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COMMENTARY

When seizure counts are not seizures: Measurement error and its implications for epilepsy management and driving policy

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1 | LIMITATIONS OF PATIENT-REPORTED SEIZURE COUNTS

A common clinical scenario illustrates the challenge of measuring seizures in routine care. A patient reports that their seizures have stopped following a medication change and asks whether they can resume driving. The clinician must decide whether seizure control has genuinely improved or whether the apparent change reflects incomplete recognition or reporting of events.

Seizure frequency remains the central metric guiding epilepsy management. Medication adjustments, treatment response, and eligibility for driving commonly depend on seizure counts derived from patient history or seizure diaries. At its core, therefore, much of epilepsy management rests on a measurement problem; the clinical variable guiding treatment and policy decisions is not directly observed but inferred from patient report, and this proxy measure is known to contain substantial and systematic error.

Although clinicians recognize that reported seizure counts are imperfect, clinical decisions and regulatory frameworks nevertheless rely heavily on these reports as the primary measure of seizure occurrence. Both underreporting of true seizures and overreporting of events that are not epileptic seizures occur commonly. When such reporting errors affect the primary variable used for treatment decisions and regulatory policy, the validity of those decisions becomes uncertain.

The implications extend beyond routine clinical management. Because generalized tonic–clonic seizure frequency is one of the strongest predictors of sudden unexpected death in epilepsy, inaccurate seizure counting may also lead to substantial misestimation of individual patient risk.[1]

In practice, clinicians attempt to mitigate these limitations through longitudinal assessment, collateral information, and, where available, epilepsy monitoring unit data. However, these approaches do not directly measure seizure occurrence and may themselves be subject to similar sources of uncertainty. Also, such data are not available for most patients, and even when present represent only a limited sampling of seizure occurrence.

2 | ORIGINS AND LIMITATIONS OF SEIZURE DIARIES

Seizure diaries became the default method for measuring seizure frequency largely because no practical alternative existed. Continuous electroencephalographic monitoring was historically limited to short inpatient recordings. Patient-reported seizure counts therefore represented a pragmatic means of tracking disease course and evaluating treatment response. For convulsive seizures with prominent motor features, particularly when witnessed or captured on home video, event recognition is often more reliable. However, even in this setting, misclassification may arise in the differential diagnosis with psychogenic nonepileptic seizures or convulsive syncope, and frequency estimates may still be affected by unobserved events. The first-in-human UMPIRE study of bilateral subscalp electroencephalographic (EEG) monitoring demonstrated substantial discrepancies between electrographic seizure activity and reported events. Only 31% of patient-reported events corresponded to electrographic seizures, whereas 56% of electrographic seizures were not reported by the patient during monitoring periods.[2] Similar findings have been reported in longer term real-world monitoring. In Viana et al.,[3] 73% of patient-reported events corresponded to electrographic seizures, whereas 52% of electrographic seizures were not reported by the patient; a diary entry was considered a true report if it occurred within ±2 h of an electrographic event.[3] Together, these studies demonstrate substantial and bidirectional inaccuracy in seizure diaries, with both false-positive and unreported electrographic seizures occurring frequently even with prolonged monitoring.

Underreporting of seizures has long been recognized in both inpatient and ambulatory monitoring studies. In a classic epilepsy monitoring unit study, Blum and colleagues reported that patients were unaware of approximately 55% of electrographically recorded seizures, highlighting the limitations of relying on patient recall to quantify seizure frequency.[4]

Subsequent studies confirmed similar findings. Patients frequently fail to report seizures recorded during monitoring,[5] and impaired awareness and postictal amnesia often prevent patients from recognizing seizure events.[6,7] Notably, this results in a particular underreporting of seizure types with impaired consciousness and reactivity, which are particularly relevant to the ability to drive. In one study, the median percentage of focal impaired awareness seizures reported by the patient during monitoring was 0%, a striking figure that highlights the extent to which clinically important seizures may go unrecognized and unreported.

