



UNIVERSITY OF CAPE TOWN
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**THE UTILITY OF MOBILE TELEPHONE RECORDED VIDEOS AS ADJUNCTS TO
THE DIAGNOSIS OF SEIZURES AND PAROXYSMAL EVENTS IN CHILDREN
WITH SUSPECTED EPILEPTIC SEIZURES**

By

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A Dissertation Proposal submitted in part fulfilment of the requirements for the
Degree of Master of
Philosophy
In Paediatric Neurology
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Cape Town, South Africa

2021

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SYNOPSIS

Background:

Epilepsy is largely a clinical diagnosis based on the patient's history. Neurological examination, interictal electroencephalogram and neuroimaging can all be normal in patients with epilepsy. Making the correct diagnosis in patients with suspected epilepsy is often difficult. Studies show that some 30% of patients are incorrectly diagnosed as suffering from epilepsy. Further, the diagnosis and treatment of epilepsy is often delayed. In the majority of patients, the diagnosis of epilepsy depends on the description of the attack by a witness but the inter-observer interpretations of verbal descriptions of events can be diverse and challenging. The use of mobile phone video recordings has gained worldwide prominence in recent years, including resource limited settings. This study explores the utility of mobile phone video recordings of paroxysmal events as adjuncts in the diagnosis of epilepsy, particularly in resource poor settings where there may exist significant diagnostic delays and misdiagnoses with far reaching implications on resource allocation and poor clinical outcomes. The aim of the study is to assess the accuracy of witness and referring clinician descriptions and to determine the impact, ideally enabling earlier diagnosis and management, of the use of home video recordings i.e the accuracy and timeliness of epilepsy diagnosis in paediatrics with the aim of improving practice in our setting. The existing literature is explored to guide optimal outcomes and ethical approaches to the tool which can be adapted for the paediatric setting.

Objective:

This study aims at outlining the utility of home videos in the diagnosis of paediatric epilepsy, and specifically describing how home videos influence the accuracy and timeliness of epilepsy diagnosis in clinical practice.

Study design:

This study has several arms, firstly a literature review to establish the current body of knowledge and established common practice for this intervention. The literature review critiques if there is an accepted and normed model for the use of this tool or existing evidence to support its use beyond anecdotal practice. Further, to define the apparent advantages and potential disadvantages of the intervention and to identify and develop subsequent study questions for a future prospective arm of the study. This will include questions relating to optimal recommended models for the intervention and safe ethical practice. To further assist with this consolidation of data a convenience sampling of videos randomly sent through to the neurology department over the previous year were retrospectively reviewed to assess the nature and route of the referral, the information included, the quality of the video, any ethical or safety concerns and any subsequent change in practice.

Results: Eight studies met the inclusion criteria. Methodologies varied, only three included videos of children and quality of the videos was formally scored in two. Overall the studies supported that home videos of good quality had a role in assisting in the differentiation of epilepsy from non-epileptic events, this outcome increased in the setting that history was provided and with the level of experience of the clinician. Studies did not focus on the ethics or risks of home videos and for some of the studies only a small proportion of the epilepsy client load were able to provide video material.

Outcome: Data relating to the role of home video of events in children is overall lacking. There are no official guidelines recommended to families for the acquisition of good quality videos in the management and assessment of seizures. Further, the ethical implications of transfer of sensitive recorded material has not been adequately addressed for this group.

LIST OF TERMS AND ABBREVIATIONS USED

Seizure: A 'seizure' is any sudden event which 'seizes' the patient. The term seizure includes epileptic seizures and also other types of non-epileptic episodes as well, e.g. vasovagal faints, episodes due to cardiac problems, non-epileptic attack.

Paroxysmal event: Paroxysmal spells are non-epileptic, paroxysmal events that may mimic epileptic seizures but are not associated with rhythmic discharges of cortical neurons typical of seizures. They may also clinically manifest as a transient loss of consciousness, often occurring suddenly, with or without a prodrome

Epileptic seizure: A transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain.

Epilepsy: A disease characterized by an enduring predisposition to generate seizures; Recurrent (2 or more) epileptic seizures occurring >24 hours apart. Additional features could be one unprovoked (or reflex) seizure and a probability of further seizures of >60%. Also, where there is a diagnosis of an epilepsy syndrome.

