

promoting access to White Rose research papers



Universities of Leeds, Sheffield and York
<http://eprints.whiterose.ac.uk/>

This is an author produced version of a paper published in **Epilepsy & Behavior**.

White Rose Research Online URL for this paper:

<http://eprints.whiterose.ac.uk/42937>

Published paper

Toerien, M., Shaw, R., Duncan, R., Reuber, M. (2011) *Offering patients choices: A pilot study of interactions in the seizure clinic*, *Epilepsy & Behavior*, 20 (2), pp. 312-320

<http://dx.doi.org/10.1016/j.yebeh.2010.11.004>

Offering patients choices: a pilot study of interactions in the seizure clinic

Merran Toerien, Department of Sociology, University of York

Rebecca Shaw, Section of Public Health and Health Policy, University of Glasgow

Roderick Duncan, Department of Neurology, Southern General Hospital, Glasgow

Markus Reuber, Academic Neurology Unit, University of Sheffield

Correspondence address:

Merran Toerien

Department of Sociology

University of York

Heslington

York, YO10 5DD

Email: mgt100@york.ac.uk

Telephone: +44 (0)1904 433061

Fax: Fax: +44(0)1904 433043

Abstract

Using Conversation Analysis (CA), we studied conversations between one UK-based epilepsy specialist and thirteen seizure patients in whom there was uncertainty about the diagnosis, and for whom different treatment and investigational options were being considered. In line with recent communication guidance, the specialist offered some form of choice to all patients: in eight cases, a course of action was proposed, to be accepted or rejected, and in the remaining five a 'menu' of options was offered. Even when presenting a menu, the specialist sometimes conveyed his own preferences in how he described the options, and in some cases the menu was used for reasons other than offering choice (e.g. to address patient resistance). Close linguistic and interactional analysis of clinical encounters can show why doctors may feel they are offering choices when patients report that the decision was clinician-dominated.

Keywords: Conversation Analysis; Epilepsy; Non-epileptic seizures; Decision-making; Patient choice; Patient participation

1. Introduction

There is evidence that shared decision-making brings a range of physical and psychological benefits for patients [1-3]. Offering choice is one way in which clinicians can attempt to realise these benefits. Within the UK's National Health Service, increasing patient choice has become a policy objective [4], with chronic conditions – such as epilepsy and non-epileptic seizures (NES) – considered particularly suitable [5-6]. In clinical epileptology, information provision about treatment *options* is part of the evidence-based guidance for high quality care [7]; and patient engagement is critical for the negotiation of anti-epileptic drug (AED) adherence [8] or the referral of patients with nonepileptic seizures (NES) for psychotherapy [9]. However, observational studies have found low levels of patient participation in decision-making [10-15], and patients often report a lack of negotiation about treatment options [15-16]. A study of AED treatment decisions found that the process was perceived to be clinician-dominated [17].

While identifying that problems with the decision-making process exist, the type of research outlined above does not analyse what was said *during* the consultation; it therefore cannot give insight into how the interaction itself might be improved. The precise wording clinicians use can be crucial [18-21]. For example, Heritage et al. compared two question forms used by General Practitioners: “is there ANYthing else” vs. “is there SOMETHing else you want to address today” [22]. In response to “anything”, patients were no more likely to express their additional concerns than if the question was not asked at all. By contrast, the use of “something” eliminated 78% of unvoiced concerns compared with no question. The precise wording used by patients can also be consequential. For example, differences in how patients describe their seizure experiences can distinguish epileptic from non-epileptic

seizures [23-24]. Increasingly, therefore, researchers are using conversation analysis (CA) to focus on the detail of communication [25]. By analysing recorded conversations, this method overcomes the known problems with retrospective accounts of events, such as incomplete recall, inaccuracies and ‘reframing’ over time [26].

Using CA, we examined the strategies used by a UK-based seizure specialist in interaction with patients during real consultations, in which diagnostic uncertainty remained and different treatment and investigational options were being considered. The aim of this paper is to describe how choice for patients with seizures can operate *in practice*, and to highlight how CA can be used to improve our understanding of the ‘machinery’ of clinical conversations in order to maximize their therapeutic effect.

2. Methods

2.1. Data collection and analysis

We audio-recorded consultations between one clinician and thirteen patients, in two hospital-based outpatient clinics in the UK. The recordings ranged in length from 28 to 63 minutes, with a mean of 44 minutes and 30 seconds. We used conversation analysis (CA) to examine how choice was managed, following three key stages:

1. Recordings were transcribed verbatim, including pauses, overlapping speech, and emphasis. To improve clarity in this paper we present simplified transcripts, which

include details crucial to the analysis but exclude other notation. See Example 1 for transcription key. All transcripts were anonymised.

2. Collections of all instances of particular interactional activities (in this case, offers of choice) were assembled.
3. All instances were examined in order to identify how speakers accomplished the given activity.

The overall aim is to describe, in detail, exactly how different communicative approaches operate [18-19].