Key points

- Epilepsy management and driving eligibility decisions rely heavily on self-reported seizure counts.
- Video-EEG and ambulatory EEG studies demonstrate substantial underreporting of true seizures and overreporting of nonepileptic events.
- Reported seizure counts therefore represent a mixture of true seizures, missed seizures, and falsely reported events.
- When clinical decisions and policy rely on reported episodes, outcomes may reflect reporting behavior rather than seizure biology.
- Long-term EEG monitoring technologies may provide more reliable measures of seizure burden.

Several mechanisms contribute to underreporting. Seizures may occur during sleep, impair awareness, or occur without witnesses. Even when seizures are observed, recognition may be incomplete. Furthermore, postictal confusion and associated cognitive or behavioral disturbance may impair subsequent recall of the event. Recent work examining eyewitness recognition of seizures has highlighted substantial gaps in observer awareness and interpretation of seizure manifestations.[8]

The complementary problem of overreporting has received increasing attention. In a large ambulatory video-EEG cohort analyzing more than 17 231 reported events, Hannon et al.[9] found that 58% of reported events had no electroclinical correlate, whereas only 27% represented confirmed epileptic seizures. Similar overreporting has also been demonstrated in inpatient video-EEG settings[10] and in the reporting of nonepileptic seizures as epileptic (Figure 1).[11]

These noncorrelated events may represent benign physiological sensations, anxiety-related symptoms, psychiatric phenomena, or symptoms unrelated to epilepsy yet falsely attributed as potential indicators of an ongoing or past seizure. Regardless of their origin, these findings demonstrate that patient-reported "typical events" frequently do not correspond to electrographic seizures.

Importantly, both forms of reporting error occur simultaneously. In the same ambulatory EEG cohort, 64% of electrographic seizures were not reported by the patient, and among reported events, 58% had no electroclinical correlate and only 27% represented confirmed epileptic seizures.[9] Similarly, a highly variable correspondence between electrographic seizures and patient reports was also

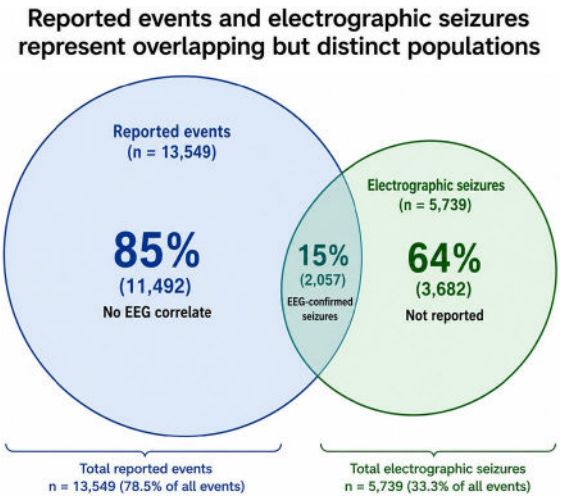

FIGURE 1 Disparity between reported and video-electroencephalographically (EEG) confirmed events. Data were derived from Hannon et al.[9] based on 21 024 events recorded in 3407 ambulatory video-EEG studies. Noncorrelated events accounted for 12 239 events or 58% of all recorded events, whereas epileptic seizures accounted for 5739 events or 27%. Among epileptic seizures, 2057 were reported by patients and 3682 were discovered only on clinical review, meaning that 36% of epileptic seizures were reported and 64% were not reported. These findings demonstrate the coexistence of overreporting and underreporting in seizure diaries.

found when using a different device for ultra-long-term recordings.[12] These data illustrate that reported events both omit a substantial proportion of true seizures and include a large number of nonepileptic events.

Consequently, reported seizure counts represent a mixture of three components:

- True seizures that are reported
- True seizures that are missed
- Nonepileptic events reported as seizures

From an epidemiologic perspective, this represents outcome misclassification, where measurement error in the primary outcome variable can bias estimates of treatment or policy effects.[13] Decisions based solely on reported events may therefore frequently be based on episodes that are not epileptic seizures.