Telemedicine: The remote diagnosis and treatment of patients by means of telecommunications technology

Smartphone: A mobile phone that performs many of the functions of a computer, typically having a touchscreen interface, Internet access, and an operating system capable of running downloaded apps.

Abbreviations

ILAE – International League Against Epilepsy

PWE – People with Epilepsy

WHO- World Health Organisation

EEG- Electroencephalogram

WhatsApp - software modality used by cell-phone users to send messages, images and videos

SPSS - Statistical Package for Social Science

ANOVA - analysis of variance

ES- Epileptic seizures

PNES-Paroxysmal non-epileptic seizures

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2. Chapter 2: Main paper (publication ready)

Figure 1 PRISMA flow diagram for the identified papers.

INTRODUCTION

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- **Available literature on home video recordings for seizures and paroxysmal events in children with the following areas of interest:**
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Chapter 1: Literature Review.

Methodology of literature review:

Literature search was undertaken to assess data relating to the role and use of smartphone videos to assist in the delineation of children with seizures and paroxysmal events. Databases searched were Pubmed, Scopus, EBSCOHOST, Web of Science and Google Scholar. Search terms were “Neurology”; “home video OR home videos OR mobile video OR mobile videos OR smartphone videos OR smartphone videography”; “Diagnosis OR diagnose OR delineation”. With MeSH search headings included where available. Summary of the search strategy is included in supplement 1. Only human clinical studies were searched, including case reports of over 5 patients and papers published in English language. Most recent review articles were read to search for additional papers. Figure 1 illustrates the PRISMA flow diagram for the identified papers. After removal of duplications, 193 articles were screened based on abstracts and from these 21 were identified for full review.

The identified studies were collated and critiqued to establish the current body of knowledge and the common practice for this intervention. Any accepted models for the use of this tool (assessment of home video to delineate seizures and paroxysmal events), or evidence to support its use beyond anecdotal practice were highlighted. The studies were further critiqued to define the apparent advantages and potential disadvantages of the intervention (home video), to identify and develop subsequent study questions for future prospective studies. The intent was to identify aspects which are necessary for optimal recommended models for the intervention encompassing safe ethical practice.

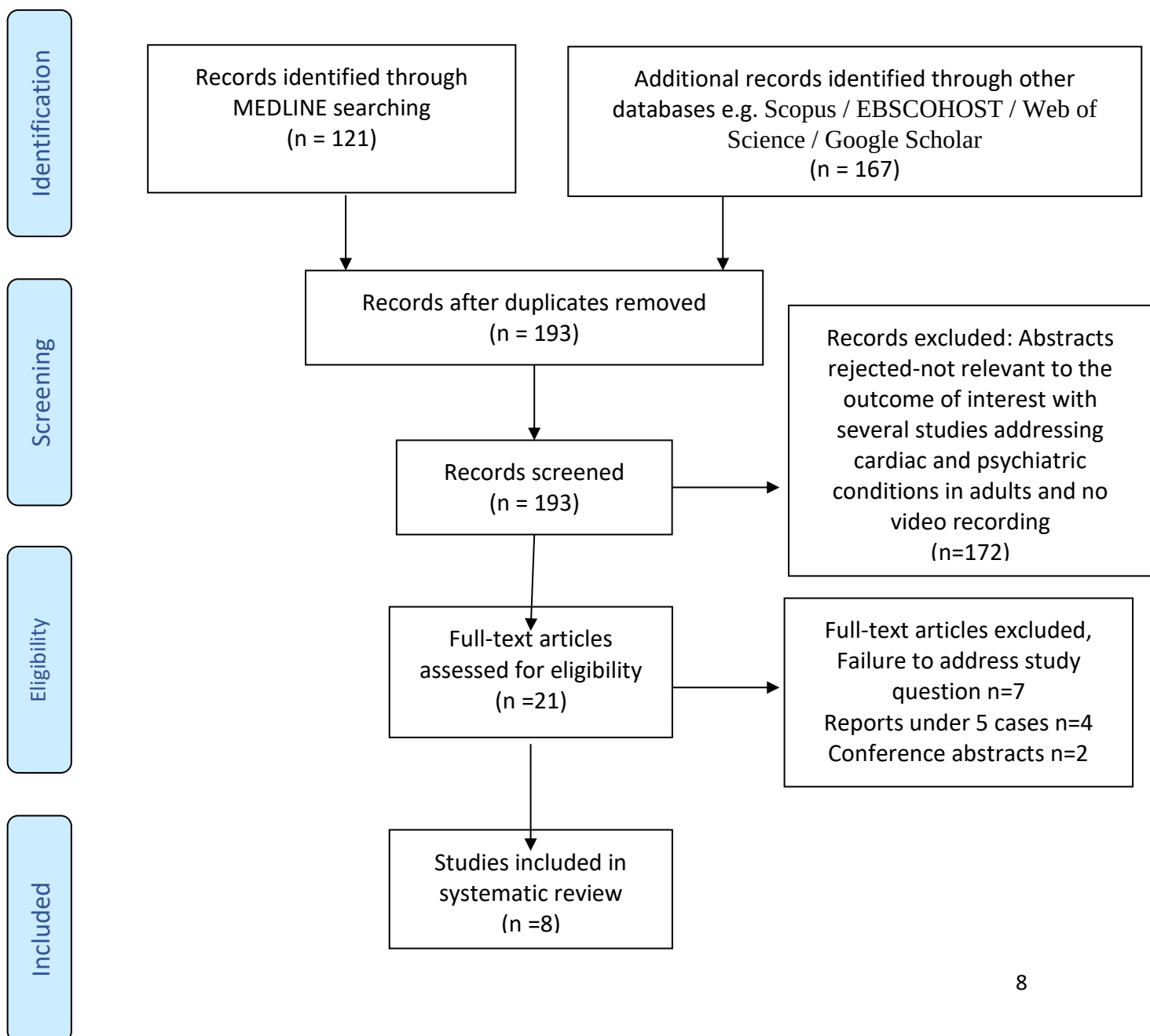
The target areas which were collated and explored from the identified papers were to:

