

Between fear of death and just a warning sign: Seizure severity scales neglect the subjective quality of periictal perceptions

Raphael Rauh ^a, Stephane Auvin ^{b,c,d,e,f}, Andreas Schulze-Bonhage ^{a,f,*}

^a Epilepsy Center, University Medical Center, University of Freiburg, Germany

^b Paris-Cité University & Robert-Debré University Hospital Paris, France

^c APHP, Robert Debré University Hospital, Pediatric Neurology Department, CRMR Epilepsies Rares, Member of ERN EpiCARE, Paris, France

^d Université Paris Cité, INSERM NeuroDiderot, Paris, France

^e Institut Universitaire de France (IUF), Paris, France

^f EpiCare, European Reference Network Epilepsy

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ABSTRACT

The burden of epilepsy is not only related to seizure frequency; the severity of epileptic seizures considerably affects patient's lives. A number of seizure severity scales have thus been developed for a systematic assessment. Items considered relevant in these scales mainly pertain to objective features, such as seizure duration, loss of consciousness, and seizure-related injuries. In contrast, subjective experiences of seizures are considered only in their functionality as “warnings”, whereas the quality of subjective perceptions and feelings are disregarded phenomena. This leads to a gap between the often-distressing subjective experiences which people with epilepsy remember from their seizures and the perception of physicians which may negatively impact physician-patient communication and interaction and question their valid use as treatment outcomes. We advocate here to develop new seizure severity assessments in collaboration with patient organizations which integrate also the subjective quality of seizures.

Epileptic seizures have a wide range of clinical manifestations depending on the affected brain structures. Given this clinical diversity of epileptic seizures [1], a wide range of quantitative and qualitative aspects of seizures may determine the “severity” of seizures. Attributes of the severity of seizures can negatively impact mood and lead to dysfunctional and isolating behaviors and worsen quality of life [2,3]. For this purpose, several seizure severity scales have been developed which comprise and weight a spectrum of features.

Severity, however, can be assessed under various aspects: physical risk (e.g. related to loss of motor control or cardiorespiratory dysfunction), social stigma (e.g. related to inadequate behavior of embarrassing manifestations like enuresis), or functional disturbances relevant to occupational capabilities or driving and mobility. Aside from these aspects, epileptic seizures contain often unique subjective experiences, which mostly determine how people with epilepsy themselves perceive their disease. These hard-to-describe subjective aspects comprise periictal phenomena, such as illusory or hallucinatory perceptions, emotions, as well as cognitive and behavioral disturbances during the postictal period [4–6].

Various scales have been developed to integrate heterogeneous aspects into one overall seizure severity score. For a critical discussion of the validity of the existing seizure severity scales see Cramer and French [7], who reviews the US Department of Veterans Affairs Scale (designed in 1978), the Chalfont-National Hospital seizure severity scale, the Liverpool seizure severity scale, and the Hague seizure severity scale for children [8]. A recent systematic review [9] discusses eight severity scales: the Veteran Administration Scale (VA) [10], The Chalfont Seizure Severity Scale (CSSS) [11], The National Hospital Seizure Severity Scale (NHS3) [12], Liverpool Seizure Severity Scale (Original LSSS) [13], Revised Liverpool Seizure Severity Scale (Revised LSSS) [14], Liverpool Seizure Severity Scale 2.0 (LSSS 2.0) [15], Seizure Severity Questionnaires (SSQ) [16], and finally The Personal Impact of Epilepsy Scale (PIES) [17], which integrates an assessment of seizure severity as a subscale.

Seizure severity scales, as developed out of the original studies, have different layers:

* Corresponding author.

E-mail address: andreas.schulze-bonhage@uniklinik-freiburg.de (A. Schulze-Bonhage).

1. Clinical Assessment: to provide systematical information supporting diagnostic and therapeutic decisions.
2. Research Standardization: to provide a patient-relevant outcome measure, ensure consistency in research studies and facilitate comparisons across studies and patient populations.
3. Treatment Monitoring: to monitor treatment efficacy and provide a target for treatment adjustments.
4. Communication: to enable unambiguous communication among healthcare professionals, researchers, and patients about the nature and severity of seizures. This can improve collaboration and shared decision-making in managing epilepsy.

