frankel 2000)—is increasingly applied in the area of medicine to improve understanding of doctors’ and patients’ communicative practices and as a training method in health communication (Peräkylä 1997; Drew, Chatwin and Collins 2001; Maynard and Heritage 2005). For example, conversation analytic studies have shown the benefits of using open-ended questions, such as *What can I do for you?* or *What seems to be the trouble?*, to start medical consultations, and of adopting a communicative stance that is centred on listening and encouraging rather than directing the patient’s presentation of concerns (Coupland, Robinson and Coupland 1994; Frankel 1995; Heritage and Robinson 2005). We will return to this point below.

Initially, the Bielefeld team described a range of features in patients’ conversations with the doctor, focussing on features which differed between patients. These included who introduces topics relating to the patient’s seizure experience (the patient or the doctor); whether the patient retains the focus on topics such as individual seizure episodes once the doctor has brought them up; how detailed the patient’s descriptions of particular seizure symptoms are; and how much formulation effort the patient expends to make the doctor understand what they mean, especially when talking about highly subjective, experiential symptoms. Having studied these features in a large group of patients with different (epileptic and non-epileptic) seizure disorders, the researchers noted that certain features seemed to cluster together and that two distinct communication profiles could be identified. A comparison of the two groups defined by linguistic criteria with the medical diagnoses revealed that one communication style was typically used

	Epilepsy	NES
Overall focus on the seizure experience	Volunteered	Requires prompting
Description of subjective seizure symptoms and phases of reduced consciousness or control	Volunteered, detailed and with evidence of formulation effort	Requires prompting, with little detail and frequent negative, holistic statements
Description of individual seizure episodes	Coherent	Focus not maintained or resisted
Seizure suppression attempts	Volunteered	Rarely mentioned
Metaphoric conceptualisation of the seizure experience	Coherent, describing the seizure as an external and threatening entity	Absent or incoherent

Table 1: Summary of differential diagnostic features found in the Bielefeld project

by people with epilepsy, the other by individuals with NES (Schwabe, Reuber, Schöndienst and Güllich submitted). Table 1 summarises the most important findings.

Two years ago we decided to take this research further by testing firstly whether the findings in the German patient population are generalisable to an English one, and secondly whether communication differences can *predict* the medical diagnosis of epilepsy or NES made by the recording of typical seizures with video-EEG. Our research is based on conversations with patients who were admitted to the Sheffield Royal Hallamshire Hospital for video-EEG monitoring because their consultant neurologist was uncertain about the correct diagnosis of their seizure disorder. The conversations follow a protocol which will be described below. A linguist who is unaware of the patient’s medical history and the outcome of the video-EEG monitoring analyses audio-visual recordings of the conversations with a particular focus on the differential features described by the Bielefeld team. This process generates a communication profile which informs a ‘linguistic’ diagnostic hypothesis—epilepsy or NES. This hypothesis is then compared to the ‘gold standard’ medical diagnosis based on the video-EEG monitoring.

At the time of writing this analysis has been carried out for 13 patients. In all 13 cases, the linguist was able to correctly predict the outcome of the video-EEG monitoring (see Table 2). This result is remarkable, and strongly suggests that the analytic method we are applying is of value in the differential diagnosis of seizure disorders.

Patient (pseudonym)	Prior antiepileptic drug treatment	Admission diagnosis	Video-EEG confirmed diagnosis
Barbara	yes	epilepsy	NES
Betty	yes	epilepsy/fainting	NES
Carl	yes	epilepsy	epilepsy
Chris	yes	NES	NES
David	yes	NES	epilepsy
Jack	yes	NES	epilepsy
Ken	yes	epilepsy	epilepsy
Laura	yes	epilepsy	NES
Patsy	yes	epilepsy	NES
Samantha	yes	epilepsy	epilepsy
Sandra	yes	NES	epilepsy
Sue	yes	epilepsy	NES
Tallulah	yes	NES	NES

Table 2: Treatment and diagnosis details of patients diagnosed in the Sheffield project

1.2. This paper

Previous publications have summarised the findings of the Bielefeld research collaboration (Schwabe et al. submitted) and shown that the results obtained in German patients can be replicated in English speakers (Schwabe, Howell and Reuber in press). Both papers used particularly clear transcript fragments from different patients to illustrate the distinguishing features described. In this paper we take a different approach. Here, we present a comparison of two patients, one with epilepsy and one with NES. The main purpose of this comparison is to demonstrate how we analyse individual patients’ talk about their seizures. The comparison

is presented in Section 3. However, we must stress that the success of our method crucially depends on the way the doctor conducts the conversation with the patient. We therefore first turn to the guidelines followed by the doctor in all conversations in our study.

2. Conversation outline

As in most research on health communication, the material we are working with cannot be classified as ‘spontaneous conversation’: the conversations we analyse are *consultations* led by a doctor. Moreover, the consultations are rather different from routine clinical consultations. Firstly, they are relatively long—between 20 and 30 minutes—and secondly, the role of the doctor in directing the topical trajectory of the conversation is severely constrained.

