

Which seizure elements do patients memorize? A comparison of history and seizure documentation

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Abstract

Objective: People with epilepsy (PWE) are frequently unable to recall the core manifestation of their disease, epileptic seizures. This means that seizure frequency is often underestimated by practitioners and that seizure classification based on reports of patients or their relatives is difficult because seizure semiology remains unclear. The purpose of this study, therefore, was to prospectively explore patients' memory regarding seizure elements and to assess the role of seizure types.

Method: Ninety patients diagnosed with focal epilepsy undergoing diagnostic electroencephalography (EEG)–video monitoring were included. The ability to memorize individual seizure elements was assessed using a questionnaire. Patient knowledge was then compared to the findings of subsequent seizure documentation during EEG-video monitoring. Seizure elements were categorized in four groups: subjective, motor, autonomic, and postictal elements.

Results: In all categories, the number of documented seizure elements during monitoring strongly exceeded the number of elements that were recalled. Only 45.6% of subjective elements, 5.4% of motor phenomena, 11.9% of autonomic findings, and 2.1% of postictal impairments were recalled. The ability to recall seizure elements varied significantly depending on seizure types (secondarily generalized tonic-clonic seizures [SGTCS] < complex partial seizures [CPS] < simple partial seizures [SPS]), but not on the relative timing of the element during the seizure.

Significance: Patients' memory of seizure semiology is almost always fragmentary. Although the rate of correctly remembered seizure elements depends on the seizure type, complete recall of a seizure is almost never obtained. Consequently, 89 of 90 patients in this cohort would only have had seizures classified as a seizure with “impaired awareness” according to the new International League Against Epilepsy (ILAE) seizure classification. The involvement of brain areas involved in memory encoding and consolidation and in the context of seizure classification schemes.

KEYWORDS

awareness, epilepsy, memory, seizure elements, semiology

1 | INTRODUCTION

Seizures are the key manifestation of epilepsy. Unlike with most other diseases, many people with epilepsy (PWE) are not aware of the key symptom at all or can remember only minor parts of what happens during their seizures.¹ Frequently, information from relatives, friends, or other witnesses to a seizure is needed as sources of information about the clinical manifestation. In line with this problem, patient-based seizure diaries may reflect seizure occurrence to some extent,² but often remain incomplete.³ Witnesses' descriptions of epileptic seizures have also been shown to lack accuracy.⁴ On the other hand, the exact seizure semiology is essential to practitioners, as clinical manifestations are major determinants for diagnosing epilepsy and for the selection of anticonvulsive treatment. The completeness of memory for seizure elements is a key criterion for the 2017 International League Against Epilepsy (ILAE) seizure classification, and its study is relevant for its application.

It is well known that a lack of valid information about seizure frequency and seizure semiology can prevent PWE from receiving optimal therapy. PWE have consistently been shown to underreport seizures,^{5,6,7} with 44.2%,⁵ 63.0%,⁶ and 55%⁷ of documented seizures reported to have gone unnoticed by patients in three different studies. In several studies with patients undergoing video-EEG recording, it was shown that the ability to recall a seizure depends on the localization and lateralization of seizure onset. Patients with frontal lobe epilepsy tend to remember seizure elements better than patients with temporal lobe epilepsy or occipital lobe epilepsy.⁸ Likewise, a left-sided electroencephalographic lesion and epileptic activity involving both hemispheres were associated with impairment of memory for seizures.^{6,8,9} In a prospective study with 91 participants, Hoppe et al (2007) showed that participants with a left-sided focus were significantly less likely to be aware of having had a seizure.⁷ Similarly, the accuracy of patient seizure count depended on the seizure type. In their prospective study with 27 participants, Blum et al (1996) reported that primary generalized seizures were always noted. In contrast, participants with limited focal-onset seizures remembered their seizures more often than patients in which seizures progressed to bilateral tonic-clonic seizures. Therefore, the authors concluded that seizure awareness depends on seizure intensity.⁶ To the best of our knowledge, all studies so far have focused on the quantity of remembered seizures rather than on the quality of information about individual seizure elements.