Depending on the semiology of the seizure and any associated somatic and psychiatric comorbidities, epileptic seizures can impose significant distress, leading to social isolation, suicidal ideation, i.e. overall impairment of quality of life [18–20]. In focal epilepsy, the focal aware phase (until recently called “aura”) constitutes the key determinant of what patients memorize and know about their own seizures [21]. This may encompass uncommon experiences like sensory illusions or hallucinations, unpleasant sensory phenomena like pain, cognitive alterations like feelings of familiarity or strangeness, and emotional changes, in particular, anxiety [22].

Particularly ictal anxiety, as expression of the seizure event itself [23,24] is a major determinant of the subjectively experienced severity of seizures. Anxiety may evolve as a reaction to perceiving early symptoms during a seizure, based on the feeling of loss of control, sometimes even as a fear of death, or as a direct subjective correlate of amygdala involvement [25].

It is thus critical to which degree the qualitative dimension of seizures is integrated into presently used scales of the severity of epileptic seizures, and how these are evaluated or weighted, finally how this relates to patient views on factors determining the severity of the individual epilepsy.

Seizure severity is already an implicit part of the classification of focal seizures [1]. Seizures with preserved awareness are usually considered to be less severe than those with impaired awareness, and these are less severe than focal to bilateral tonic-clonic seizures. This may be justified based on the consideration that loss of awareness frequently is associated with an inability of patients to adequately react to their environment, which again can lead to potential hazards to their

physical health. Similarly, motor signs like tonic or clonic muscle contractions are considered elements of a more severe seizure, which may again be a consequence of potential physical injury and social stigma resulting from unphysiological and uncoordinated movements.

In the Chalfont Seizure Severity Scale (CSSS, [11]) the highest score of symptoms is given for the duration until complete recovery, followed by injuries and motor phenomena (convulsions, severe automatisms). In contrast, an aura (comprising all subjective phenomena experienced during seizures) is given 0 points, and their absence 1 point. Thus, an aura contributes only 1 % e.g. of the duration of overall impairments to the total score, with an absence rather than the experience of the aura minimally increasing the score (Fig. 1).

The revised version by O’Donoghue et al. [12], The National Hospital Seizure Severity Scale (NHS3), allows to answer to different seizure types with “auras” as a specific type of epilepsy. In the case of loss of consciousness, an item assesses a warning that might help to protect oneself. O’Donoghue et al. [12] argue that subjective consequences of seizures – as dimensions of quality of life – have as “subjective or ‘patient-based-factors’” strictly to be differentiated from “objective clinical phenomena”. The authors seem to identify in their argumentation the subjective consequences of seizures, i.e. quality of life, with the qualitative experience of seizures. They therefore argue that the severity of seizures is highly context dependent, referring to countries where driving is omitted in the case of absences but permitted in the case of simple partial seizures. In this context, they interestingly drop as an advantage of their scale that simple partial seizures have the same impact as absences.

The Liverpool Seizure Severity Scale (LSSS) was revised twice. The original version had two subscales, an “ictal” subscale with ten items, measuring ictal and postictal phenomena (loss of consciousness, postictal confusion, headache, and injury) and a “percept” subscale with six items, related to the timing and predictability of the seizures including aura sensations [13], discussed in O’Donoghue et al. [12]. The presence of subjective (aura) experiences, in contrast, has a low score if usually present, whereas a seizure without aura is given a higher score. The contribution of the aura, however, is overall low (<10 % of the total score), and its presence reduces rather than increases the total score. The latter subscale was criticized for not being sensitive to change in measuring the severity of seizures, and thus not being useful [7]. Furthermore, patients that suffered from more than just one seizure type