2.2. Participants

All thirteen patients presented with a history of spells. Eleven were accompanied. One required assistance by his father due to learning difficulties. Only two of the patients had met this neurologist before (in both cases, over a year previously). In twelve cases, the neurologist delivered a likely diagnosis after assessment. To varying degrees, diagnostic uncertainty remained in twelve; one patient had a video/EEG-confirmed diagnosis. Candidate diagnoses are shown in Table 1. The neurologist included in this study is based in the UK, and has a specialist interest in the differential diagnosis of seizures; since he is recognised as an expert in this field, many patients in the sample had been referred due to long-standing uncertainty about whether their seizures were epileptic or non-epileptic.

All patients gave written informed consent for their consultation to be recorded and used for research purposes. Recording protocols were approved by the South Sheffield and Frenchay Research Ethics Committees.

Table 1

Patients: candidate diagnoses

Patient	Sex	Likely conditions
Patient 1	Female	Epilepsy most likely; NES possible
Patient 2	Female	NES most likely
Patient 3	Female	Migraine with loss of consciousness most likely; epilepsy possible
Patient 4	Female	Uncertain; previous diagnosis of stiff person syndrome
Patient 5	Male	Epilepsy most likely but only had one seizure, so diagnosis uncertain
Patient 6	Male	NES and depression most likely
Patient 7	Female	NES most likely; epilepsy possible
Patient 8	Female	NES most likely; previous doctor agrees
Patient 9	Male	NES most likely; previous doctor agrees
Patient 10	Male	NES most likely; previous diagnoses of fibromyalgia and osteoarthritis
Patient 11	Female	NES most likely; previous doctor agrees but epilepsy diagnosed in the past
Patient 12	Female	NES most likely (described to patient as 'functional symptoms')
Patient 13	Male	NES most likely

3. Results

3.1. Proposing a course of action vs. offering a menu of choice

The neurologist took two general approaches to talking about what might happen next regarding treatment and/or further investigation.

1. In eight of the thirteen consultations (Patients 4, 5 and 8-13) he proposed a particular course of action, which the patient might accept or reject. Example 1 illustrates this.

Because the patient in Example 1 had only experienced one seizure, the neurologist explained that treatment was not recommended (data not shown). He therefore only suggested further investigations at this stage.

Example 1 (Patient 5)

1 Neu: So **my suggestion would be** that um we we do er this MRI scan
2 (.) the EEG test, (0.6) um that I write to you about the results,
3 [that would be in about um two months and then I'll see you once
4 Pat: [Okay
5 Neu: more in six months [um to see how things are, (0.4) and have
6 Pat: [Right
7 Neu: another chat about (0.2) smaller (.) funny
8 Rel: Mm
9 Neu: tur[ns um
10 Rel: [(Mm)
11 Rel: Yeah
12 (1.0)
13 Neu: uh If nothing has happened at this point I would discharge you
14 um and only see you again if there was a another another turn
15 Pat: Right
16 Neu: Yeah?
17 Pat: Yeah (no problem)

Key to transcription symbols [27]:

Neu = Neurologist; Pat = Patient; Rel = Patient's relative

[Start of overlapping talk

(0.2) An interval within or between talk (measured in tenths of a second)

(.) An interval of less than two tenths of a second

wor- A cut off word or sound

(word) Possible hearing (when recording is unclear)

((word)) Comments by transcriber

.hh An in-breath

Boldface is used to highlight key features of the neurologist's talk identified in this paper.

In Example 1, the neurologist was clearly oriented to the patient's right to choose: he framed the proposed course of action as a *suggestion*, not a directive (line 1). In this case, the patient (and his mother) agreed to the proposal (lines 4, 11, 15, 17). In others, patients (or relatives) pursued alternatives not initially raised by the neurologist. Both clinicians and patients are, in other words, alive to opportunities for negotiation over what will happen next – even when only one option is first offered [28].

2. In the remaining five consultations (1-3, 6, 7) the neurologist used a more conventional model of choice – one in which the patient could pick from at least two options [29].

Example 2 illustrates this. The neurologist spelled out that there were “a number of things” (line 1) that could be done, explicitly listed the options (lines 1, 7 and 12) and, after the patient's husband expressed a preference (lines 29-32), asked the patient for hers (line 33).