Therefore, the aim of our study was to prospectively explore patients' memory regarding individual seizure elements and to compare the number and type of remembered seizure elements to the number and type of documented seizure elements during video-EEG monitoring. A secondary objective was to examine whether memory of seizure elements

Key points

- Patients' memory of seizure semiology is almost always fragmentary. This increases the risk of misclassifying seizure types.
- Patients' memory regarding seizure elements was prospectively explored and the role of seizure type assessed.
- Results showed that the rate of correctly memorized seizure elements depends on the seizure type, but complete recall of a seizure is almost never obtained.
- Most seizures disturb the network of medial temporal lobe and connected association cortices required for stable long-term memories.
- The operationalization of awareness as used in the new ILAE seizure classification shifts a considerable number of cases from "focal aware" to "impaired awareness" seizures, creating a strong asymmetry between seizure types.

depended on the predominant seizure type. In accordance with the literature, we hypothesized that patients formerly considered to have preserved consciousness (simple partial seizures [SPS] like auras or seizures with preserved reactivity) would remember seizure elements more completely than patients with complex partial seizures (CPS) or with a transition to a bilateral tonic-clonic phase. Furthermore, we hypothesized that early seizure elements occurring during more limited spread of epileptic activity would be remembered better than elements occurring later during the course of a seizure.

2 | MATERIAL AND METHODS

2.1 | Participants

From April 2014 to August 2016, a total of 90 epilepsy patients with focal-onset seizures who were referred to the epilepsy center of the University Hospital Freiburg, Germany for diagnostic EEG-video monitoring were prospectively included in the study. All patients were diagnosed with focal epilepsy and were 12 years of age or older. The study excluded patients who had difficulty understanding questionnaires due to mental disability or language problems. All analyzed participants gave their written informed consent to participate in the study. Sociodemographic data (age, gender, education level, and professional qualification) and clinical characteristics (predominant seizure type, age at onset of

epilepsy, years with epilepsy, etiology of epilepsy, and number of recorded seizures) were collected from all participants.

2.2 | Procedure

After admission, yet prior to video-EEG recordings, participants who agreed to participate in the study answered a questionnaire. Throughout the course of their hospitalization, epileptic seizures were recorded by means of simultaneous video and EEG recording. At the time of each seizure, patients underwent a standardized testing procedure consisting of remembering a word, remembering an object, reporting their full name, shaking hands, naming objects, showing objects, reading, carrying out body commands, and repeating words.

Seizure elements of each seizure were documented according to their time of appearance during a seizure by EEG technicians following review with certified epileptologists. Data provided by the questionnaire were compared to the video-EEG monitoring seizure documentation.

2.3 | Study material

2.3.1 | Memory questionnaire

The participants responded to the following questionnaire, which was developed specifically for use in the present study.

The questionnaire comprises nine items, which evaluate the participants' knowledge about epilepsy, whether he/she has already watched an epileptic seizure on videotape and the impact of this experience, memories of one's own seizure, and the participant's opinion on duration of the seizure and postictal impaired consciousness. For the purpose of the present study, we focused on item 6:

- Do you remember seizure elements? (yes/no)
- Which seizure elements do you remember?

The second question was formulated as an open-ended question.

2.3.2 | Semiology list

Each seizure element was documented by medical technical assistants (MTAs) using a list of semiological items. This list was developed at the University Hospital Freiburg Epilepsy Center in 2002 to standardize the documentation of seizures. It derives from the "Glossary of Descriptive Terminology for Ictal Semiology" of Blume et al (2001).¹⁰ In the slightly modified version used in our epilepsy center, seizure elements are categorized into four subcategories: subjective, motor

(including motor and behavioral signs visible on videos either based on spontaneous behaviour or obtained during interactions during testing), autonomic, and postictal elements. Subjective elements by definition are not directly objectifiable yet were assessed using a standardized testing procedure in which technicians asked for subjective experiences. Seizure elements of each recorded seizure during the hospitalization were documented in the sequence of appearance. In patients undergoing several video-EEG monitorings, data from previous hospitalizations were also used in this study.

2.4 | Statistical analysis

Statistical analysis was performed using the Statistics Package for the Social Sciences (SPSS) version 24.0 software (SPSS Inc). Descriptive data were expressed in median, 25th/75th percentiles, minimum, maximum, and percentage. A chi-square test of independence was performed to analyze the relation between memory of seizure elements and prior knowledge of seizure elements through videotapes/reports of relatives as well as memory of seizure elements and seizure type. The significance level was set at 5%.

3 | RESULTS

3.1 | Description of the sample

Of 1123 patients who were admitted to the the University Hospital Freiburg Epilepsy Center from April 2014 to August 2016, a total of 180 patients met the including criteria for the study and were asked to participate in the study. Thirty-three of these patients were excluded because they did not have a video-documented seizure throughout the course of their hospitalization; 42 patients refused to participate; nine patients were excluded due to problems in communication; five patients turned out to have dissociative seizures, which were not included; and one patient was excluded due to his psychologically unstable condition. A total of 90 patients were included in the study. Table 1 shows the sociodemographic and clinical characteristics of the participants. Imaging-based etiology included hippocampal sclerosis (HS; 19), focal cortical dysplasia (FCD; 14), other malformations of cortical development (MCDs; 3), long-term epilepsy-associated tumors (LEAT; 6), encephalitis (4), hypothalamic hamartoma (HH; 3), other lesion types (including posttraumatic defects, bleeding, encephalocele; 12), and unknown/ nonlesional (29).