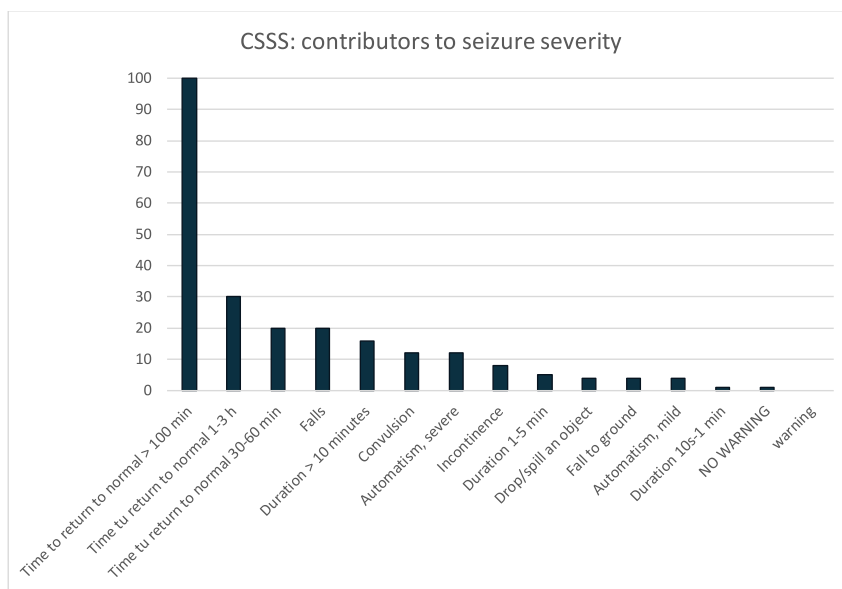


Fig. 1. Contributors to the seizure severity score in the Chalfont Seizure Severity Scale (CSSS [11]). Note that subjective phenomena during the focal aware phase of seizures in this scale as in several others do not contribute at all to the score, and the absence of perceived subjective phenomena results in one point of the total score, as subjective aspects are seen only as presence or absence of a “warning”.

confused the validity of the scale, which led to a new 20-item version. The latest version of this scale is discussed by [15], as LSSS 2.0, and has 12 items. It excluded the subjective percept subscale because qualitative reevaluation of this subscale – deduced from interviews with five patients (patient focus group) and ten epileptologists (expert panel) – expressed the opinion that the items of this subscale are more likely to represent issues concerning the quality of life and not the severity of seizures.

Cramer et al. [16] developed the Seizure Severity Questionnaire (SSQ) out of a constructive critique of the above assessments. It integrates subjective accounts considering “severity” and “bothersomeness” in three subscales addressing warning, ictal activity, and postictal recovery, and uses combined assessments by patients and caregivers. Whereas bothersomeness is assessed for ictal motor signs and postictal impairments, the aura is only considered a possible “warning”, neither severity nor bothersomeness contributes to the seizure severity score but rather its potential “helpfulness”.

Overall, in seven out of these eight scales, the subjective quality of seizures is completely disregarded. Only the PIES, which explicitly aims at assessing “patient concerns,” notes fear and anxiety as components of the assessment. However, it does not specify whether ictal fear/anxiety or interictal fear is considered. The mostly addressed motor, autonomic, and postictal signs of seizures are not remembered by patients [21] and only contribute indirectly to the patient’s seizure perception, e.g. when experiencing reactions of others to their seizures, or when experiencing physical injuries. Assessment scores are in striking contrast to patient reports for whom the aura or focal aware phase is the major, and often severely distressing part of seizures. One example is ictal anxiety, which can encompass the fear of suffocating, the fear of losing control, and even the fear of death. In qualitative studies, statements like “No one has ever cared about my fears for over 40 years, but it’s the worst part of all of this.” [26] suggest that the patient’s perspective is partially neglected when assessing only objective signs in seizure severity scores and considering the subjective phase only in its potential function of a warning.

We agree that the impact of symptoms is always in some regard context-dependent, as O’Donoghue et al. [12] state. But this has little to do with the type of epilepsy. When you listen to the patients’ accounts also subtle subjective phenomena get objectifiable. Patients with similar periictal symptoms may feel not taken seriously by the treating professionals and perceive a misunderstanding on the communication level when the physician categorizes these focal aware discharges as ‘minor’ seizures. The current seizure severity scales are not reflecting the patient’s reality and the seizure terminology and classification used by the treating physicians don’t raise awareness on these points. Considering experiences like fear, hallucinations or pain as “minor” events based on preserved awareness may miss the patient’s perception and thus counteract to a trustful patient-physician-relationship.

