Conversation Analysis in epileptology: Listening to patients with non-epileptic seizures

Markus Reuber
Senior Clinical Lecturer in Neurology

Glasgow, 18.04. 2008

Academic Neurology Unit
University of Sheffield
Royal Hallamshire Hospital

Listening to patients with non-epileptic seizures
Overview

Interactional characteristics

- Conversation Analysis: Communication behaviour, NES versus epilepsy
- Psychological insights

Seizure metaphors

- Cognitive Linguistic Analysis: Metaphors for NES and epileptic seizures
- Psychological insights

Diagnostic labels

- Applied linguistics: Patients' use of labels for NES or epileptic seizures
- Psychological insights

Listening to patients with non-epileptic seizures
Background

Non-epileptic seizures: a serious diagnostic challenge

- NES are common (approx. 20% of patients in epilepsy clinics)
- Misdiagnosis rates of epilepsy range from 5-50%
- Mean delay of the diagnosis of NES is over 7 years
- Failure to recognise NES can cause injuries and death
- Interictal tests are usually unhelpful
- Video-EEG is expensive and only captures attacks in 2/3 patients
- “History taking” is the diagnostic gold standard

Listening to patients with non-epileptic seizures
Background

Limitations of factual features in the history of seizure patients

Limitation	Feature in the history
No differentiating value	Ictal injury, seizures from (apparant) sleep, incontinence, tongue biting, pelvic thrusting
Differentiate but not noticed / described reliably	Duration, closed eyes during tonic-clonic movements, closed mouth during tonic phase, cyanosis
Differentiate but not commonly reported	Pre-ictal anxiety symptoms, ictal crying, ictal weeping, vocalisation during tonic-clonic phase
Differentiate but require expert observation	Unusually rapid or slow recovery, variation in amplitude but not frequency of motor activity, ictal reactivity

Depend on observations of a seizure witness

Listening to patients with non-epileptic seizures

Background: Bielefeld project

Conversation Analysis: Most important interactional features

	Epilepsy	NES
Seizures as a topic	Self-initiated, main focus	Focus on situations in which seizures occur, consequences of seizures
Subjective seizure symptoms	Volunteered	Rarely mentioned

Schwabe M, Reuber M, Schöndienst M, Gülich E. Listening to people with seizures: How can linguistic analysis help in the differential diagnosis of seizure disorders? Communication and Medicine, in press.

Listening to patients with non-epileptic seizures

Background: Bielefeld project

Conversation Analysis: Most important topical features

	Epilepsy	NES
Subjective seizure symptoms	Discussed in detail	Little detail
Phase of reduced control / consciousness (“gap“)	Exactly characterised	“Holistic“ depiction

Schwabe M, Reuber M, Schöndienst M, Gülich E. Listening to people with seizures: How can linguistic analysis help in the differential diagnosis of seizure disorders? Communication and Medicine, in press.

Listening to patients with non-epileptic seizures
Background: Bielefeld project

Conversation Analysis: Most important linguistic features

	Epilepsy	NES
Subjective seizure symptoms	Trigger formulation work	Little formulation effort, negations
Metaphoric conceptualisation	Consistent. Seizures act independently, are external & threatening	Inconsistent

Schwabe M, Reuber M, Schöndienst M, Gülich E. Listening to people with seizures: How can linguistic analysis help in the differential diagnosis of seizure disorders? Communication and Medicine, in press.

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

Methodology

Question:

- Can we prove that CA can help in the differential diagnosis of seizure disorders?

Method:

- Prospective study, consecutive patients
- Only patients referred for video-EEG by consultant neurologists because of diagnostic uncertainty
- Only patients with video-EEG “proven” diagnosis
- Linguist blinded to video-EEG and other clinical information
- Interview schedule based on German guidelines

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

Methodology: 30min Interview schedule

Structure:

- 1. Open phase: What were your expectations?
- 2. Elicited accounts: First / last / worst seizure
- 3. Challenge

Rules:

- Listen, do not interrupt, let the patient talk.
- When the patient stops talking, tolerate silence, use reception indicators, repeat last thing patient said.
- Avoid additional questions other then for clarification.
- Do not introduce new topics into the conversation.

Listening to patients with non-epileptic seizures

Sheffield project: CA in epileptology

Comparison: “Carl” and “Tallulah”, open phase

Doctor

Patient

Pause (>1sec)

“Carl“

p1

```
I:   thank you very much for (-)
C:   <<f>(ya: it=s a)> pl[easure
I:                       [for helping us with this
     mister SURNAME-1;
     (0.4) em:<.h=er (-) <<p> er er eh::>
     (0.4) perhaps you could tell me what your
     expectations are hh
     <<p> (eh er fro-)> (1.4) for COMing here,
     what er were you happing ha-
     HOPing to (0.3) get OUT of this STAY.
     (0.4)
C:   i wasn=t really HOPing
     to get anything(g) OUT of it;
     (0.4) in the sense tha(t) i didn=t THINK
     (--) necessarily that you would pick
     anything(g) UP;
     (0.4)
I:   mhmh\/
C:   (-)
     cause you didn=t pick anything up (.)
     beFORE, ((clicking sound))
     so (-) i wasn-t very optimistic,
              \_______________/
               voices from the corridor

     ((interruption by nurse))

     it=s (alrigh) (0.6) so THAT was thee: em
     (---) thought that i HAD; (-)
     that (---) (it) (1.3) mh (-)
     NOT that it was a waste of EXcercise,
     (or) that (0.6) (perhaps) because i KNEW
     (-) what the (1.0) neCESSity of it was
     from the point of view of .h (-) medical
     proFESSion;
I:   mhmh\/
C:   (well) I i JUST (-) !REAL!ly didn=t think
     (that=y=would) pick anything UP;
     (0.6) because i=ve ALways considered that
     the absences were TAKing place,
     in cer:tain situations of EVERYday (.) life,
```

