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RESEARCH ARTICLE

Reliability and diagnostic accuracy of home video recording in differentiating sleep-related hypermotor epilepsy from disorders of arousal

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Abstract

Objective: This study evaluates the interobserver reliability (IR) and diagnostic accuracy of home video in distinguishing sleep-related hypermotor epilepsy (SHE) from disorders of arousal (DoA) among neurologists with varying levels of expertise. Additionally, it assesses the learning effect in nonexpert raters and extrapolates key diagnostic elements and confounding factors.

Methods: We selected 24 home videos capturing sleep-related events recognized as typical from 12 patients with confirmed SHE and 12 with DoA. During a full-day video session, a panel of 18 experts in epileptology or in sleep medicine and 12 general neurologists and residents were asked to classify each video as "SHE," "DoA," or "unknown," based on the semiology of the event. Baseline IR among all raters and among neurologists before and after experts' discussion was calculated using kappa statistics. The learning effect for nonexperts was assessed using McNemar test by comparing performance before and after training. A thematic analysis of raters' comments was conducted to extrapolate discriminatory features for diagnosis and to identify confounding factors.

Results: The overall agreement was 75%, with a "moderate" IR (kappa = .56). Raw agreement among experts was 79%, with "substantial" IR (kappa = .62). Among general neurologists, raw agreement improved from 70% to 82% after training, corresponding to "moderate" IR (kappa = .47) and "substantial" IR (kappa = .65), respectively. Disagreement was higher for DoA cases. The thematic analysis identified abrupt onset and brief duration of episodes, ambulatory behavior, and irregular breathing as the main confounders.

Federica Provini and Francesca Bisulli contributed equally.

SHE-DOA study group: A separate listing of collaborators is provided under Appendix A.

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Significance: Home video is a reliable tool for distinguishing between SHE and DoA. IR is substantial when assessed by experts and among nonexperts after appropriate educational training. The use of home video as a diagnostic tool is feasible for clinicians with limited access to specialized diagnostic facilities, as well as for sleep and epilepsy specialists, aiding in the diagnostic process and in the follow-up assessment.

KEYWORDS
differential diagnosis, educational training, interobserver reliability, nocturnal frontal lobe epilepsy, sleep disorders

1 | INTRODUCTION

Sleep-related hypermotor epilepsy (SHE) is a distinct epilepsy syndrome characterized by stereotyped motor events of varying duration and complexity with an abrupt onset and offset typically arising from stage 2 of nonrapid eye movement (NREM) sleep. The spectrum of ictal manifestations includes stereotyped arousals and complex hyperkinetic seizures, often accompanied by affective symptoms and prolonged ambulatory behaviors.[1]

Disorders of arousal (DoA) are a group of NREM parasomnias characterized by complex, seemingly purposeful, goal-directed behaviors of increasing intensity and complexity, such as confusional arousals, sleep terrors, and sleepwalking.[2] DoA typically remit spontaneously during childhood, although they may persist or even debut in adulthood. When occurring in adults, DoA are often associated with violent behaviors, making it more challenging to distinguish them from SHE based on clinical history alone.[3]

Long-term video-electroencephalographic monitoring is required for the confirmed diagnosis of SHE, and video-polysomnography (VPSG) is considered the recommended diagnostic reference standard for differentiating SHE from DoA.[1] However, these exams have several limitations in terms of accessibility and cost, being available only at selected tertiary care centers and requiring hospitalization and supervision. Furthermore, their sensitivity is suboptimal, as they may fail to capture infrequent events.[4–6] For NREM parasomnias, the likelihood of catching a typical episode during a single baseline VPSG night is 30%–70%.[7–11] These limitations may be mitigated by the use of home videos, which are widely accessible, easily repeatable, and allow for multiple nights of recording in a familiar environment, thus increasing the likelihood of capturing several DoA events.[6] Episodes recorded at home are also often more complex than those recorded during VPSG, improving the evaluation of the phenotype and severity of parasomnias as shown in a study on the feasibility of home nocturnal infrared video monitoring of NREM sleep parasomnias.[12] Moreover, considering that SHE diagnosis often relies solely on semiological criteria alone, as electroencephalographic findings are uninformative in nearly half of the patients,[13] home video recordings could enhance the sensitivity of the diagnostic process.[14] The use of supporting information, including outpatient smartphone videos recorded by family members, is increasingly recognized as a useful adjunctive tool in the diagnosis of seizure-like events[15,16] and it is also encouraged by the International League Against Epilepsy (ILAE) as part of the diagnostic process for seizures.[17]