Present-day seizure severity assessments do not take enough consideration of the subjective quality of seizures and reduce subjective experiences to their role as potential “warnings”. Notably, unpleasant experiences and negative emotions like hard-to-describe stress, tension, and anxiety are, at least in the preictal and ictal phase, disregarded as symptoms per se. This is inadequate when communicating with patients and neglects highly distressing seizure elements and almost only considers elements as “severe” that patients do not experience or recall.

We thus propose that new seizure severity assessments are needed which – beyond unarguably relevant objective signs – also integrate the patient’s reality and perception of seizures. This can avoid a devaluation of the patient’s perspective and may facilitate communication about the severity of the role seizures have.

Generating items for standardized questionnaires that capture patients’ subjective experiences during a seizure is a complex process (an overview of different methods of qualitative interviewing and their pitfalls is provided by [27]). Qualitative interviews should be conducted in a replicable manner, giving participants enough time to express, for

example, their periictal subjective experiences. Microphenomenological interviewing techniques may sensitize and point to specific expressions that encapsulate hard-to-describe emotions, which can then be hermeneutically deciphered [5,6]. These must be transcribed and substantially analyzed, and clustered into overarching topics (for example into body sensations, altered cognition, altered emotions, etc.). This can serve to generate pilot versions for testing and refining of new instruments to be validated for content validity and reliability.

Integrative assessments of phenomena of *peri-ictal anxiety* [26] may be one step in this direction. Especially in qualitative interviewing, the participant has the opportunity to address subjective experiences. When the interviewer approaches an epilepsy patient with the open-ended question about the subjective sensations experienced shortly before, during, and shortly after the seizure, there is an opportunity to appropriately weigh these experiences. It may require a significant amount of time and empathy to accurately classify and understand the subject’s statements through follow-up questions. It appears to be part of this symptomatology that it is very difficult to articulate interpersonally [28], which can be an additional burdening factor.

Collaborative efforts of medical experts in conjunction with patient organizations may offer a way to find a reasonable balance between subjective and objective seizure elements, and integrate subjective phenomena into a comprehensive seizure severity scale that better respects the patient perspective and thus leads to a trustful and compliant physician-patient-relationship.

Well-conducted mixed-methods research offers a significant advancement in understanding complex phenomena by combining broad quantitative indicators with in-depth qualitative probes. Thus, quantitative methods can contribute large-scale surveys collecting data on seizure frequency, medication adherence, and overall quality of life providing a broad overview of the patient population, highlighting common trends and generalizable patterns. Qualitative methods such as in-depth interview can complement this and gain a deeper understanding of the nuanced personal experiences behind these numbers. In combination, individual stories and subjective experiences of epilepsy patients can reveal insights into how the condition impacts their daily lives, emotional well-being, and social interactions. With regard to anxiety, quantitative data can be complemented by qualitative interviews uncovering the specific fears and challenges that contribute to this anxiety, such as the unpredictability of seizures, loss of control and eerie sensations during a seizure, or the particularly isolating stigma associated with the condition. Further studies using mixed-methods may thus pave the way to a more comprehensive understanding on the impact and forms of anxiety and integrate this into a more patient-oriented seizure severity assessment.

CRedit authorship contribution statement

Raphael Rauh: Writing – review & editing, Writing – original draft, Validation, Formal analysis, Conceptualization. **Stephane Auvin:** Writing – review & editing. **Andreas Schulze-Bonhage:** Writing – review & editing, Supervision, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- [1] Fisher RS, Cross JH, French JA, Higurashi N, Hirsch E, Jansen FE, et al. Operational classification of seizure types by the international league against epilepsy: position paper of the ILAE commission for classification and terminology. *Epilepsia* 2017 Apr;58(4):522–30. <https://doi.org/10.1111/epi.13670>. Epub 2017 Mar 8 PMID: 28276060.

