



Emotional Reaction to viewing one's own epileptic seizure

Sonja Meißner^{a,1,*}, Kathrin Wagner^a, Andreas Joos^b, Birgitta Metternich^a,
Andreas Schulze-Bonhage^a

^a Epilepsy Center, Freiburg University Medical Center, Germany

^b Department of Psychosomatic Medicine and Psychotherapy, Freiburg University Medical Center, Germany



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ABSTRACT

Purpose: If consciousness or memory are impaired during an epileptic seizure, the patient may not experience or know how his/her own seizure looks like. It is disputed, whether being confronted with own seizures may lead to emotional stress or empower patients and decrease negative psychosocial consequences. We assessed patients' reactions to watching a video of their own seizure on measures of anxiety, depression and ten emotions.

Method: Forty-three patients (mean age 38, range 18–70 years, 21 male, 22 female) undergoing diagnostic video-EEG monitoring were included in this prospective study. Before (T1), immediately (T2), several days (T3) and three months after video presentation (T4), participants completed questionnaires including an emotion rating, a depression and an anxiety questionnaire (NDDI-E, State-Trait-Anxiety Inventory).

Results: Depression scores showed no changes over time. Anxiety decreased briefly a few days after video-presentation (T3) and returned to initial scores at the follow-up (T4). There were transient changes regarding four emotions. Sadness, surprise and embarrassment showed significant increases directly after video presentation (T2) as well as happiness a few days later (T3). In subsequent assessments, all four emotions had returned to or below baseline. A subgroup analysis comparing partial versus secondarily generalized tonic-clonic seizures showed a decrease of depression and state-anxiety in the partial seizure group.

Conclusions: Viewing one's own seizure did not induce depressive reactions or persistent anxiety symptoms. Transient emotional reactions were observed. Differential effects depending on the seizure type presented are of relevance for the setting of presentation, therapeutic and educational approaches.

1. Introduction

In contrast to most sufferers of chronic diseases, epilepsy patients are only partially aware of the main characteristics of their condition, as many epileptic seizures are accompanied by various degrees of clouding of consciousness and amnesia for the event [1,2]. Accordingly, many patients learn about the crucial manifestations of their disease only by reports of relatives or other bystanders. The unpredictable nature of seizures can be experienced as particularly threatening not only due to possible physical harm but also due to possible embarrassment in case of seizures with loss of consciousness and motor control occurring in public. The subjective loss of control induced by and the fear of such events can affect quality of life adversely [3–6]. Incomplete knowledge of their seizures may contribute to this, and stigmatization based on misconceptions of the disease represents a serious problem causing patients to feel ashamed [7,8].

The dearth of studies facing patients' reactions to viewing their own

seizures is remarkable. Apart from two rather old studies there are no publications to be found concerning this topic. In 1976, Feldman and Paul used video presentation to strengthen patients' awareness on possible emotional induction of seizures. Consequently, persons affected could recognize emotional triggers and learn to avoid them in order to prevent seizures. The authors described a decrease in seizure frequency due to patients' awareness of provoking situations, but did not study potential harm to patients [9]. In a different approach, Sanders et al. (1995) investigated whether viewing one's own seizure is harmful to patients. The Spielberger State-Trait-Anxiety Inventory [10] was used as well as a 'seizure viewing questionnaire' that allowed patients to evaluate their feelings before, directly after and a month after video presentation. Results, along with the investigators' subjective evaluation of patients' reactions, showed that neither depression nor anxiety are affected adversely by the seizure viewing [6]. Whereas anxiety was studied using the State-Trait-Anxiety Inventory, this study did not use a detailed instrument to assess the development of

* Corresponding author at: Epilepsiezentrum, Neurozentrum des Universitätsklinikum Freiburg, Breisacher Strasse 64, 79106 Germany.

E-mail address: sonja.meissner@uniklinik-freiburg.de (S. Meißner).

¹ Neusser Wall 21, 50670 Köln.

depressive tendencies.