Key points

- Home video recordings show substantial interobserver reliability (kappa = .62) among experts in differentiating SHE from DoA.
- Educational training significantly improves diagnostic accuracy among nonexpert neurologists (kappa from .47 to .65).
- Disagreement was higher for DoA cases; abrupt onset, brief duration, ambulatory behavior, and irregular breathing are the main confounders.
- Home videos are a reliable, accessible alternative when specialized diagnostic facilities like video-polysomnography are unavailable.

Furthermore, home video has been proposed as a valuable diagnostic tool to differentiate between SHE and DoA, especially when major events are recorded.[6,18] Video documentation is currently included in the diagnostic criteria for SHE[1] and in the three-step diagnostic algorithm for distinguishing SHE from DoA.[19]

The importance of home video recording for diagnosing sleep-related events has been emphasized in a consensus review by the European Academy of Neurology, the European Sleep Research Society, and the ILAE-Europe.[14] However, interobserver reliability (IR) and diagnostic accuracy of home video recordings remain underexplored

and still represent a research gap.[14] The only study investigating IR based on video in diagnosing sleep-related behavioral events was performed in a tertiary care hospital setting, using video from VPSG recordings of patients with suspected SHE, without incorporating polygraphic tracing.[20] The study demonstrated substantial IR in distinguishing major motor events but a low agreement even among experts for paroxysmal arousals (PAs), which are widely regarded as nondiscriminatory events between DoA and SHE,[21] and are not currently considered in the diagnostic criteria for SHE.[1]

The primary objective of this study was to assess the IR in the diagnosis of SHE versus DoA based on home-recorded videos of sleep-related phenomena among clinicians with varying levels of expertise. We aimed also to assess the learning effect for nonexpert raters and to extrapolate key diagnostic elements and potential confounding factors. Finally, we explored the accuracy of home video recordings in differentiating between SHE and DoA.

2 | MATERIALS AND METHODS

2.1 | Study design

The study was conducted at the IRCCS, Istituto delle Scienze Neurologiche di Bologna in 2023, following approval by our local ethical committee (17176).

The design and reporting of this study adhered to the recommendations of the Guidelines for Reporting Reliability and Agreement Studies.[22]

2.2 | Materials

From the historical databases of our Epilepsy and Sleep Centers, we selected all patients diagnosed with SHE and DoA who had available homemade videos capturing at least one informative event, confirmed to be typical by a witness. In all cases, participants underwent an extensive diagnostic workup that included a detailed clinical history, VPSG, follow-up of evolution and response to treatment over time. In particular, diagnosis of confirmed SHE was made according to the current established diagnostic criteria.[1] In patients with DoA, whose diagnosis is primarily based on clinical criteria[2] and reserved for VPSG only in atypical cases,[3] the diagnosis was confirmed by VPSG recordings of at least one major event. The homemade videos were initially recorded either spontaneously by patients or caregivers or, more frequently, at the request of neurologists at our institute for diagnostic review during outpatient visits. For this reason, the videos were acquired using various devices, including mobile phones or cameras, without a standardized acquisition protocol or setup. Given the challenges in diagnosing minor motor events,[20] we excluded video recordings of episodes with features typical of PAs, focusing instead on the major sleep-related events. When multiple videos of the same patient were available, sleep and epilepsy experts (F.P., P.T., F.Bi.) selected the most informative one in terms of both semiology and technical quality (framing, lighting, and visibility).

