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Home Recording And Video Selection: Their use In A Low-Resource Setting For Epilepsy Diagnosis

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Authors' contributions

This work was carried out in collaboration between both authors. Both authors were involved in conceptualization, data collection, analysis and manuscript writing. Both authors read and approved the final manuscript.

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ABSTRACT

Objective: In management of epilepsy, identification of an epileptic seizure, classification, epilepsy syndromes, and management decisions relies heavily on seizure semiology. However, since most seizures are not witnessed, obtained semiology has its limitations. This study aimed to determine how many patients could successfully submit a home recording of a seizure event and if adapted video compilations would improve epilepsy diagnosis and classification in a low resource setting.
Methods: A prospective cross-sectional study carried out at a neurology clinic in a teaching hospital in a low-resource setting. Sixty-seven randomly selected patients with recurrent unprovoked seizures and an informant who had regular observed the seizures and had access to video recording facilities were enrolled. Participants were required to fill an interviewer-administered questionnaire, select from a pre-designed video compilation what best described seizure witnessed, then encouraged on acquisition of video recordings at home. In the absence of video electroencephalography, information obtained was compared with a pre-defined algorithm which combined clinical history, physical examination, EEG results and neuro-images. Accuracy and reliability was calculated for different semiological signs and seizure classification.
Results: Sixty seven patients were recruited comprising of 30 females and 37 male patients. Only eight (12%) participants returned with an adequate home recording of seizure episode. Incorporating video selection with questionnaire obtained description improved accuracy for

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generalized seizure (0.85 vs 0.79) and focal onset seizure (0.84 vs 0.73). Test-retest reliability on video selections by informants showed kappa coefficients ranging from 0.88 – 1.000.
Significance: Home video recording may not be as practical in our environment depending on the setting as adjustments may be required to make it routine. However, selecting videos from pre-selected video compilation may be a viable alternative to improve accuracy.

Keywords: Seizure diagnosis; accuracy; video compilation; reliability; seizure classification.

1. INTRODUCTION

Recent estimates suggest that 65 million people are affected with epilepsy worldwide, with about 80% living in resource-poor settings and as many as 90% receive no form of treatment [1]. In sub-Saharan Africa (SSA), prevalence of epilepsy is estimated to be about twice that of other continents.[2] Birth trauma, poor antenatal care, brain infections, parasitic infections, vascular events and traumatic brain injury have been identified as major etiologies in this region [2]. Therefore, with the persistence of poor health services, negative cultural beliefs, political instability, stigmatization, economic misfortune and poverty, it can be assumed that epilepsy will remain a burden in SSA in the immediate future.

With as many as 20% of patients seen in specialist epilepsy centers and 50% of patients with intractable seizures eventually diagnosed with psychogenic non-epileptic seizures [3], the first task for the physician is to decide if the ictus is truly an epileptic seizure, or some other paroxysmal neurological disorders. However, the physicians do not commonly have the opportunity to observe the seizure(s) [4]. Therefore, emphasis should be placed on the circumstances under which the seizure occurred and seizure semiology [5] as failure to obtain adequate history is a common reason for misdiagnosis [6]. This could prove costly as the effect of misdiagnosis on the individual, caregivers and community range from stigma, negative cost implication and adverse drug reaction in a false positive diagnosis to premature mortality [7], mood disorders [8], cognitive impairment [9], personality change [10], and poor quality of life [11] in a false negative diagnosis.

Seizure semiology is also key to seizure classification, determining epilepsy syndromes and by extension treatment decision [12]. It is therefore not surprising that the ILAE (International League Against Epilepsy Task Force on ICD codes on epilepsy) recommends seizure semiology in Axis 1 in its 5-axis diagnosis of epilepsy [5] as details like version, unilateral clonic movements, dystonic posturing, asymmetric ending and grimacing have been shown to be key for lateralization [13,14] with positive predictive value as high as 100% [14]. Semiology also helps in accurate localization depending on epilepsy onset and may also suggest a specific diagnosis like autoimmune epilepsy in the presence of facio-brachial dystonic seizures [15,16]. Localization seems best in patients with temporal lobe lesions, lateralization highest in parietal lobe lesions [17] and correct information on seizure-onset zone in over 80% of patients with medical refractory frontal lobe epilepsy [13].