p2

```
     (---) which i had thought (--) erm were (removed),
I:   mh,
C:   (-) by the nature of being in=A (-)
     artificial situation;
I:   <<p> mhmh\/>
C:   which (-) this room really IS;
I:   <<p> mhmh\/>
C:   and SO for THAT reason (0.3) i (--) i sort of
     <<f> (veered)> on to the (0.6) (pessimistic)
     (0.8) view (-) [of
I:                  [right, (-) ya
C:   of of the WHOLE excercise;
     & we(ll) THAT isn=t te
     to make any criticisms of (--) medical profession;
I:   mhmh\/
C:   (0.4) er:m (0.8) and of COURse (0.4) i DID think
     that MAYbe with taking LESS of the tablets,
     that might (1.8) produce <<p> something>;
     (0.6)
I:   mh,
C:   er:m (1.5) i DID have
     a couple of attacks this week,
     (that) i=ve remembered, (0.9)
     but (-) as you KNOW (-) they are (-)
     they=re very mb- (--)QUICK;
I:   (-) mhmh/\
C:   and=er: (1.0) (de- de=s) no WARning of them
     they just oCCUR:
I:   mhmh\/
C:   (-) and i=ve ALways likened them to: erm (0.8)
     you know somebody having the finger on an

     electric socket,
     turning it OFF and on;
I:   mhmh\/
C:   so you=ve got the POwer on the RAdio and then
     it it (cha- sud(.)denly) just keeps going off,
     (then) .hh cause somebody=s doing it (h)ere
     you CAN=t see (that/them);
I:   mh,
C:   i=ve always envisaged that THAT=s
     what=s (-) happening inside me head;
I:   mh,
     (2.7)
```

p3

```
C:   but=erm (1.6) you know apart from the fact
     that er (.) i(t)- (.) f- f-
     (its tired when) you <<f> sat>
     here is (what er er) (you know)
     <<p> you get all (of it done); [(sometimes);>
I:                                  [mh,
C:   (-) (yet) cause beFORE you see,
     when i was in (0.6) i was FULL of toxins
     with thee (1.8)
     i=d had (.) waited for the (uthorotomy)
I:   right;
C:   and i WASn=t really very well (apart) from the
     epilepsy,
     (-)
I:   mhmh
C:   and i=d HAD (---) i was in in november o three
     and i had HAD (-) (er/a:) (--)
     seventy five percent of me BOdy
     (0.4) was covered in (a urticaria);
I:   mh;
C:   (-) from (EAster)
I:   mh
C:   (-) which (0.9) i think (.) was- (---)
     the view taken of it (--) NOW probably was r-
     was related to: (--) the fact that i wasn=t
     Urinating;
I:   mh;
C:   (0.8) so was <<f> RAther> (1.3) i was wearing
     a (lot of) (shorts); (-) and (-) it was coming OUT
     in me sleep; [Urine was coming out in me SLEEP;
I:                [mh;
C:   (1.0) and so REALly i was (in a/the)
     worse STAte of health,
     (-)
I:   mh=
C:   =then i am NOW;
     (-)
I:   <<pp> mhmh>
     (---)
C:   but erm (0.4) having SAID that (---)
     there HASn=t been a difference: (-)
     IN the seizures;
I:   mh
```

“Tallulah“

p1

```
I:   okey; thank you very much for (-)
     for helping with this. .h
     can you tell me what=erm (.)
     you were expecting, when you came here
     on monday,
     what were your expectations?
     (2.2)
T:   i DIDN=t think that i i=d av=em;
     (---) cause you can=t (-) say when you gonna
     have=em (or not); (3.3) but i were SCAred;
     (8.8)
I:   you were scared?
     (-)
T:   <<p> yeah;>
     (1.7)
I:   scared (about) WHAT?
     (---)
T:   being: (here) (-) on me own;
     (10.3)
I:   <<p> and what> (-) what was (.) what=s
     (-) what=s SCAry about being on your own?
     (2.1)
T:   because (-) i DON=t know (1.0) er:
     (-) (how me fits) (1.0) ARE, on (.)
     me (.) BEing on me own;
     (-) (a lot/ i=m not) (--) when i were (under)
     n SPEcialist (at TOWN-1) (-) says i (weren=t)
     allowed to be on me own;
     (-)
I:   right;
T:   i HAD (to have some(one)=wi=me);
I:   yeah,
     (--)
T:   and (0.9) FIRST night i stayed on me own
     i were (scared) (so i not) (.) (go to sleep);
     (1.5)
I:   first night you were on your own HERE?
T:   ye,
     (-)
I:   okAY;
     (---)
T:   i didn=t SLEEP, (cause) i were scared;
     (1.6)
```