2.3 | Procedures

A full-day video session was held on November 18, 2023 at our institute. During this session, the selected home-recorded videos were shown twice, in a random sequence, to specialists and residents with different levels of expertise in epilepsy and sleep medicine, who acted as observers.

Each video was accompanied by a few clinical data regarding the patient's condition at the time of their presentation to our institute (age at onset, age at video recording, frequency of episodes at the time of recording, and description of typical episodes as reported by the patient or a witness during the first visit). The clinical features provided to the raters alongside the home videos are shown in Table S1.

A panel of 18 experts in epileptology or in sleep medicine, and 12 nonexperts among general neurologists and residents in neurology or child neurology, were invited as raters. The level of expertise was defined based on a documented track record of scientific publications in the field of SHE or DoA. Raters were asked to independently classify each video as "SHE," "DoA," or "unknown" based on the semiology of the event and the limited clinical data provided. An anonymous electronic polling system, based on REDCap software,[23] facilitated the voting process and data collection. Observers were also invited to comment on their votes, specifying the semiological features that guided their classification in a free text space.

Subsequently, as part of a training procedure for nonexpert raters, two leading experts—an epileptologist (P.T.) and a sleep specialist (L.N.)—provided a comprehensive overview of the key semiological features of SHE and DoA, drawing on both published literature (including established diagnostic criteria) and their own clinical experience. The session covered several crucial semiological and clinical features that aid in differentiating SHE from DoA, along with additional factors, like episode duration, verbalization, and environmental

triggers. Other members of the expert panel actively contributed to the session, ultimately helping to formulate the final diagnostic statements. The videos of the first session were not shown and discussed directly during the teaching phase.

During a second video session, the nonexpert group was invited to reclassify again each video according to the same diagnostic categories, considering the key clinical features emphasized by the experts.

2.4 | Statistical analysis

We evaluated the overall proportion of agreement and IR (with 95% confidence intervals [CIs]) among all observers and by subgroups in the first video session. After the training session, IR was calculated only for nonexperts. IR was estimated using kappa statistics, the ratio of observed agreement beyond chance to the potential agreement, according to Fleiss's formula for generalized kappa for dichotomous or polychotomous data with more than two raters.[24] Kappa values were interpreted according to conventional categories: .0–.20 (slight agreement), .21–.40 (fair agreement), .41–.60 (moderate agreement), .61–.80 (substantial agreement), and .81–1.00 (almost perfect agreement).[25,26]

The learning effect for nonexperts was assessed by comparing their performance (in terms of correct classification rates), before and after the training procedure, using McNemar exact test.[27]

Diagnostic accuracy was reported as sensitivity and specificity for each observer considering the perspective of the SHE diagnosis in the first video session. Due to the study design, sensitivity for SHE corresponds to specificity for DoA and specificity for SHE corresponds to sensitivity for DoA. Sensitivities and specificities were summarized using the median and interquartile range (IQR) for all observers and by subgroups (experts vs. nonexperts).

2.5 | Thematic analysis

A thematic analysis of the raters' comments on both (1) the episodes that generated the most disagreement and (2) the correctly classified events was performed to identify confounding factors and key diagnostic features. Following a standardized approach, based on data and statements from the existing literature,[1,4,21,28,29] each individual comment, provided as an open response, was analyzed according to the following categories: onset, duration, offset and progression of the episode, type of motor manifestations, complexity of the motor pattern, vocalization, purposeful/semipurposeful behavior and interaction with the environment, emotional content, and facial expression.

3 | RESULTS

We selected 24 home videos from 12 patients diagnosed with confirmed SHE and 12 with DoA. In the group of patients with SHE (male:female = 6:6, mean age at the time of video recording = 24 years, range = 8–53 years), the mean age at seizure onset was 15 years (range = 3 months–36 years). The DoA sample included 12 patients (male:female = 10:2, mean age at the time of video recording = 24 years, range = 3–66 years) with a mean age at onset of 9 years (range = 3–24 years).

The videos selected lasted between 23 and 102 s (mean duration = 48 s).