Figure 1 provides an outline of the conversations we are working with. As indicated there, each conversation comprises three main phases. The first, the ‘open’ phase, is initiated by the doctor’s inquiry as to the patient’s expectations of the present stay in hospital. Notice that the doctor does not mention seizures. It is largely left to the patient to direct the interaction in this phase of the conversation: the doctor should listen to what the patient chooses to talk about without interrupting. If the patient stops talking, the doctor is encouraged to tolerate silence or use ‘continuers’ such as *mmm* or *right* to indicate that he is listening. He may also repeat something the patient has said, to encourage the patient to keep talking. The latter strategy allows the doctor to exert some influence over the topical trajectory, for example by focussing the patient’s attention on something they have said ‘in passing’. Crucially, the doctor is not allowed to introduce any information which the patient has not already referred to. This clearly sets our conversations apart from most routine clinical consultations, in which the doctor presents the patient with a series of inquiries on matters which the patient may not voluntarily bring up. From the viewpoint of differential diagnosis, the ‘open’ phase allows the doctor to assess the extent to which the patient *volunteers*—freely, or with minimal direction—information about the seizure experience and individual seizure episodes.

The second phase is initiated by the doctor’s request to talk about the first seizure episode the patient can remember. The doctor then asks for accounts of the patient’s last and worst seizure episodes. This is to ensure that patients offer at least a few accounts of individual seizures. From the viewpoint of differential diagnosis, what matters is how easily the patient focuses on individual episodes and how much information the accounts offered provide about the patient’s seizure *experience*. Other than by making these three requests the doctor is expected to direct the course of the conversation as little as possible. However, it is part of the procedure that the doctor formulates one inquiry that challenges the patient’s account of the seizure experience so

<p>‘Open’ phase <i>What were your expectations when you came to hospital?</i></p> <p>Elicited seizure episode accounts <i>Can you tell me about the first seizure you can remember?</i> <i>Can you tell me about the last seizure you can remember?</i> <i>Can you tell me about the worst seizure you can remember?</i> Inquiry challenging the patient’s description</p> <p>Talk on a different topic <i>Can you tell me about things you enjoy doing?</i></p>

Figure 1: Summary of the conversation outline developed for in our study

far. This challenge, which particularly targets the patient's description of levels of consciousness, often takes the form 'You say you experience *x*, but have you ever experienced *y*'? From the viewpoint of differential diagnosis, the 'challenge' allows the doctor to assess the extent to which the patient is willing to revisit and revise or elaborate on previous description.

Finally, the doctor asks the patient to talk about something completely different: things they enjoy doing. This phase allows the doctor and patient to move to closing the conversation on an unproblematic topic—rather than on the traumatic topic of the patient's worst seizure. Moreover, it allows us to assess to what extent the patient's communication style in the conversation so far is specific to the topic of seizures.

3. Case comparison

We now turn to a consideration of two conversations, and an illustration of the analysis method applied in our project. This section outlines the analysis of two cases: Barbara and Jack (pseudonyms). Neither of these patients has been discussed in previous publications describing our research. Both patients were thought to have epilepsy prior to video-EEG monitoring and were receiving antiepileptic drug treatment. Moreover, both suffered from seizures with no or little prior 'warning', often starting during sleep. However, as Table 2 shows, one of the two patients was diagnosed with NES on the basis of video-EEG monitoring. Both diagnoses were correctly predicted by linguistic analysis. The following subsections show how the linguistic diagnostic hypothesis was formulated.¹

3.1. The 'open' phase

As indicated in Section 2, each conversation starts with an open inquiry by the doctor as to the patient's expectations of the test period. From the viewpoint of differential diagnosis an important question is whether the patient volunteers information about the seizure experience. As shown in Table 1, patients with epilepsy tend to volunteer information easily when faced with this communication challenge and are prepared to exert a great deal of formulation effort to convey to the doctor what it feels like to have a seizure. Patients with NES on the other hand tend to choose to talk about other topics need more overt direction before describing seizure symptoms.

The 'open' phase: Barbara Barbara's response to the initial inquiry is that, given her treatment history, she is not overly optimistic as to the outcome of the video-EEG monitoring exercise. This brings her onto her past experience with medication. At this early stage in the conversation she volunteers what appears to be an account of a particular seizure episode, represented in (1).²

(1) Barbara [0.31–0.50]

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1 B: i got to the stage where i was FOUND (.) in the middle of winter
2 SEven miles from home because i was on THAT much different
3 medicAtion .hhhh i'd walked out of home in the middle of the
4 night .hh down country lanes (-) and i i was found (.) SEven
5 miles from home .hhh so BASically they TOOK me off the medication
6 and this is the next (---) to try and see what's causing the-
7 seizures
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However, notice that Barbara does not explicitly present this episode as a *seizure* episode: rather, she attributes her wandering to the fact that she was heavily medicated, and does not indicate whether she considers it a seizure. She returns to the episode several times during the interview, and none of her accounts indicates clearly whether she thinks the wandering was caused by a seizure. In any case, in none of her accounts of this episode does Barbara elaborate her experience at the time: in other words, whether Barbara considers the episode a seizure or not, her accounts do not tell us much about her subjective experience. In the remainder of the ‘open’ phase of the interview Barbara provides more information about her treatment history and repeats that her expectations are low. She does not volunteer any additional accounts of memorable episodes or a description of typical seizure symptoms, despite attempts by the doctor to move the focus to the nature of her seizures. For example, in fragment (2) the doctor inquires into Barbara’s recent state of health. Her response treats the inquiry as relating to how many seizures she has been having, rather than to what her seizures have been like. In fragment (3) Barbara repeatedly suggests that her seizures were “better” when she was on medication, but her focus is on describing the extent to which she was “WORSE .hhh in (-) other ways”.