In the present investigation patients' reactions to viewing their own seizures were assessed. Regarding depressive symptoms and anxiety, no changes were expected. Besides the development of symptoms of depression and anxiety, we studied possible effects on ten specific emotions. In addition to basic emotions (happiness, anger, fear, sadness, disgust, surprise) according to the emotion theories of Ekman et al. [11], we evaluated more complex emotions related to interpersonal experiences and of personal relevance to patients, i.e. embarrassment, strain, relief and curiosity. Results were analyzed at several time points and depending on the seizure type presented.

2. Methods

2.1. Participants

Participants were recruited at the Epilepsy Center of the Freiburg University Medical Center consecutively between April 2014 and April 2015. Requirements were a minimum age of 18 years, willingness to participate in the study and the recording of a habitual seizure during the EEG-video-monitoring. Patients with linguistic or intellectual impairment which restricted them from completing questionnaires were excluded; likewise, patients with severe impairment in attention or exclusively psychogenic seizures. About two-thirds of the patients considered for this study showed an interest in viewing their seizures. The remaining third completed a separate questionnaire which will allow to conclude reasons and motives of not wanting to participate and will be part of future analyses. The study protocol was approved by the local Ethics Committee, and informed written consent was obtained after explaining the procedure and the goals of the study to the patients.

2.2. Procedure

Data were collected once prior to video presentation (T1) as well as directly after seizure viewing (T2), a few days later (T3, $M = 4,36$ days, $SD = 7,98$) and several weeks after T2 as a later follow-up (T4, $M = 13,04$, $SD = 6,55$).

Fig. 1 illustrates the study design. The questionnaires which were filled out by the patients at each point of data collection (T1–T4) included a subjective emotion rating of ten emotions (happiness, anger, fear, sadness, disgust, surprise, embarrassment, strain, relief and curiosity) as well as the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) [12] to assess the development of depressive symptoms over time and the State-Trait-Anxiety Inventory (STAI) [13] to detect possible changes in state- and trait-anxiety. Seizures for video presentation were chosen in cooperation with the treating physicians and technicians to present a recorded habitual seizure characteristic for the individual patient. For each patient one video was chosen. Seizures shown included five simple partial seizures (SPS, 4/5 with automotor or hypermotor components), 26 complex partial seizures (CPS), 10 secondarily generalized seizures (SGS) and two non-classifiable seizures.

2.3. Measures

Standardized questionnaires were used to detect patients' emotional reactions to viewing their own seizure as well as possible changes in depressive and anxiety symptoms caused by this stimulus.

The Subjective Emotion Rating allowed patients to assess their current perception of happiness, anger, fear, sadness, disgust, surprise, embarrassment, strain, relief and curiosity on a seven-point rating scale from one (very little) to seven (a lot). This instrument allows a simple and rapid detection of emotional changes [14–16].

The NDDI-E served to reveal depressive tendencies and possible changes over time caused by the video presentation. This questionnaire is based on six items concerning depressive symptoms (e.g. "Nothing I do is right.") which are rated by the patient on a four-point-rating scale ranging from one (never) to four (always/often). In a validation study for the German version of the NDDI-E, the cut-off with highest sensitivity (.84) and specificity (.88) for Major Depression was shown to be ≥ 14 [12]. Because of its short duration, this instrument can be easily applied in daily hospital routine [17] and is also used to observe depressive tendencies, but the NDDI-E is a screening tool, not a diagnostic instrument. In the present study, it was applied to observe the development of depressive tendencies over the course of time.

The German version of the Spielberger State-Trait-Anxiety Inventory [13] was applied to detect changes in patients' anxiety levels. Based on the state-trait theory [18,19] it includes two scales each with 20 items distinguishing between state-anxiety as a temporary condition which can be influenced by external circumstances and trait-anxiety as a longer-lasting quality or personality trait [13].