3.1 | IR and learning effect

The overall proportion of agreement on the final diagnosis was 75%, corresponding to "moderate" IR (kappa = .56, 95% CI = .43–.69). Figure 1 illustrates at a glance the study's procedure and provides details on raw agreement and IR for the different rater groups. Among experts, IR was "substantial," whereas among nonexperts, baseline IR was "moderate." After the training, the nonexpert group's agreement increased from 70% to 82%, reaching "substantial" agreement. The McNemar exact test indicated that this increase was statistically significant ($p < .0001$), demonstrating a clear learning effect.

3.2 | Sources of disagreement, confounding factors, and key features

Disagreement was more frequent for DoA, with a percentage of discordance of >20% in six of 12 (50%) DoA cases compared to one of 12 (8%) SHE cases, as shown in Figure 2A,B. Videos S1 and S2 show an episode with a high degree of agreement from patients with SHE and DoA, respectively, and Video S3 presents one of the DoA cases with the highest disagreement among the raters. Table S2 provides the classification by the 30 raters of the 24 cases, sorted by the percentage of disagreement.

The thematic analysis identified several sources of disagreement, including (1) true confounders—clinical features common to both SHE and DoA, without discriminating value—such as abrupt onset and brief duration of events, ambulatory behavior, and breathing changes; (2)

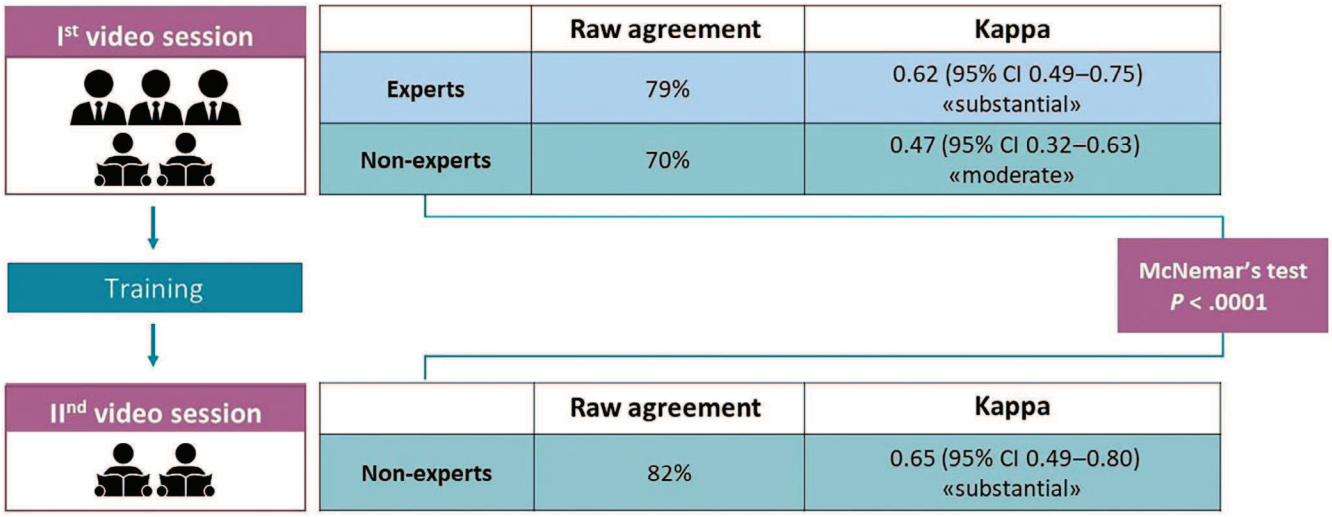

FIGURE 1 Procedures and main results of the study. CI, confidence interval.