Example 2 (Patient 1)

1 Neu: Um now **we can do a number of things**. Um **option one** is uh really
2 that we we leave things as they are and I'll just see you again in

3 case of change[s
4 Pat: [Mm[m
5 Rel: [Yeah
6 Neu: Um uh um m the arguments in favour of this would be...
((neurologist details other arguments in favour))
7 Neu: Um **option two** is um we we try to to um to change your medication
8 a bit, um, because the Zonisamide has uh been a success uh the
9 Lamotrigine you're now taking a tiny dose of [um and you are
10 Pat: [Mm
11 Neu: describing some symptoms which could be side effects
((continues explaining arguments in favour and against))
12 Neu: **Option three** (there) would be (0.4) we try to get to the bottom
13 of it, um and and see whether there are um any other treatment
14 options, I don't know whether Dr Jackson has talked to you about
15 epilepsy surgery, that's uh [a uh
16 Rel: [(He[]) DID (yeah he) [(actually)
17 Pat: [(Mm:)
((Neurologist gives more information about surgery))
18 Neu: but I think we'd need more information be- before uh we could
19 really think abou[t dramatic changes to your treatment at this
20 Rel: [Mm
21 Neu: point.
22 (.)
23 Neu: So um uh option three would involve you c- coming for more video
24 EEG uh [we would stop the medication and and record you f[or a week
25 Pat: [(Mm)
26 Rel: [Mm

27 Neu: um I guess (0.2) uh to see whether we could um capture seizures and
 28 and um and become clear about the diagnosis
 ((discussion about the couple's preference for avoiding further testing at this stage))

29 Rel: Um (1.0) so I think, (0.2) at this point like [you say (0.6)
 30 Neu: [Yeah
 31 Rel: tests (0.4) maybe not appropriate, u:m (0.4) maybe a little
 32 reduction in medication like you said about Lamictal.
 33 Neu: **Well what do you think.**
 ((Patient discusses her concerns, asks for recommendation and then reaches a decision))

In all five of these conversations, the same *structure* was evident: the neurologist explicitly listed alternatives from which the patient might choose. However, there were significant variations in: I) *how* the options were described; II) *who* initiated talk about each option; and III) *when* the approach was used in the course of the interaction.

3.2. Variation I: how were the options described?

The options provided by the neurologist were not always described in equivalent terms. For instance, in Example 3, the neurologist listed three options: further testing (lines 10, 11), psychotherapy (lines 24, 25), and a drug increase (lines 63, 64). *How* he described each option served to position them on a continuum: from least to most favoured. At the 'least favoured' end was an increase in the patient's AEDs; at the 'most favoured' end was psychotherapy. To make these contrasts easier to follow the neurologist's description of the three options have been laid out under separate headings.

The AED increase was produced as a *non*-option in a number of ways:

- The option is introduced with a hesitancy marker: “I guess” (line 63);
- He voiced his opinion and a rationale *against* this option: they have already tried AEDs (lines 64-70);
- And he explicitly advised against it: “I wouldn’t suggest changing epilepsy treatment” (line 71).

By contrast, psychotherapy was produced as the *preferable* option in several ways:

- In addition to the basic rationale for trying this option, the neurologist spelled out *an extra reason* for choosing it: “help with the anxiety symptoms” (lines 30-56);
- He also voiced his *opinion in favour of* trying psychotherapy: the patient had little to lose (lines 56-58);
- And he kept psychotherapy on the table when describing the third option (line 73).

Further testing and an increase in dosage of the antidepressant drug (sertraline) lay somewhere between these extremes; both were treated as justifiable, but neither were ‘sold’ to the patient in the way that psychotherapy was.

Example 3 (Patient 7)

Option 1 – further testing

1 Neu: what I would (1.2) suggest (1.0) Well there’re (a) number of things
 2 I can suggest. I cou- (you) c- u there’s there’s there’s choice
 3 really.

4 Pat: Yeah.

5 Neu: **Option one** is (.) we say “well we still don’t know what this is um
 6 (0.5) the right treatment depends very much on what it is

7 Pat: Ye[h.

8 Neu: [Is it epilepsy (are) these non-epileptic attacks and therefore
9 we need to find out what it is before we make any real changes. Um
10 so (.) you know I'm coming in for more video EEG this time for a
11 week."

12 (0.2)

13 Neu: That's one option.

((Discussion about why taking a home video won't work))

Option 2 – psychotherapy

14 Neu: **The second option** is um (0.5) "I er well we don't know exactly what
15 this is. Um I (0.5) we have tried anti-epileptic drugs they've
16 never made a real difference"

17 Pat: Yeah

18 Neu: "to the attacks um so (0.5) I want to try something else"

19 (0.6)

20 Neu: "just in case these are non-epileptic attacks"

21 (0.4)

22 Neu: "um I want to try something else."

23 Pat: Yeah.

24 Neu: And the something else would be a a way of talking treatment to see
25 a psychologist or therapist

26 Pat: Yeah

27 Neu: who could see you regularly uh maybe once a week or once a
28 fortnight

29 and who would work on these symptoms with you um with this option

30 **another reason why why you might want to choose this option is that**

31 you know never mind what these blackouts and attacks with shaking

32 are (0.4) **you do have a lot of (0.4) anxiety symptom[ms**

33 Pat: [Yeah

34 Neu: **that um that they can focus on.**

35 (0.2)

36 Neu: And it would be surprising um if these were non-epileptic attacks
37 then it would be surprising if they had nothing to do with your
38 anxiety symptoms. And helping with anxiety symptoms and you know
39 the risk of panic attacks you know helping with that

40 Pat: Yeah

41 Neu: might make you better all the time anyway yeah? In terms of the
42 anxiety symptoms and if these attacks have something to do with
43 anxiety if they are non-epileptic attacks then they may get better
44 as well.