The predominant seizure type of half of the sample according to the 1981 ILAE classification was complex-partial, whereas it was secondarily generalized for a further third of the sample, and simple partial for 16% (reclassification according to the 2017 ILAE classification is discussed below).

TABLE 1 Sociodemographic and clinical characteristics of 90 patients using the 1981 ILAE classification

	Total sample (N = 90)
Gender (N (%))	
Male	45 (50)
Female	45 (50)
Median age in years (25th-75th percentile)	34.5 (22.75-47.25)
Min	15
Max	70
Median age at onset of epilepsy (25th-75th percentile)	18 (11-28)
Min	0.1
Max	66
Median years with epilepsy (25th-75th percentile)	12 (6-22)
Min	1
Max	55.9
Seizure type (N (%))	
Simple partial seizure (SPS)	14 (15.6)
Complex partial seizures (CPS)	45 (50)
Secondarily generalized tonic clonic seizures (SGTCS)	24 (26.7)
Unclassified	7 (7.8)
Seizure aetiology (N (%))	
Cryptogenic/ non-lesional	29 (32.2)
Hippocampal sclerosis (HS)	19 (21.1)
Focal cortical dysplasia (FCD)	14 (15.6)
Other ^a	13 (14.4)
Long-term epilepsy-associated tumors (LEAT)	5 (5.6)
Malformations of cortical development (MCD)	4 (4.4)
Encephalitis	2 (2.2)
Number of recorded seizures in total (N)	
Hypothalamic hamartoma (HH)	599
Number of recorded seizures per patient (N)	
Min	1
Max	15

Note: Differences to the 2017 classification are discussed in the manuscript.

^aIncluding posttraumatic defects, bleeding, encephalocele

3.2 | Descriptive analysis of memory of seizure elements (N = 90)

First the number of participants who reported any kind of memories of seizure elements was assessed. Forty-nine participants (54.4%) stated not to have any memories with regard to any details of their seizures. Forty-one participants, who remembered seizure elements, specified in their own words which elements they remembered. According to the subcategories of the semiology list, answers were assigned to the subcategories subjective, motor, autonomic, and postictal elements (for all remembered elements in absolute numbers see the tables in section 3.3).

Of 41 remembered subjective elements “Unspecified” (n = 13), “Epigastric” (n = 9), “Visual” (n = 8), and “Somatosensory” (n = 7) auras were reported most frequently. Note that imprecise answers of participants like “aura,” “indescribable feeling,” or “premonition” were categorized as unspecified auras. Thirty-eight motor elements were remembered in total. In this subcategory “tonic movement”, “clonic movement,” and “myoclonus of the lid” were remembered most frequently (n = 9; 5; 3, respectively). Of 11 autonomic elements “changes in heartrate” (n = 4) and “hypersalivation” (n = 3) were the most frequently stated. Note that answers of four patients who remembered “tachycardia” or “heart palpitations” were categorized as “changes in heart

rate,” although these feelings must not obligatorily be objectifiable (eg, increased heart rate). Twelve postictal elements were remembered of which “postictal confusion” was most frequently stated ($n = 10$). “Postictal amnesia” and “postictal aphasia” were remembered once each.

It was stated that a participant’s memory of their own seizure elements was possibly influenced by having watched a videotape of their own seizure or by having heard reports of others about single seizure elements. Participants were therefore asked whether they had already seen a videotape of their own seizure or knew about their seizure elements through reports of others. Participants who had seen a videotape ($n = 26$) or had heard about their seizures from reports of others ($n = 68$) did not significantly more often memorize seizure elements (video presentation of a seizure: $\chi^2 = 0.895$, $df = 1$, $P = .344$, reports of others: $\chi^2 = 0.703$, $df = 1$, $P = .402$).

3.3 | Differences in frequencies of remembered and documented seizure elements

The number of remembered seizure elements was then compared to the number of documented elements during video-EEG recording (for detailed information on the distribution of documented semiological elements depending on seizure type see Appendix A).

3.3.1 | Subjective elements

Table 2 shows absolute frequencies of remembered and documented subjective elements, as well as the percentage of the remembered elements in the number of documented elements.