p2

```
I:   so SINCE this (1.0) this doctor in
     TOWN-1 (.) when did he TELL you that you should
     not BE on your own?
     (1.5)
T:   two (months) after i got diagnosed with=it;
     (1.3)
I:   so that=s a long TIme ago; is it?=
T:   =YEAH;
     (1.0)
I:   and since THEN have you never
     BEEN on your own?
T:   no.
     (4.5)
I:   so what IS it that you=re worried about,
     BEing on your own, (1.7) what worries you about
                              it?
T:   (just not waking up)?
     (26.3)
I:   what waking up?
     be- because of (-) WHY would you not WAKE up?
     (3.7)
T:   <<annoyed> i DON=t know, it=s just
     one=o my (feys);>
     (---)
I:   one of your fears?
T:   yeah;
     (--)
I:   ((clears throat)) ((clicks tongue))
     is this related to (.) to the seizures,
     er er not waking up from a SEIzure,
     or just not (.) waking UP?
     (--)
T:   not waking up from (--) a sei-
     er HAvin a fit;
     (5.9)
I:   so does THIS link to (-) it is linked to
     just that i u- understand, (--)
     worries LINked to SEIzures;
     (--) not (-) you=re not worried that you
     might go to SLEEP in the evening and
     not wake up in the MORning; you (--)
     it=s beCAUSE you might have a seizure
     and then not (-) wake [up from THAT;
T:                         [<<p> yeah;>
```

p3

```
I:   is that, THAT=s what you worry [about?
T:                                  [yeah;
     (16.9)
I:   .h is this something that is (--)
     did you think has (nearly) happened? or,
     (--) (you know) or is it,
     (1.8) cause you HAVE had LOTS of seizures,
     haven=t you?
     (--)
T:   yeah; (-) i had (-) LOADS of=em;
     (31.2)
I:   was there anything ELSE that you were worried
                           about,
     when you came here?
     (2.0)
T:   no;
     (2.6)
I:   so it was JUST that you would be on your own?
     (-)
T:   yeah;
     (24.9)
I:   you said that you didn=t THINK
     we would SEE a seizure, (--) at first;
     (4.1)
T:   yeah, (i think) (1.6) i (1.6) it=s (-)
     like all: (.) everyone says to me can you
     (for     ) having em, (.) you CAN=t;
I:   sorry what do you say? (-) can you,
     (-)
T:   can you (throw yoursen) into a fit?
     (.)
I:   can you [THROW yourself into
T:           [(    )
T:   yeah, (1.7) but i=m telling=m you can=t;
     (-)
I:   mhmh\/
T:   the only way you=re go into a fit is if you
     stressed or: upset OR:
     in front of a flashing LIGHT;
     (-)
I:   right,
T:   cause that=s what i=ve been TOLD;
     (1.1)
I:   have YOU noticed that that you (.)
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

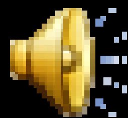
"Carl", lines 58-85 (initial open phase)

```
C: er:m (1.5) i DID have a
   couple of attacks this
   week,(that) i=ve
   remembered,(0.9) but (-) as
   you KNOW (-)they are (-)
   they=re very mb-(--)QUICK;
I: (-)mhmh/\
C: and=er: (1.0) (de- de=s) no
   WARning of them they just
   oCCUR:
I: mhmh\/
C: (-) and i=ve ALways likened
   them to: erm (0.8) you know
   somebody having the finger on
   an electric socket, turning it
   OFF and on;
I: mhmh\/
C: so you=ve got the POwer on the
   RAdio and then it it (cha-
   sud(.)denly) just keeps going
   off,(then) .hh cause
   somebodies doing it (h)ere you
   CAN=t see (that/them);
I: mh,
C: i=ve always envisaged that
   THAT=swhat=s (-) happening
   inside me head
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

"Carl", lines 58-85 (initial open phase)

```
C: er:m (1.5) i DID have a
   couple of attacks this
   week,(that) i=ve
   remembered,(0.9) but (-) as
   you KNOW (-)they are (-)
   they=re very mb-(--)QUICK;
I: (-)mhmh/\
C: and=er: (1.0) (de- de=s) no
   WARning of them they just
   oCCUR:
I: mhmh\/
```



```
C: (-) and i=ve ALways likened
   them to: erm (0.8) you know
   somebody having the finger on
   an electric socket, turning it
   OFF and on;
I: mhmh\/
C: so you=ve got the POwer on the
   RAdio and then it it (cha-
   sud(.)denly) just keeps going
   off,(then) .hh cause
   somebodies doing it (h)ere you
   CAN=t see (that/them);
I: mh,
C: i=ve always envisaged that
   THAT=swhat=s (-) happening
   inside me head
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

"Carl", lines 58-85 (initial open phase)

```
C:      er:m (1.5) i DID have
        a couple of attacks this week,
```
self initiates discussion of seizures
```
        (that) i=ve remembered, (0.9)
        but (-) as you KNOW (-) they are
        (-)they=re very mb- (--)QUICK;
```
volunteers description of subjective seizure experience
```
I:      (-) mhmh/\
C:      and=er: (1.0) (de- de=s) no
        WARning of them they just oCCUR:
```
reformulates their suddenness
```
I:    mhmh\/
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

"Carl", lines 58-85 (initial open phase)

```
C:     (-) and i=ve ALways likened them to: erm (0.8)
       you know somebody having the finger on an
       electric socket, turning it OFF and on;
```

develops a system of consistent metaphors

```
I:     mhmh\/
C:     so you=ve got the POwer on the RAdio and then
       it it (cha- sud(.)denly) just keeps going off,
       (then) .hh cause somebodies doing it (h)ere
       you CAN=t see (that/them);
```

metaphorical externalisation of seizure cause

```
I:     mh,
C:     i=ve always envisaged that THAT=s
       what=s (-) happening inside me head
```

