Supporting information for:

Reliability of patient self-report of cognition, awareness and consciousness during seizures

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Table S1. Patient demographic and clinical characteristics. FA: focal aware, FIA: focal impaired awareness, UF: Focal with unknown awareness, FtBTC: focal to bilateral tonic-clonic, GTC: primary generalized tonic-clonic, UTC: tonic-clonic seizure of unknown onset, L: left, R: right, Bi: bilateral

Pt	Age (yr)	Sex	No. Szs	Seizure types	MRI	PET hypometabolism	Ictal-interictal SPECT hyper-perfusion	Scalp EEG onset (*intra-cranial)	Surgery	Pathology	Duration of latest post-op outcome (yrs)	Engel Outcome Scale	Overall localization
1	46	M	6	FA, FIA, UF	Residual L hippocampal tail from previous resection	R lateral temporal	R temporal, occipital	R inferior occipital, medial temporal (simultaneous onset)*	R hippocampus and lateral temporal lobe RNS placement	N/A	4.7	I	R temporal, occipital
2	28	F	1	FIA	Normal	L occipital, temporal	Bi occipital	L temporal, occipital*	L parietal-occipital lobectomy	Diffuse mild reactive gliosis	2.3	IV	Nonlocalized
3	50	F	1	FtBTC	Nonspecific white matter changes	None		L temporal					L temporal
4	20	M	3	FIA, UF, FtBTC	R hippocampal body and tail smaller than L	L parietal, temporal	L frontal, parietal, temporal	Diffuse	Corpus callosotomy		1.0	III	Nonlocalized
5	35	M	2	FA, UF	Nonspecific white matter changes	None		L frontal, temporal					L frontal, temporal
6	48	F	1	FtBTC	L medial temporal encephalocele	None		L frontal, temporal	L temporal encephalocele resection	Reactive astrocytosis with collagenous fibrovascular tissue	1.3	II	L temporal
7	48	F	1	FIA	L temporal atrophy with hippocampal sclerosis		L temporal, basal ganglia	L temporal					L temporal
8	50	F	3	FIA, UF	Previous R lateral temporal resection, increased FLAIR in Bi hippocampi	L medial temporal, R parietal		Bi temporal					Bi temporal
9	57	M	1	FA	Nonspecific white matter changes			L temporal					L temporal
10	26	M	1	FtBTC	L acoustic neuroma			R frontal					R frontal

Table S1, continued

Pt	Age (yr)	Sex	No. Szs	Seizure types	MRI	PET hypome tabolism	Ictal-interictal SPECT hyper-perfusion	Scalp EEG onset (*intra-cranial)	Surgery	Pathology	Duration of latest post-op outcome (yrs)	Engel Outcome Scale	Overall localization
11	35	F	4	FA, FIA, UF	Increased FLAIR in medulla, cerebellum and frontal white matter			L temporal					L temporal
12	27	F	1	GTC	Normal	None		Diffuse					Nonlocalized
13	30	F	2	FA, FtBTC	Normal	None		Diffuse					Nonlocalized
14	50	M	2	FtBTC	Normal			L hemisphere					L hemisphere
15	45	M	1	FtBTC	R parietal 9mm cavernoma, L inferior frontal smaller cavernoma			R parasagittal	R parietal cavernoma resection	Cavernous hemangioma	6.0	I	R parietal
16	32	M	1	UF	Normal	R anterior temporal	L inferior temporal, occipital	L temporal, occipital*	L temporal-occipital lobe epileptogenic focus excision	Focal cortical dysplasia	1.8	II	L temporal, occipital
17	22	M	2	FA, UF	L mesial temporal sclerosis	L temporal	L temporal	L lateral inferior temporal*	L temporal-parietal epileptogenic focus excision	Mild reactive gliosis	2.8	II	L temporal, parietal
18	37	F	1	FA	Normal	R lateral temporal		R mesial temporal*	R temporal lobe resection	Mild reactive gliosis	2.5	I	R temporal
19	27	F	4	UF	L frontal, parietal encephalomalacia	L frontal, parietal, temporal		L frontal, temporal*	L frontal RNS placement	N/A	3.1	II	L frontal
20	24	M	6	FA, UF	Normal	R>L temporal, frontal		R>L amygdala and hippocampus*	Bi medial temporal RNS placement	N/A	3.3	II	Bi temporal