The overall number of remembered subjective elements ($n = 41$) represents a percentage of 45.6% in the number of documented subjective elements ($N = 90$). Only visual auras

were reported more often than documented during the period of video-EEG recording.

3.3.2 | Motor elements

Table 3 shows absolute frequencies of remembered and documented motor elements, as well as the percentage of the remembered elements in the number of documented elements.

In this subcategory, the difference between remembered and documented elements is higher than in the category of subjective elements. The percentage of remembered elements in the number of documented elements represents <10 percent for 19 of 26 elements.,

3.3.3 | Autonomic elements

Table 4 shows absolute frequencies of remembered and documented autonomic elements, as well as the percentage of the remembered elements in the number of documented elements.

Participants reported autonomic elements 11 times, whereas 92 were documented (12.0%). The three most often remembered elements—hypersalivation, hyperventilation, and electrocardiography (ECG) alteration, represent a percentage of a similar range with 13.6%, 11.1%, and 9.3%, respectively.

3.3.4 | Postictal elements

Table 5 shows absolute frequencies of remembered and documented postictal elements, as well as the percentage of the remembered elements in the number of documented elements.

Only two items of postictal elements were remembered, in contrast to 95 elements documented (2.1%). The semiology list did not comprise the element “postictal confusion,” which was stated by participants 10 times and was not classified;

TABLE 2 Remembered and documented subjective elements in absolute frequencies; remembered/documentated elements in %

Seizure element	Absolute number of documented elements	Absolute number of remembered elements	Percentage of remembered elements (%)
All elements	90	41	45.6
Gustatory aura	3	0	0.0
Cephalic aura	3	0	0.0
Auditory aura	3	2	66.7
Psychic aura	10	2	20.0
Somatosensory aura	13	7	53.9
Visual aura	4	8	200.0
Epigastric aura	23	9	39.1
Unspecified aura	31	13	41.9

TABLE 3 Remembered and documented motor elements in absolute frequencies; remembered/documentated elements in %

Seizure element	Absolute number of documented elements	Absolute number of remembered elements	Percentage of remembered elements (%)
All elements	641	38	5.9
Oroalimentary automatism	55	0	0.0
Dystonia	22	0	0.0
Grimacing	11	0	0.0
Hypokinetic movement	8	0	0.0
Motor agitation	23	0	0.0
Myoclonus	7	0	0.0
Nystagmus	1	0	0.0
Eye rotation	30	0	0.0
Head rotation	35	0	0.0
Laughter	5	0	0.0
Impaired language comprehension	70	4	5.7
Arousal	16	1	6.3
Arrest	28	2	7.1
Staring	36	2	5.6
Manual automatism	51	2	3.9
Vocalizations	40	2	5.0
Clonic movement	49	5	10.2
Lid myoclonus	25	3	12.0
Hyperkinetic movement	8	1	12.5
Tonic movement	56	9	16.1
Ictal speech	9	2	22.2
Truncal rotation	6	2	33.3

TABLE 4 Remembered and documented autonomic elements in absolute frequencies; remembered/documentated elements in %

Seizure element	Absolute number of documented elements	Absolute number of remembered elements	Percentage of remembered elements (%)
All elements	92	11	12.0
Flush	15	0	0.0
Tachycardia/bradycardia	43	4	9.3
Hyperventilation	9	1	11.1
Hypersalivation	22	3	13.6
Enuresis	2	1	50.0
Hyperhidrosis	1	1	100.0
Vomiting	0	1	/

adding this to “all elements” would have increased the percentage of remembered elements to 12.6%.

3.4 | Memory depending on the predominant seizure type

To examine whether memory of seizure elements differed significantly according to the predominant seizure

type, a cross table with the characteristics of seizure type and memory of seizure elements ($N = 90$) was calculated (Table 6).

By means of the cross table a chi-square test was performed to explore whether memories of seizure elements depended on predominant seizure type. The results suggest a significant difference in the ability to remember seizure elements depending on the predominant seizure type ($\chi^2 = 7.30$, $df = 2$, $P = .026$).

TABLE 5 Remembered and documented postictal elements in absolute frequencies; remembered/documentated elements in %

Seizure element	Absolute numbers of documented elements	Absolute numbers of remembered elements	Percentage of remembered elements (%)
All elements	95	2	2.1
Postictal noserubbing	24	0	0.0
Postictal cough	14	0	0.0
Postictal motoric agitation	9	0	0.0
Postictal amnesia	26	1	3.9
Postictal aphasia	22	1	4.6

TABLE 6 Number of participants with/ without memory of seizure elements according to predominant seizure type in absolute frequencies

Seizure type	Memory of all seizure elements	Memory of any seizure element	No memory
SPS	0	10	4
CPS	0	14	31
SGTCS	1	10	13

Hereafter, two subgroups of participants were examined more closely.