2.4. Statistical analysis

Data was analyzed using SPSS-Statistics (PASW 18 und SPSS 22). Kolmogorov-Smirnov-Tests were used to analyze data distribution. In case of not normally distributed data, non-parametric Friedman-Tests as well as Mann-Whitney-/Wilcoxon-Tests were calculated (subjective emotion rating). Data has been reanalyzed using (Bonferroni-) correction. The NDDI-E and the STAI were analyzed with repeated-measures-ANOVAs (rmANOVA) using 'time' as the within-subject factor. Two subgroups SPS/CPS ($N = 31$) and SGS ($N = 10$) were analyzed separately using non-parametric Friedman-Tests and Mann-Whitney-/Wilcoxon-Tests as well as rmANOVAs.

3. Results

Demography of the study sample is shown in Table 1. Forty-three patients (21 male, 22 female) completed T1 through T3, 24 the late follow-up (T4). The remaining 19 patients did not reply to the late follow-up.

NDDI-E scores showed no effect of video presentation on depression. In the rmANOVA including T1 to T3 no differences over time were found ($F = 1.37$, $df = 2$, $p = .26$). Results are shown in Fig. 2.

In parallel with the NDDI-E, the State-Trait-Anxiety Inventory was analyzed calculating two rmANOVAs for each scale. On the state-anxiety scale significant changes were found comparing T1–T3 ($F = 5.22$, $df = 2$, $p = .007$). Pairwise comparisons analyzing T1 compared to the other points of data collection showed a significant decrease between T1 and T3 ($p = .004$) illustrated in Fig. 3. Trait-anxiety scores showed no significant changes.

In contrast to the NDDI-E and the STAI, results of the emotion ratings did not show normal distribution in the Kolmogorov-Smirnov-Test. Therefore, Friedman-Tests were calculated twice for each emotion including T1–T3 and T1–T4. After Bonferroni correction (alpha divided by

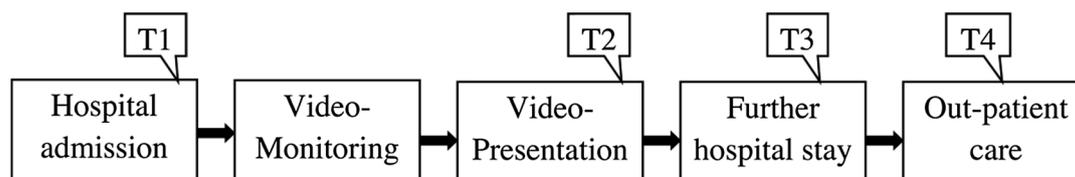


Fig. 1. Study design including 4 points of data collection.

Table 1
Demography of the study sample.

	Complete Cohort <i>N</i> = 43	Patients completing T1 – T4 <i>N</i> = 24	Patients completing T1 – T3 <i>N</i> = 19
Gender (<i>N</i> (%))	21 (48.8)	13 (54.2)	8 (42.1)
Male	22 (51.2)	11 (45.8)	11 (57.9)
Female			
Age (<i>M</i> (<i>SD</i>))	38.0 (13.66)	40.17 (13.13)	35.26 (14.18)
Education degree (<i>N</i> (%))	1 (2.3)	0 (0)	1 (5.3)
None	11 (25.6)	5 (20.8)	6 (31.6)
High-school exam	10 (23.3)	7 (29.2)	3 (15.8)
Vocational	14 (32.6)	7 (29.2)	7 (36.8)
baccalaureate diploma	7 (16.3)	5 (20.8)	2 (10.5)
Secondary modern school			
Basic secondary school			
Professional Qualification (<i>N</i> (%))	5 (11.6)	3 (12.5)	2 (10.5)
None	21 (48.8)	13 (54.2)	8 (42.1)
Apprenticeship	6 (14.0)	3 (12.5)	3 (15.8)
Technical College	10 (23.3)	4 (16.7)	6 (31.6)
University	1 (2.3)	1 (4.2)	0 (0)
Other			