45 Pat: Yea[h.]

46 Neu: [Yeah? So... if we go for that option (that) you could definitely
47 get help with the anxiety symptoms and hopefully also with the
48 blackouts

49 Pat: Yeah

50 Neu: Uh even if the seizures were epileptic uh you know anxiety is a
51 common problem in epilepsy and [sometimes the two things are

52 Pat: [Yeah

53 Neu: linked.. and sometimes um (0.2) talking to a therapist and (0.4)
54 learning techniques how you can (0.2) deal with anxiety symptoms
55 differently... **these are all things that can also help you with**
56 **epilepsy. So I'm I think the- the- the- therapy really (or this)**
57 **talking therapy is- is- is a situation where where you you can't**
58 **really lose very much** other than (0.5) you know the (0.5) I suppose
59 people don't- don't wanna see a- a shrink or [or a or a

60 Pat: [It don't bother me

61 Neu: or a therapist because it- you know [they-

62 Neu: [Mm it don't bother me.

((Neurologist clarifies that a referral for psychotherapy does not mean he thinks the patient is 'mad' or that the seizures are not real))

Option 3 – drug increase

63 Neu: I mean **a third option I guess** would be to increase the anti-
64 epileptic drug treatment in case this is epilepsy. Um **I'm a bit**
65 **reluctant to go with that optio[n without knowing more that it**

66 Pat: [Yeah I (know)/(am)

67 Neu: **really is epil[epsey**

68 Pat: [Yeah

69 (0.8)

70 Neu: **Because we've tried that route.** We can change your medication

71 (0.4) but **I wouldn't suggest changing epilepsy treatment** so if you

72 wanted to change your medication (0.4) we can do this (.) you know

73 **as well as the psychotherapy** but um er what we could do there is we

74 could try and increase the sertraline in the first instance.

75 Pat: Yeah

76 Neu: Sertraline is a tablet which can help with anxiety it can help with

77 um with sleep in principle.

78 Pat: Yeah

79 Neu: And if it's not doing that for [you then we can try a higher dose.

80 Pat: [Mm no I'm not getting no sleep.

3.3. Variation II: Who raised each option?

The options on the menu were not always produced *solely* by the neurologist. In the following example, the neurologist announced that there was more than one option (line 1), but before he came to list a second, the patient enquired about drug treatment (line 17).

Example 4 (Patient 3)

1 Neu: **There are a number of things we can do** (0.2) um we can- I- I can

2 write you a letter and say that I think this is migraine (0.4) um
3 er the attacks are relatively infrequent (0.6) um therefore we
4 don't think that er taking tablets everyday is a good way forward
5 Pat: Mm
6 Neu: Um uh given that we're not giving you any treatment I can't
7 guarantee that it will never happen again. (0.4) The attacks don't
8 involve much warning and do involve loss of consciousness (0.4)
9 therefore you have to talk to the DVLA ((the Driver and Vehicle
10 Licensing Authority)) about driving
11 Pat: (Okay)
((Discussion about when/whether the patient will be able to drive))
12 Neu: So you might drive for a few weeks at a time unless the pattern
13 changed which it can do you know a migraine er often comes on and
14 goes away again.
15 Pat: Right
16 Neu: Um
17 Pat: **So what if you gave me medication for it.**
18 Neu: Yeah **so that's option two.** Option two is we try medication...

Patients thus helped shape the menu. Such initiatives by patients could also impact on *how* the options were constructed. For example, the neurologist's (reluctant) consideration, in Example 3, of an increase in AEDs (lines 30-33) was in response to a question the patient raised before the neurologist laid out the options: "*Would a change in medication do owt [anything]?*" (not shown in example). The neurologist's construction of an AED increase as a *non-option* – with an increase of sertraline as an alternative – functioned to resist the possibility that the patient might be seeking such an increase.

3.4. Variation III: When is the approach used?

A menu of choice was sometimes offered immediately after discussion of the diagnosis – as an approach to initiating the decision about what to do next. Alternatively, a menu could emerge after discussion, which might include initial efforts by the neurologist to propose a single course of action. In Example 5a, for instance, the neurologist first proposed psychotherapy as a possible course of action (lines 2-5, 7-21).

