Integrating the systematic assessment of psychological states in the epilepsy monitoring unit: Concept and compliance

Rosa Michaelis, Helmut Schöller, Yvonne Höller, Gudrun Kalsse, Margarita Kirschner, Elisabeth Schmid, Eugen Trinka, Günter Schiepek

1. Introduction

1.1. Background

Epilepsies are one of the largest group of serious chronic neurological conditions associated with substantial morbidity including mood disorders and cognitive dysfunction [1–3]. Admission to the Epilepsy Monitoring Unit (EMU) for diagnostic evaluations with long-term inpatient video-EEG (electroencephalography) monitoring (VEEG) constitutes the diagnostic gold standard in epileptology to confirm seizure diagnosis, differentiate epilepsy syndromes, and optimize therapeutic approaches [4]. While it was Hans Berger’s original intent to address the mind–body problem, we now know that qualitative EEG analysis has little to add to the investigation of the nature of particular neurological states and processes. Epilepsies have nonetheless repeatedly been referred to as a “window to mind–brain interaction” [5]. If we ever want to come closer to unraveling this biggest mystery of our time, we are in need of frequent and systematic psychological

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assessments yielding time series of psychological dynamics, as well as analysis tools to investigate the nonlinear nature of psychological processes [6–8]. Up to date, only very few studies have integrated systematic psychological assessments into inpatient VEEG monitoring [9].

The potential applications of regularly sampling subjective states in epileptology are manifold: Possible applications for research include, for instance, the investigation of the relationship between interictal stress and mood states, seizure occurrence, and postictal mood changes. In terms of clinical applications and quality control, real-time monitoring of psychological data during hospitalization may help to introduce support systems that aim at rapid identification and alleviation of stressful situations. Considering the heterogeneity of the patient population in EMU settings, clinical applications may also include the development of personalized therapeutic strategies, e.g., for patients whose epilepsy syndromes are associated with specific behavioral seizure risk factors [10] or patients with psychiatric comorbidities including psychogenic nonepileptic seizures (PNES) [11–16].

1.2. Systematic assessment of psychological states and processes: concepts to improve data validity

1.2.1. Paper-based vs. electronic data capture

Paper-based studies may decrease data validity as they may allow patients to record or modify data retrospectively. Electronic data capture has already been used in outpatient settings to provide a more reliable time-stamped data collection method [17]. Modern web-based devices such as tablets, smartphones, or laptops yield easy access to questionnaires for such electronic time-stamped data collection.

1.2.2. Daily vs. high-frequent data capture

Self-report studies in people with epilepsy have been limited by infrequent measurements [17,18]. Irregular and infrequent sampling rates decrease data validity and impede the identification of psychological dynamics and the relationship between psychological and neurological variables [6]. The frequent and systematic (i.e., regular, equidistant) assessment of subjective experiences in close temporal proximity to their actual occurrence may reduce memory biases and distortions by averaging over many events [19–22]. Fig. 1 illustrates how the dynamics of a time series with assessments every 5 h (Fig. 1a) is distorted and the information on the dynamic pattern is lost if measurement points are omitted and information is averaged (Fig. 1b). In addition, only regular and frequent assessments allow for meaningful application of time series analysis methods in the frequency domain (e.g., Fast Fourier Transformations) and particularly in the domain of nonlinear dynamics [6–8,23,24].

1.3. Feasibility and hypotheses

This is a feasibility study aiming at the investigation of compliance, i.e., we specifically aim at reporting on the possibility and difficulties of the frequent 4 times per day daily administration of electronic questionnaires in the EMU setting. The following is of particular interest: how many patients participated in this study, how many measurements patients missed to fill in throughout their stay in the EMU, and reasons for missing measurements. In addition, this is a pilot study of dynamic psychological patterns in the EMU setting. We anticipated that psychological support can be provided based on obtained psychological data. In this pilot study, we aim to describe meaningful observations and derive hypotheses that might be investigated in the future in more specifically designed follow-up studies.