Table S1, continued

Pt	Age (yr)	Sex	No. Szs	Seizure types	MRI	PET hypome tabolism	Ictal-interictal SPECT hyper-perfusion	Scalp EEG onset (*intra-cranial)	Surgery	Pathology	Duration of latest post-op outcome (yrs)	Engel Outcome Scale	Overall localization
21	30	F	2	FIA	Normal	R>L temporal		L temporal					Bi temporal
22	28	F	2	FtBTC	Normal	None		L temporal					L temporal
23	50	M	1	FtBTC	Dysmorphic Bi temporal lobes with polymicrogyria, heterotopic gray matter in R periventricular region	Bi temporal		L>R frontal					Nonlocalized
24	37	F	5	FA, FIA, FtBTC	R>L diffuse encephalomalacia	R occipital		R frontal, parietal					R hemisphere
25	64	F	2	FA, UF	Normal	L lateral frontal, superior temporal		L>R temporal					L hemisphere
26	67	M	2	FIA, UF	R medial temporal sclerosis, hippocampal atrophy	R temporal, frontal		R temporal					R temporal
27	44	F	2	FA, UF	Normal			L temporal					L temporal
28	34	F	2	GTC	Nonspecific white matter changes	Bi medial temporal, parietal, occipital		Diffuse					Nonlocalized
29	24	F	3	FA	Nonspecific FLAIR changes in cerebellum	Bi medial temporal		Diffuse					Nonlocalized
30	48	M	3	FA, UF, FtBTC	R temporal encephalomalacia	R temporal		R temporal, occipital	R temporal lobe resection	Reactive gliosis	3.0	I	R temporal

Table S1, continued

Pt	Age (yr)	Sex	No. Szs	Seizure types	MRI	PET hypome tabolism	Ictal-interictal SPECT hyper-perfusion	Scalp EEG onset (*intra-cranial)	Surgery	Pathology	Duration of latest post-op outcome (yrs)	Engel Outcome Scale	Overall localization
31	59	M	1	FtBTC	Nonspecific white matter changes			Diffuse					Nonlocalized
32	47	F	1	FIA	Slight FLAIR signal in L hippocampus	L posterior parietal		L temporal					L hemisphere
33	45	F	2	FtBTC	Nonspecific white matter changes			R frontal, temporal					R hemisphere
34	30	F	1	FIA	R occipital region polymicrogyria	R temporal, occipital		R temporal, parietal, occipital	Resection of cortical dysplasia	Reactive gliosis and polymicrogyria	2.7	III	R hemisphere
35	39	M	2	UF, FtBTC				R parietal, temporal					R parietal, temporal
36	26	M	2	FA, FIA	Previous R hippocampal head resection, increased signal in residual superior temporal gyrus	R temporal		R frontal, temporal	R temporal lobe resection	Reactive gliosis and some heterotopic neurons	1.4	I	R temporal
37	35	M	3	FIA, FtBTC	L inferior frontal cavernoma	Bi temporal		L medial temporal, R frontal, medial temporal*					Nonlocalized
38	31	F	4	FIA, UF, FtBTC	R parietal-occipital cortical dysplasia	L temporal, parietal, occipital	R temporal, parietal, occipital	R temporal, occipital*	R temporal and occipital lobe resections	Multifocal cortical dysplasia	5.3	I	R temporal, occipital
39	18	M	2	UTC	Normal	None		Diffuse					Nonlocalized

Table S2: Formulas Used in Analysis

	Subjective Function: Questionnaire Responses		
Objective Function: Video Review	**Intact**	**Impaired**	**Totals**
Intact	A	B	G1
Impaired	C	D	G2
Totals	F1	F2	N

$$k = \frac{p_o - p_e}{1 - p_e}$$ *Cohen's kappa value*

$$p_o = \frac{\mathrm{A} + \mathrm{D}}{\mathrm{N}}$$ *Observed proportion of agreement*

$$p_e = \left(\frac{\mathrm{F1}}{\mathrm{N}}\right)\left(\frac{\mathrm{G1}}{\mathrm{N}}\right) + \left(\frac{\mathrm{F2}}{\mathrm{N}}\right)\left(\frac{\mathrm{G2}}{\mathrm{N}}\right)$$ *Proportion of agreement expected by chance*

$$p_{pos} = \frac{\mathrm{A}}{(\mathrm{F1} + \mathrm{G1})/2}$$ *Proportion of positive agreement*

$$P_{neg} = \frac{D}{(F2\ + \mathrm{G2})/2}$$ *Proportion of negative agreement*

References

1. Cohen J. A coefficient of agreement for nominal scales. Educational and Psychological Measurement 1960; 20:37-46.
2. Feinstein AR, Cicchetti DV. High agreement but low kappa: I. the problems of two paradoxes. J Clin Epidemiol 1990; 43: 543-548
3. Cicchetti DV, Feinstein AR. High agreement but low kappa: II. resolving the paradoxes. J Clin Epidemiol 1990; 43:551-558.

Table S3. Patient answers to the daily seizure questionnaire and admissions questionnaire in comparison to objective video analysis. Reported values are number of seizures in each class. The left columns show patient answers to the questions, and other columns show number of seizures (for daily seizure questionnaire) or patients (for admission questionnaire) with each type of behavioral rating based on objective video review.

Daily seizure questionnaire

Item 2: Were you able to respond to other people during your seizure?

Patient answer	Normal responsiveness throughout	Partially normal responsiveness	Abnormal responsiveness throughout	TOTAL
Yes	10	6	3	19
No	5	9	37	51
TOTAL	15	15	40	70

Item 3: Were you able to speak during your seizure?