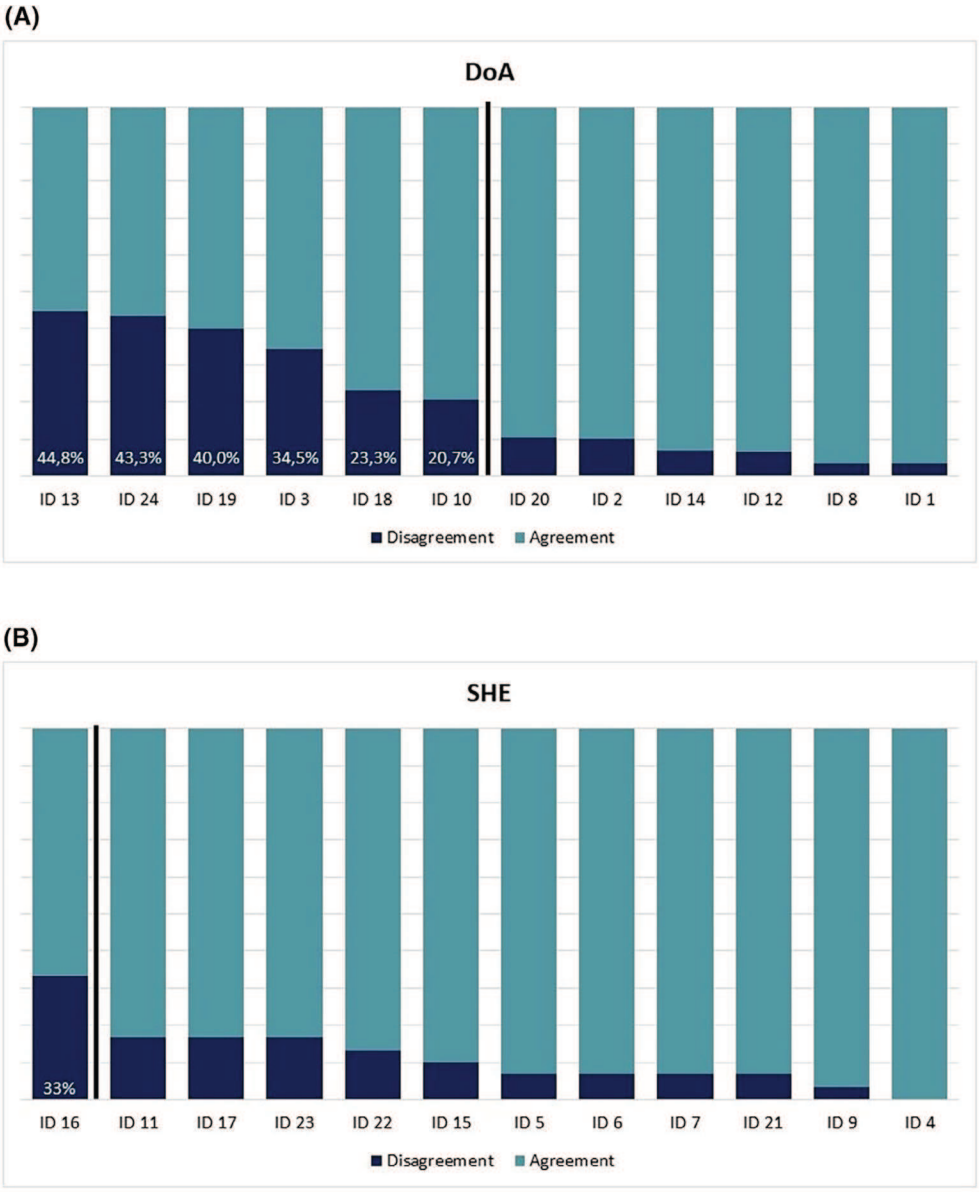

FIGURE 2 (A) Disagreement for disorders of arousal (DoA) cases with highlighted percentage of discordance of >20% (6/12 cases). (B) Disagreement for sleep-related hypermotor epilepsy (SHE) cases with highlighted percentage of discordance of >20% (1/12 cases).

technical limitations, such as recordings that missed the onset of the event; and (3) semiological elements misinterpreted by raters, leading to incorrect classifications (e.g., nose wiping).