Example 5a (Patient 2)

1 Neu: So you can retrain your brain and that's something that can work
2 for non-epileptic seizures. (0.8) Um and- er and **the people who**
3 **would offer that sort of treatment are psychologists or**
4 **psychotherapists (1.0) and an- and that sort of treatment would be**
5 **on offer. Um (0.2) and I could offer that to you here..**

((Patient provides no verbal response to this option and they move into a discussion about remaining diagnostic uncertainty))

6 Neu: So at the moment (0.2) I would say (0.2) I'm ninety per cent (1.2)
7 sure that these are non-epileptic seizures. (1.8) And as far as I'm
8 concerned um the treatment that I've (0.4) mentioned (0.6) **seeing**
9 (0.2) **one of our therapists** (0.4) and trying to work with them on
10 you can- on what might have brought the attacks on what might be
11 bringing the attacks on in situations now, what you can do when the
12 attack happens. You have quite a lot of control um perhaps. You say
13 you have no control but at you're aware in the attacks so there
14 i[s you know there are bits of your brain that are working during

15 Pat: [Yeah

16 Neu: the attacks. So the- **the therapist could work with you** on um (1.8)
17 on- on getting more control in the attacks yeah? So that perhaps
18 you can bring yourself out of them. **So I think there is a basis**

19 (0.6) for you to work with them (0.4) in principal um (2.0) as far
20 as I'm concerned you would have very little to lose from this sort
21 of treatment.

((Patient does not respond verbally to this suggestion and the neurologist goes on to acknowledge that some people feel uncomfortable about visiting a psychotherapist, and to explain that therapy is also sometimes used to treat people with epilepsy))

In addition, he ruled out two alternative options: AEDs (lines 2-3, 15-16) and further testing (lines 13-14).

Example 5b (Patient 2)

1 Neu: So in terms of of taking things forward (1.2) non-epileptic
2 seizures (0.8) are a bit like a reflex (0.6) yeah? **So taking**
3 **tablets for them (1.6) is not really gonna gonna shift it**

4 Pat: No

((Neurologist explains that it is possible to change reflexes and explains how – psychotherapy))

5 Neu: I think it is more likely that- (.) that these attacks are non-
6 epileptic but I can't be a hundred per cent sure and your attacks
7 happen so infrequently (0.4) that it would be quite difficult for
8 us to be su[re. I said we can do an EEG test during an attack and

9 Rel: [Mm

10 maybe that would prove it yeah? But um

11 Pat: H[ow d'you do it mm

12 [how're we gonna do it? You know we've tried the sleep deprived

13 Neu: EEG **I think it's highly unlikely (0.2) that- that we'll we'll get**
14 **(0.4) more information...**

((and later))

15 Neu: I certainly I- I would- **I would be so unconvinced about tablets**
16 **that I wouldn't recommend (0.4) tablet treatment to you.**

((Patient does not respond verbally and the next bit of talk is shown as line 1 of Example 5c.))

The menu of choice he finally produced, then, contained neither of these options, and was produced against the backdrop of his prior construction of psychotherapy as the preferred choice – which he spelled out again (lines 10-12) after listing two clear alternatives (lines 1-8).

Example 5c (Patient 2)

1 Neu: **So really the choice is** (0.4) either you know we wait and see (0.4)
2 whether it changes er you know whether you need more time to think
3 about it whether you want to see me again I'll look at the notes
4 we'll meet again when I have looked at all your notes all your
5 tests (0.4) **that's option one. Option two** is I tell the therapists
6 about you now (0.4) and when you get the letter in about a month
7 (0.4) you write back to them and say "yeh I want to (to) have a go
8 with this." (0.2) And then I'll see you again. So I'll you know
9 definitely happy to see you again I'm keen to see you again (0.8)
10 and I'm keen to help you with this (1.4) and **as far as I'm**
11 **concerned (0.2) the best (0.8) way forward which doesn't help**
12 **everyone (1.2) would be to try with the therapist.** (1.2) See
13 whether he can crack these attacks.
14 Pat: Yeah
15 (2.8)
16 Neu: So what d'you think?
17 (0.2)
18 Pat: Yeah anything

In this example, the ‘machinery’ of choice – offering a menu of options – was used. As in Examples 2-4, the neurologist made it clear that there were alternatives from which to choose. However, the *total package* functioned more like a recommendation for psychotherapy than an offer of choice.

The following example serves as a contrast. Here the neurologist also uses the ‘machinery’ of choice only after more extended discussion of what they might do next (data not shown). However, he does so in response to the patient’s request for a recommendation (lines 2-3, 5). By listing options instead of providing one, he effectively did the opposite of what we saw in Example 5: the total package functioned to resist making a recommendation in favour of trying to engage the patient in decision-making.

Example 6 (Patient 6)

1 Pat: I don't know what to say uh in response (1.0) to your
2 suggestion. **I can I can only rely on on (1.8) on asking you**
3 **what what (you're) think[in'=which is**
4 Neu: [.hh
5 Pat: **which is the best (.) course to take now**
6 Neu: The the problem with what I've I've said is that there are no
7 hard an' fast tests. We can't do a scan to prove what I've said.
8 Yeah?
9 (.)
10 Neu: Um **there are a number of treatments we can try** and um you know
11 they they can make you better. (.) so um (0.5) there there are
12 antidepressant tablets...