2. Methods

Taking into account the achievements and limitations of previously conducted studies, the study aims at monitoring psychological states (such as self-perceived stress level, mood, and self-efficacy) by integrating partially personalized, high-frequency time-stamped electronic questionnaires into the intensive EMU environment.

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**Fig. 1.** Ratings of stress every 5 h versus averaged ratings of stress per day. a: Ratings of stress every 5 h by a female patient (42 years) with borderline personality disorder (BPD) and temporal lobe epilepsy (TLE) who was admitted to differentiate if the etiology of postsurgically reoccurring episodes was epileptic or nonepileptic; Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. b: Averaged ratings of stress per day; Y-axis indicates averaged answers on the visual analog scale (0–100); X-axis indicates consecutive responses.
2.1. Setting

This pilot study was conducted in the routine care of the intensive EMU of the Department of Neurology, Christian Doppler Medical Center, Salzburg, Austria. In this EMU, admitted patients undergo the usual diagnostic evaluations consisting of long-term VEEG monitoring. These recordings are performed over a mean period of 5 days (Monday to Friday). In order to promote a timely occurrence of seizures during the monitoring period, it is common practice to taper the dosage of antiepileptic drugs (AEDs) and administer sleep deprivation. Informed consent for serious adverse events was completed routinely upon EMU admission.

2.2. Ethical aspects

The study was designed and conducted in accordance with the World Medical Association Declaration of Helsinki and Good Clinical Practice Guidelines. Ethical approval was obtained from the ethics board Salzburg (Paracelsus Medical University, 415-E/2206/9-2017). Written informed consent was obtained from all participants.

2.3. Process questionnaire

The nonvalidated process questionnaire included eight standardized and up to six personalized items. While filling out the questionnaire, patients could add text related to a particular item or the questionnaire as a whole.

2.3.1. Standardized items

The standardized items of the questionnaire were designed in the interdisciplinary team of authors (psychologist (GS), neuropsychologists (ES, MK), neurologists (GK, RM), and psychotherapist (RM)). Although being in an EMU constitutes a stressful situation on its own for some patients, hospitalization may also remove some of the patients’ usual stressors. Item development therefore considered briefness (to prevent disruption of routine EMU activities), comprehensibility, and assumed meaningfulness and variability within the EMU setting. Patients were asked to rate the following items on visual analogue scales (VAS):

1. Stress level: “I feel nervous and stressed.” (0 = not at all to 100 = very much).
2. Energy level: “I have energy.” (0 = none at all to 100 = very much).
3. Mood: “My mood is…” (0 = very bad to 100 = very good).
4. Ward atmosphere: “The atmosphere is…” (0 = very bad to 100 = very good).
5. Seizure likelihood: “The likelihood of me having a seizure within the next hours is…” (0 = very low to 100 = very high).
6. Hopefulness/frustration: “I am…” (0 = frustrated to 100 = hopeful).
7. Boredom: “I am bored.” (0 = not at all to 100 = very).
8. Self-efficacy: “I can make use of things that help me to get along with the situation.” (0 = not at all to 100 = very well).

2.3.2. Personalized items

The personalized items included up to two personal seizure-warning signs and one postictal symptom that had been reported during the initial intake interview. These items were only included if patients spontaneously reported known seizure warning signs or postictal symptoms.

2.4. Resource-oriented interview

Question number eight (“I can make use of things that help me to get along with the situation.”) probed the use of resources that had been identified during the short resource-oriented interview at admission. During this interview, the interviewer acknowledged the obvious challenges of an EMU stay, including restricted privacy, mobility, and hygiene, and explored potential resources that might support the patient during the EMU stay in a semistructured fashion. The interviewer (RM) documented this interview by taking notes. The notes were reported back to the interviewed patient at the end of the interview to affirm their accuracy.