- assess the accuracy of witness accounts and clinician interpretations
- assess the role of video in accurate seizure semiology and phenomenology descriptions in aiding history taking for the timely diagnosis of epilepsy
- understand how the intervention impacts on misdiagnosis of epilepsy
- assess patient/carers access to mobile technology
- define the utility of home video recordings in epilepsy diagnosis
- identify the confounders to the use of mobile video recordings in epilepsy diagnosis describe the ethical practices of release of confidential data.

Outcome of the literature on home video recordings for seizures and paroxysmal events in children

Twenty-one studies were identified and critiqued in full as they addressed all or part of the study question, of these, 13 were removed as they did not address the study question,¹⁻⁷ were studies of under 5 cases⁸⁻¹¹, or were conference abstract proceedings^{12, 13}. Some of the excluded studies which focused on unrelated research questions, used and promoted home videos within the studies with the assumption that they had an established diagnostic role^{1-4, 6, 10}. Eight full papers addressed the study question and were included in the literature review¹⁴⁻²¹. Figure 1 PRISMA chart summarises the literature search flow.

Figure 1: PRISMA Flow Diagram for literature assessing the role of home videos



All were prospective studies. Some recruited large numbers of clinicians and showed them small numbers of carefully selected videos to verify their ability to differentiate epileptic from non-epileptic seizures^{14, 15, 18}. Other studies selected large numbers of home videos and showed them to small select groups of clinicians. Some of these videos were selected following screening for the best quality videos after direction was given to caregivers for best quality, whilst others were random selections as presented by caregivers^{16, 21}. Some studies provided additional information such as history or verified outcomes when compared to vEEG telemetry^{14, 16}. Three of the studies (2 from the same group) used the same quality of video scoring system^{16, 18, 21}. Videos were assessed from predominantly adult patients in all except two studies^{15, 19}. As such, there were variances in the directness and consistency of the studies.

Chronologically, from the most recent publication date, the following text and Table 1 summarises the eight studies analysed in full.