10), significant results were analyzed using Mann–Whitney–/Wilcoxon-Tests to separately compare T1 with the other three points of data collection. Significant changes after video-presentation of seizures were found for happiness, sadness, surprise and embarrassment. Happiness increased significantly a few days after video-presentation (T3). Sadness, surprise and embarrassment increased directly after viewing the seizure (T2). Embarrassment consecutively decreased significantly between T1 and T3. Fear, anger, disgust, strain, curiosity and relief showed no changes. Results of the emotion rating are shown in Fig. 4. Regarding the late follow-up (T4) the patient cohort only consisted of 24 patients due to lack of response to the sent questionnaires. Including the late follow-up (T4) no significant changes could be found neither for the NDDI-E and STAI scores nor for the ten specific emotions.

To assess possible effects of seizure types, subgroups with SPS/CPS (*N* = 31, 72%) and SGS (*N* = 10, 23%) were analyzed separately

including T1–T3. Due to the rare number of patients, interpretations for the SGS group are very limited.

There was a number of 26 patients who have been considered for participation in the study but refused to. A number of 12 (46%) suffered from SPS/CPS, 7 (27%) suffered from SGS and 7 (27%) could not be classified to any of those groups. These frequencies are comparable to those of the participants. It will be subject of further analyses to determine the individual reasons of non-participants to refuse watching their own seizure.

Patients who were shown SPS/CPS showed significantly fewer depressive tendencies at T3 scores (T1 – T3, *N* = 31: $F = 4.271$, $df = 2$, $p = .018$). Pairwise comparisons for the SPS/CPS group showed a significant decrease in depression scores (NDDI-E) at T2 ($p = .008$) and T3 ($p = .022$) compared to baseline (Fig. 5). Similarly, state-anxiety decreased in the SPS/CPS group at T3 compared to T1 ($p = .022$) (Fig. 6). The emotion rating showed an increase of sadness and surprise towards T2, as well as an increase of happiness towards T3 in the SPS/CPS group.

Regarding the individual patient level, several cases could be reported. Most relevant seems to be the case of one patient who reported to feel depressed after having seen the own seizure. Regarding this patient's NDDI-E scores no increase of depressive symptoms could be noticed. Already at T1 a value of 18 (cut-off ≥ 14) had been measured which decreased at T2 (12 points) and increased again at T3 (18 points). In general, as far as single patient level of the NDDI-E is concerned, there were three patients who increased starting at a score below 12 at T1 towards a value > 14 at T2. Two of those decreased at T3 or rather T4. One patient stayed at a level of 18 points. Three other patients showed an increase of NDDI-scores towards T3 and T4. Two of those had been shown SPS/CPS, one had been shown SGS.

4. Discussion

Video presentation has been used in a wide range of therapeutic as well as diagnostic settings beyond the context of epilepsy, allowing therapists and patients to retrospectively analyze certain situations [20,21]. It has also been shown to be useful in educational programs for epilepsy patients to inform them and provide a more valid view on their disease [22,23]. The present study aimed to identify the emotional