2.5. Systematic sampling of the process questionnaire

Data collection was realized using the Synergetic Navigation System (SNS); SNS is a web-based generic system that allows for the implementation of various questionnaires at any chosen interval. The response options to the items combine Likert-type scales and VAS. Data can be entered using web-compatible devices, which permits maximal spatial and temporal flexibility for entering data. Data privacy and data security are guaranteed by https-pages, anonymized usernames, and passwords. Its feasibility is supported by various case reports [e.g., (16)] and a compliance study on 151 psychiatric clients treated in an inpatient and a day-treatment clinic [11]. The raw data can be visualized by time series graphs that can be subjected to several time series analysis methods and used for feedback sessions [see Section 2.6] [6,21,25–27].

In this pilot study, SNS was used to collect daytime self-assessments every 5 h, three times daily prior to meal times (6:30 am, 11:30 am, and 4:30 pm) and at 9:30 pm, using the process questionnaire outlined above. Each patient was provided with a tablet. The participating patients were made aware of the measuring times by an alarm set in the tablet and were free to access the questionnaires via internet through a personalized account whose password had to be changed upon first log-in. Each time that the questionnaire was accessed, the items appeared in random order. Participants could enter comments related to single items.

2.6. Feedback session

For the feedback sessions, the time series of each item of a participant’s questionnaire was plotted in one diagram each. This resulting time series, i.e., the detailed visualizations of the patients’ replies and their dynamics, were discussed with each participant during the feedback sessions at the end of their EMU stay. The interviewer (RM) documented the feedback session. The notes were reported back to the patient at the end of the feedback session to affirm their accuracy. Afterwards, all patients were offered a copy of their personal diagrams and the opportunity to continue outpatient self-assessments one to two times daily following discharge from the EMU including additional feedback sessions, using a personal web-compatible device.

2.7. Pretests

The following validated questionnaires were applied to assess perceived stress, psychiatric comorbidity (depression), and Health Related Quality of Life (HRQOL) at admission:

Perceived Stress Scale (PSS) [28]

This 10-item scale was developed to measure a person’s appraisal of nonspecific stress. Patients are requested to indicate how frequently they have experienced certain thoughts or feelings over the past month on a 5-point Likert scale. The PSS scores are obtained by reversing responses to the four positively stated items and then summing across all items, with higher scores corresponding to a higher stress level.

Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) [29]

The NDDI-E is an epilepsy-specific 6-item self-report depression screening measure. Patients are instructed to report how frequently they have experienced six symptoms over the past two weeks on a
4-point Likert scale. The scores are summed to give a total score with a maximum of 24; individual validation studies of the NDDIE have identified different cutoff scores (Italy = 13; France = 15; Germany = 16) for a major depressive episode [30].

Quality of Life in Epilepsy-10 (QOLIE-10) [31]

The QOLIE-10 is a brief version developed from the original QOLIE-89 [32] to assess the quality of life of people with epilepsy. The scale assesses seizure worry, emotional worry, energy/fatigue, cognition, medication effects, social function, and overall quality of life during the past four weeks. Each of the 10 items is rated on a 5-point Likert scale. Responses to each item are summed to yield a total score, with higher scores corresponding to a higher quality of life.

It was hypothesized that these pretests would correlate with the intraindividual medians of the time series of the process questionnaire.

2.8. Recruitment of patients

A consecutive sample was enrolled: All patients who were 18 years and older and who were admitted to the EMU between November 6th 2017 and January 22nd 2018 were approached on the first day of admission. Eligible patients received an introduction to the SNS. Upon willingness to participate, pretest questionnaires (see Section 2.7) were applied via the SNS. Successful completion of pretest questionnaires via SNS was interpreted as an indicator of sufficient literacy and capability to operate the tablet and therefore to participate in the study.