3 | IMPLICATIONS FOR TREATMENT AND TRIALS

When clinicians rely on reported seizure counts, treatment decisions may be influenced by reporting behavior rather than seizure biology. Overreported events may lead to unnecessary medication escalation and increased exposure to adverse effects. Conversely, underreported seizures may lead clinicians to conclude that treatment has been effective when seizures continue to occur.

These measurement limitations also affect interpretation of therapeutic studies. Many epilepsy trials rely on seizure diaries as the primary outcome measure. If the outcome variable itself contains substantial misclassification, treatment effects may be distorted.[14]

4 | CLINICAL AND POLICY IMPLICATIONS

Other areas of medicine have faced similar measurement challenges. In cardiology, continuous rhythm monitoring has replaced symptom diaries for detecting arrhythmias. In sleep medicine, polysomnography and wearable monitoring devices have replaced subjective reports of sleep disruption. Diabetes management has been transformed by continuous glucose monitoring, which revealed substantial discrepancies between perceived symptoms and actual glycemic variability. These transitions illustrate how objective physiological monitoring can fundamentally change disease management once reliable measurement becomes available.

Driving eligibility for people with epilepsy typically depends on seizure-free intervals determined from clinical history. If seizure occurrence is misclassified, driving restrictions may not accurately reflect true risk.

Moreover, studies evaluating the effectiveness of driving restrictions frequently rely on reported seizures as the exposure variable when estimating crash risk. When the exposure variable contains a substantial false-positive component, restrictions may appear more effective than they truly are, because individuals whose seizure risk has been overestimated are excluded from the driving population.

5 | OBJECTIVE MONITORING AND FUTURE DIRECTIONS

Advances in long-term EEG technologies are beginning to allow more direct and continuous measurement of electrographic seizure occurrence in real-world settings. Continuous ambulatory monitoring systems can capture seizures across diverse epilepsy syndromes while revealing substantial discrepancies between electrographic seizures and patient-reported events. It has been shown that the presence of electrographic seizures is associated with very high occurrence rates of clinically manifest seizures as well.[15]

Although objective long-term monitoring offers a promising future direction, it is not yet widely available in routine

practice. In the interim, clinicians should remain aware of the limitations of self-reported seizure counts and actively seek corroborating information, including collateral histories, home video recordings, and careful longitudinal assessment. Explicit discussion with patients and families about the potential for both missed and misattributed events may improve the accuracy of clinical assessment. It is also important to recognize that electrographic and clinical seizure definitions do not always align. Some electrographic seizures may not have an overt clinical correlate, and some clinically apparent events may occur without a clear EEG signature, particularly with limited or focal recording systems. These considerations further complicate the interpretation of both reported and device-detected events. Although important limitations remain, emerging objective recording technologies may ultimately provide a more reliable basis for evaluating treatment response, estimating risk associated with activities such as driving, and advancing seizure forecasting research.[16,17]

6 | CONCLUSIONS

Self-reported seizure counts remain the principal metric guiding epilepsy management and driving eligibility decisions, yet accumulating evidence indicates that these reports frequently misclassify seizure occurrence. In many areas of epilepsy care, we are not measuring seizures directly, but measuring reports of seizures, and the difference between those two quantities may be clinically and socially important.

Although clinicians can partially mitigate these limitations through collateral histories, longitudinal assessment, and video-EEG evaluation, objective long-term monitoring technologies may provide a more reliable basis for assessing seizure burden and informing treatment, research, and policy decisions in the future.

AUTHOR CONTRIBUTIONS

Mark J. Cook conceived the commentary and drafted the manuscript. Mark P. Richardson and Andreas Schulze-Bonhage contributed to conceptual development, critical revision of the manuscript, and interpretation of the literature. All authors approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

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COMMENTARY STATEMENT

The views expressed in this article are solely those of the authors and do not necessarily reflect the official position of *Epilepsia* or the International League Against Epilepsy.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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