(2) Barbara [5.29–5.46]

1 D: so you’ve been better have you?
 2 B: no not really though there was a a while where i was sort of .hh
 3 not TOO bad when they’d got me on the pills i was on a (--) .hh i
 4 went a couple of years where they weren’t too bad but i’ve never
 5 really been (1.2) seizure FREE.

(3) Barbara [6.30–6.56]

1 D: you said you didn’t f- quite feel your same- er yourself when you
 2 were on the tablets
 3 B: no .hhh even though the FITS were better
 4 D: mmm
 5 B: i was sort of (1.2) i was in another WORLD i was like a ZOMBIE so
 6 (.) obviously .hh the pills helped the seizures (-) but (--) they
 7 left me (-) z- like a zombie i didn’t know whether i was coming
 8 or GOing so even though the pills helped the seizures i was a lot
 9 WORSE .hhh in (-) other ways

As far as the seizure experience is concerned, then, Barbara does not provide any information other than that she *has* a seizure disorder, until she is asked explicitly by the doctor to talk about the first seizure she can remember. Before we turn to Jack, we should note that Barbara appears to struggle with the doctor’s interview style. At various points during this phase of the conversation she repeats her response to the doctor’s initial inquiry, in the absence of a follow-up. Fragment (4) is a case in point.

(4) Barbara [2.00–2.35]

1 B: so (--) THAT’S what i expect NOTHING really (---) just the BEST
 2 that (they) can DO (-) tha- they can only DO their best can’t
 3 they really
 4 D: [mmm
 5 B: [i don’t know more than that (--) so (--) to have .hh high
 6 expectations it’d be (.) unfair- .hh on the people that are
 7 treating me wouldn’t it really
 8 D: mmm
 9 B: cos they can only DO their best (---) so
 10 (1.0)
 11 D: mmm

12 (1.2)
 13 B: the only expectations i have is that they Give me (.) the best
 14 they can and i s- i should iMAGine they WILL
 15 (1.4)
 16 so that's it
 17 (3.8)
 18 D: so you said at the moment the medication has been stopped

Prior to this fragment, Barbara has already indicated that her expectations of the test period are low. Here she makes the same point several times. Notice her use of *so* in lines 1, 5 and 9. In all three cases the item is preceded and followed by a pause and has the phonetic characteristics of what Local and Walker (2005) call 'trailoff-*so*': most notably, it is quieter and produced at a lower pitch than Barbara's preceding talk. Local and Walker show that this use of *so* indicates that 'at this point, the speaker does not wish to offer any further talk' (Local and Walker 2005: 125) and as such encourages the co-participant to take a turn and initiate topic shift. In the case of (4), however, the doctor repeatedly offers the minimal response token "mmm" only: see in particular lines 9 to 11. In the end, Barbara overtly closes her extended turn with "so that's it" (line 16). The doctor does not respond to this immediately, again leaving Barbara the opportunity to introduce a new topic for discussion herself. After a long pause he finally initiates topic shift himself, by referring back to something Barbara has said earlier (line 18).

As indicated in Section 2, the conversation guidelines we work with encourage the doctor to provide very little direction as to the topics covered—particularly in the 'open' phase. Patients must adapt to this lack of direction. What is significant from the viewpoint of differential diagnosis is whether they do this by self-directing the conversation to the seizure experience. Barbara does not: while all of the long silences in fragment (4) constitute opportunities for her to initiate topic shift, and while the doctor's inquiries in fragments (2) and (3) are treatable as moves in the direction of the description of her seizures, Barbara's focus remains on sharing with the doctor the failure and side-effects of prior treatment, rather than on informing him about the precise nature of her seizures.

The 'open' phase: Jack Turning now to our second patient under consideration, Jack is unique among our patients in that he overtly addresses the extent to which he is 'allowed' to direct the course of the conversation. Fragment (5) is from the first minute of the conversation, after Jack has indicated that he hopes to find out why he has had a relatively high number of seizures recently.

(5) Jack [0.48–0.55]

1 J: and i was hoping that something here will (-) sort of point a
 2 finger on it
 3 D: mmm
 4 (1.8)
 5 J: erm you ask the questions i believe or
 6 D: no
 7 (1.2)
 8 J: er it's okay to go ahead and SPEAK?
 9 D: YEAH yeah

Thus, in this case doctor and patient overtly establish, on the patient's initiative, what is left covert in our other conversations—namely, that the patient is free to determine the topical trajectory.

From the viewpoint of differential diagnosis Jack's request for confirmation of his license to "go ahead and SPEAK" is not significant in itself: what is significant is what Jack does with this

license following the doctor's confirmation. In a similar way to Barbara, Jack first stays on the topic of his general hopes of the outcome of the test period. He elaborates on recent traumatic events that he thinks may have caused him to have more seizures than before, and on his prior medical history. However, when talking about his medical history he formulates an account of his first seizure, represented in (6).

(6) Jack [3.32–3.60]

1 J: i didn't realise what the illness was all about at the time (-)
2 as a matter of fact i woke up one morning and foun- i was lying
3 on the floor (--) and there were two ambula- two ambulancemen
4 there my next door neighbours my WIFE (---) looking ghasted (--)
5 at ME and everything; (1.0) ah (.) i had about eight people in
6 the house looking at me because i'd fallen off the bed
7 D: mmm
8 J: but they didn't (.) er describe it as epilepsy until after some
9 more attacks (six) months afterwards

Jack refers to this episode explicitly as his first “attack”; in other words, this is clearly a volunteered account of a *seizure* episode. Moreover, Jack formulates the account in terms of his experience at the time: for example, he remembers his wife and others “looking ghasted (–) at ME” (line 5).