Listening to patients with non-epileptic seizures

Sheffield project: CA in epileptology

“Tallulah”, lines 362-374 (worst seizure prompt)

```
I: what about you WORST seizure ever?
T: (3.0) tha:t=s when (--) i were sat on a FENce,
   (--) and (1.0) i were TALKin,
   An (---) next minute (.) when i came OUT o it,
   i were on=d floor; (--) and (1.8) i were (   )
   down the floor for=bout (-) TWO hours;
   (--) i tried getting up, (---) and (.)
   me collarbone smacked, (--) cause i (landed on me)
   collarbone;(---) and (2.0) i went home; (1.5)…
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

"Tallulah", lines 362-374 (worst seizure prompt)

```
I: what about you WORST seizure ever?
T: (3.0) tha:t=s when (--) i were sat on a FENce,
   (--) and (1.0) i were TALKin,
   An (---) next minute (.) when i came OUT o it,
   i were on=d floor; (--) and (1.8) i were (   )
   down the floor for=bout (-) TWO hours;
   (--) i tried getting up, (---) and (.)
   me collarbone smacked, (--) cause i (landed on me)
   collarbone;(---) and (2.0) i went home; (1.5)…
```

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

"Tallulah", lines 362-374 (worst seizure prompt)

```
I:     what about you WORST seizure ever?
T:     (3.0) tha:t=s when (--) i were sat on a FENce,
       (--) and (1.0) i were TALKin,
```

Sets scene but does not detail seizure onset

```
       An (---) next minute (.) when i came OUT o it,
       i were on=d floor;
```

Jumps forward in time – no account of seizure itself, experience of regaining consciousness in subordinate clause