2.9. Data analysis

The patients’ clinical characteristics and compliance are summarized using descriptive statistical methods. For interitem correlation as well as for correlating the intraindividual medians of the process questionnaires’ items with the pretest questionnaires’ total scores, two-sided t-tests were performed. The p-values were corrected for false-discovery rates (FDR) [33]. Qualitative content analysis of the interviewer’s notes that were recorded during the initial resource-oriented interview and of the feedback-session was conducted.

3. Results

During the 10-week enrollment period, a total number of 40 patients had been referred to the EMU. Eleven patients had not been eligible with the main reasons being a) motor deficits and/or aphasic dysfunctions that severely limited the handling of the tablet and/or comprehension of the survey questions (n = 6), or b) under age (n = 3). Eight patients declined to participate because they a) were already participating in another study (n = 3), b) felt considerable unease with handling a tablet (n = 3), or c) already felt too distressed by the EMU inpatient situation (n = 2). Consequently, the sample included a consecutively recruited cohort of 21 participants (Fig. 2).

3.1. Patient characteristics and characteristics of the EMU stay

The majority of the participating patients were admitted to the EMU within the first year after their first seizure (see Table 1 for sample characteristics). During their stay in the EMU, 15 patients (71%) underwent sleep deprivation at least once. Medication was tapered in 12 patients (57% of all 15 patients who had been taking at least one AED upon admission to the EMU), and at least one epileptic seizure was recorded in four patients (19%).

Table 1

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total n = 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years median [range]</td>
<td>29 [18–74]</td>
</tr>
<tr>
<td>Gender (female) total (%)</td>
<td>12 (57%)</td>
</tr>
<tr>
<td>Yrs since 1st event median [range]</td>
<td>0 [0–17]</td>
</tr>
<tr>
<td>Reason for admission total (%)</td>
<td></td>
</tr>
<tr>
<td>Classification of epilepsy syndrome</td>
<td>9 (43%)</td>
</tr>
<tr>
<td>Investigation of differential diagnosis</td>
<td>6 (29%)</td>
</tr>
<tr>
<td>Assessment of seizure frequency</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>Optimization of medication</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>Diagnosis total (%)</td>
<td></td>
</tr>
<tr>
<td>Structural epilepsy</td>
<td>12 (52%)</td>
</tr>
<tr>
<td>IGE</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>PNES</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>Syncope</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Migraine with aura</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>Medication total (%)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>6 (29%)</td>
</tr>
<tr>
<td>1 AED</td>
<td>14 (71%)</td>
</tr>
<tr>
<td>&gt;2 AEDs</td>
<td>1 (5%)</td>
</tr>
</tbody>
</table>

AED: antiepileptic drugs, IGE: idiopathic generalized epilepsy, PNES: psychogenic nonepileptic seizures, yrs.: years.

3.2. Compliance

During their five-day inpatient hospitalization (including three full and two half days), patients were prompted to fill in the process questionnaire four times a day. Therefore, the usual maximum number of measurement points between admission on the first day and discharge on the fifth day was 15 measurement points (1st day: two measurement points (afternoon and evening), 2nd–4th day: four measurement points each, 5th day: 1 measurement point in the morning). In three cases, this number was reduced because of a national holiday. The median compliance of this sample was 92% (range 60%–100%), i.e., 92 of
all questionnaires were submitted at the required measurement points. The median number of submitted questionnaires was 13 (range 9–15). Seven patients (33%) completed the questionnaires at all measurement points. Altogether, 14% (43 measurement points) of the total number of measurement points were missing for the following reasons in decreasing order: Noncompliance (n = 18 measurement points), technical issues (n = 11 measurement points), difficulties in handling the tablet (n = 6 measurement points), postictal impairment (n = 4 measurement points), and early discharge requested by one patient (n = 4). Four of the included patients (19%) were unfamiliar with the use of a tablet and required initial help with filling out the questionnaires. Delayed submissions of more than 1 h were counted as noncompliance. In a few cases, patients filled out the questionnaire more than once in a row. In such cases, only the first entry was counted toward compliance. It took the participants a median time of 3 min [range: <1 min to 12 min] to fill out the questionnaires.