From a medical point of view this first account of a seizure episode does not provide us with a great deal of information about Jack's seizure experience. However, he maintains the focus on the seizure experience throughout the remainder of the ‘open’ phase. With occasional minor prompting by the doctor—mostly repeating something that Jack has said, or asking for clarification—Jack adds to the description. He provides several additional accounts of seizure episodes in which he describes his experience in some detail. For example, he refers to “waking up” and “going back to sleep” in the description of a particular seizure. When the doctor prompts for clarification, Jack offers a precise description of another seizure symptom, as shown in fragment (7).

(7) Jack [8.20–8.49]

1 D: is that what it feels like to you like going to sleep?
2 (1.9)
3 J: i have a slight (.) headache (--) as well AFterwards like
4 YESTerday and (.) the day before i h- i had a (-) slight pain
5 like across (-) the top of my he- (---) head here ((points to his
6 head)) (-) and it felt very you know and (1.9) it didn't feel
7 (1.6) er very HURting, but er i could FEEL like a heaviness on
8 the top of my HEAD;

Notice that Jack describes his headache in considerable detail, specifying what type of “pain” was involved: not a “very HURting” pain, but more of a “heaviness on the top of my HEAD” (lines 5 to 6). He perseveres with the description despite some apparent difficulty: especially the restart and long pauses in “and it felt very you know and (1.9) it didn't feel (1.6) er very HURting” (lines 4 to 5) suggest that Jack is putting considerable effort into the formulation of what he considers an accurate description of his experience.

To summarise the analysis so far, by the end of the ‘open’ phase of the conversation, the doctor has already gained a fairly clear impression of Jack's seizure experience: Jack has described subjective symptoms such as a headache in considerable detail and has provided accounts of particular seizure episodes. In contrast, the doctor has not been able to form any kind of impression of Barbara's seizure experience: Barbara's own focus is on other matters, such as the failure of previous treatment and the side-effects of her antiepileptic drugs.

3.2. Elicited seizure episode accounts

As indicated in Section 2, after the ‘open’ phase of the conversation, in which the patient is given the opportunity to direct the course of the interaction, the doctor focuses the patient’s attention on three respective seizure episodes: the first episode that the patient can remember, the last and the worst. As Table 1 suggests, patients with epilepsy typically focus easily and provide coherent, structured accounts of seizure episodes based on their own recollections or additional information they have gathered from witnesses. Patients with NES seem to resist a focus on particular episodes, offering negative and holistic statements such as ‘I never remember anything about my seizures’ or ‘I just pass out’, or provide elaborate accounts of the circumstances in which the seizures took place, their consequences and so on—but little information on what they can remember *feeling* before, during and after the seizure.

Elicited seizure episode accounts: Barbara Fragment (8) shows Barbara’s account of her first seizure.

(8) Barbara [6.28–6.54]

1 D: can i hhhh take you back to the first seizure you’ve had
2 B: hhhhh (-) that’s a VErY long time ago (-) .hh like i say i was
3 hhh (--) five and half month pregnant (1.0) and (1.2) the first
4 thing i remember was .hhh (.) the doctor being there- (--) cos MY
5 husband had rang the doctor because i (1.0) collAPSEd and
6 (2.2)
7 like i say i don’t REAlly have any recollection of what happens
8 .hhhh (.) i were just (.) bang (.) that’s it i’m gone

Barbara claims that she can only remember “the doctor being there” after she had “collapsed”. This amounts to a claim that she has no recollection of events before she lost consciousness. She does not go into detail about the circumstances in which the seizure took place and, most importantly, does not attempt to describe how she felt when she lost or regained consciousness, how long she may have been unconscious, what she may have done while she was unconscious and so on. Notice that she generalises away from her first seizure account quickly, shifting from past-tense to present-tense narration with “i don’t REAlly have any recollection of what happens” (line 7).

Nevertheless, immediately following the seizure account given in (8), Barbara describes three subjective seizure symptoms, as seen in (9).

(9) Barbara [6.55–7.20]

1 B: the only time i know .hh i’ve had one is when i COME round .hhh
2 (1.0) i’m hard of hear- i don’t hear straight away it takes a few
3 MInutes .hh for my hearing to come back i car- can’t hear a thing
4 .hhh um i’m VErY sl- my c- coordination’s slow (--) really really
5 slow .hh i c- i can’t hear anything and it leaves me with a
6 BLINDing headache .hh that is the only WAY i KNOW (.) that i’ve
7 had one

Barbara indicates that when coming round from a seizure, she experiences hearing loss, lack of coordination and a headache. Notice the self-repairs “i’m hard of hear- i don’t hear straight away” and “i’m VErY sl- my c- coordination’s slow”, which suggest that Barbara is at pains to formulate a precise description of the symptoms: her hearing loss is complete rather than partial, and her ‘slowness’ is due to an inability to coordinate her movements.

Barbara’s account of her last seizure is again brief, as seen in (10).