However, seizure description is associated with various forms of bias which may be witness-based, clinician-based or the way the clinical history was acquired [18-23]. Studies have focused on various ways to improve epilepsy description and diagnosis with the use of questionnaires [24], scoring systems [25,26], smartphone app [27], wearable electromyography devices [28], contact sensors [29], smartphones based video recordings [30] and home recorded videos [23,31]. However, do informants – more often family members – have emotional state to notice useful details or even start a video recording? Also, in low-income setting there may be limitations of these modalities due to cultural differences, significant gap in smartphones use [32,33], limitation in human resource, and poor healthcare financing to fund hospital-based diagnosis. [34], his study aimed to determine how many patients could successfully submit a home recording of a seizure event and if an adaption of video recording would improve epilepsy diagnosis and classification in a low resource setting.

2. METHODOLOGY

2.1 Study Design

This was a prospective study carried out over a year period at the Neurology out-patient, University College Hospital, Ibadan. The study population included patients aged at least 16 years diagnosed to have recurrent unprovoked seizures or epilepsy and an informant (any person who had witnessed the clinical

manifestation of the seizure at least thrice). Participants were excluded if; more than one seizure type was witnessed, they were unconscious at the time of recruitment, seizures occurred only at night, they resided alone, suffered from severe neurological impairment e.g. mental retardation, hearing impairment etc. or seizures were well-controlled. A patient was deemed to have well-controlled epilepsy if seizure frequency was less than once in a month. Those with well-controlled epilepsy were excluded to limit measurement bias as informants were less likely to remember details of seizure semiology.

2.2 Variables and their Measurements

In the absence of a video-EEG or functional imaging at the time of the study, the criterion or reference standard for diagnosis and classification in this study was based on a predefined algorithm which combined clinical history, physical examination, EEG results based on standard criteria [35,36], and neuro-images where available. See supplementary file. At least two trained neurologists reviewed these information separately and determined seizure classification according to the 2017 ILAE criteria [37].

The study used pre-selected video compilations of various seizure manifestations edited based on the current ILAE classification with no oral or written instructions. Therefore, education and language were not issues as the video was interviewer-administered. At clinic visits, the study participants studied the video compilation and selected which manifestation(s) occurred during the patient's ictal episode. In a few situations where participants submitted video recordings that contained full ictal episode, the home recording was compared with video selections to determine reliability of video selection. An interviewer-based questionnaire modified from the questionnaire designed and validated by Reutens et al. [24] was used to obtain seizure description.

The steps for carrying out the EEG procedure included; explaining procedure to the patients, scalp preparation using alcohol and a hair brush, application of disposable EEG cap – electrodes on the caps positioned to the International 10 – 20 method, application of conductive gel, skin preparation of facial and mastoid areas, application of facials and mastoid channels, connection of electrodes to differential amplifier, commencement of procedure with recordings in eye closure, hyperventilation and photic stimulation. To limit bias, two EEG trained physicians interpreted the EEG result.

Since no specific symptom or sign allowed for the diagnosis of non-epileptic seizures to be made with absolute certainty [38], the screening tool designed by Ali et al. was used in this study to assist in distinguishing non-epileptic from epileptic seizures [39]. Using the 2013 ILAE Non-epileptic Seizure Task Force recommendation, the unavailability of a video-EEG and ambulatory EEG for this study implied that the diagnostic level of certainty for psychogenic non-epileptic seizures (PNES) in this study was at best possible or probable [40].

2.3 Data Collection Procedure

Participants who gave permission were recruited into the study after review by the physicians – who were unaware of the study details. The patients and informants were then required to fill an interviewer-administered questionnaire. Subsequently each participant was required to identify video clips from the pre-selected video compilation that best described the patient's seizure type. The investigator then trained and encouraged all participants on home acquisition of video recordings of seizure episodes with video enabled mobile phones. The participants were contacted regularly to ascertain if any video recordings was available. Participants were required to return 2–4 weeks later to re-fill previously administered questionnaire and re-select video clips that best described seizure manifestation after which they completed the study. Relevant details of all recruited participants are available in the supplementary file.