- [2] Harden CL, Maroof DA, Nikolov B, Fowler K, Sperling M, Liporace J, et al. The effect of seizure severity on quality of life in epilepsy. *Epilepsy Behav* 2007;11(2): 208–11. <https://doi.org/10.1016/j.yebeh.2007.05.002>. Epub 2007 Jul 2 PMID: 17604229.
- [3] Kaddumukasa M, Mugenyi L, Lhatoo S, Sewankambo N, Blixen C, Sajatovic M, Katabira E. Seizure severity is associated with poor quality of life in people living with epilepsy (PLWE) in Uganda: A cross-sectional study. *Epilepsy Behav*. 2019 Jul; 96:104–108. doi: 10.1016/j.yebeh.2019.04.033. Epub 2019 May 21. PMID: 31125798; PMCID: PMC6597271.
- [4] Bauer PR, Bronnec MLA, Schulze-Bonhage A, Altenmüller DM, Fuchs T. Seizures as a Struggle between Life and Death: An Existential Approach to the Psychosocial Impact of Seizures in Candidates for Epilepsy Surgery. *Psychopathology* 2023;56(6):417–29. <https://doi.org/10.1159/000528924>. Epub 2023 Mar 16 PMID: 36927809.
- [5] Bronnec MLA, Altenmüller DM, Fuchs T, Lahmann C, Schulze-Bonhage A, Bauer PR. “What is this strange sensation?” A qualitative exploration of metaphors used to verbalise hard-to-describe experiences by people with epilepsy. *Epilepsy Behav* 2023;138:108963. <https://doi.org/10.1016/j.yebeh.2022.108963>. Epub 2022 Nov 17 PMID: 36403424.
- [6] Carrizosa MJ. Perceptions and metaphors of patients about epileptic seizures and postictal state in Medellín-Colombia: A qualitative study. *EpilepsyBehav* 2024 Jan; 150:109589. <https://doi.org/10.1016/j.yebeh.2023.109589>. Epub 2023 Dec 12 PMID: 38091905.
- [7] Cramer JA, French J. Quantitative assessment of seizure severity for clinical trials: a review of approaches to seizure components. *Epilepsia* 2001 Jan;42(1):119–29. <https://doi.org/10.1046/j.1528-1157.2001.19400.x>. PMID: 11207795.
- [8] Carpay JA, Vermuelen J, Stroink H, Brouwer OF, Peters AC, Aldenkamp AP, et al. Seizure severity in children with epilepsy: a parent-completed scale compared with clinical data. *Epilepsia* 1997 Mar;38(3):346–52. <https://doi.org/10.1111/j.1528-1157.1997.tb01127.x>. PMID: 9070598.
- [9] Rusli RA, Makmor Bakry M, Mohamed Shah N, Hui JT. Seizure severity assessment tools for adult epilepsy patients: A systematic review. *EpilepsyBehav* 2023 May; 142:109154. <https://doi.org/10.1016/j.yebeh.2023.109154>. Epub 2023 Mar 29 PMID: 37001468.
- [10] Cramer JA, Smith DB, Mattson RH, Delgado Escueta AV, Collins JF. A method of quantification for the evaluation of antiepileptic drug therapy. *Neurology* 1983;33(3 Suppl 1):26–37. https://doi.org/10.1212/wnl.33.3_suppl.1.26. PMID: 6681889.
- [11] Duncan JS, Sander JW. The Chalfont Seizure Severity Scale. *J Neurol Neurosurg Psychiatry* 1991;54(10):873–6.
- [12] O’Donoghue MF, Duncan JS, Sander JW. The National hospital seizure severity scale: a further development of the chalfont seizure severity scale. *Epilepsia* 1996; 37(6):563–71. <https://doi.org/10.1111/j.1528-1157.1996.tb00610.x>. PMID: 8641234.
- [13] Baker GA, Smith DF, Dewey M, Morrow J, Crawford PM, Chadwick DW. The development of a seizure severity scale as an outcome measure in epilepsy. *Epilepsy Res* 1991;8:245–51. [https://doi.org/10.1016/0920-1211\(91\)90071-m](https://doi.org/10.1016/0920-1211(91)90071-m). PMID: 1868824.
- [14] Baker GA, Smith DF, Jacoby A, Hayes JA, Chadwick DW. Liverpool Seizure Severity Scale revisited. *Seizure* 1998;7(3):201–5. [https://doi.org/10.1016/s1059-1311\(98\)80036-8](https://doi.org/10.1016/s1059-1311(98)80036-8). PMID: 9700832.