((Neurologist goes on to list three options))

4. Discussion

4.1. Summary of findings

We have identified two broad approaches to initiating decision-making used by the neurologist in our pilot sample. The first gives the patient the opportunity to accept or reject *one* possible course of action. The second gives the patient *a menu of options* from which to choose. We focused, in this paper, on the latter since at least two alternatives are conventionally required for a choice to be said to have been made.

The ‘machinery’ of a menu-based approach was evident in five of our thirteen recordings. How that ‘machinery’ operated, however, showed substantial variability. The key sources of variability lay in: I) *how* the options were described; II) *who* raised each option; and III) *when* the approach was used in the course of the interaction. Despite this being a single approach, then, the decision-making processes that are generated can be markedly different. In what follows we consider the implications of this variability.

4.2. A spectrum of openness

On the face of it, explicitly listing a menu of options appears to be an approach that offers *more choice* than proposing a single course of action for acceptance or rejection. Our analysis suggests, however, that this is not necessarily the case; it is possible to use the ‘machinery’ of a menu-based approach in such a way that the outcome is akin to a *recommendation* for a particular option. This can be accomplished in a range of ways:

- By describing the options in a way that makes a case for or against an option
- By conveying that the neurologist has a preference
- By providing a menu *after* other discussion of possible courses of action, which builds a case for or against an option
- By ruling out certain options (so they are not included on the menu).

In Example 5, these features combined to produce a very limited choice – psychotherapy or nothing – with the neurologist making a strong case, and expressing a preference for, the former. By contrast, the ‘machinery’ may be used to produce a more open choice: in Example 2, a three-option menu was listed, with a rationale for each option and no indication of the neurologist’s preference. As we have shown, patients may also actively intervene, raising options that may not have otherwise appeared on the neurologist’s menu. Simply using the ‘machinery’ of providing a menu does not, in itself, ensure that the patient is offered a fully open choice. Rather, the choices offered may vary in openness, depending on how the individual options are presented.

4.3. ‘Providing a menu’ as an interactional practice: what is the approach being used to do?

This spectrum of openness appears to be strongly related to the question of what the neurologist is attempting to do, *interactionally*, by providing a menu. Our data suggest that this may be done in pursuit of additional interactional objectives, other than simply offering choice. For instance, in Example 5, the neurologist had decided that a diagnosis of NES was most likely and that psychotherapy was most likely to help – issues that may be difficult to communicate [30]. His initial attempts to propose psychotherapy elicited minimal response, this being generally treated by clinicians as a form of covert resistance [31]. The menu he

finally offered the patient was thus highly constrained, strongly favouring psychotherapy. Although the patient was being given an explicit choice, the ‘machinery’ of the menu was being used to do something more: as a strategy for dealing with treatment resistance.

At the other end of the spectrum, a menu of options was used to very different interactional ends in Example 6, where the neurologist was responding to the patient’s request for a treatment recommendation. Again, the neurologist was not simply offering choice; he was also resisting telling the patient what to do. The choice was therefore presented more ‘openly’.

4.4. Limitations

This was a pilot study, focusing on the communication strategies of a single neurologist with a particular interest in distinguishing epileptic from non-epileptic seizures. Consequently, we are not yet in a position to generalise from these findings to other clinicians or contexts. It is likely both that other strategies for offering choice will be evident in a larger dataset, and that the strategies discussed here may ‘play out’ differently, depending on what decisions are under discussion. A significant feature of our pilot dataset is the degree of ongoing uncertainty around many of the diagnoses. Thus, the discussion about treatment options is partly bound up with the neurologist’s efforts to explain alternative diagnoses and the reasons for not being certain. Moreover, the diagnosis of non-epileptic seizures is known to be particularly delicate, implying that the decision-making process may differ in important ways from what happens in, for example, routine follow-up appointments with patients already diagnosed with epilepsy.

A range of other, potentially relevant factors could also be taken into account in a larger-scale study, including time constraints, neurologist and patient preferences – both with respect to treatment/investigations and the extent to which each wants to engage in shared decision-making – and the ways in which earlier patient contributions may shape the approach the neurologist takes to decision-making. Such investigations would be pursued best using a mixed methods design (e.g. a combination of CA, to analyse the recordings, and thematic analysis of interviews with both neurologists and patients).

We were also limited by our use of audio- rather than video-recording to capture these interactions, making it impossible to analyse the non-verbal aspects of the interaction. A particular concern is that we were unable to tell whether a silence indicated a complete absence of a response or if the patient responded non-verbally (e.g. with a nod or smile). This was a pragmatic decision, since participants typically find audio-recording less daunting. However, conversation analysts are increasingly using video to capture institutional interactions (including that in clinical settings) [22-23, 28, 31-32], and this should be seen as the gold standard for future work. Finally, we acknowledge that the mere fact of recording could, to some extent, alter how participants interact. Ethically, there is no way to avoid this. We therefore take the pragmatic view that these kinds of data are as close to ‘naturalistic’ as one can getⁱ.