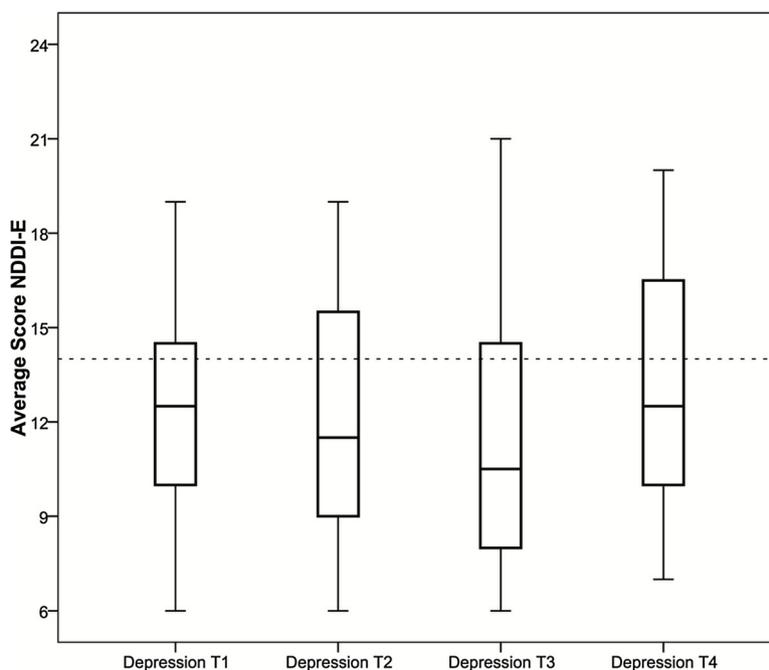


Fig. 2. Medians, 1st and 3rd quartiles, minimum and maximum values of Depression (NDDI-E).

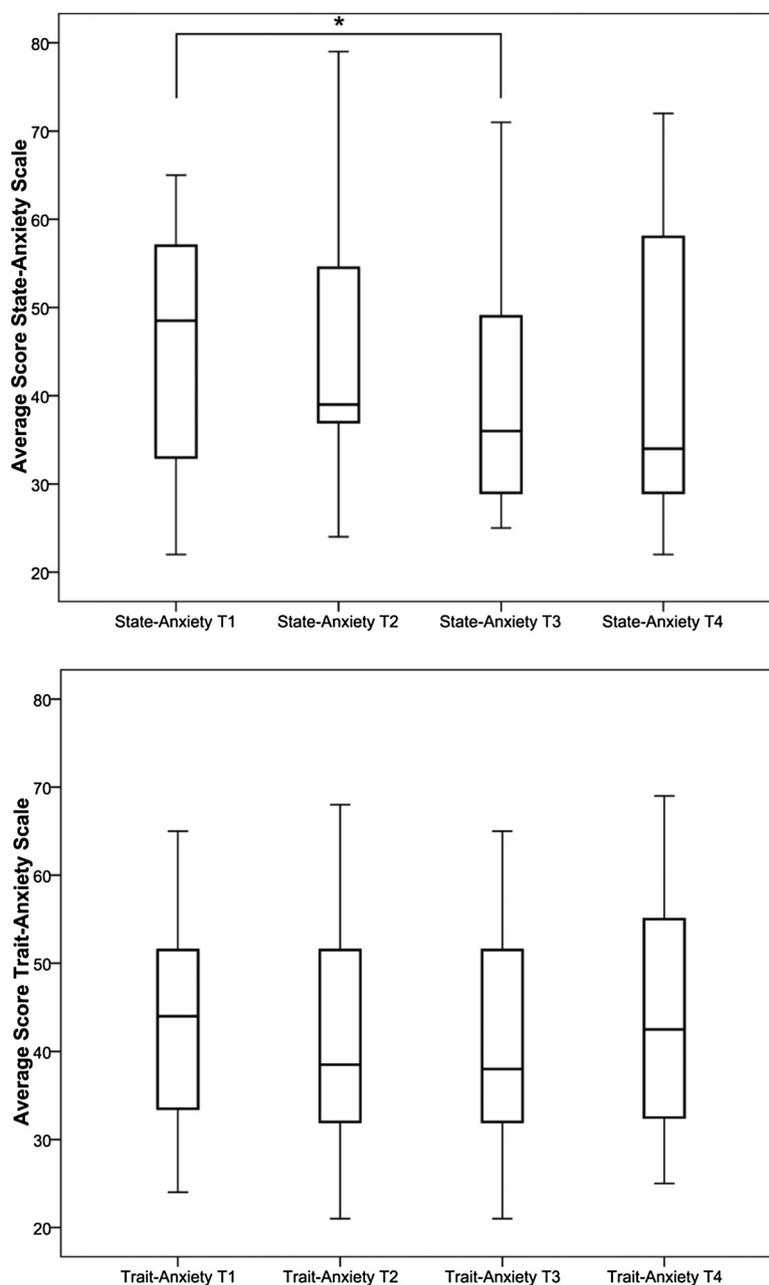


Fig. 3. Medians, 1st and 3rd quartiles, minimum and maximum values of State-Anxiety (above) and Trait-Anxiety (below).

reactions of patients to viewing their own epileptic seizures and its effect on anxiety, depression and specific emotions. It has been designed to serve as an explorative study. The study design did not include a control group, and video-EEG monitoring on its own may induce emotional reactions.