(10) Barbara [8.33–8.51]

1 D: what about the last one you've had
2 (1.0)
3 B: last night
4 D: mmm
5 B: .hhh more or less the same thing (--) i was (-) on the bed
6 watching teevee (---) i've had a seizure i've come round (---) i
7 can't hear (--) that's it and then i just carry on with life as
8 normal (1.2) just sort of (-) wake up (1.6) takes me a few
9 minutes to sort of get me bearings and (1.2) and then that's it

Again, Barbara generalises away from the individual episode very quickly. In fact, the only part of the account that is *specifically* about her last seizure episode is “i was (-) on the bed watching teevee” (line 6): immediately after this ‘scene setting’ she switches to present tense to revisit her earlier description of a typical seizure experience. Initially she mentions only one of the seizure symptoms she has already described (“i can’t hear”), and only indirectly refers to the other two with “takes me a few minutes to sort of get me bearings” (line 9).

Barbara, then, shows some resistance to focusing on an individual seizure episode. This is particularly evident in her response to the doctor’s ‘worst seizure’ inquiry, the start of which is given in (11).

(11) Barbara [9.42–9.64]

1 D: what about the worst seizure you've hhh ever had
2 B: .hh i've had a few i've had them in the bath (.) where i've
3 nearly drowned .hhhhh i've been caught out on the stairs by the
4 fire brigade (-) because i've (.) come down the stairs and my
5 leg's .hh actually GONE and wrapped THROUGH the banister thing
6 .hh and the (.) fire brigade have had to come (.) and (-) saw the
7 s- and get the- .hhh cut me out the STAIRS (--) i've had them
8 while i'm cooking (---) i've had them in the middle of the road
9 (--) so i've had a few where .hhh it's been quite dangerous

Here Barbara does not describe a single seizure; instead, she lists multiple seizure episodes without going into detail about her experience of any of them. She subsequently elaborates with minimal prompting on how much embarrassment her disorder causes her and how she feels excluded from society. She does not return to the topic of her seizure experience until the doctor explicitly directs her attention to it. Before we proceed with Barbara’s response to the doctor’s ‘challenging’ inquiry, we turn to Jack.

Elicited seizure accounts: Jack As indicated above, Jack has already provided an account of his first seizure episode in the ‘open’ phase of the conversation: see fragment (6). When the doctor asks him to revisit the episode, following the interview protocol, Jack elaborates on the initial account: compare fragments (6)—repeated here in (12)—and (13).

(12) Jack [3.32–3.60]

1 J: i didn't realise what the illness was all about at the time (-)
2 as a matter of fact i woke up one morning and foun- i was lying
3 on the floor (--) and there were two ambula- two ambulancemen
4 there my next door neighbours my WIFE (---) looking ghasted (--)
5 at ME and everything; (1.0) ah (.) i had about eight people in
6 the house looking at me because i'd fallen off the bed
7 D: mmm

8 J: but they didn't (.) er describe it as epilepsy until after some
9 more attacks (six) months afterwards

(13) Jack [10.34–11.16]

1 J: i (.) felt quite good i went to bed feeling tired (1.5) and that
2 was ALL (1.0) and then i WOKE up about er (.) MIDnight (-)
3 between midnight and one o'clock in the MORning (---) and just
4 saw all these faces the ambulancemen the (1.3) NEIGHbours just er
5 looking at me- and my wife looking quite (1.0) er (--) harassed
6 (---) and er (---) i'd hit my face on the side of the (--)
7 cupboard (1.3) and it was sore and all RED (1.2) and THAT's (.)
8 all i remember i was taken to the (.) hospital in the ambulance
9 (1.3) and i CAN't really remember because that was in nineteen
10 seventy (-) THREE

Notice that Jack adds a description of his mental and physical state before the seizure (“i (.) felt quite good i went to bed feeling tired”, line 1), an indication of the time when he regained consciousness (“about er (.) MIDnight (-) between midnight and one o'clock in the MORning”, lines 2 to 3), a partial reconstruction of what had happened during the seizure (“i'd hit my face on the side of the (--) cupboard”, lines 6 to 7) and an indication of what happened after he regained consciousness (“i was taken to the (.) hospital in the ambulance”, line 8). Notably, Jack concludes the account with the claim that “I can't really remember” (line 9)—after telling the doctor what he *can* remember.

Jack's subsequent accounts of his last and worst seizure episodes arguably do not add much to what he has already told the doctor about his seizure symptoms. Nevertheless, in comparison with Barbara's, Jack's accounts are more elaborate, with more overt reliance on what he can remember of the experience. His account of his last seizure, given in (14), illustrates this.

(14) Jack [12.41–13.16]

1 D: it might be easier to remember er er er (--) more about the last
2 seizure you had (1.9) you've experienced
3 J: now that's (.) er like i said this last seizure i ha- i don't
4 really remem- i remember getting up and going er (1.9) i THINK i
5 was going to the (-) either there (-) or i'm standing there (-)
6 to get some water (---) and (-) all of a sudden (-) i just wal- i
7 (--) i was sitting down and i saw my wife looking at me (--) and
8 i realised then that i'd had a seizure (--) i didn't actually
9 feel it when i was there (--) but then i came back there i SAW
10 her looking at me and i KNEW i'd had a seizure then (--) i didn't
11 feel any chain reACTION inside or anything (0.4) but i KNEW- (-)
12 i felt (-) LIGHT i knew my my head felt light (--) and it didn't
13 feel (-) right

Here Jack starts saying “i don't really remember”, but leaves this negative statement incomplete in favour of an attempt to reconstruct, with some apparent difficulty, what he *does* remember of the episode (line 4). He describes his realisation that he had had a seizure from his wife's reaction, and although he first suggests that he did not experience any other symptoms (“i didn't feel any chain reACTION inside or anything”, line 11), he recalls feeling lightheaded. Notice that as before, Jack uses self-repair strategies to make his description more precise: here he reformulates “i felt (-) LIGHT” to the more specific “my head felt light” (line 12).