3.3. Interitem correlation, pretest scores, and correlation of time series with pretest scores

When investigating the interitem correlation in all patients, mood correlated strongly with hopefulness, and moderately with energy (Table 2).

When correlating the intra-individual medians of the process questionnaire time series with the pretest total scores (see Table 3), energy correlated moderately and negatively with the PSS while ward atmosphere and self-efficacy correlated moderately and negatively with the NDDI-E total scores in all patients. In terms of the QOLIE-10, there was a moderate positive correlation with energy (Table 4).

3.4. Reported resources and general feedback

During the initial short resource-oriented interview, three main themes emerged. Some patients stated resilient attitudes toward challenges in life in general, for example “I do not get upset too easily,” or “I always attempt to focus on positive thoughts.” Many patients reported specific positive attitudes toward the EMU stay: “I am glad to have gotten this experience.” “I know why I am here.” “This examination is meaningful.” “I hope to understand what is going on with me.” “I want clarity.” All patients were able to name activities with which they planned to distract themselves during the stay in the EMU (watching TV, listening to music, reading, etc.). Some patients were expecting visits from relatives and friends, while others had explicitly decided against receiving visitors.

The majority of patients stated that filling out the questionnaire on the tablet was no inconvenience except for the alarms going off in the morning and noon after the administration of sleep deprivation. Participants appreciated the short questions that could be answered quickly. However, only a few patients reported spontaneous helpful insights such as “It was nice to notice that hopefulness was increasing over time. I would not have noticed that without answering the questions.” or “I enjoyed the [‘self-efficacy’] question because it made me think of my family.”

3.5. Feedback sessions: personal meaningfulness

Even though only few patients spontaneously reported helpful insights prompted by filling out the questionnaire, nine patients (43%) reported that they learned something meaningful about themselves after the feedback session during which the individual time series had been interpreted by patient and study investigator (RM) together. Six of these patients requested screenshots of their time series to remind them of the knowledge gained during the feedback session. Follow-up sessions were scheduled with two patients, and one patient continued to fill out the SNS questionnaire twice a day in the outpatient setting. The following examples illustrate meaningful aspects from the patients’ perspective:

3.5.1. Development of individual psychological illness models

The interpretation of the time series yielded individual models of psychological mechanisms underlying the occurrence of nonepileptic seizures (Fig. 3a and b) and migraine attacks (Fig. 3c). These models reinforced the decision by the two patients with PNES diagnoses to seek inpatient psychiatric or outpatient psychotherapeutic treatment.

3.5.2. Resource-oriented individual investigation of the interrelationship of sleep deprivation, energy, and mood

A number of patients gained insights into the impact of sleep deprivation and resultant decreased energy levels on mood levels. Some patients found out that this relationship was associated with their personal chronotype (i.e., the individual’s propensity to sleep and wake).

Table 3

<table>
<thead>
<tr>
<th>Pretest total scores.</th>
<th>PSS</th>
<th>NDDIE</th>
<th>QOLIE-10</th>
</tr>
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<tbody>
<tr>
<td>16 [4–29]</td>
<td>13  [7–21]</td>
<td>72.5 [47.5–95]</td>
<td></td>
</tr>
</tbody>
</table>

PSS: Perceived Stress Scale, NDDIE: Neurological Disorders Depression Inventory in Epilepsy, QOLIE-10: Quality of Life in Epilepsy-10.