Sixty seven patients with a median age of 24 years (range: 16 – 76 years) and their informants, median age of 47 years (range: 18 – 76 years) were recruited. The patients comprised of 30 (45%) females and 37 (55%) male patients. 49 (73%) of the patients were single while 18 (27%) were married. The average years of education of participants was 14.0 (SD=2.6) years. Of the recruited patients, 53 (79%) returned for second assessment. However, those who did not return for a repeat assessment and those who did had similar socio-demographic and clinical characteristics. (Table 1) The median age of seizure onset was 17 (IQR: 10–27) years, and median age of diagnosis was 20 (IQR: 13–31) years. 14 (21%) participants had a positive family history of epilepsy while 51 (76%) were on

AEDs, with carbamazepine being the most prevalent. Of the participants, 12 (18%) admitted to learning difficulty. Forty six (77%) patients had an electro-encephalogram (EEG) performed to assist seizure diagnosis, classification and possible localization of the epileptogenic zone. Funding, machine breakdown and logistics were reasons why all participants could not have EEG done.

2.4 Data Analysis

The data collected from participants was imported into Microsoft Excel database for data cleaning, transferred to STATA statistical software package (Stata® release 12, 2011) for analysis. Description of auras was based on the ILAE 2017 criteria [37] and into six main symptoms – somatosensory, auditory, visual, psychic, abdominal, and olfactory – based on the CEC classification [41,42]. Versive activity was defined as an unquestionably forced and involuntary sustained unnatural positioning of the head and eyes [43]. Sensitivity, specificity, and diagnostic accuracy of seizure classification was calculated.

For inter-method and test-retest reliability, percent concordance (calculated as proportion of similar responses between methods divided by total responses) between descriptions obtained was calculated. To account for chance agreement, Cohen's kappa was computed. Kappa values were interpreted according to the conventional groups: no agreement (k≤0), slight (0.01–0.2), fair (0.21–0.4), moderate (0.41–0.6), substantial (0.61–0.8) and almost perfect agreement (>0.8) [44]. Additionally, an exact McNemar's test was carried out to determine similarity in the proportion of variables between different methods and time [44]. A p-value less than 0.05 was deemed to be statistically significant. Reasons for failing to return with a video recording were divided into five main domains: seizure characteristics (e.g. seizures duration too short, non-motor seizure manifestation), logistics-based reasons (e.g. I forgot, there was no electricity, my phone was not with me, I did not know when it started), witness characteristics (e.g. it is too scary, I am not calm enough to record), social-related issues (e.g. my beliefs doesn't permit it), and undecided domains.

Table 1. Characteristics of Persons with Epilepsy

	Two Visits N=53	One Visit N=14	TOTAL N=67	p-value
[1]Age in years, Median (Range)	24 (13 – 70)	23 (18 – 76)	24 (13 – 76)	0.859
[3]Gender, N (%)				
Female	24 (45.3)	6 (42.9)	30 (44.8)	0.571
Male	29 (54.7)	8 (57.1)	37 (55.2)	
[2]Marital Status, N (%)				
Single	39 (73.6)	10 (71.4)	49 (73.1)	1.000
Married	14 (26.4)	4 (28.6)	18 (26.9)	
[2]Religion, N (%)				
Christian	37 (69.8)	10 (71.4)	47 (70.1)	1.000
Islam	16 (30.2)	4 (28.6)	20 (29.9)	
[2]Tribe, N (%)				
Yoruba	45 (84.9)	13 (92.9)	58 (86.6)	0.811
Others	8 (15.1)	1 (7.1)	9 (13.4)	
[1]Age at onset in years, Median (Range)	18 (1 – 70)	17 (1 – 76)	18 (1 – 76)	0.774
[1]Age at diagnosis, Median (Range)	20 (2 – 70)	22 (1 – 76)	21 (2 – 76)	0.898
[2]Positive Family History, N (%)	9 (17.0)	5 (35.7)	13 (21.7)	0.125
[2]On AEDs, N (%)	39 (73.6)	12 (85.7)	46 (76.7)	0.490
Carbamazepine	25 (65.8)	7 (58.3)	28 (62.2)	
Others	13 (34.2)	5 (41.7)	17 (37.8)	
[2]Developmental Delay, N (%)	2 (3.8)	1 (7.1)	2 (3.3)	0.511
[2]Learning Difficulty, N (%)	10 (18.9)	2 (14.3)	10 (16.7)	1.000

