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

Rosa Michaelis [a,b,c,*], Helmut Schöller [d,e], Yvonne Höller [a], Gudrun Kalss [a], Margarita Kirschner [a], Elisabeth Schmid [a], Eugen Trinka [a], Günter Schiepek [d,e]

[a] Department of Neurology, Centre for Cognitive Neuroscience, Paracelsus Medical University, Salzburg, Austria
[b] Department of Neurology, Gemeinschaftskrankenhaus Herdecke, Herdecke, Germany
[c] Integrated Curriculum for Anthroposophical Medicine (ICURAM), Witten/Herdecke University, Herdecke, Germany
[d] Institute of Synergetics and Psychotherapy Research, Paracelsus Medical University, Salzburg, Austria
[e] Department of Psychiatry, Psychotherapy and Psychosomatics, Paracelsus Medical University, Salzburg, Austria

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ABSTRACT

Background: Admission to the epilepsy monitoring unit (EMU) for long-term video-electroencephalography (EEG) monitoring (VEEG) constitutes the gold standard for seizure diagnosis and presurgical evaluation. This study applied the concept of a high-frequency systematic monitoring of psychological states and tested patients' compliance in order to evaluate if its integration in the EMU is feasible and if patients benefit from the graphically underpinned discussion of their EMU stay-related cognitions and emotions.

Methods: The process-monitoring is technically realized by an internet-based device for data collection and data analysis, the Synergetic Navigation System (SNS). A convenient sample was enrolled: All eligible patients who were admitted to the EMU of the Department of Neurology, Christian Doppler Medical Center, Salzburg, Austria, between November 6th 2017 and January 26th 2018 were approached and recruited upon consent. After a short resource-oriented interview, each enrolled patient was provided with a tablet. The daily questionnaire included eight standardized and up to three personalized items. Self-assessments were collected every 5 h prior to meal times (6:30 am, 11:30 am, and 4:30 pm) and at 9:30 pm. The detailed visualizations of the patients' replies were discussed with the participants during a feedback session at the end of the EMU stay.

Results: Twenty-one patients (12 women/9 men, median age 29 years [range 18–74 years]) were consecutively recruited (72% of all eligible patients). Compliance rates were high (median: 82%, range 60%–100%) among the respondents. Mood correlated strongly with hopefulness ($r = 0.71$) and moderately with energy ($r = 0.63$) in all patients. When correlating the intraindividual medians of the process questionnaire time series with the pre-test total scores, energy correlated moderately and negatively with the Perceived Stress Scale (PSS) ($r = -0.45$), while self-efficacy correlated moderately and negatively with the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) total scores in all patients ($r = -0.5$). Nine patients (43%) reported that they learned something meaningful about themselves after the feedback discussion of their individual time series.

Conclusion: The results support the feasibility of high-frequency monitoring of psychological states and processes in routine EMU settings. Repeated daily collections four times per day of psychological surveys allow for the assessment of highly resolved, equidistant time series data, which gives insight into psychological states and processes during EMU admission.

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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 psychological 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

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.
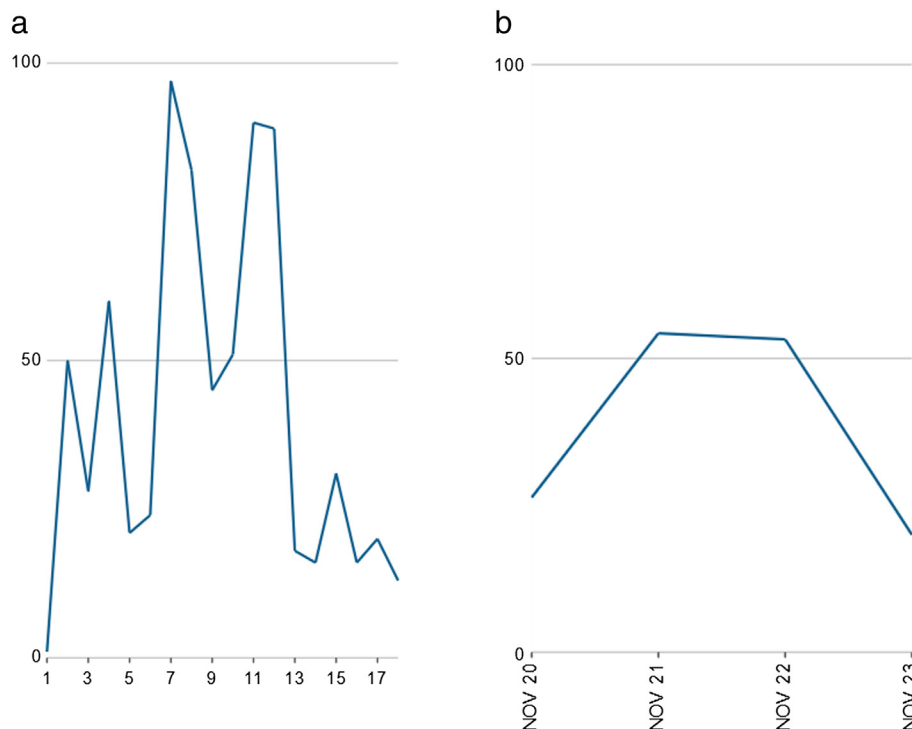
Fig. 1. Ratings of stress every 5 h versus averaged ratings of stress per day. a: Ratings of stress every 5 h by a female patient (42 years) with borderline personality disorder (BPD) and temporal lobe epilepsy (TLE) who was admitted to differentiate if the etiology of postsurgically reoccurring episodes 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.