Table 4

<table>
<thead>
<tr>
<th>Correlation of process questionnaire with pretests in all patients.</th>
<th>PSS</th>
<th>NDDIE</th>
<th>QOLIE-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>0.17</td>
<td>0.30</td>
<td>−0.03</td>
</tr>
<tr>
<td>Energy</td>
<td>−0.45*</td>
<td>−0.43</td>
<td>0.36</td>
</tr>
<tr>
<td>Mood</td>
<td>−0.35</td>
<td>−0.29</td>
<td>0.07</td>
</tr>
<tr>
<td>Ward atmosphere</td>
<td>−0.34</td>
<td>−0.51*</td>
<td>0.05</td>
</tr>
<tr>
<td>Seizure likelihood</td>
<td>0.03</td>
<td>0.04</td>
<td>−0.25</td>
</tr>
<tr>
<td>Hopefulness</td>
<td>−0.22</td>
<td>0.22</td>
<td>−0.17</td>
</tr>
<tr>
<td>Boredom</td>
<td>0.10</td>
<td>−0.16</td>
<td>0.07</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>0.32</td>
<td>−0.5*</td>
<td>−0.11</td>
</tr>
</tbody>
</table>

Correlations between Perceived Stress Scale (PSS), Neurological Disorders Depression Inventory in Epilepsy (NDDIE), Quality of Life in Epilepsy-10 (QOLIE-10) and intra-individual median process questionnaire time series in patients with epilepsy. *: p ≤ 0.05, **: p ≤ 0.01, p-values corrected for multiple testing.
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wake up at a particular time during a 24-hour period) and that this relationship was mediated especially by social factors (Fig. 4a) and intrinsic factors such as self-efficacy (Fig. 4b). In patients with idiopathic generalized epilepsy (IGE), this visualization of the psychological effects of sleep deprivation provided an opportunity for a resource-oriented cognitive reframing of the common advice to avoid sleep deprivation in order to prevent an increased risk of seizures.

3.5.3. Reflecting challenges during the inpatient monitoring

Some patients were relieved by the opportunity to talk about situations during the inpatient monitoring that they had found specifically challenging and/or distressful such as witnessing seizures by fellow patients (Fig. 5a) or being worried about the administration of sleep deprivation (Fig. 5b).

3.5.4. Outpatient monitoring of AED side effects

One patient continued to fill out the process questionnaire twice a day after discharge to monitor side effects during AED tapering. Daily dependent fluctuations of the side effect (dizziness) continued while a general decrease of the side effect could be observed (Fig. 6).

3.5.5. Supporting coping with seizures and with comorbidity

The patient who continued outpatient follow-up had also suffered a seizure in the inpatient setting and several seizures during the outpatient follow-up. His resources in terms of coping with the psychosocial discomfort after seizures were discussed based on his individual time series (Fig. 7a and b). One patient had disclosed feeling socially isolated at work and memory difficulties that had not been objectified by neuropsychological testing and were eventually rather seen as symptoms of a moderate depressive episode. Two follow-up consultative appointments were scheduled with him and his spouse to offer prompt support and discuss therapeutic strategies.

4. Discussion

The results of this pilot study illustrate the feasibility of a high-frequency psychological monitoring procedure in the busy setting of an inpatient EMU. A large proportion of the participants revealed high compliance rates, resulting in equidistant time series of high frequency. The application of the questionnaires was accomplished using an internet-based device (SNS) with a process questionnaire. These results indicate the strong relation between certain psychological variables in regard to patients’ mood and their perception of ward atmosphere during EMU admission. As such, some of the variables (e.g., hopefulness, energy, and self-efficacy) highlight the potential impact that conversations with doctors and nurses, sleep deprivation, and proposed activities might have on patients’ mood. In addition, the psychological dynamic patterns during EMU admission seemed to be associated with patients’ pretest total scores.