- Four of 14 participants with documented SPS (ie, with preserved reactivity to external stimuli) stated not to have memories of seizure elements. Notably in three of four cases, auras (epigastric/mental/unspecific) were documented, which patients did not remember after the seizure.
- Fourteen of 45 participants with CPS and eleven of 24 participants with SGTCS, respectively, did remember some of their seizure elements. Notably, participants remembered elements of all subcategories. Twelve participants with CPS and nine participants with SGTCS remembered elements that were not documented during the video-EEG monitoring.

3.5 | Memory and the serial sequence of semiological elements

Finally, we examined whether the serial position of a seizure element within a seizure affected recall of objective signs. Therefore, all motor elements of all recorded seizures were divided into three equally sized groups depending on the time of occurrence. The remembered element was then allocated to the respective third (see Appendix B for patients' list of remembered elements).

Of the 41 patients with any memory of seizure elements, 15 remembered video-documented motor elements (note that seizure elements could vary in relative order between different seizures). Four patients remembered only seizure elements that occurred during the last third of a seizure, another four patients remembered only elements occurring

within the second third of their seizure; and none of these eight patients remembered motor elements at seizure onset. In contrast, three other patients remembered elements that occurred at the beginning of their seizures. Overall, we found no evidence that relative timing within a seizure consistently modified intact memory for the respective seizure element, in contrast to our hypothesis of a primacy effect.

4 | DISCUSSION

It is well known that PWE are often not aware of their seizures or can only fragmentarily remember them. Several studies have shown that witnesses may contribute to the description of the semiology. Chen et al (2019) showed that the accuracy of differentiation between epilepsy, syncope, and psychogenic non-epileptic seizures improved by taking into account reports of witnesses in addition to patient's report.¹¹ Nonetheless, these reports are far from perfect. Rugg-Gun et al (2001) showed that inaccuracies exist, especially when describing postictal behavior or limb movements.¹² In another study by Heo et al (2008), a correct seizure classification was obtained in only 85% of cases using the witness description. The reliability of semiology description also depended on the educational level of the observer.¹³ These factors result in a risk of underestimating seizure frequency and misclassifying seizure types, which can result in patients not being optimally treated.

Continuous video-EEG recording allows not only assessment of the memory of seizures having occurred but also the memory of details of the seizure semiology. In the present study, we found that patients do not recall the vast majority of objective manifestations of their seizures, and even fail to recall the majority of subjective experiences that they can report during a seizure.

4.1 | Evaluation of patients' memory of seizures in comparison to documented seizure semiology and depending on seizure type

Participants remembered seizure elements of all subcategories. Subjective and motor elements were remembered most

frequently, with 41 elements and 38 elements, respectively. In contrast, 11 autonomic and 12 postictal elements were remembered. Remarkably, we did not find evidence that previous video presentation of one's own seizure or reports about seizure elements by others influence the ability to remember seizure elements, despite the fact that mixing the information gained from direct experience and knowledge from other sources is a frequent finding in everyday memory research.^{14,15,16}

We confirmed that the number of documented seizure elements by far exceeds the number of remembered elements in all subcategories. In all subcategories, the percentage of remembered to documented seizure elements was <15 percent (motor elements 5.9%, autonomic elements 12.0%, and postictal elements 2.1%). Even the number of subjective elements, which by definition are only indirectly objectifiable as they rely on the patients' reports, was more than twice as high as the number of remembered subjective elements (41 vs 90 elements, 45.6%). This result stresses the need to perform standardized testing in patients undergoing video-EEG monitoring, actively asking them for possible experienced phenomena. Patients are often able to report their auras only ictally while not encoding this information, which is then lost for history taking. This matches the results of Schulz et al (1995), who reported a dependence of memory for auras depending on EEG patterns and seizure severity.¹⁷

It is important to note that our study suggests that the serial position of seizure elements does not determine later recall, in contrast to primacy and recency effects known for free recall in healthy participants.¹⁸ This suggests that rather global effects on the memory encoding and consolidation are affected by seizures, as reflected by the dependence of recall on seizure type. Patients with impaired consciousness and progression to bilateral tonic-clonic phenomena showed more severe impairments, followed by complex partial seizures and simple partial seizures. However, four patients classified as having SPS according to the 1981 ILAE classification (28.6%) stated that they did not have any memories of their seizures. This is in accordance with the finding of Hoppe et al (2007), who reported that a large percentage of SPS are not counted by patients⁷ (notably, here seizure elements rather than seizure occurrence were studied).