4.5 Implications for practice

Our findings suggest that the concept of ‘choice’ in the context of doctor-patient interactions is not as simple as the literature may suggest, and that the simple course of telling clinicians to ‘offer patients more choice’ may not achieve its objective. Our research helps account for previous findings of a discrepancy between doctors’ and patients’ perceptions of the decision-

making process [33-34]. It may be that, having used the ‘machinery’ of the menu-based approach, doctors perceive themselves to have offered the patient ‘choice,’ while the patient may (sometimes quite correctly) perceive the way in which the doctor produces the options as constraining. Our study suggests that conversation analysis could be used to educate doctors about the consequences of their actual (rather than their intended) communication practices.

However, it is crucial to recognise that what counts as ‘effective practice’ will always depend both on the goal the neurologist is trying to achieve, and on what the patient wants. Future assessments need, therefore, to ask the question, ‘effective for what?’ For example, Patient 2 was not offered a very open choice. One could argue, therefore, that the ‘machinery’ was used ineffectively *as a means of increasing patient choice*. However, if we consider that the ‘machinery’ was being used in an attempt to avoid conflict and make a recommendation for a potentially controversial treatment, it may have been effective *in carrying out these difficult interactional tasks*. Similarly, attempts to engage the patient in decision-making may be valued by some patients and not by others (e.g. Patient 6 clearly wants the neurologist to make the decision). Evaluations of effectiveness must, therefore, take account of the interactional context. Future research might do this, qualitatively, by examining patterns in how patients respond to different strategies, and quantitatively, by correlating strategies and outcome measures (e.g. whether patients adhere to the agreed treatment, and measures of patient satisfaction with the consultation).

5. Conclusions

While increasing patient choice may in general be beneficial for patients [4], our data suggest that ‘offering choice’ in everyday practice is more complex than the policy documents imply [35]. In the seizure clinic, patient engagement is critical for improved treatment adherence, whether that be to AEDs or psychotherapy. Conversations in which the diagnosis and treatment of NES are discussed are particularly difficult [36-37]. However, as many as 40% of patients may stop having spells after being given the diagnosis and explanation of NES, with no other intervention [38-41], underlining the crucial nature of some patient-doctor conversations in epilepsy practice. CA could be used to improve our understanding of the ‘machinery’ of such conversations and to maximize their therapeutic effect.

Acknowledgement

We would like to thank all the patients who allowed their consultation to be recorded; this work would not have been possible without their input. We are also grateful to Chiara Monzoni for useful feedback on an earlier version of this paper and to our two anonymous reviewers for their sympathetic reading and constructive guidance.

References

- [1] Guadagnoli E, Ward P. Patient participation in decision-making. *Soc Sci Med* 1998;47:329-339.
- [2] Crawford M, Rutter D, Manley C, Weaver T, Bhui K, Fulop N et al. Systematic review of involving patients in the planning and development of health care. *BMJ* 2002;325:1263-1266.

[3] Lewin S, Skea Z, Entwistle V, Zwarenstein M, Dick J. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev* 2001; 4.

[4] Department of Health. *Choice Matters: 2007-8 Putting patients in control*. London: DH;2007. 40p.

[5] Department of Health. *The expert patient: a new approach to chronic disease management for the 21st century*. London:DH;2000. 39p.

[6] Department of Health. *The National Service Framework for Long-term conditions*. London: DH;2005. 108p.

[7] Pugh MJV, Berlowitz DR, Montouris G, Bokhour B, Cramer JA, Bohm MPH et al. What constitutes high quality of care for adults with epilepsy? *Neurology* 2007;69:2020–2027.

[8] Brown I, Sheeran P, Reuber M. Enhancing antiepileptic drug adherence: A randomized controlled trial. *Epilepsy Behav* 2009;16:634–639.

[9] Howlett S, Grünewald RA, Khan, A, Reuber M. Engagement in psychological treatment for functional neurological symptoms – barriers and solutions. *Psych Theory, Research, Practice, Training* 2007;44:354-360.

- [10] Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision-making in outpatient practice: Time to get back to basics. *JAMA* 1999;282(24):2313-2320.
- [11] Ford S, Schofield T, Hope T. Observing decision-making in the general practice consultation: who makes which decisions? *Health Expect* 2006;9:130-137.
- [12] Champion P, Foulkes J, Neighbour R, Tate P. Patient centredness in the MRCGP video examination: analysis of large cohort. *BMJ* 2002;325:691-2.
- [13] Elwyn G, Gwyn R, Edwards A, Grol R. Is 'shared decision-making' feasible in consultations for upper respiratory tract infections? Assessing the influence of antibiotic expectations using discourse analysis. *Health Expect* 1999;2:105-117.
- [14] Karnieli-Miller O, Eisikovits Z. Physician as partner or salesman? Shared decision-making in real-time encounters. *Soc Sci Med* 2009;69:1-8.
- [15] Stevenson FA, Barry CA, Britten N, Barber N, Bradley CP. Doctor-patient communication about drugs: the evidence for shared decision making. *Soc Sci Med* 2000;50:829-840.
- [16] Cohen H, Britten N. Who decides about prostate cancer treatment? A qualitative study. *Fam Pract* 2003; 20(6): 724-729.