As one major finding, our results confirm that video presentation had no negative effect on depressive or anxiety reactions. This result supports the report of Sanders et al. (1995) suggesting that viewing one's own seizure is not harmful to patients [6]. When assessing emotions in more detail, however, alterations induced by video-presentation became evident. This includes mainly transient emotional responses to viewing one's own seizures. Long-term changes suggesting possible benefits of seizure viewing could not be found in this study. Interestingly, results of the STAI showed a decrease of anxiety a few days after seizure presentation. This result may indicate that better knowledge of one's own seizure characteristics and a better understanding of one's own disease can reduce specific fears and epilepsy-

related anxiety. Nevertheless, a randomized controlled study is needed to validate possible positive effects.

A beneficial effect on patient perception of unpredictability has been reported when additional knowledge of seizure precipitants and prodromal symptoms were assessed [24,25]. Schulze-Bonhage et al. reported that improved knowledge on triggering emotional situations resulted in avoidance of these specific situations and a lower seizure frequency [24,25]. After additional validation, the results presented here could lend further support to possible empowering positive effects of systematic seizure presentation in a controlled setting and indicate that improved patient information has a potential therapeutic role in psychosocial domains. This could also be underlined by the finding that disease perception might be of importance to improve quality of life in patients with epilepsy [26]. Beyond anxiety, perceived stigmatization and epilepsy-specific fears may show changes and should be analyzed in detail.