While data entry itself only prompted meaningful self-awareness in very few patients, the feedback sessions were regarded as a source of informative insights by more than a third of all patients. The current study design does not allow a differentiation of the various factors that might have influenced this judgment including the visualized time series, the attention by the study investigator, and the content of the conversations. Given the lack of privacy during hospitalization and the busy clinical setting, the additional offer of a personal conversation may have been a rather meaningful influential factor.
Fig. 4. Resource-oriented individual investigation of the interrelationship of energy and mood. a: This female patient (26 years) with idiopathic generalized epilepsy (IGE) observed low energy levels (blue line) in the mornings (m) and especially after sleep deprivation (1). Low energy was usually accompanied by bad mood (red line) and decreased hopefulness (green line). However, after sleep deprivation, (1) this effect was suspended by her boyfriend’s visit (2), indicated by increased ward atmosphere (yellow line) in this time series. During the feedback session, this patient became aware of the important mediating influence of social resources in her life; Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. b: This male patient (64 years) with structural epilepsy had reported an accepting attitude toward hardship during the resource-interview. Despite low energy levels (blue line) after sleep deprivation, his mood remained good, which he attributed to his pronounced sense of self-efficacy (yellow line); Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)

Fig. 5. Reflecting challenges during the inpatient monitoring. a: During the feedback session, this female patient (46 years) felt relieved by the opportunity to share how burdened and helpless she had felt when she witnessed a fellow patient’s focal to bilateral tonic–clonic seizure (1) (blue line: stress, red line: mood); Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses; the blue rectangles underneath the X-axis indicate that a comment had been submitted with the questionnaire. b: During the feedback session, this female patient (26 years) shared that she had been worried (blue line: stress) if the administration of sleep deprivation would be brought up during rounds (1). However, she had avoided to bring up the topic herself. This time-series made her aware of the importance of speaking up to increase clarity concerning worrisome issues; Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)
The individual examples illustrate a range of potentially useful clinical applications: While VEEG monitoring remains the gold standard for establishing the diagnosis of PNES, this usual diagnostic means can only determine that seizures are nonepileptic. The underlying “psychogenic” model can only be derived explicitly from additional psychological diagnostic means. It has been suggested that the explanation of such an explicit and personalized model may be important to support acceptance of PNES and to increase the likelihood that patients with PNES seek appropriate psychotherapeutic treatment [34]. Data obtained from personalized process questionnaires administered during EMU monitoring may provide an informative basis for the development of such explicit individualized psychological models and the formulation of personalized psychotherapeutic treatment plans (e.g., by the method of idiographic system modeling, [16,35]). This opportunity to develop an understanding of precipitating factors may also apply to other conditions such as primary headache disorders and epilepsy syndromes [36].

Epileptic seizures may be precipitated by the interaction of various clinical factors, but – especially in some idiopathic generalized epilepsy syndromes such as juvenile myoclonic epilepsy – sleep loss stands out as an independent seizure trigger that is used as a diagnostic means to increase the likelihood of seizure occurrence in the EMU setting [37, 38]. Little attention has been paid to the potentially mediating role of the psychological effects associated with sleep deprivation, which may also be modified by other factors such as social resources and self-efficacy.

Being in an EMU may constitute a challenging situation for patients [39]. On the one hand, reinforcing the active use of existing resources upon admission such as resilient attitudes, specific positive attitudes toward the purpose of the EMU stay, and/or planned activities to distract themselves may help to promote coping. Providing an opportunity to reflect past challenges at the end of the stay in the EMU, on the other hand, may serve as a relieving outlet.

The side effects of AEDs are rarely monitored systematically in the outpatient setting [40]. As has been shown in the case of one patient whose outpatient follow-up questionnaire included a personalized item to monitor a severely disabling AED side effect, process questionnaires can be used to monitor AED side effects in the outpatient setting and therefore provide a more objective basis for their assessment and inclusion in medical decisions.