[17] McCorry D, Marson T, Jacoby A. Understanding routine antiepileptic drug decisions: A qualitative analysis of patients' accounts of hospital consultations. *Epilepsy Behav* 2009;14:210-214.

[18] Drew P, Chatwin J, Collins S. Conversation analysis: a method for research into interactions between patients and health-care professionals. *Health Expect* 2001;4:58-70.

[19] Drew P, Heritage J. *Talk at work: Interaction in Institutional Settings*. Cambridge: Cambridge University Press; 1992.

[20] Britten N. Patients' expectations of consultations. *BMJ* 2004;328:416-417.

[21] Heritage J, Maynard DW. *Communication in Medical Care: Interaction between Primary Care Physicians and Patients*. Cambridge: Cambridge University Press; 2006.

[22] Heritage J, Robinson JD, Elliott M N, Beckett, M, Wilkes, M. Reducing patients' unmet concerns in primary care: the difference one word can make. *J Gen Intern Med* 2007;22:1429-33.

[23] Reuber M, Monzoni C, Sharrack B, Plug L. Using Conversation Analysis to distinguish between epileptic and psychogenic non-epileptic seizures: a prospective blinded multi-rater study. *Epilepsy Behav* 2009;16:139-144.

[24] Plug L, Sharrack B, Reuber M. Seizure metaphors differ in patients' accounts of epileptic and non-epileptic seizures. *Epilepsia* 2009;50:994-1000.

[25] Kitzinger C, Toerien M. The turn of talk. No interpretation please! In-depth paper, AQR; Summer 2009 [available at: <http://www.aqr.org.uk/indepth/summer2009/>]

[26] Waitzkin H. Information giving in medical care. *J Health Soc Behav* 1985;26:81-101.

[27] Atkinson JM, Heritage J. (eds.) *Structures of social action: studies in conversation analysis*. Cambridge: Cambridge University Press; 1984.

[28] Stivers T. *Prescribing under pressure: parent-physician conversations and antibiotics*. Oxford: Oxford University Press, 2007.

[29] Edwards A, Elwyn G. (editors) *Shared decision-making in health care: achieving evidence-based patient choice*. Oxford: Oxford University Press; 2009. p. 17-22.

[30] Kanaan R, Armstrong D, Wessely S. Limits to truth-telling: neurologists' communication in conversion disorder. *Patient Educ Couns* 2009; 77: 296-301.

[31] Stivers T. Parent resistance to physicians' treatment recommendations: one resource for initiating a negotiation of the treatment decision. *Health Commun* 2005;18:41-74.

[32] Drew P, Toerien M, Irvine A, Sainsbury R. *A study of language and communication between advisers and claimants in work focused interviews*. Department for Work and Pensions Research Report 633. Norwich: HMSO; 2010. 232p.

[33] Makoul G, Arntson Paul, Schofield T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. *Soc Sci Med* 1995;41:1241-1254.

[34] England SL, Evans J. Patients' choices and perceptions after an invitation to participate in treatment decisions. *Soc Sci Med* 1992; 34:1217-1225.

[35] Antaki C, Finlay WML, Walton C. Choices for People With Intellectual Disabilities: Official Discourse and Everyday Practice *J Pol Prac Intell Disabil* 2009;6:260–266.

[36] Hall-Patch L, Brown R, House A, Howlett S, Kemp S, Lawton G et al. Acceptability and effectiveness of a strategy for the communication of the diagnosis of psychogenic nonepileptic seizures. *Epilepsia* 2010;51:70-78.

[37] Carton S, Thompson PJ, Duncan JS. Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure* 2003; 12:287-294.

[38] Buchanan N, Snars J. Pseudoseizures (non epileptic attack disorder) - clinical management and outcome in 50 patients. *Seizure* 1993; 2:141–146.

[39] Ettinger AB, Dhoon A, Weisbrod DM, Devinsky O, et al. A comprehensive profile of clinical, psychiatric, and psychosocial characteristics of patients with psychogenic nonepileptic seizures. *Epilepsia* 1999;40:1292- 1298.

[40] Farias ST, Thieman C. Psychogenic nonepileptic seizures: acute change in event frequency after presentation of the diagnosis. *Epilepsy Behav* 2003;4:424-429

[41] McKenzie P, Oto M, Russell A, Pelosi A, Duncan R. Early outcomes and predictors in 260 patients with psychogenic nonepileptic attacks (PNEA). *Neurology* 2010;74:64-69

ⁱ We are indebted to two anonymous reviewers for raising a number of the points discussed in the section on limitations and for advising us to expand the data extracts to show more of the patients' talk.