In the 1981 ILAE classification of seizures, consciousness during epileptic seizures had been defined as unimpaired responsiveness (thus ability to follow simple commands) and/or awareness, being understood as the patients' contact with the event and its recall.¹⁹ This definition comprises three aspects of consciousness: perceptions of the objects around, intentions concerning the future, and memories of the past.²⁰ As reported, for example, by Lux et al (2002), an appropriate assessment of these aspects can be performed by examining the patients' ability to react to exogenous stimuli (perception),

to follow simple commands (intention), and to recall seizure elements (memory).⁹ These aspects of consciousness reflect involvement of different brain areas, whereas the ability to recall seizure elements requires a functioning medial temporal lobe and its inputs.²¹ Accordingly, a seizure during which a patient can either respond/react adequately to external stimuli, follow simple commands, or later report the events that occurred during the seizure was defined as "simple partial." The new ILAE classification, in contrast, requires memory of the complete seizure semiology for the definition of focal aware seizures (FAS), not only for seizure occurrence.²² Seizures during which patients do not react to external stimuli are classified as aware seizures as long as patients are able to report their inability to react afterward. On the other hand, seizures during which patients react to external stimuli and show unimpaired responsiveness but later do not remember all seizure elements, previously classified as SPS, are not classified as FAS but as focal impaired awareness seizures (FIAS). The results of this study thus show that there is no direct mapping of the old term "simple partial seizure" to the new label "focal aware seizures." In our patient sample, only one of 90 patients remembered all seizure elements, while several "auras" had to be classified as FIAS due to an associated disturbance of memory encoding. Selective deficits in memory encoding were thus extremely frequent in the patient cohort investigated here and were not limited to focal epilepsies originating in the temporal lobe. Additional studies involving patients undergoing intracranial EEG recording may further elucidate the exact influence of areas involved during seizures and the resulting encoding problems. Taking the frequency of such memory problems into account, it remains to be discussed whether basing the operationalization of awareness only on intact memory encoding and recall captures the concept of consciousness during seizures adequately.

4.2 | Limitations and outlook

The exact knowledge of patients' seizure semiology is of utmost importance for correct diagnosis and treatment of epilepsy. In this context, the value of video-EEG monitoring was shown in the present study by documenting the large difference between remembered and documented seizure elements. However, participants were asked to report seizure elements of every seizure type in the past, whereas the number of documented seizure elements here represents only the duration of admission to our epilepsy center. Because patients may also have remembered elements from nondocumented seizure types in the past, the results obtained may thus underestimate the number of semiological elements that are lost to memory. On the other hand, patients' memory of seizure elements might worsen as time passes after a seizure, as a manifestation of accelerated forgetting.²³ Thus some primarily remembered

seizure elements might not have been recalled and reported for the present study if the last seizure occurred further in the past. Furthermore, patients assessed here had a certain minimum seizure frequency in order for video-EEG documentation to be possible; extrapolation for patients with very rare seizures may not be warranted. Additional investigations in the time course of memory loss of seizure elements will be of interest for a better understanding of the mechanisms involved.

A further limitation of the present study is the assessment of data by free recall using patients' terminology. There were some answers that could not be mapped precisely to a standardized medical term. We attempted to minimize this problem by a shared decision between the epilepsy team and study leader for interpretation of patient responses.

Whether memory for seizure semiology changes over time needs to be examined in future studies by assessing memory at various time points after seizures. Assessing memory formation vs forgetting could clarify if disturbed primary encoding by hippocampal involvement by epileptic activity of impairments in memory consolidation in hippocampal-neocortical networks in the course of the seizure, or both,^{21,24,25} are the determinants for later impaired recall of seizure elements. The fact that impaired recall was also observed for seizures originating outside the temporal lobe underscores network effects, possibly due to propagation of ictal activity to temporal structures and/or ictal or postictal impairments in hippocampal-neocortical interactions.

5 | CONCLUSION

The present study shows that the ability to remember seizure elements appears not to depend on the serial position during a seizure but rather on seizure type. Memory of seizure semiology almost always remains fragmentary: Complete recall of video-documented seizure semiology was obtained in just one of 90 patients. Consequently, only seizures of this respective patient could be classified as FAS according to the new ILAE seizure classification. We conclude that most seizures disturb networks within the medial temporal lobe and connected association cortices required for stable long-term memories. This leads to a strong asymmetry between seizure types with regard to the operationalization of awareness as used in the new ILAE seizure classification and a vanishingly small number of PWE with complete recall of seizure semiology and resulting "intact awareness." The fact that most elements of seizures cannot be recalled by patients has major relevance for history-based epilepsy and seizure classification.