- [15] Scott-Lennox J, Bryant-Comstock L, Lennox R, Baker GA. Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy Res* 2001 Apr;44(1):53–63. [https://doi.org/10.1016/s0920-1211\(01\)00186-3](https://doi.org/10.1016/s0920-1211(01)00186-3). PMID: 11255073.
- [16] Cramer JA, Baker GA, Jacoby A. Development of a new seizure severity questionnaire: initial reliability and validity testing. *Epilepsy Res* 2002 Feb;48(3): 187–97. [https://doi.org/10.1016/s0920-1211\(02\)00003-7](https://doi.org/10.1016/s0920-1211(02)00003-7). PMID: 11904237.
- [17] Fisher RS, Nune G, Roberts SE, Cramer JA. The Personal Impact of Epilepsy Scale (PIES). *EpilepsyBehav* 2015 Jan;42:140–6. <https://doi.org/10.1016/j.yebeh.2014.09.060>.
- [18] Cramer JA, Brandenburg N, Xu X. Differentiating anxiety and depression symptoms in patients with partial epilepsy. *Epilepsy Behav* 2005 Jun;6(4):563–9. <https://doi.org/10.1016/j.yebeh.2005.02.017>. Epub 2005 Apr 26 PMID: 15907750.
- [19] Josephson CB, Jetté N. Psychiatric comorbidities in epilepsy. *Int Rev Psychiatry* 2017 Oct;29(5):409–24. <https://doi.org/10.1080/09540261.2017.1302412>. Epub 2017 Jul 6 PMID: 28681667.
- [20] Sancho J, Iváñez V, Molins A, López Gómez V, Masramón X, Pérez M. Changes in seizure severity and quality of life in patients with refractory partial epilepsy. *Epilepsy Behav* 2010 Nov;19(3):409–13. <https://doi.org/10.1016/j.yebeh.2010.08.011>. Epub 2010 Sep 19 PMID: 20855235.
- [21] Mielke H, Meissner S, Wagner K, Joos A, Schulze-Bonhage A. Which seizure elements do patients memorize? A comparison of history and seizure documentation. *Epilepsia* 2020 Jul;61(7):1365–75. <https://doi.org/10.1111/epi.16550>.
- [22] Nascimento FA, Friedman D, Peters JM, Bensalem-Owen MK, Cendes F, Rampp S, et al. Focal epilepsies: Update on diagnosis and classification. *Epileptic Disord* 2023 Feb;25(1):1–17. <https://doi.org/10.1002/epd2.20045>.
- [23] Kanner AM. Ictal panic and interictal panic attacks: diagnostic and therapeutic principles. *Neurol Clin*. 2011 Feb;29(1):163–75, ix. doi: 10.1016/j.ncl.2010.11.002. PMID: 21172577.
- [24] Teixeira AL. Peri-Ictal and Para-Ictal Psychiatric Phenomena: a Relatively Common Yet Unrecognized Disorder. *Curr Top Behav Neurosci* 2022;55:171–81. https://doi.org/10.1007/7854_2021_223. PMID: 33728598.
- [25] Rauh R, Schulze-Bonhage A, Metternich B. Assessment of anxiety in patients with epilepsy: a literature review. *Front Neurol* 2022;25(13):836321. <https://doi.org/10.3389/fneur.2022.836321>. PMID: 35547374; PMCID: PMC9081800.
- [26] Rauh R, Domschke K, Hirsch M, Schulze-Bonhage A. Listening to anxiety in persons with epilepsy. Development of an integrative assessment model based on qualitative interviews. *Epilepsy Behav*. 2023 Aug;145:109319. doi: 10.1016/j.yebeh.2023.109319. Epub 2023 Jul 3. PMID: 37406558.
- [27] Ricci L, Lanfranchi J-B, Lemetayer F, et al. Qualitative Methods Used to Generate Questionnaire Items: A Systematic Review. *Qual Health Res* 2019;29(1):149–56. <https://doi.org/10.1177/1049732318783186>.
- [28] Schwabe M, Reuber M, Schöndienst M, Gülich E. Listening to people with seizures: how can linguistic analysis help in the differential diagnosis of seizure disorders? *Commun Med* 2008;5(1):59–72. <https://doi.org/10.1558/cam.v5i1.59>. PMID: 19363880.