- a) Adult patient based study of small number of convenience video samples shown to a large cohort of clinicians: In a prospective, masked, diagnostic accuracy study, Tatum *et al* collated a convenience sample of 44 smartphone videos from outpatient attendees¹⁴. These patients were formally investigated with video EEG telemetry to definitively confirm whether the events were epileptic or non-epileptic seizures. A study group of epileptologists and trainees (N=530) blinded to the diagnosis were shown the videos. The study demonstrated that smartphone videos were an effective differentiating tool, and that the more experienced clinicians were, the greater accuracy in the assessments. The additional inclusion of history and examination findings increased the yield even further. With regard to the content of the videos, the main useful marker which increased outcomes was when there were motor signs recorded. Further, enhancing interaction with the subjects, prolonging duration of recording and broadening the field of view were also observed to be helpful.
- b) Infant patient based study of small number of video samples shown to a large cohort of clinicians: Huang *et al*, assessed clinician's ability to differentiate epileptic from non-

epileptic seizures in 12 infants with paroxysmal events from China¹⁵. This was the only study solely focused on the paediatric age group. Initially the description of the events was conveyed to a cohort of 452 clinicians from six centres during paediatric conferences who then completed questionnaires of their diagnostic opinions. The same questions were then administered after the clinicians had viewed the home videos. Assessment was made in how this information affected the diagnostic accuracy and subsequent investigation cost savings for these infants. The group found that there was a significant improvement in diagnoses of both epileptic and non-epileptic seizures with the additional video information. Further, the more senior the clinicians, the better the accuracy. The authors concluded that the earlier more targeted diagnosis would lead to cost savings as further investigations could be more focused or avoided. Recommendation was put forward for senior neurologists to provide consultation via online video uploads of infants with paroxysmal events.

- c) Child and adult based study of a large number of videos shown to a small number of clinicians: Ramanujam *et al* assessed the contribution of home-videos to diagnosing Psychogenic Nonepileptic Seizures (PNES)¹⁶. Caregivers of consecutive patients (N=783) attending a neurology service between 10 and 50 years of age were invited to make home recordings of their events. The Quality of Video scale, previously devised by members of the study group for the evaluation of home video quality and published in the Dash *et al* report was used to critique the videos.¹⁸ Of this group 269 videos were considered of fair or good quality and included. The analysis of these was then compared to the video EEG telemetry findings. The study concluded that home-videos of good quality can complement vEEG in diagnosing PNES in a cost-effective way and help initiate appropriate management. The most commonly noted semiological features on home videos pointing to diagnosis of PNES were: Eye closure; accuracy of 96.2% (95% CI: 92.3%-98.45%) Crying or shouting; accuracy of 89.6% (95% CI: 83.1%-93.2%) Hyperventilating; accuracy 89.1% (95% CI: 83.7%- 93.2%) Wild, uncoordinated movements; accuracy 71.74% (95% CI: 64.6%-75.7%) Lying still/no movements; accuracy 81.6% (95% CI: 75.3%-86.8%). As only the fair and good quality videos were included in this study, there was some bias in the data collected.
- d) Adolescent and adult based study of a small number of selected videos shown to a moderate number of clinicians: Wasserman *et al* recruited 46 clinicians (20 neurologists and 26 non-neurologists) and showed them 10 videos (5 PNES and 5 ES). Clinicians with neurology training were statistically more likely to recognise seizures through the

semiology viewed on the videos than the general physicians ¹⁷. The group encouraged the need for video taking of episodes and education plan to first responders who were noted to have low diagnosing ability.

- e) Adult based study of a moderate number of videos shown to a small number of clinicians: Ojeda *et al* consecutively invited caregivers of adult patients attending an epilepsy clinic to record home videos of events²¹. These were assessed by three neurologists and epileptologists who attempted to differentiate if events were epileptic or not. They then reviewed the patients at a later point with the addition of other information including history and investigations, to assess if the original diagnosis changed. Fifty percent of the patient's caregivers elected not to be part of the study citing that it would be too challenging to capture an event. From the original 317 patients, after recruitment completed and only viable videos were included, the group had 50 videos from 22 patients to analyse. There was further bias in the patient cohort as although the assessors were blinded to the diagnosis, these were patients already known to the service and the caregivers were given instructions on how to take optimal videos. This study documented a range of different recording methods, although most used mobile phone or webcam. The authors promoted the use of webcams for long term recordings. They also used the same Quality of video score system to analyse the videos as reported in the studies by Dash *et al* and Ramanujam *et al* ^{16, 18}. The group recommended that homemade videos may be of diagnostic value in epilepsy management. Training in performing good-quality videos is necessary. Webcam long term recordings should be recommended as the best recording option. It was also highlighted that non-epileptic seizures were more likely to be recorded and yielded better QOV scores than epileptic seizures, though no statistical conclusions could be drawn due to low numbers.
- f) Adult based study on a large number of videos reviewed by a small number of clinicians: Dash *et al* completed a 29 point questionnaire on 624 home videos from 312 patients and compared the findings of the same questionnaire being administered to the caregivers when the patients were admitted for vEEG ¹⁸. As such the study compared assessment of the same information captured from the videos and then from the history. Assessment of the home videos detected significantly more semiological signs than the history alone. Videos which included bilateral generalized clonic movements of limbs, motor movement around mouth, fear, visual phenomena, hemisensory phenomena, and post-ictal unilateral weakness had the highest accuracy. The group devised a useful scoring system referred to as the Quality of video (QOV)