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CONFLICT OF INTEREST

There is no conflict of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

ETHICAL APPROVAL

This study received ethical approval from the ethics committee of the Albert-Ludwigs-University of Freiburg i. Br, Germany.

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REFERENCES

- Charidimou A, Selai C. The effect of alterations in consciousness on quality of life (QoL) in epilepsy: searching for evidence. *Behav Neurol*. 2011;24:83–93.
- Neugebauer R. Reliability of seizure diaries in adult epileptic patients. *Neuroepidemiology*. 1989;5:228–33.
- Liu L, Yiu C, Yen D, Chou M, Lin M. Medication education for patients with Epilepsy in Taiwan. *Seizure*. 2003;12:473–7.
- Mannan JB, Wiesmann UC. How accurate are witness descriptions of epileptic seizures? *Seizure*. 2003;12:444–7.
- Kerling F, Mueller S, Pauli E, Stefan H. When do patients forget their seizures? An electroclinical study. *Epilepsy Behav*. 2006;9:281–5.
- Blum DE, Eskola J, Bortz JJ, Fisher RS. Patient awareness of Seizures. *Neurology*. 1996;47:260–4.
- Hoppe C, Poepl A, Elger CE. Accuracy of patient seizure counts. *Arch Neurol*. 2007;64:1595–9.
- Inoue Y, Mihara T. Awareness and responsiveness during partial seizures. *Epilepsia*. 1998;39:7–10.
- Lux S, Kurthen M, Helmstaedter C, Hartje W, Reuber M, Elger CE. The localizing value of ictal consciousness and its constituent functions: a video-EEG study in patients with focal epilepsy. *Brain*. 2002;125:2691–8. <https://doi.org/10.1093/brain/awf276>
- Blume WT, Lüders HO, Mizrahi E, Tassinari C, van Emde Boas W, Engel J Jr. Glossary of descriptive terminology for ictal semiology: report of the ILAE task force on classification and terminology. *Epilepsia*. 2001;42(9):1212–8.
- Chen M, Jamnadas-Khoda J, Broadhurst M, Wall M, Grünwald R, Howell SJL, et al. Value of witness observations in the differential diagnosis of transient loss of consciousness. *Neurologie*. 2019;92(9):e895–e904.
- Rugg-Gunn FJ, Harrison NA, Duncan JS. Evaluation of the accuracy of seizure descriptions by the relatives of patients with epilepsy. *Epilepsy Res*. 2001;43:193–9.
- Heo J-H, Kim DW, Lee S-Y, Cho J, Lee S-K, Nam H. Reliability of semiology description. *Neurologist*. 2008;14:7–11.
- Wade K, Garry M, Don Read J, Lindsay DSA. picture is worth a thousand lies: using false photographs to create false childhood memories. *Psychon Bull Rev*. 2002;9(3):597–603.
- Hyman I, Husband TH, Billings FJ. False memories of childhood experiences. *Appl Cogn Psychol*. 1995;9:181–97.
- Loftus EF, Pickrell JE. The formation of false memories. *Psychiatr Ann*. 1995;25(12):720–5.

17. Schulz R, Lüders HO, Noachtar S, May T, Sakamoto A, Holthausen H. Amnesia of the epileptic aura. *Neurology*. 1995;45:374–6.
18. Howard MW, Kahana MJ. Contextual variability and serial position effects in free recall. *J Exp Psychol*. 1999;25(4):923–41.
19. Angeles DK, et al. Proposal for revised clinical and electroencephalographic classification of epileptic seizures. *Epilepsia*. 1981;22:489–501.
20. Frith C, Perry R, Lumer E. The neural correlates of conscious experience: an experimental framework. *Trends Cogn Sci*. 1999;3:105–14.
21. Eichenbaum H. A cortical-hippocampal system for declarative memory. *Nature Rev Neurosci*. 2000;1:41–50.
22. Fisher RS, Cross JH, D'Souza C, French JA, Haut SR, Higurashi N, et al. Instruction manual for the ILAE 2017 operational classification of seizure types. *Epilepsia*. 2017;58:531–42.
23. Butler CR, Zeman AZ. Recent insights into the impairment of memory in epilepsy: transient epileptic amnesia, accelerated long-term forgetting and remote memory impairment. *Brain*. 2008;131:2243–63.
24. Alvarez P, Squire LR. Memory consolidation and the medial temporal lobe: a simple network model. *PNAS*. 1994;91:7041–5.
25. Frankland PW, Bontempi B. The organization of recent and remote memories. *Nature Rev Neurosci*. 2005;6:119–30.