Moreover, when encouraged by the doctor to elaborate on his experience of lightheadedness, Jack provides a more precise description, given in (15), on the basis of a further seizure episode account: he characterises his lightheadedness as a reduced ability to concentrate and to perform basic cognitive tasks such as matching thoughts to words.

(15) Jack [15.73–16.30]

1 J: i could underSTAND what people were saying but i couldn't (-)
2 RESPOND to that my head felt a bit (---) erm (-) i don't know if
3 you could call it LIGHTheaded or (--) woozy or (1.5) or well but
4 i couldn't concentrate and just couldn't (1.0) adJUST the (.) the
5 words together (-) and the subjects

To summarise the analysis so far, after an 'open phase' in which Barbara has not voluntarily offered information on her seizure experience, she shows resistance to focussing on individual seizure episodes, although she does describe a *typical* seizure experience in some detail. Jack shows no 'focussing resistance' and adds several details to his description of his seizure experience in the context of his accounts of individual seizure episodes.

3.3. Response to 'challenge'

As indicated in Section 2, following the patient's seizure episode accounts, the doctor formulates an inquiry that 'challenges'—or invites the patient to reconsider—an aspect of the description so far. The doctor can do this by introducing a symptom and asking whether the patient has ever experienced this, or by asking the patient to confirm or disconfirm a prior statement. Patients with epilepsy typically respond to this inquiry by revising or elaborating their description, while patients with NES often display a reluctance to do so.

Response to 'challenge': Barbara In Barbara's case, the doctor's 'challenge' is an inquiry which the doctor overtly relates to Barbara's previous statement that she often cannot *hear* when she regains consciousness after a seizure. Given Barbara's brevity on the subject of her seizure experience so far, her response to this inquiry is remarkably elaborate, as seen in fragment (16).

(16) Barbara [13.58–14.61]

1 D: you said after the seizures you lie there and you can't hear
2 B: no it takes=
3 D: =so is there a state (1.0) when you (---) but when you're out
4 you're completely out (.) is there a state when when you can er
5 (-) see what's going on but you [can't react to people
6 B: [yeah that's when i come round
7 .hh when i first come round i sort of .hh (.) i can SEE them and
8 i know they're there .hh and i can SEE their mouths moving (-)
9 but i just can't (-) HEAR a thing they're saying to me and i'm
10 sort of just .hhhh LOOKing at them as if to say (---) y'know (--)
11 WHAT are you- (.) i can't i just can't .hhh (-) it's like
12 everything's in slow motion (--) i can't sort of .hh RESPOND
13 because i don't kno:w what they're trying to say to me i'm sort
14 of .hh LOOKing at them as if to say (-) y'know (.) WHAT (1.4)
15 because i just can't (.) sort of .hhh like i say my
16 coordination's REALLY SLOW .hh i can't (1.0) y'know y'know when i
17 (.) wipe my mouth cos i f- froth at the mouth .hh it's sort of
18 (-) like (.) y'know (---) like THIS (.) sort of really really
19 slow .hh because i can't sort of (---) GRASP (1.0) i KNOW what i
20 want to do but .hh the hand seems to be in slow motion .hh and
21 the same with .hh EVerything around me when i first come round
22 it's like .hhh (.) EVerybody's wh- moving around in slow motion
23 (-) that's what it seems like .hh and then i i just can't hear
24 (.) anything they SAY

Barbara elaborates considerably, providing a precise description of her perception of herself and people around her when she regains consciousness after a seizure. In particular, she suggests that there is a stage in the recovery in which she is conscious enough to know what she wants to do, but physically unable to do so, and illustrates this with reference to wiping her mouth (lines 16 to 20). Notice that she refers to a seizure symptom here—frothing at the mouth—which she has not mentioned so far. She further suggests that not only her own movements, but “EVERYthing around me” seems slow (line 21). Combined with the loss of hearing she has already described, this state of reduced consciousness is likely to be a cause of frustration and discomfort, and Barbara appears to have trouble formulating what she considers an accurate description: notice the many hesitations, repetitions and restarts.

Response to ‘challenge’: Jack In Jack’s case, the doctor’s ‘challenge’ is a request to confirm an inference that can be drawn from Jack’s prior description—namely, that except for some of his early seizures, his loss of consciousness during seizures is complete. Jack’s response is minimal, as seen in fragment (17).

(17) Jack [17.22–17.41]

1 D: and er er er (-) in (-) so in your blackouts you are COMPLETEly
 2 er out of [your
 3 J: [out yes
 4 D: you CANnot remember what’s happened apart from (-) years ago
 5 J: apart- years yes
 6 (1.6)
 7 yes that’s co- that’s true
 8 (3.4)
 9 mmm (--) so
 10 (3.4)
 11 D: mmm

Jack briefly confirms the doctor’s formulation, and does not use the opportunity to repeat or revise his description, despite the long pauses. Notice that Jack closes his extended turn with *so* in the use discussed above for Barbara: here Jack invites the doctor to take a turn and initiate topic shift. To summarise, while Barbara elaborates considerably in this phase of the conversation, Jack adds nothing to his prior description of his seizure experience.