```
       (--) and (1.8) i were (   ) down the floor
       for=bout (-) TWO hours;
       (--) i tried getting up,
       (---) and (.) me collarbone smacked,
       (--) cause i (landed on me) collarbone;
       (---) and (2.0) i went home; (1.5)
```

No closing contour, emphasises consequence of seizure

Listening to patients with non-epileptic seizures

Sheffield project: CA in epileptology

Replication of German findings in British patients

Patient number	1	2	3	4	5	6	7	8	9	10	11
Seizures interactional	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES	Epilepsy	NES	Epilepsy	NES
Subjective symptoms interactional	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES	Epilepsy	Epilepsy	NES	Epilepsy	NES
Subjective symptoms topical	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES
“Gaps“ topical	Epilepsy	Epilepsy	Epilepsy	NES	Epilepsy	NES	NES	Epilepsy	Inconclusive	NES	NES
Subjective symptoms linguistic	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES	NES	Epilepsy	Epilepsy	Epilepsy	NES
Metaphoric conceptualisation	Inconclusive	Epilepsy	Inconclusive	Inconclusive	Epilepsy	Epilepsy	Inconclusive	Epilepsy	Epilepsy	NES	Inconclusive
Linguistic hypothesis	**N**	**E**	**E**	**E**	**E**	**N**	**N**	**E**	**E**	**N**	**N**

Feature typical of: NES Epilepsy Inconclusive

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

Replication of German findings in British patients

Patient number	1	6	7	10	11	2	3	4	5	8	9
Seizures interactional	NES	Epilepsy	NES	Epilepsy	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES
Subjective symptoms interactional	NES	NES	Epilepsy	Epilepsy	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy	NES
Subjective symptoms topical	NES	NES	Epilepsy	Epilepsy	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy
“Gaps“ topical	Epilepsy	NES	NES	NES	NES	Epilepsy	Epilepsy	NES	Epilepsy	Epilepsy	Inconclusive
Subjective symptoms linguistic	NES	NES	NES	Epilepsy	NES	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy	Epilepsy
Metaphoric conceptualisation	Inconclusive	Epilepsy	Inconclusive	NES	Inconclusive	Epilepsy	Inconclusive	Inconclusive	Epilepsy	Epilepsy	Epilepsy
Medical diagnosis	NES					Epilepsy					

Feature typical of: NES (red) · Epilepsy (green) · Inconclusive (black)

Listening to patients with non-epileptic seizures
Sheffield project: CA in epileptology

Replication of German findings in British patients

ELSEVIER

Social Science & Medicine ▮ (▮▮▮▮) ▮▮▮–▮▮▮

SOCIAL SCIENCE & MEDICINE

www.elsevier.com/locate/socscimed

Differential diagnosis of seizure disorders: A conversation analytic approach

Meike Schwabe[a], Stephen J. Howell[b], Markus Reuber[a,*]

[a]University of Sheffield, South Yorkshire, Sheffield, UK
[b]Sheffield Teaching Hospitals NHS Trust, UK

Schwabe M, Howell SJ, Reuber M. Differential diagnosis of seizure disorders: a conversation analytic approach. Soc Sci Med 2007;65:712-724.

Listening to patients with non-epileptic seizures

What I have tried to say so far