Patient answer	Normal speech throughout	Partially normal speech	Abnormal speech throughout	TOTAL
Yes	7	3	0	10
No	3	17	35	55
TOTAL	10	20	35	65

Item 4: Do you remember what happened during the actual seizure?

Patient answer	Early recall	No early recall	TOTAL
Yes	17	3	20
No	3	15	18
TOTAL	20	18	38

Patient answer	Late recall	No late recall	TOTAL
Yes	24	1	25
No	3	24	27
TOTAL	27	25	52

Item 6: Were you aware of what was going on around you during your seizure?

Patient answer	Normal responsiveness throughout	Partially normal responsiveness	Abnormal responsiveness throughout	TOTAL
Yes	13	8	7	28
No	2	7	33	42
TOTAL	15	15	40	70

Patient answer	Normal speech throughout	Partially normal speech	Abnormal speech throughout	TOTAL
Yes	8	13	8	29
No	2	7	27	35
TOTAL	10	20	35	65

Patient answer	Early recall	No early recall	TOTAL
Yes	17	3	20
No	3	15	18
TOTAL	20	18	38

Patient answer	Late recall	No late recall	TOTAL
Yes	25	1	26
No	2	24	26
TOTAL	27	25	52

Item 7: Did you lose consciousness or black out?

Patient answer	Normal responsiveness throughout	Partially normal responsiveness	Abnormal responsiveness throughout	TOTAL
Yes	1	6	18	25
No	7	6	4	17
TOTAL	8	12	22	42

Patient answer	Normal speech throughout	Partially normal speech	Abnormal speech throughout	TOTAL
Yes	1	6	15	22
No	1	11	5	17
TOTAL	2	17	20	39

Patient answer	Early recall	No early recall	TOTAL
Yes	3	9	12
No	10	2	12
TOTAL	13	11	24

Patient answer	Late recall	No late recall	TOTAL
Yes	5	14	19
No	16	2	18
TOTAL	21	16	37

Admission questionnaire

Item 1: Are you able to respond to other people during your seizures?

Patient answer	Normal responsiveness in all seizures	Normal responsiveness in some but not all seizures	Abnormal responsiveness in all seizures	TOTAL
Always	1	0	1	2
Sometimes	3	2	11	16
Never	3	0	15	18
TOTAL	7	2	27	36

Item 2: Are you able to speak during your seizures?

Patient answer	Normal speech in all seizures	Normal speech in some but not all seizures	Abnormal speech in all seizures	TOTAL
Always	1	0	1	2
Sometimes	1	1	14	16
Never	1	0	14	15
TOTAL	3	1	29	33

Item 3: Are you aware of what is going on around you during your seizures?

Patient answer	Normal responsiveness in all seizures	Normal responsiveness in some but not all seizures	Abnormal responsiveness in all seizures	TOTAL
Always	2	0	2	4
Sometimes	5	2	10	17
Never	0	0	14	14
TOTAL	7	2	26	35

Patient answer	Normal speech in all seizures	Normal speech in some but not all seizures	Abnormal speech in all seizures	TOTAL
Always	1	0	3	4
Sometimes	2	1	14	17
Never	0	0	12	12
TOTAL	3	1	27	33

Patient answer	Early recall in all seizures	Early recall in some but not all seizures	No early recall in any seizure	TOTAL
Always	4	0	0	4
Sometimes	7	0	6	13
Never	1	0	6	7
TOTAL	12	0	12	24

Patient answer	Late recall in all seizures	Late recall in some but not all seizures	No late recall in any seizure	TOTAL
Always	3	0	0	3
Sometimes	9	0	4	13
Never	1	0	9	10
TOTAL	13	0	13	26

Table S4. Results from concordance analysis of patient reports and behavioral rating via video review. Non-bootstrapped values are reported. DSQ: daily seizure questionnaire. For bootstrapped values see Table 2.

Comparator 1: Patient answer	**Comparator 2: Behavioral rating**	**κ**	p_{pos}	p_{neg}
Responsiveness (DSQ item 2)	Responsiveness	0.459	0.588	0.868
Speech (DSQ item 3)	Speech	0.645	0.700	0.945
Memory (DSQ item 4)	Early recall	0.683	0.850	0.833
Memory (DSQ item 4)	Late recall	0.846	0.923	0.923
Awareness (DSQ item 6)	Responsiveness	0.452	0.605	0.825
Awareness (DSQ item 6)	Speech	0.235	0.410	0.747
Awareness (DSQ item 6)	Early recall	0.683	0.850	0.833
Awareness (DSQ item 6)	Late recall	0.885	0.943	0.941
Consciousness (DSQ item 7)	Responsiveness	0.406	0.560	0.814
Consciousness (DSQ item 7)	Speech	0.015	0.105	0.712
Consciousness (DSQ item 7)	Early recall	0.583	0.800	0.783
Consciousness (DSQ item 7)	Late recall	0.623	0.821	0.800