Comorbid depression and postictal psychosocial discomfort are common phenomena in people with epilepsy [2,41]. There is moderate evidence that psychotherapeutic interventions may improve health-related quality of life in people with epilepsy, and some of these psychotherapeutic interventions specifically target depressive symptoms and/or coping with uncomfortable postictal states [42,43]. However, psychotherapeutic treatment is not comprehensively integrated into usual care for people with epilepsy. Various barriers have been described: Routine screening for comorbidities is not usually performed despite recommendations by the Association of American Neurology and the availability of cost-free short epilepsy-specific screening instruments. In addition, there are structural barriers (e.g., waiting lists, costs, accessibility, etc.) and barriers related to professional attitude (e.g., discomfort initiating treatment for symptoms related to depression and anxiety) [44]. In this pilot study, the integration of screening procedures and feedback sessions allowed for personalized outpatient follow-up treatment offers to address psychosocial needs.

4.1. Limitations and future studies

In order to realize high-frequency data collection, we limited the number of items asked, i.e., the items of the process questionnaire were well-defined, but the questionnaire is not validated. We deliberately traded this shortcoming for an increased feasibility and compliance in a busy intensive EMU. However, only the combination of the process questionnaire with validated outcome measures would have allowed us to determine if the items in our process questionnaire were sensitive to meaningful change. In addition, the sampling rate of the process questionnaire was chosen for pragmatic reasons, and the optimal sampling rate still needs to be determined in future studies. Ideally, the items of the process questionnaire should be subjected to Rasch analysis and factor analysis in future studies with larger sample sizes.

A major limitation is the restriction of the data to the inpatient setting in which patients were not in contact with their usual everyday stressors and resources. This raises the question of generalizability of our results. This concern can be addressed by implementing the procedure in an outpatient monitoring setting. A future application and improvement of these monitoring procedures could include a broader personalized item selection (e.g., by integrating personal topics, problems, and goals of a patient into a questionnaire), which has already been demonstrated in psychiatric patients [11,16].

The small sample size in this pilot study constitutes the biggest limitation to interpret our findings. Given the small number of patients in the respective subgroups, specific psychological (i.e., cognitive–emotional) differences between patients with different seizure disorders could not be determined based on the presented data. Optimal follow-up studies with more specific designs would include sufficient numbers of patients in all subgroups. The narrative result section presenting qualitative data constitutes a merely anecdotal evidence level. In addition, qualitative content analysis was performed based on notes and not transcripts. However, we believe that we did not overstate our evidence but simply portrayed opportunities for potential clinical application and hypotheses that will need further investigation in the future. Furthermore, neither validated outcome measures nor follow-up data...
were collected, and therefore, we have no means to determine if the insights that patients reported during feedback sessions translated into functional improvements.

Potential selection bias was introduced by the five patients who declined to participate because they felt considerable unease with handling a tablet or already felt too distressed by the EMU inpatient situation. This study failed to investigate factors that could have made participation acceptable or even attractive for these patients. The motivation of these patients will need special attention in future studies, esp. when the potential application of SNS as a support system is under investigation.

The SNS provides an opportunity to investigate the correlation between neural and mental (cognitive/affective) states by correlating process questionnaires with quantitative EEG analysis in future studies [45, 46].

5. Conclusions

This pilot study demonstrated the feasibility of integrating high-frequency monitoring of psychological states and processes in the busy setting of an EMU with good compliance. In addition, the study suggested that individual feedback and feedback-related interviewing sessions were meaningful for the participants.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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Fig. 7. Supporting coping with seizures. a: Outpatient monitoring continued with measurements twice daily in this male patient (26 years) with TLE and revealed the detrimental impact of seizures (sz) on the atmosphere at home due to parental worries (blue line); Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. b: This time series in the same patient as in Fig. 7a (and Fig. 6) revealed how meaningful resources in terms of coping with the psychosocial discomfort after seizures (red line) led to the recovery of mood (yellow line), hopefulness (green line), and energy (blue line) shortly after a seizure (sz). Measurements were taken twice daily, Y-axis indicates answers on the visual analog scale (0–100); X-axis indicates all consecutive responses. (For interpretation of the references to color in this figure legend, the reader is referred to the web version of this article.)
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