Less can be more

Seizure metaphors

Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Methodology

- Interviews with 21 patients
- Analysis: Listing and categorisation of metaphorical expressions
- Definition of metaphor taken from Lakoff and Johnson (1980)
- Figures (per patient, per category):
  - Token count: impression of frequency of metaphorical expressions
  - Type count: impression of richness of metaphoric conceptualisation

Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Results

- Major metaphoric categories (>75% of metaphor types / tokens):
  - The seizure is an **agent / force**
  - The seizure is an **event / situation**
  - The seizure is a **space / place**

Listening to patients with non-epileptic seizures

Patients' use of seizure metaphors

Results

- **The seizure is an agent/force**

seizures come, go

seizures come in, come on, come up

seizures creep up on you, get you

seizures (try to) do things

seizures set off, are sent in

seizures are straight there

seizures are fought, counteracted, contained

seizures are let pass, wear off

Listening to patients with non-epileptic seizures

Patients' use of seizure metaphors

Results

- **The seizure is an event / situation**

seizures happen, occur, take place
seizures are due, start, finish
seizures go on, develop
seizures are experienced, witnessed
seizures are handled, controlled, stopped
seizures are avoided, put off
seizures are brought on
seizures run their course

Listening to patients with non-epileptic seizures
Patients’ use of seizure metaphors

Results

- **The seizure is a space/place**

drifting off, being off somewhere else
going, going off, being gone, coming back
coming round, coming to
going down, being down
not being there, being out
into seizures, in seizures, out of seizures
within seizures, through seizures

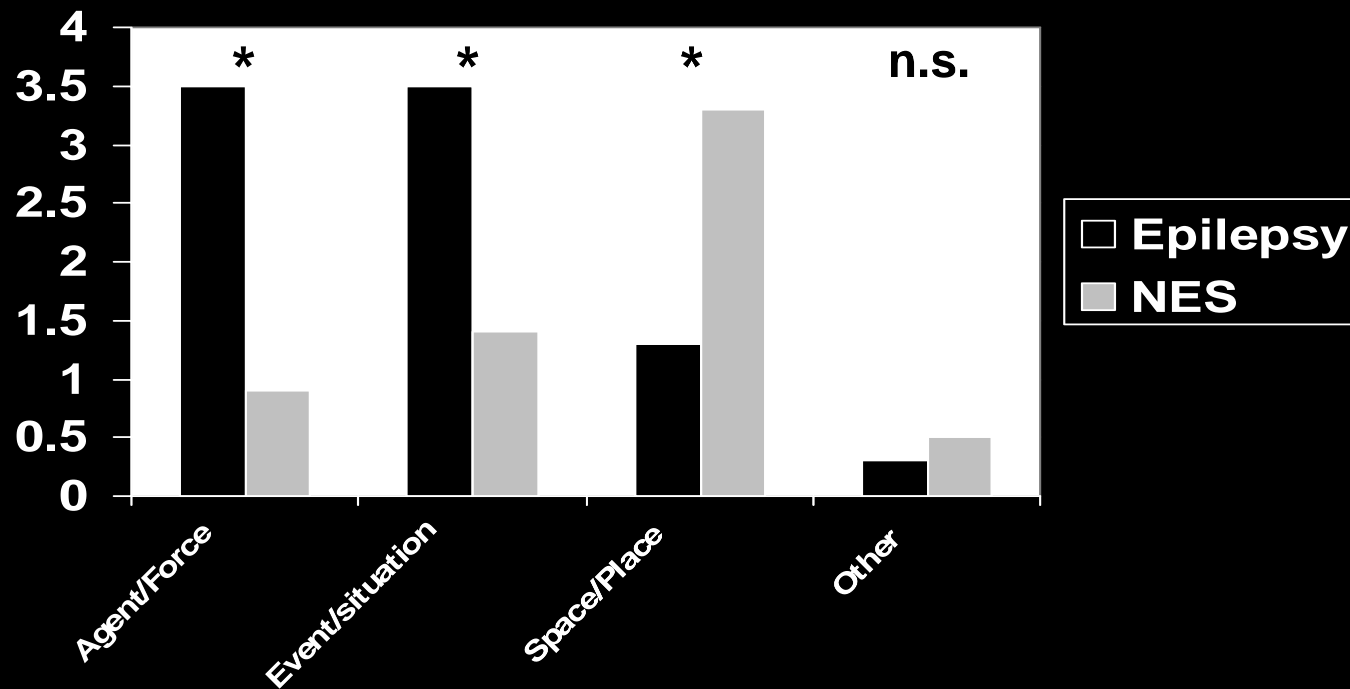
Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Results

- Main observation: similarities across patient groups
- No difference of total number of metaphor types / tokens used by patients with epilepsy or NES
- Most patients used metaphors from all categories
  - The seizure is an **event / situation**: used by 16 patients
  - The seizure is an **agent / force**: used by 15 patients
  - The seizure is a **space / place**: used by 18 patients

Listening to patients with non-epileptic seizures
Patients’ use of seizure metaphors

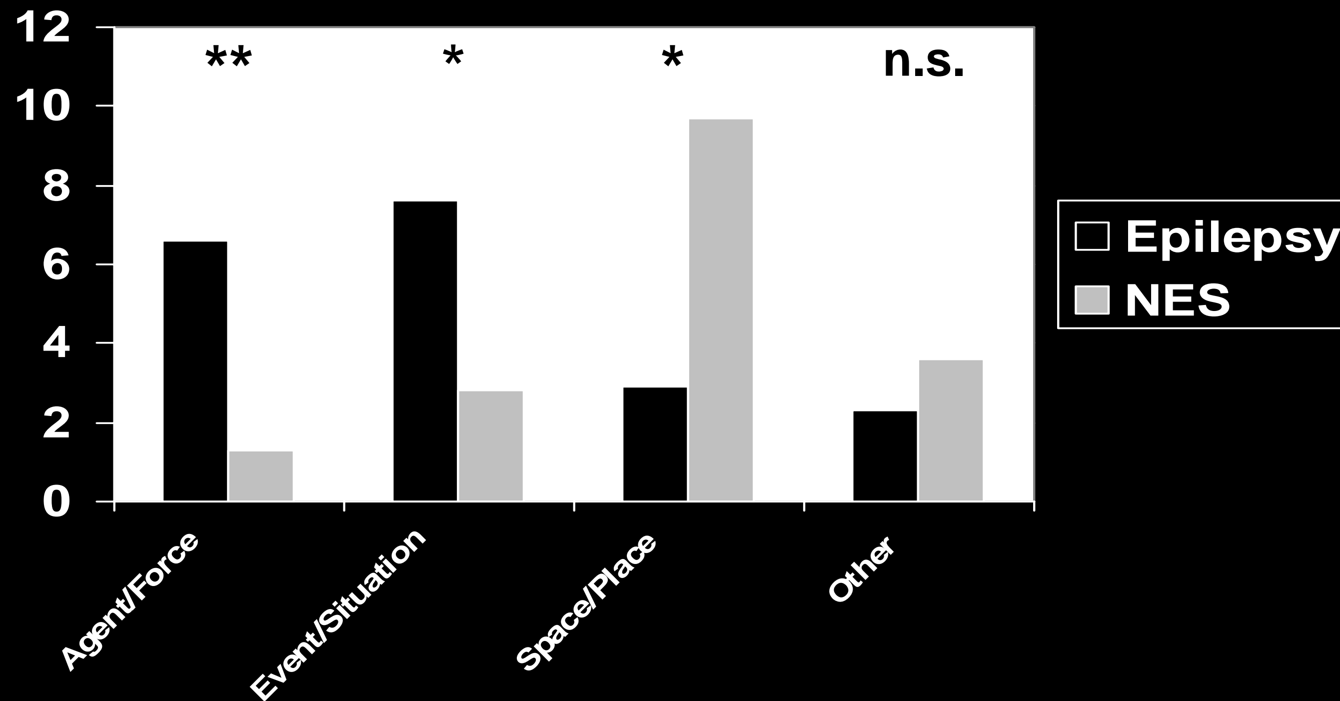
Mean metaphor type counts



* : p<O.O5 **: p<O.O1 n.s.: not significant

Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Mean metaphor token counts



* : p<O.O5 **: p<O.O1 n.s.: not significant

Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Logistic regression analysis

- Variables: Event, agent/force, place/space type & token counts
- Model: $Chi^2=20.35$, $p=0.0024$

Overall correct categorisation: 90.5%		Predicted		
		Epilepsy	NES	
Observed	Epilepsy	7	1	87.5%
	NES	1	12	92.3%