3.4. Talk on a different topic

We do not discuss Barbara and Jack’s responses to the doctor’s final inquiry in detail here, since, as indicated in Section 2, the final phase of the conversation was not included to facilitate the diagnostic process. Our working hypothesis has been that the communicative differences we observe between the two patient groups are due to differences in the way that the patients experience and conceptualise their disorders—not to differences in their *general* communicative competence. So far, we have no reason to abandon this hypothesis. For example, a patient with NES who has seemed reluctant to provide detailed information about subjective seizure symptoms may talk just as freely and elaborately about hobbies as a patient with epilepsy who has voluntarily described various seizure symptoms and episodes. Similarly, a patient with epilepsy who has described subjective seizure symptoms with repeated hesitations, reformulations and other instances of self-repair, indicative of formulation difficulty, may talk about hobbies without comparable disfluencies.

3.5. Differential diagnosis

Let us now summarise the analysis and formulate the linguistic “diagnosis” for Barbara and Jack. Recall from Table 1 that in the type of conversations that we have been analysing, patients with epilepsy typically direct the focus to their seizure experience voluntarily, without prompting from the doctor, while patients with NES tend to require prompting to do so. We have seen that Barbara does not begin to describe her seizure experience until after the doctor has asked her to describe her first seizure: in the ‘open’ phase of the conversation, Barbara’s focus is on other topics, such as the failure of prior treatment. Jack, on the other hand, self-directs the conversation to his seizure experience, and provides the doctor with information about individual seizure episodes and subjective seizure symptoms before the doctor elicits such accounts. In this respect, then, Jack behaves as we would expect from a patient with epilepsy, while Barbara behaves as we would expect from a patient with NES, as indicated in Table 3.

With respect to the description of subjective seizure symptoms and phases of reduced consciousness or control, we have seen that Barbara describes several subjective seizure symptoms after her account of her first seizure, and elaborates considerably on the description after the doctor’s ‘challenge’. In the latter respect, she behaves as we would expect from a patient with epilepsy, as indicated in Table 3. However, her description prior to the doctor’s ‘challenge’ has been far from elaborate: in particular, in her accounts of individual seizure episodes Barbara only briefly mentions subjective symptoms, and uses holistic and negative statements—for example “i don’t REALLY have any recollection of what happens” and “bang (.) that’s it i’m gone” in fragment (8)—to refer to her loss of consciousness. In this respect her behaviour is more like that of a typical NES patient. In Jack’s case the situation is the exact reverse: his minimal response to the doctor’s ‘challenge’ is similar to that of a typical patient with NES, but his prior description of seizure symptoms and his loss of consciousness is more like that of patients with epilepsy in terms of level of detail and formulation effort—and the fact that he *volunteers* the information throughout the conversation.

	Barbara	Jack
‘Open’ phase	No focus on seizure experience NES	Volunteered focus on seizure experience and volunteered accounts of individual seizure episodes Epilepsy
Elicited seizure accounts	Minimal accounts of individual seizure episodes, resistance to focussing on individual episodes, brief descriptions of subjective seizure symptoms NES	Coherent accounts of individual seizure episodes, detailed description of subjective seizure symptoms Epilepsy
Response to ‘challenge’	Considerable elaboration on prior description of subjective seizure symptoms Epilepsy	No elaboration on prior description of subjective seizure symptoms NES

Table 3: Summary of the case comparison

We have seen that Barbara shows some resistance to focusing on individual seizure episodes: she does not volunteer any descriptions of particular seizures, she generalises quickly in her accounts of her first and last seizures, and provides a list of brief references to seizure episodes, rather than a single coherent account in response to the doctor's inquiry about her worst seizure. Jack volunteers several accounts of seizure episodes and provides full responses in reply to the doctor's elicitation. The two accounts of his first seizure—the first volunteered, the second elicited—are particularly significant: at the doctor's prompting, Jack shows no reluctance to describe the event a second time. Instead he uses the opportunity to formulate a more elaborate account. In general, he relies on his own recollections to formulate coherent, chronological accounts of the events. In this respect, then, Jack behaves as we would expect from a patient with epilepsy, while Barbara behaves as we would expect from a patient with NES.

Finally, we have said little so far about the two remaining diagnostic features in Table 1: "seizure suppression attempts" and "metaphoric conceptualisation of the seizure experience". Our experience with these features suggests that unlike the features discussed in this section so far, these have what we may call an 'asymmetric' differential diagnostic value. That is, if a patient voluntarily describes an attempt at trying to stop a seizure from progressing by mental or physical means, this strongly suggests the patient suffers from epilepsy rather than NES. However, the lack of such an account does not suggest as strongly that the patient suffers from NES. So far, the majority of the English patients with epilepsy interviewed and analysed using our method fall into the latter category too. Neither of the cases under consideration here mentions attempts at suppressing seizures. This is to be expected since both Barbara and Jack suffer from seizures that occur with little or no warning; for these particular patients, then, this feature is of little diagnostic value. Likewise, the consistent description of the seizure as an external and threatening entity, exemplified by expressions such as "it ceeps up on me" or "the seizure knocks me out", strongly suggests that the patient suffers from epilepsy. However, several of our patients with epilepsy use such metaphorical expressions sparingly. Neither Barbara nor Jack uses this sort of metaphorical language when they describe their seizures.