scale which had 11 items, each of which was given points ranging from -1 to 2. Two points were given if a full view of the face and/or whole body was visible and if the event was recorded from the very beginning. One point was given if part of the face and/or body were visible, or if there was adequate illumination and the recording included post-ictal events. One point was deducted if the view of the patient was obscured by the caregiver and/or movement, or if the recording was done too close to or too far from the patient. The maximum score for the QOV scale was 10. A score of 1–4 was considered poor quality, 5–7 moderate quality, and 8–10 good quality. The study concluded that home videos were more reliable in picking up semiological signs and classifying epilepsy type than history provided by caregivers of PWEs. The scoring tool was adapted for the subsequent convenience sample assessment in the paediatric population reviewed in this project.

- g) Adult based study with a moderate number of videos reviewed by a small number of clinicians: Goodwin *et al* recruited a group of 45 patients (adults and children) who were undergoing ambulatory EEG and asked caregivers to simultaneously video events¹⁹. Half the videos were of good enough quality to permit assessment. The main challenge was that events were often too brief to capture. Events were more successfully captured for children than adults. There was good correlation with the adequate videos aiding the ambulatory EEG analysis. The authors invited 130 caregivers to participate but the majority declined mostly citing concern that events would be too brief to capture. As such, whilst the video enhanced the analysis in a proportion of the patients, there were significant challenges illustrated with the ability to capture the events. This study also highlights the importance of appropriate patient selection for take home interventions.
- h) Adult based study with a moderate number of videos reviewed by a small number of clinicians: Samuel and Duncan used a hand held video camcorder to record events from 22 patients with undiagnosed seizures²⁰. The videotapes assisted the diagnosis of non-epileptic attacks in nine of 22 patients (41%), and of epileptic attacks in eight of 22 patients (36%). Interactions with patients during filming were particularly helpful. Five patients (23%) could not be filmed, three of whom had seizures that were too short-lived to be recorded. In two patients (9%) a confident diagnosis of non-epileptic seizures could be made from the videotapes alone. Seven patients subsequently required video-EEG telemetry. It was concluded that the handheld video camera was a useful and inexpensive tool to provide accurate seizure descriptions but should be used

in conjunction with other evidence to classify seizures. Interactions with patients during filming were also observed to be particularly helpful.

Overall, the studies from USA, China and India are comparable as they had large study populations in the form of the recruited clinicians and both explored similar outcomes^{14, 15, 18}. Although the interventions differed, these studies established that home videos are useful to aid differentiation between epileptic and non-epileptic seizures, especially when viewed by a more experienced clinician and if accompanying history was provided. Wasserman had a smaller study group but also demonstrated that the more experienced the clinician in the field of neurology the higher the ability to differentiate PNES from ES on the video alone¹⁷. Some of the studies had bias as only good quality videos or events with increased likelihood to capture on video were recruited^{16, 19}. Overall, all the studies identified the benefits from the inclusion of home videos to aid in the assessment of patients with undiagnosed paroxysmal events. All emphasized that the studies can be challenging to capture and should be vetted to ensure that fair to good QOV scores are incorporated for the most useful findings^{16, 18, 21}. Whilst the QOV scoring system has some important points it focused on analysis of adult events.