The present study also showed that the sensitivity of detecting

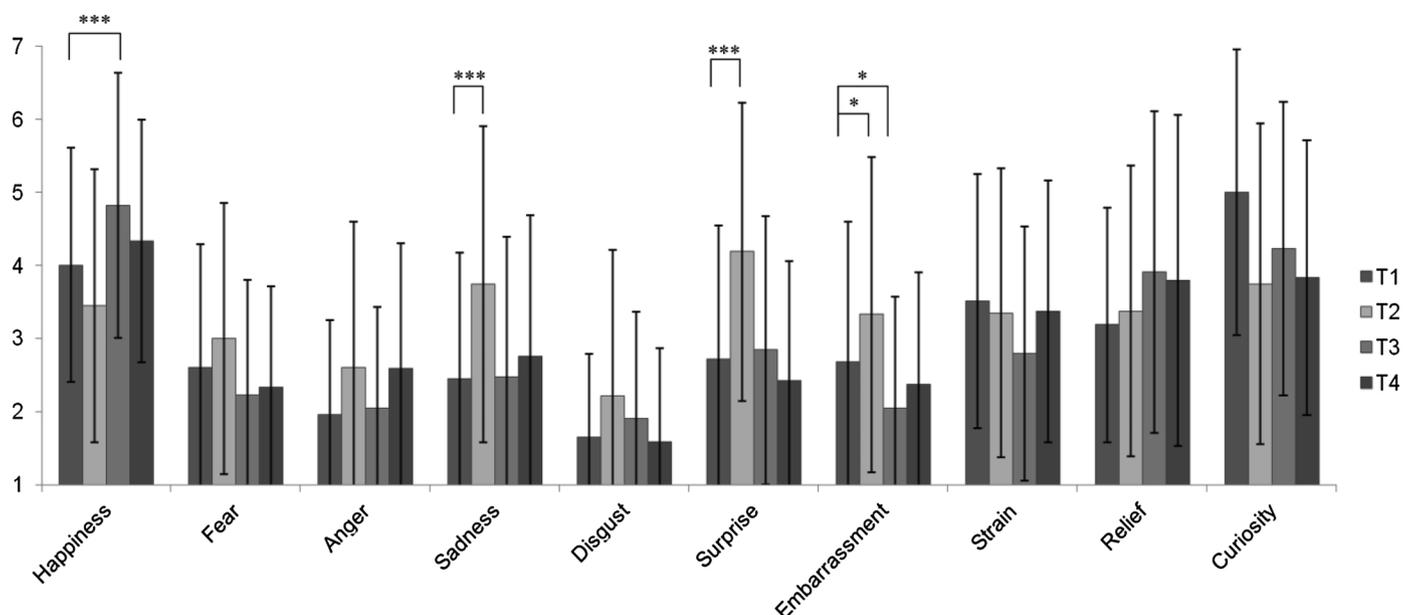


Fig. 4. Averages, Standard deviations and Significances of ten emotions over four points of time.

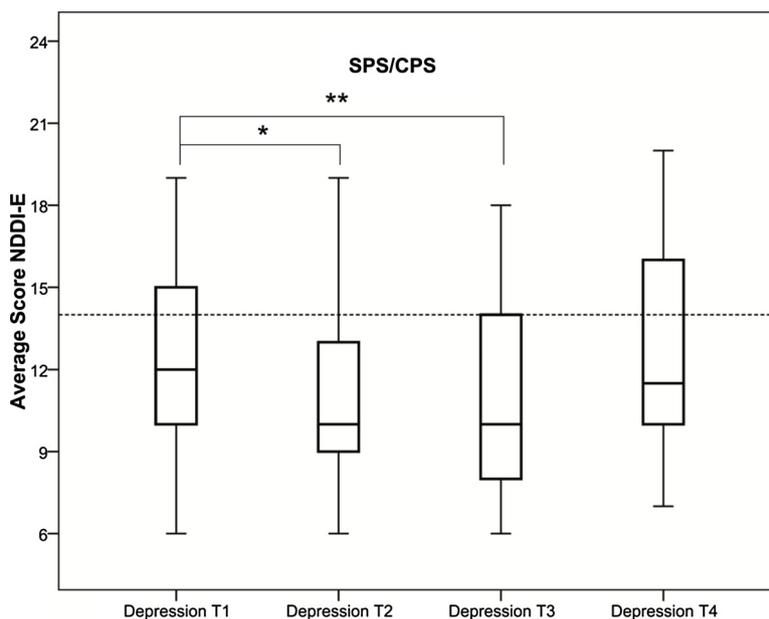


Fig. 5. Medians, 1 st and 3rd quartiles, minimum and maximum values of Depression (NDDI-E) for the subgroup SPS/CPS.

affective consequences of seizure presentation strongly depends on the used instruments. Therefore, it is of importance to undertake a closer examination using more detailed instruments to evaluate certain aspects of emotional processing. We used the NDDI-E in order to detect changes in depressive symptoms before and after video presentation. The short questionnaire is a valid tool for the detection of depressive tendencies, but so far little is known about the sensitivity of the NDDI-E in detection of mild changes in depressive or dysphoric tendencies when applied repeatedly within a short period of time. The presented data showed that the patient cohort did not develop clinically relevant depressive symptoms shortly after video presentation of their own seizures.

The development of emotions measured by the Subjective Emotion Rating showed that watching one’s own seizure is a significant event for patients. Negatively attributed emotions such as sadness and embarrassment increased immediately after video presentation, whereas the positive emotion happiness increased only a few days later. Exposing

patients to their seizures should thus be performed in a setting which allows patients to communicate possible concerns to the multi-professional team involved in treating medical and psychological aspects of the disease. Nevertheless, in our setting, none of the patients needed professional help and support after viewing their own seizure. It could also be shown that emotions returned to baseline within a few days, suggesting beneficial coping processes, reflected and complemented by the observed decrease of fear and anxiety. However, further qualitative studies are needed. Remarkably, the observed decrease of depression and anxiety scores was only noticeable in patients who had been shown SPS/CPS but not in the group who had been shown SGS. This effect could be due to relief from possible expectations and fears about the own seizures. As secondarily generalized tonic-clonic seizures are the socially most known and stigmatizing seizure type, patients could have been relieved by realizing that they suffer from a less severe seizure type. The number of patients in the SGS group being lower than the number of patients in the SPS/CPS group could be