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APPENDIX A

DISTRIBUTION OF DOCUMENTED SEMIOLOGICAL ELEMENTS DEPENDING ON SEIZURE TYPE IN ABSOLUTE FREQUENCIES

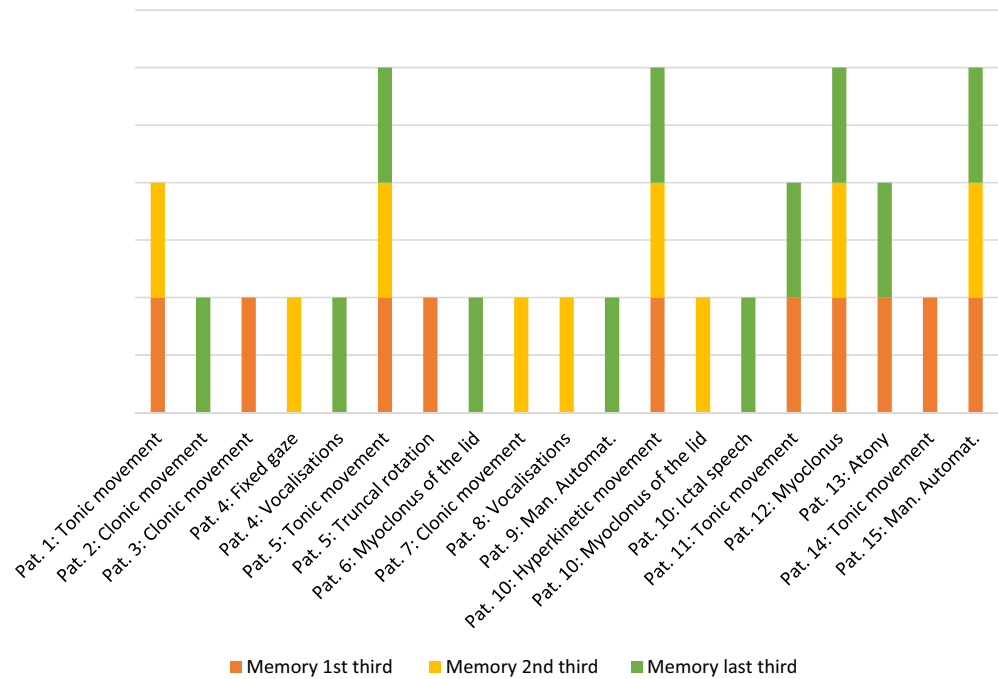
Semiology element	Frequencies SPS	Frequencies CPS	Frequencies SGTCS
Gustatory aura	0	1	2
Cephalic aura	0	3	0
Auditory aura	0	1	2
Mental aura	2	5	3
Somatosensory aura	5	5	2
Visual aura	2	1	0
Epigastric aura	5	12	4
Unspecified aura	4	19	8
Oroalimentary automatism	3	33	15
Dystonia	0	12	10
Grimacing	1	4	6
Hypokinetic movement	0	5	2
Motor agitation	4	14	4
Myoclonus	1	2	4
Nystagmus	0	1	0
Eye-Rotation	3	9	17
Head-Rotation	1	15	18
Laughter	3	2	0
Impaired language comprehension	1	41	18
Arousal	3	8	2
Arrest	4	20	4
Staring	0	25	10
Manual automatism	4	35	7
Vocalisations	2	19	18
Clonic movement	4	24	19
Myoclonus of the lid	2	14	8
Hyperkinetic movement	1	5	1

(Continues)

APPENDIX A (Continued)

Semiology element	Frequencies SPS	Frequencies CPS	Frequencies SGTCS
Tonic movement	4	28	22
Ictal speech	2	7	5
Truncal rotation	2	2	2
Flush	1	11	3
Tachy-/Bradycardia	7	22	12
Hyperventilation	2	4	2
Hypersalivation	1	9	11
Enuresis	0	0	2
Hyperhidrosis	0	1	0
Vomiting	0	0	0
Postictalnose rubbing	1	20	3
Postictal cough	0	11	3
Postictal motoric agitation	0	7	1
Postictal amnesia	0	19	6
Postictal aphasia	1	17	4

APPENDIX B



APPENDIX B Time of occurrence of remembered motor elements (n = 15)