Listening to patients with non-epileptic seizures

Patients’ use of seizure metaphors

Psychological insights

	Agent / force	**Event / situation**	**Space / Place**	**Other**
Seizure	Active, independent agent	Passive, independent entity	Passive, location	variable
Patient	Victim, object	Witness, observer	Active, traveller	variable

Listening to patients with non-epileptic seizures
Patients' use of seizure metaphors

Psychological insights

	Agent / force	**Event / situation**	**Space / Place**	**Other**
Seizure	Active, independent agent	Passive, independent entity	Passive, location	variable
Patient	Victim, object	Witness, observer	Active, traveller	variable

Typical of: NES Epilepsy

Diagnostic labels

Listening to patients with non-epileptic seizures

Patients' use of diagnostic labels

Methodology

- Based on verbatim transcripts of interviews with 21 patients
- Identification of all seizure labels used by patients and doctor
- Linguistic analysis of differences in meaning and register of the lables used
- Statistical comparison of differences in label choice between patients with epilepsy and NES
- Microanalytic qualitative analysis of label usage (Discourse Analysis)

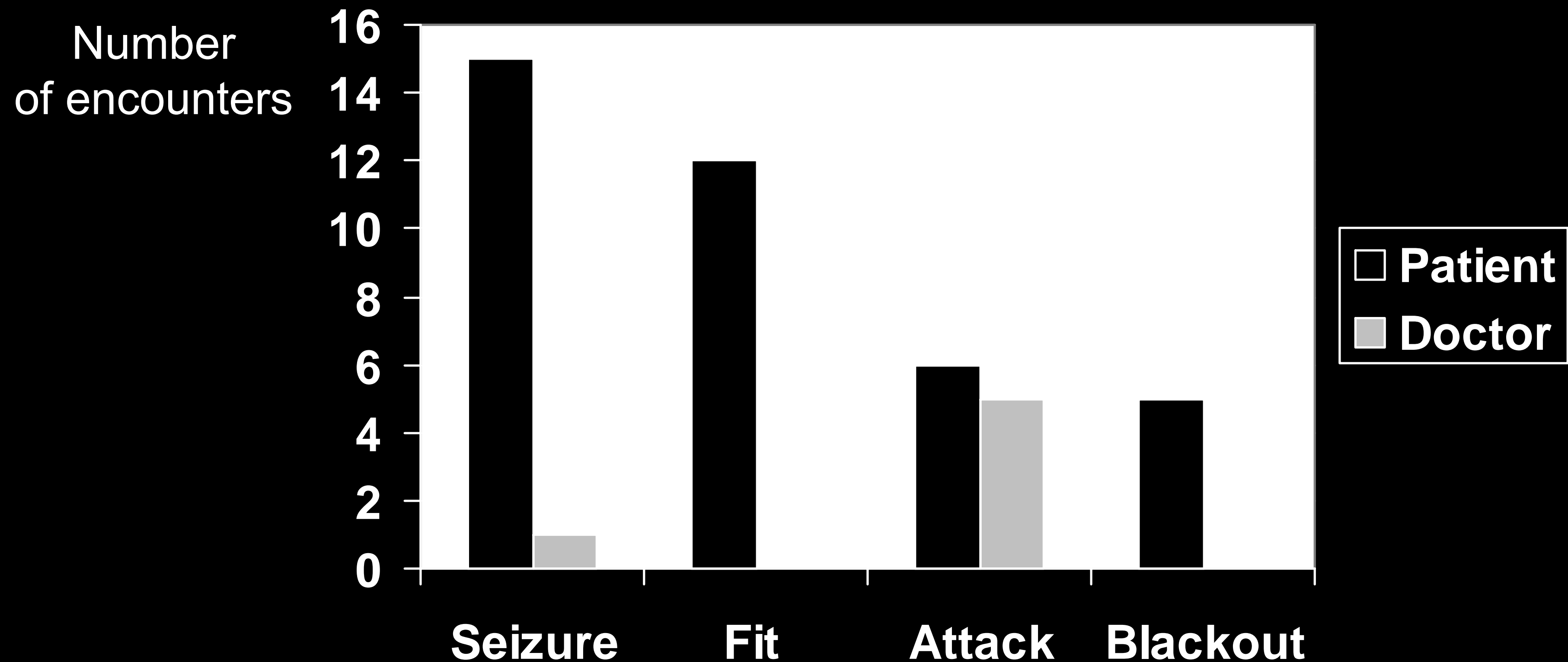
Listening to patients with non-epileptic seizures
Patients’ use of diagnostic labels

Results

Diagnostic label	Patients‘ usage		Doctor‘s usage		Difference	
	N	Encounters	N	Encounters	N	Encounters
Seizure	132	16	123	15	n.s.	n.s.
Fit	41	12	6	3	p=0.006	p=0.004
Attack	66	11	99	17	p=0.02	p=0.05
Blackout	22	4	6	5	n.s.	n.s.
Other	≤10	≤3	≤2	≤1	n.s.	n.s.

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Results: Initiation of label usage

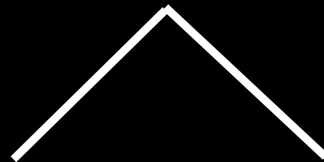


Listening to patients with non-epileptic seizures
Patients’ use of diagnostic labels

Results

Most frequently used labels	Denotation
Seizure / attack	General
Fit / Blackout	Specific

Seizure / attack



Fit

Blackout

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Example: Meaning of *seizure*, *blackout* and *fit*

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

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

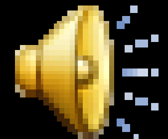
Example: Meaning of *seizure*, *blackout* and *fit*

Doctor: well can I (.) take you back to your first (1.0) seizure (1.6)

Chris: which one

Doctor: well you know you've come here because of these blackouts(0.3) what about the first one you can remember (0.3) What can you tell me about that (1.6)

Chris: the blackout or the (.) fit cos i'm having like (.)two different types at the moment



Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Examples: Register of *seizure*, *blackout* and *fit*

a. "as I say I thought epilepsy was someone thrashing about having a fit on the floor" (Samantha)

b. "I kept having these like fits, just collapsing and having fits, like grand mal symptoms, jerking and losing consciousness" (Chris)

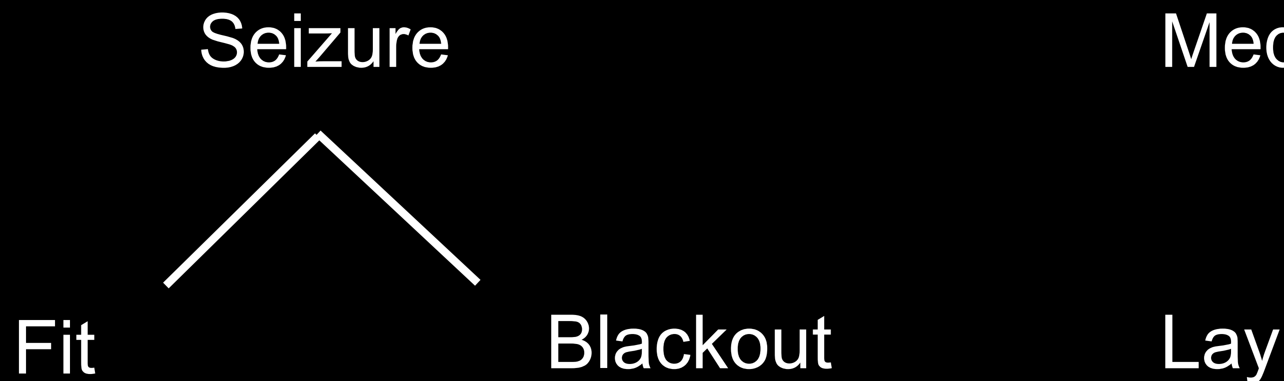