[1]Wilcoxon Rank Sum Test Used
[2]Fisher's Exact Test Used
[3]Pearson Chi Square Test Used
**AED: anti-epileptic drugs. Others include; Levetiracetam (4), Phenobarbitone (6), Phenytoin (3), Valproate (3), Pregabalin (1)*
[1]Wilcoxon Signed Rank Sum Test Used
[2]Fisher's Exact Test Used

3. RESULTS

Only eight (12%) participants returned with an adequate home recording of seizure episode. Reasons given for failing to return where divided into five main domains. Most participants, 25 (37.2%) were uncertain as to why they couldn't return with an adequate recording, 22 (32.8%) participants had logistics-based reasons, and 6 (9.0) were unable to return due to witness and seizure characteristics. Of the eight participants who returned with home recordings, 6 (75%) were females and 2 (25%) were males and their ages ranged from 14 – 32 years.

Based on the reference criteria, 56 (84%) were deemed to have focal onset seizures with 49 (73%) having secondary generalization. 8 (12%) participants had primary generalized, 3 (4%) were deemed to have PNES. Using questionnaire obtained history, 40 (60%) had focal onset seizures, 14 (21%) were in keeping with generalized onset seizures and 13 (19%) could not be classified. Using video selection with details of aura and awareness, 45 (67%) had focal onset seizures, 18 (27%) had generalized onset seizures and 4 (6%) were deemed to have PNES.

For questionnaire obtained history, sensitivity for generalized onset seizure was 0.50, with specificity of 0.83, and accuracy of 0.79. Sensitivity for focal onset seizure was 0.70, specificity of 0.91, and an accuracy of 0.73. With regards to video assisted diagnosis, there was a higher sensitivity of 1.00 for generalized onset seizure, a specificity of 0.83, and an accuracy of 0.85. Sensitivity for focal onset seizure was 0.80, specificity of 1.00, and an accuracy of 0.84. Table 3 shows the predictive values.

Test-retest reliability was carried out on video selections by participants. The percent concordance was almost perfect (>80%) for all semiology assessed with automatisms having the least percent concordance (86.0%). Kappa coefficients ranged between 0.88 – 1.000 except for automatisms where kappa coefficients was 0.45. McNemar test carried out showed no difference in proportions between both selections. For inter-method reliability between questionnaire details and video selections, percent concordance ranged from 83.6% to 92.4%. However, kappa estimates ranged from 0.56 – 0.78. McNemar's test determined that there was a significant difference in proportion of clonus, p: 0.020 identified using the questionnaire as opposed to video selection (80.3% v 68.8% respectively). Comparison of video selections and home-based video recordings are shown in Chart 1.

Table 2. Seizure classification from various methods

	Reference	Questionnaire	Video Assisted
Focal onset, N (%)	7 (10.5)	5 (7.5)	5 (7.5)
Focal to Bilateral, N (%)	49 (73.1)	35 (52.2)	40 (59.7)
Generalized, N (%)	8 (11.9)	14 (20.9)	18 (26.9)
*PNES, N (%)	3 (4.5)	-	4 (6.0)
Unclassified, N (%)	-	13 (19.4)	-