Key clinical elements of SHE included abrupt offset, hyperkinetic manifestations (e.g., body rocking), asymmetric tonic–dystonic posturing, unintelligible vocalizations or guttural sounds, and facial grimacing. Brief duration and constant progression of the event were suggestive of SHE, whereas waxing and waning were suggestive of DoA. Key features of DoA included prolonged duration of the event (>2 min), interaction with the environment, slow and purposeful movements with explorative behavior, and inconsolable crying or sobbing (Figure 3).

3.3 | Diagnostic accuracy

In the first video session, considering the perspective of diagnosing SHE, the median sensitivity of all raters was 91.7% (IQR = 83.3%–100%) and the median specificity was 75.0% (IQR = 75.0%–91.7%). Among experts, the median sensitivity was 95.8% (IQR = 83.3%–100%) and the median specificity 79.1% (IQR = 75.0%–100%). In nonexpert group, the median sensitivity was 91.7% (IQR = 75.0%–100%) and the median specificity was 75.0% (IQR = 66.7%–83.3%).

4 | DISCUSSION

This study evaluates the IR among neurologists with varying levels of expertise for diagnosing behavioral sleep-related events based on home video recordings. Our results show that IR was "substantial" among experts in distinguishing between SHE and DoA. Notably, this reliability improved significantly among nonexperts, reaching a "substantial" level after an educational training session.

In general, sources of variance in agreement can be categorized into criterion, information, and interpretation variances.[30] Criterion variance refers to variability in the diagnostic rules applied, whereas information variance pertains to differences in the collection of clinical data necessary for diagnosis. In this study, information variance was eliminated, as all clinicians independently reviewed the same video recordings of the same patient, and criterion variance was theoretically minimized by relying on the definitions of SHE and DoA[1,2] and further reduced in the group of nonexperts after the education session. The remaining source of variance, interpretation variance, arose from differences in how raters interpreted the recorded phenomena and applied the diagnostic criteria. In our study, disagreement was more frequent in DoA. Thematic analysis identified abrupt onset and brief duration of the events, changes in breathing, and ambulatory behavior as main confounders. Brief events with

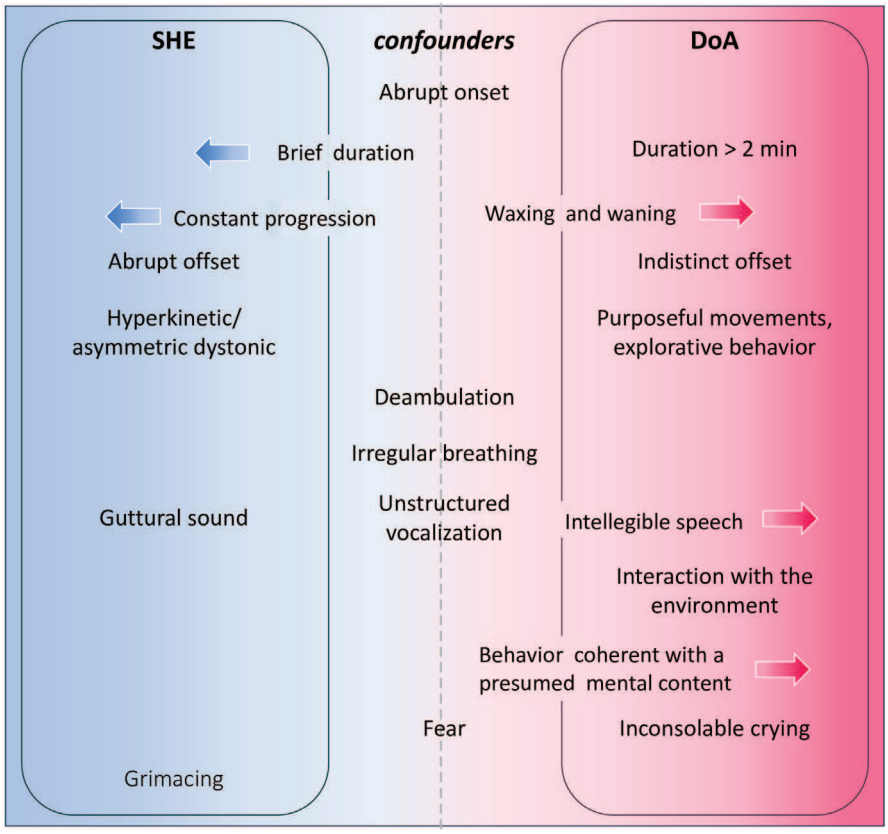

FIGURE 3 Confounding factors and clinical features strongly suggestive of sleep-related hypermotor epilepsy (SHE) or disorders of arousal (DoA) diagnosis, as emerged from the discussion with experts and video analysis (single event).