The analysis outlined above suggests that Barbara behaves as we would expect from a patient with NES in all respects except her response to the doctor's 'challenge'. Jack behaves as we would expect from a patient with epilepsy in all respects with the same exception. Given that the patient's behaviour during the 'open' phase is of the greatest differential diagnostic significance, since it is here that the patient's own focus in discussing his or her disorder is most evident, the linguist formulated the hypothesis that Barbara has NES whereas Jack has epilepsy. As seen in Table 2, these diagnoses were confirmed by video-EEG in both cases.

4. Discussion

In this paper we have described an unusual procedure for 'taking the history' from patients with seizure disorders which is proving helpful in the differential diagnosis of epilepsy and NES. Moreover, we have demonstrated our method of analysis with particular reference to two patients.

We should emphasise that our elicitation procedure and analytic method are intimately connected. The comparison of Barbara and Jack's conversations has shown that a crucial differential diagnostic feature is the extent to which the patient *volunteers* a focus on the seizure experience and the description of subjective seizure symptoms. It would be impossible to assess this feature in a conventional, fact-oriented consultation: in this type of interaction it is invariably the *doctor* who determines the topical trajectory of the consultation. Assessing the feature requires a procedure that allows the patient to set the agenda, at least in the opening

phase of the consultation. In this sense our study contributes to the literature that promotes an open, ‘patient-oriented’ interview style in medical consultations (Gafaranga and Britten 2003; Silverman, Kurz and Draper 2004): while previous research has shown that such a style leaves patients more satisfied that the doctor has addressed all of their concerns (Robinson and Heritage 2006), our study shows that giving patients room to develop their own agenda can yield information of diagnostic value.

Two further points deserve discussion. Firstly, while our analysis method involves assessing the patient’s talk on a limited number of features, we should point out that the analysis of patients’ communicative strategies does not lend itself to simple ‘box-ticking’. It involves not only assessing whether or not the patient provides certain items of information, but also in what precise context the patient does so—or does not. Ignoring the local context can have serious consequences for the accuracy of the linguistic diagnostic hypothesis. For example, if we compared Barbara’s description of seizure symptoms in (16) with any of Jack’s descriptions in the context of his accounts of individual seizure episodes, we might well conclude that Barbara offers more detail with more formulation effort; and therefore, that Barbara is more likely to have epilepsy, and Jack more likely to have NES. However, what matters crucially is that Barbara’s description comes after explicit prompting, late in the conversation, after she has passed on various opportunities to direct the focus of the conversation to her seizure experience. Jack’s apparently less elaborate prompted descriptions, on the other hand, add to information he has already provided voluntarily in the ‘open’ phase of the conversation. It is important, then, to see any content of the patient’s descriptions in the sequential context of the conversation as a whole. In practical terms this means that the conversations need to be analysed systematically from beginning to end.

Secondly, we contend that our analytic method is by no means too ‘academic’ to be applied in clinical practice. It is particularly promising that the linguistic diagnostic hypothesis can in many cases be established on the basis of the ‘open’ phase of the conversation alone. If, like Barbara, the patient does not focus on the seizure experience and offers no description of subjective seizure symptoms in this phase, the patient is likely to be a patient with NES. If, like Jack, the patient directs the focus of the conversation to the seizure experience and volunteers descriptions of subjective symptoms during the ‘open’ phase, the patient is likely to be one with epilepsy. While there are undoubtedly exceptions to this generalisation, it at least suggests that it is feasible to develop elicitation procedures along the lines discussed in Section 2. These would take up less than the 20 to 30 minutes of our conversations, and may therefore be adapted more readily in routine clinical practice. We appreciate that the application of our method would require significant changes to something doctors do on a daily basis—taking the patients’ history. However, we hope that our finding that the open interview style used here improves diagnostic accuracy will help to persuade doctors to make even more of an effort to adopt a more passive, receptive stance towards their patients.

Finally, we remain agnostic as to *why* patients with epilepsy and NES behave differently in consultations of the type we have discussed here. Importantly, our research does not prove that patients with epilepsy and NES have distinct seizure experiences, or that they differ in their ability to describe aspects of their experience. All we can show is that there are important differences between the two patient groups in the particular interactive setting of the doctor–patient interaction. While we cannot as yet explain this observation, we can—and should—use it to improve the accuracy of the differential diagnosis of these seizure disorders.

Notes

1. It is perhaps worth emphasising that our aim is not to provide a detailed interactional-linguistic study of the two interviews. While the analyses we carry out draw on insights from linguistic and conversation-analytic work, they have a clear practical objective: that of generating a communication profile of the patient which informs the diagnosis of their seizure disorder, based on the findings of the Bielefeld project. We accept that much more could be said about the data from a less clinically focused perspective.
2. In our transcripts, (.) represents a ‘micropause’ of around 0.10 sec, (-), (–) or (—) represent pauses between 0.15 and 1 sec, depending on the precise duration, and (1.0), (2.0) etc. represent pauses longer than 1 sec, measured in seconds. Capitalisation is used to mark particularly prominent syllables. Inbreaths are marked .h, .hh, .hhh etc, depending on the duration. Square brackets are used to mark simultaneous talk, and transcriber’s comments are enclosed in double brackets. The heading of each fragment indicates the name of the patient and the portion of the interview that is transcribed, in the format [min.sec–min.sec].

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