**PNES: Psychogenic Non-epileptic Seizure*

Table 3. Summary of accuracy of routine and questionnaire obtained history

	Accuracy	Sensitivity	Specificity
Focal Onset			
[1]Video-Assisted	0.84	0.80	1.00
[2]Questionnaire	0.73	0.70	0.91
Generalized Onset			
[3]Video Assisted	0.85	1.00	0.83
[4]Questionnaire	0.79	0.50	0.83

[1]p-value: 0.002. PPV: 1.00. NPV: 0.50. [2]p-value <0.001. PPV: 0.98. NPV: 0.37
[3]p-value: 0.002. PPV: 0.44. NPV: 1.00. [4]p-value <0.001. PPV: 0.29. NPV: 0.92
Algorithm Used for Classification Standard in Appendix VII

Table 4. Comparing routine and questionnaire history to reference

	Questionnaire		Repeat Selection	
	% Concordance	Kappa	% Concordance	Kappa
Blank spell	83.6	0.56	98.2	0.95
Clonus	[2]85.1	[2]0.64	98.2	0.96
Tonic Posturing	89.6	0.76	100.0	1.00
Myoclonus	83.3	0.60	94.6	0.88
Version	89.3	0.66	100.0	1.00
Automatisms	92.4	0.78	86.0	0.45

[2]*McNemar p-value: 0.022*

Chart 1. Comparison between video selection and home recording

Myoclonus	●	●	●	●	×	●	×	●
Version	●	●	●	×	●	●	●	●
Clonus	●	●	●	●	●	●	×	●
Dystonic Posturing	●	●	●	●	●	●	●	●
Automatism	●	●	●	●	●	●	●	●
Blank Spell	●	●	●	●	●	●	●	●
	***1**	**2**	**3**	**4**	***5**	**6**	***7**	**8**

*●: Selection similar to home recording × :selection different to home recording *final diagnosis was PNES*

4. DISCUSSION

As reported by a number of authors, home recording can go a long way to supplement and improve epilepsy diagnosis and classification [23,30,45]. However, results here suggest that this may not be as practical depending on the setting, probably due to beliefs, cultural and personality related factors. The low number of participants who could return with adequate home video recordings seen in this study may imply that some adjustments to be made before that becomes common place. Improving knowledge and experience of care-givers may also help increase the rate of successful home video recordings as panic is expected to reduce. The number of participants who return video recordings is likely to increase if mobile phones that can easily take good quality videos are issued to patients (funding could be obtained from phone companies, pharmaceutical agencies etc.

In the meantime, selecting videos from pre-selected video compilation may be a viable alternative that could be introduced in low resource settings. During routine clinical reviews, relevant motor details with treatment implications e.g. dystonic posturing, automatisms,[20,29] version, myoclonus, and other post-ictal details are not routinely documented [18,20]. There is a tendency for the clinician to focus on presence or absence of tonic and clonic manifestations despite other semiological features with higher accuracy [23], and predictive value [20,28]. However, using video clips imply that the clinician is more likely to consider these important semiological details. It should also be noted that using video selections, four participants were selected as having PNES and the singular patient who whose seizure wrongly classified as PNES was later diagnosed with a mixture of PNES and epileptic seizures. This shows video selections may play a role in diagnosis too.

From this study, the contrast between the different methods of obtaining seizure semiology was due to random errors. This therefore shows that “outside noise” plays a significant role in the accuracy of seizure description. Informants may be over-dramatic in their descriptions, physicians’ interpretation of obtained descriptions can be subjective, or the environment in which history is being obtained amidst other factors come to play. It may however be possible that precision is better on video selection. From experience during data collection, informants tended to mistake absent mindedness for blank spells and physicians also confused myoclonic jerks and tremors for clonic seizures. The use of video recording or at least video selection should help clarify these confusions and also help with the choice of appropriate AED selection. As a number of patients with myoclonic seizures were prescribed carbamazepine erroneously. Alternatively, repeated assessment could be carried out to improve semiology accuracy since

errors are random. However, how practical is that in a low resource setting?.