c. "it was more like a blackout than anything else that one […] nothing happened to me while I was gone if you like, I was just gone" (Alastair)

d. "the blackouts started being different […] you know, just dropping"(Chris)

Listening to patients with non-epileptic seizures

Patients' use of diagnostic labels

Results



Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Examples: Register of *seizure*, *blackout* and *fit*

a. **"when I first started having fits" (Betty)**

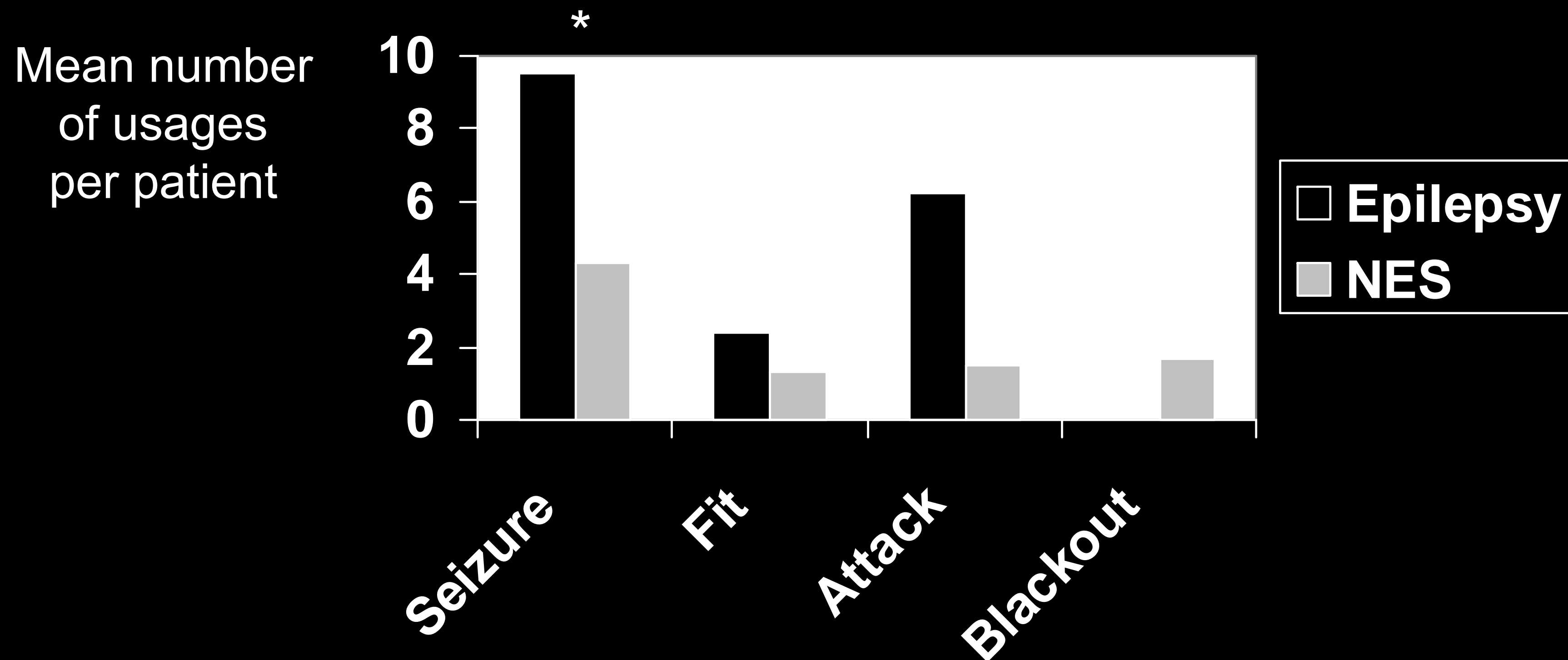
b. **"and that's when the blackouts started" (Chris)**

c. **"and I'd maybe have a cluster of seizures, but I didn't know they were seizures at the time" (Samantha)**

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

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Results: Group differences in diagnostic label preference



Differences between epilepsy and NES: *Seizure* p=0.034, others n.s.

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Examples: Resistance to use of *seizure*

a. Doctor: is this related to (.) to the seizures er er not waking up from a seizure or just not (.) waking up

Tallulah: not waking up from (0.3) a sei- er having a fit

b. "I've never had any problem with er (0.8) seizures or anything" (Trudie)

c. "because there's – I seem to have erm two different sorts of (0.9) seizures happening" (Pat)

d. "just really to find out what the problem is or what's causing (.) .hhh erm (0.3) the seizures" (Sandra)

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Results: Resistance to the medical label "seizure"

	N	No use of *seizure*	No self-initiation of *seizure*	Use of *seizure* with evidence of resistence	Any evidence of resistance to *seizure*
Epilepsy	8	0	0	1 (13%)	1 (13%)
NES	13	5 (38%)	6 (46%)	4 (31%)	10 (77%)
Significance (x^2 test)		p=0.04	p=0.02	n. s.	p=0.004

Listening to patients with non-epileptic seizures
Patients’ use of diagnostic labels

Psychological insights

- Patients with NES have a tendency to avoid medical labels for their seizures
- Patients’ avoidance of medical labels projects responsibility for naming the disorder onto the doctor

Listening to patients with non-epileptic seizures
Patients' use of diagnostic labels

Somatisation is a collaborative process

Listening to patients with non-epileptic seizures

Summary

Interaction	Metaphors	Diagnostic labels
• A unusally passive but receptive stance taken by the doctor enables patients to demonstrate communication behaviour of diagnostic value • Interactive behaviour is characterised by avoidance	• Patients with epileptic and non-epileptic seizures use different profiles of metaphors for their seizures • In NES the patient is the acting subject, the seizure is a passive location	• Patients with epileptic and non-epileptic seizures differ in their use of labels • NES patients‘ avoidance of \`medical´ labels encourages the to doctor to accept responsibility for the disorder

The End