sudden onset led some raters to incorrectly classify DoA episodes as SHE. A short duration is usually suggestive for SHE, whereas a duration longer than 2 min is one of the diagnostic elements for DoA. However, the spectrum of DoA also includes short arousal with rising movements, and it has been recognized that abrupt onset alone has limited discriminating value, particularly in adults with DoA (Video S3).[3] Another confounding factor was the presence of irregular breathing and respiratory difficulties with choking, which can occur in insulo-opercular seizures but can also be an expression of arousal disorders.[31] In insulo-opercular seizures, the sensation is often described as "pressure on the salivary glands" or "strangulation" and may be accompanied by retrosternal or abdominal heaviness, shortness of breath, facial or diffuse paresthesias, or various somatomotor manifestations.[32,33] In contrast, in DoA, this sensation is typically associated with hallucinations of swallowing an object obstructing the upper airways, followed by attempts to clear the obstruction.[31] Deambulation emerged as another confounder, as already highlighted by the existing literature.[21] Ambulatory behavior per se is not a distinguishing feature, being possibly the expression of the same inborn fixed action pattern generators,[34] and further additional characteristics must be considered.[21,28,35] Epileptic wandering is often accompanied by automatisms, dystonic postures, or agitated motor behaviors with abrupt changes in direction, jumping, screaming, and ambulation generally confined to the bedroom. In contrast, sleepwalking in individuals with DoA typically exhibits more "physiological" movement patterns, semipurposeful behavior, and interaction with the environment, with ambulation not only confined to the bedroom.[21,36,37] Additionally, DoA episodes typically have an indistinct offset, whereas patients with epileptic wandering generally exhibit the opposite behavior.[21,38,39]

Sources of disagreement due to interpretation variance were also seen in misclassification of nose wiping, which was incorrectly categorized by some raters as an ictal sign, even when occurring at the onset of the event. Nose wiping has been recognized as a postictal ipsilateral sign in up to 60% of patients with temporal seizures and 33% of patients with extratemporal lobe seizures.[40–43] However, scratching or rubbing the nose is also a common physiological movement during spontaneous arousals,[44] even more frequent in those individuals with disrupted arousal mechanisms, whether due to DoA[21,45] or epilepsy.[46,47]

Consistent with existing literature,[1,3–5,21,28,29] the main diagnostic features for SHE identified by the experts' statements and through video analysis were abrupt offset, hyperkinetic pattern (Video S1) or asymmetric dystonic posturing with possible facial grimacing and guttural sound, and the absence of integrated or purposeful movements, which were instead strongly suggestive for DoA (Video S2). Similarly, complex behavior that appears to enact a mental content or fragments of a mental scene, perhaps associated with coherent verbalization, would point to a diagnosis of DoA (Video S3). However, it has been recognized that integrated behaviors (such as distal stereotypies, speech production, and utilization behaviors) and gestural behaviors with high emotional content can also occur in seizures arising from frontopolar and orbitofrontal cortex and temporal lobe.[48] Figure 3 summarizes the key features for both SHE and DoA and confounders, as emerged from video analysis.