It should be noted that automatism from the questionnaire-based history had relatively low agreement with video selections. This is not surprising as Rugg-Gunn et al. noted that informants did not usually recall limb automatism, [46] and also, automatism existed in various manifestations making it hard to identify even on video selections. This may be one of the main limitations of video selections as further details may be required to clarify automatism in seizure patients. One may argue that a referral bias may come into play with regards to findings of this study since participants with multiple seizure types, severe epilepsy, and those with associated cognitive impairment were unlikely to make accurate video selections and are likely the ones who require more details for management. However, since most of the information was obtained from an informant, this helps alleviate the referral bias effect.

In classifying seizures, accuracy from video selection leaves room for improvement. It is however an upgrade on questionnaire based history which has been shown to be an improvement on routine seizure history. Studies has shown higher accuracy when video recordings are used as opposed to routine clinical descriptions, [31] however the use of video selection has not been objectively tested. While routine seizure seem to bias towards generalized onset seizure, [19,20,23] using video selections seem to reduce that bias and come in handy with regards to assisting in seizure classification. Suboptimal information obtained during seizure description has been shown to be a factor in unreliable seizure classification [47]. An issue that can easily be sorted with a pre-selected video clips for clinic based selections. Diagnostic review bias is however acknowledged as the final classification is still based on the aura description from the index method being assessed.

Improving the content quantity and quality of semiology details is the objective of the physician. This has led researchers to the use of questionnaires [24,48] video devices [23,31,49], repeated viewing of event [50], and specialty diagnosis [50] are various options explored. Cultural acceptable and relatable videos selection may be a pragmatic option for the under-resourced communities. An option that can be explored by epilepsy organizations interested in improving diagnosis and treatment in these areas. Our findings are expected to help improve seizure and epilepsy diagnosis despite existing challenges. The author are of the opinion that the distribution of a compilation of relevant semiological manifestations coupled with re-training should improve epilepsy diagnosis and by extension reduce treatment gap in low resource setting. While physicians and other health care providers should encourage caregivers to bring along seizure recordings captured on their smart phones, this may require counselling of care-givers to remove the fears associated with seizures and the cultural bias. The role of certain interventions e.g. education in ensuring increased home video recordings seems like a worthwhile study. The use of video-enabled mobile phones would restrict video acquisition in very poor areas are not readily available. To this end, funding must be found for mobile phones that have video facilities to enable more patients to use this.

5. CONCLUSION

In conclusion, home video recording for epilepsy diagnosis and classification may not be practical in all low resource settings as it is dependent on myriads of factors. Some adjustments may be required before this becomes common place in clinical practice. In the meantime, selecting videos from pre-selected video compilation may be a viable alternative that could be introduced in low resource settings.

6. STUDY LIMITATION

A few limitations were encountered in the study with the lack of a better reference standard being the notable one. The inability to correlate seizure details and video recordings with intra-cerebral activity adds a limitation to the conclusion that can be made. While VEEG, ictal EEG or functional imaging are preferred options, it is not readily available in our resource limited. It is however felt that the algorithm used would closely approaches the ideal reference standard. Also, the fact that the few video selections were comparable to real life scenarios seen adds to the validity of the finding. The gross low number of participants that returned with is a worry too. While the study was aimed to determine the proportion of participants that could return with home video recording, the number is too few to make generalizable inference. A repeat study in a control situation that addresses limiting factors to home recording may be carried out.

Interventions that can ensure this include; Authors should give some suggestions on how the percentage can be improved; 2) the fact that the informants did not have the phone with them, were “shocked by the event and could not react” and the lighting were low etc. There can be remedies suggested for this; (e.g., mobile phones sponsored, training of informants to desensitize them and use of solar lighting to give more illumination especially in a country where sun energy is available. Lastly, the inability to carry out EEG for all participants may be a source of worry. However, half of the participants who did not have EEG done had neuro-imaging which was useful in classification and most of the remaining either had clear seizure semiology or home recordings submitted for seizure classification.

CONSENT

Only patients and informants who gave consent were included in the study and preserved by author (s).

ETHICAL APPROVAL

The Joint University of Ibadan/University College Hospital Institutional Review Board provided ethical approval for the study. “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.”

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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