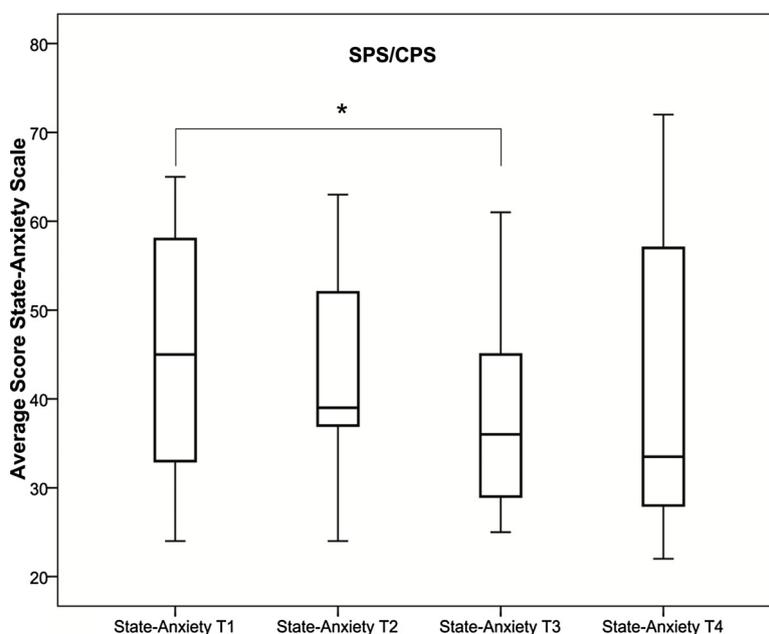


Fig. 6. Medians, 1st and 3rd quartiles, minimum and maximum values of State-Anxiety (State-Anxiety-Scale) for the subgroup SPS/CPS.

of limiting relevance. Therefore, external validity can be generalized for the SPS/CPS group, but the lack of significant results in the SGS group warrants further investigation with a larger patient cohort in order to detect possible changes.

It is of note that only about two-thirds of the patients considered for this study showed interest in viewing their seizures. It remains unclear, how the emotional reaction of the patients who did not agree to participate in the study would have been. It cannot be ruled out that these patients are more susceptible to negative emotional reactions. Therefore, results may not be transferable to a patient subsample which is more afraid of viewing their seizures than those participating here. Further research on individual reasons for not wanting to watch one's own seizure is needed to clarify respective patients' thoughts and concerns. At the same time, it is of importance to only consider patients who show an immediate interest and are not hesitant towards watching a video presentation, in order to avoid unwanted effects.

Subjectively, those who agreed to view their own seizure faced the video presentation with excited anticipation. Some patients expressed concerns about possible negative emotions caused by viewing seizures, but none of the participants withdrew from the study after having signed the informed consent. Apart from the fact that the presented video showed patients' own seizures, many participants described viewing themselves on a video tape recording as an unusual situation requiring getting used to. Self-viewing in videos has been used in several fields including therapeutic settings as well as patient training programs, showing great benefit, but also being debated and criticized for not being examined enough [24,26].

Viewing one's own epileptic seizures appears to have no negative effect on depression and anxiety, at least in patients who show an interest to be presented with a video of their own seizures, but induces transient emotional reactions. Results of this explorative study indicate that seizure viewing might serve psycho-educative purposes for certain patient populations by providing them with better information about their disease and therefore improve disease coping. Further and more detailed validation in additional patient cohorts is needed in order to evaluate possible benefits for epilepsy patients.

Ethical Publication Statement

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. The study protocol was approved by the local Ethics Committee.

DISCLOSURE OF CONFLICTS OF INTERESTS

None of the authors has any conflicts of interest to disclose.

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