Table 1 Summary of the literature on use of home videos to differentiate seizures from other paroxysmal events. Delineated via PICO analysis (Population, Intervention, Comparator, Outcome)

Paper / Location / year	Study Question Study Type	Population group	Intervention	Comparator:	Outcome:	Comment
Tatum <i>et al</i> ¹⁴ USA 2020	Assessed usefulness of OPD smartphone videos to diagnose epileptic seizures from 44 convenience samples of non-consecutive adult outpatients presenting for the first time who presented with good quality videos (as assessed by epileptologists) and were subsequently delineated with vEEG. Prospective, masked, diagnostic accuracy study	Epileptologists and trainee doctors from 8 academic epilepsy centers n=530 (530 total physician reviews)	Epileptologists and trainees reviewed studies to state opinion of diagnosis (ES or PNES). Measures of performance (accuracy, sensitivity, specificity, positive predictive value, and negative predictive value) for smartphone video-based diagnosis by experts and trainees (the index test) were compared with those for history and physical examination and video EEG monitoring (the reference standard)	Validity of the tool (smartphone video) based on level of experience.	About 80% of recorded videos were ranked by reviewers as having adequately good quality. Smartphone video was accurate in predicting diagnosis of epileptic seizures by experts 89.1% (95% CI, 84.2%-92.9%) of the time, with a specificity of 93.3% (95% CI, 88.3%-96.6%). Resident responses less accurate, despite greater confidence. Motor signs during events increased accuracy. Addition of history and examination to video, diagnoses rose from 78.6% to 95.2%. A correct diagnosis was 5.45 times greater when smartphone video accompanied history and examination (95% CI, 1.01-54.3; P = .02).	Expert review of outpatient smartphone video has predictive and additive value for diagnosing epileptic seizures. Smartphone videos may reliably aid PNES in some settings. Recommended greater interactivity, longer recordings and optimal views. 30 of the 44 subjects had PNES making generalization difficult. Promoted triage for patients at

	(the OSmartViE study).					greatest need for vEEG.
Huang <i>et al</i> ¹⁵ China 2019	Three steps: 1. role of home videos for diagnosis on the patients' first visit, 2. the cost savings of video online consultation, 3. what type of doctor is optimal. Prospective study	452 practitioners from six centers attending pediatric academic conferences.	Practitioners asked for diagnoses from descriptions alone of 12 infants with paroxysmal events	Same groups was re-questioned after watching the corresponding home videos of the episodes	301/ 452 met the criteria (66.6%) for analysis. The mean correct diagnoses with and without videos was 8.4 (SD 1.7) of 12 and 7.5 (SD 1.7) of 12, respectively. For epileptic seizures, mobile phone videos increased the mean accurate diagnoses by 3.9% (p= 0.006); for nonepileptic events, it was 11.5% (p<0.001). More senior paediatric neurologists had higher diagnostic accuracy.	Home videos are a cost-effective tool and useful for the diagnosis of paroxysmal events in infants. Recommended video infants with paroxysmal events and consult online a senior neurologist.
Ramanujam B, et al. ¹⁶ India 2018	Role of mobile phone videos to diagnose Psychogenic Non-epileptic Seizures (PNES).	Videos from n=783 Patients suspected with PNES Hospital based study Prospective study of consecutive patients aged 10-50 years of age	Selected 269 videos out of the 783 screened. Of the 269, 155 had fair quality (QOV 5-7) and 114 had good quality (QOV 8-10) Videos of all recruited subjects were reviewed by the epilepsy fellow (single reviewer, blinded to clinical history; step 1) the label of PNES was assigned if at least three of the semiological features reported by *LaFrance et al. as having "good evidence from primary studies" or by **Lazarus et al. as 'ictal characteristics'	Compared to video EEG telemetry recordings	The diagnosis at step 1 was epileptic seizures in 71.4% and PNES in 27.1%. Diagnosis at step 2 was PNES in 25.3%, other physiologic events in less than 1% and epileptic seizures in 73.6%. There was a concordance between the diagnoses in steps 1 and 2 of 97.2% of subjects with no statistically significant difference between the diagnoses of steps 1 and 2. PNES diagnosis sensitivity of 95.4% (95% CI: 87.2%-99.1%), specificity of 97.5% (95% CI: 94.3%-99.2%), positive and negative predictive values of	Concluded that good quality home-videos may be used to differentiate PNES from epileptic seizures and can complement vEEG in diagnosing PNES in a cost-effective way. Utilised "Quality of Video scale" ¹⁸ . Note significant proportion of videos could not be used.