We explored also the diagnostic accuracy of the home video recordings. Despite the limitations due to the design required to explore IR—specifically, the artificial exact matching of the number of SHE and DoA cases, which could distort realistic pretest probabilities—our findings suggest that in experienced hands, home video recordings can serve as a valuable diagnostic tool with high specificity for DoA making it possible to avoid the use of VPSG in many typical DoA cases (i.e., those without the confounding features noted above). In a real clinical setting, the diagnostic accuracy could be further improved by considering additional clinical history, such as age at onset, family history, clinical course over the years, timing of episodes during sleep, number of events per night,[49] and stereotypy of the events. We chose not to include stereotypy in the clinical history provided to participants, as it might have biased raters toward a diagnosis of SHE. For the same reason, and to replicate a real-life clinical setting in which only a single video is often available, it was decided to show only one home video for each case. However, the accuracy of the tool could potentially improve if clinicians had access to additional home videos proving stereotypy of the events.

Three potential diagnostic pitfalls of this study should be acknowledged. First is the small number of patients, which may limit the generalizability of the findings. Second is a potential selection bias of patients' videos and raters, which might not be fully representative of the broader population of patients and clinicians. Finally, without a control group of nonexpert observers, the improvement of nonexperts in IR cannot be definitively attributed solely to the educational training, as it could be due to a general learning effect resulting from the video review during the second video session. Further studies analyzing different datasets of home videos are needed to confirm the generalizability of these findings.

Despite its limitations, our study demonstrates that distinguishing between SHE and DoA using home video is feasible, with substantial IR among experts. It also highlights the potential of targeted educational interventions to improve diagnostic skills, enabling even

clinicians without extensive experience in sleep medicine or epileptology to accurately diagnose sleep-related behavioral events, using home videos. In this way, the accessibility and affordability of home video recordings become a practical tool for clinicians with limited resources or limited access to specialized diagnostic facilities, while still ensuring accurate diagnoses for patients.[50] Furthermore, home video can serve as a valuable tool for follow-up assessments, enabling accurate monitoring of episode frequency and therapy effectiveness. This makes them a useful resource for sleep and epilepsy specialists as well.

Considering the high frequency of DoA and the issues of differential diagnosis with SHE in certain cases, the training could be also included in the educational training of neurologists. Additionally, to optimize the quality of home video and increase the diagnostic yield, we could even consider providing to patients' relatives indications on how video should be recorded in a home setting (e.g., type of device to be preferred, inclusion of audio, use of infrared in case of recording in the dark). Other than having organizational economic benefits, this may improve clinical practice and patient management, avoiding incorrect therapies, and the potential social implications of misdiagnosis.

5 | CONCLUSIONS

Home video recordings are a reliable tool for distinguishing between SHE and DoA, with substantial IR among experts. The median sensitivity was 95.8%, and the median specificity 79.1%. Abrupt onset and brief duration of events, ambulatory behavior, and breathing changes represent the main confounders for differentiating DoA from SHE.

After appropriate training, nonexperts reached a substantial IR, showing that educational interventions can significantly improve diagnostic accuracy, potentially facilitating initial accurate diagnosis even when specialized diagnostic facilities are unavailable.

AUTHOR CONTRIBUTIONS

Laura Licchetta: Drafting/revision of the manuscript for content, including medical writing for content; study concept or design. **Greta Mainieri:** Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data. **Giuseppe Loddo:** Major role in the acquisition of data; analysis or interpretation of data. **Flavia Baccari:** Analysis or interpretation of data. **Giulia Bruschi:** Drafting/revision of the manuscript for content, including medical writing for content; major role in the acquisition of data. **Lisa Taruffi:** Major role in the acquisition of data. **Lino Nobili:** Drafting/revision of the manuscript for content, including medical writing for content. **Paolo Tinuper:** Drafting/revision of the manuscript for content, including medical writing for content. **Luca Vignatelli:** Study concept or design; analysis or interpretation of data. **Federica Provini:** Drafting/revision of the manuscript for content, including medical writing for content. **Francesca Bisulli:** Major role in the acquisition of data; study concept or design.

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CONFLICT OF INTEREST STATEMENT

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

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

PATIENT CONSENT STATEMENT

All participants provided written informed consent for the collection and use of their clinical data and video recordings for research purposes. Specific additional consent was obtained from patients whose videos are included as supplementary materials in this publication.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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APPENDIX A

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