			were noted in the videos^{22, 23} (Criteria were provided for labelling events as PNES using specific features such as eye closing/resistance to eye opening), ictal crying, jaw clenching, hyperventilation, pelvic thrusting, side to side head and body movements, memory recall. All patients subsequently underwent vEEG which were reviewed by an epileptologist (blinded to the diagnosis formulated by the epilepsy fellow); step 2 and concordance between their diagnoses noted in each case		92.65% (95% CI: 84.1%-96.8%) and 98.5% (95% CI: 95.6%-99.5%) respectively. The most commonly noted semiological features on home videos pointing to diagnosis of PNES were: Eye closure; accuracy of 96.2% (95% CI: 92.3%-98.45%) Crying or shouting; accuracy of 89.6% (95% CI: 83.1%-93.2%) Hyperventilating; accuracy 89.1% (95% CI: 83.7%- 93.2%) Wild, uncoordinated movements; accuracy 71.74% (95% CI: 64.6%-75.7%) Lying still/no movements; accuracy 81.6% (95% CI: 75.3%-86.8%)	
Wasserman and Herskovitz¹⁷ Israel 2017	Compared capacity of clinicians of different levels of experience to diagnose PNES from ES based on 10 videos (5 PNES and 5 ES) to reduce diagnostic delay	46 participants, 26 non-neurological and 20 neurological personnel.	Ability of neurologists to differentiate between PNES and ES in a cohort of videos from adolescents and adults.	Ability of non-neurologists to differentiate between PNES and ES	Epileptologists diagnosed correctly 87.5% of cases, General neurologists 72.8%. Neurology nurses 69.8%, ER nurses 58%, Internal Medicine physicians 54.1% and ER physicians 44.4%. Statistical significant difference between the general physicians to all neurology group professions was >0.05.	Neurologists' ability to recognize seizures using semiology alone was found to be higher than other medical personnel. The group encouraged the need for video

	and need for vEEG Prospective study					taking of episodes and education plan to first responders who were noted to have low diagnosing ability
Ojeda et al ²¹ Spain 2016	Explored the role of home video to assist epilepsy diagnosis in adults Prospective observational study	Of 317 consecutive adult patients with drug resistant epilepsy (established at least two years before) attending epilepsy service, caregivers instructed to record optimal home video. Instructions for good quality recordings were provided including turning on lights, using a steady hand, interacting with patient, asking questions to the patient, assessing the	Three neurologists/epileptologists watched the videos in clinical session, rated the quality of the recordings following some parameters (face or whole body recorded, environmental illumination, single or multiple events, early stage of event recorded) and made a clinical diagnosis.	In a second phase, previous diagnosis was revised.	87% had access to recording devices. From this group, 135 (50%) felt unable to record events. Reasons given: Low seizure frequency: 60%, seizures short duration: 80%. 50 events from 22 patients recorded. Previous epileptic syndrome diagnosed (based on description/neuroimaging/EEG): 15 focal temporal lobe epilepsy, 4 focal frontal probably symptomatic epilepsy, 3 epileptic encephalopathy. Regarding the QOV, the mean rating was 4.6 points out of a possible maximum of 8 and minimum of 3. (5 had excellent recordings, (QOV 8-10), 64% had medium quality recordings (QOV 5-6) and 27% had low quality recordings (QOV 3-4) In a second phase, there was agreement among neurologists in the clinical and semiological diagnoses but in one patient	Some bias as these patients were already in an epilepsy service and the caregivers were given instructions how to perform the video. Used different recording methods Photo camera: 100%, cell-phone: 100%, webcam: 10%, video camera: 30%). Only half of these able to capture event. Group recommended that homemade videos may be of diagnostic value in epilepsy management. Training in

		patient's awareness and memory, capturing face and whole body.			who had tremor: action tremors. Focal clonic seizure. 18 patients' diagnoses were confirmed, three patients were determined to have been misdiagnosed with temporal lobe epilepsy and they all had non epileptic seizures. It was also highlighted that non epileptic seizures were more likely to be recorded and yielded better QOVs than epileptic seizures, though no statistical conclusions could be drawn due to low numbers.	performing good-quality videos is necessary. Webcam long term recordings should be recommended as the best recording option. Also used a Quality of video rating score was the same as devised by Dash et al 2016 ¹⁸ .
Dash <i>et al</i>¹⁸ India 2016	To evaluate the yield of different semiological signs inferred from the descriptions provided by caregivers and to evaluate the role of home videos as independent tools to diagnose epilepsy by picking up seizure phenomenology and classifying epilepsy types in a resource poor setting, with the rationale that the	Home videos from 312 patients with a total of 624 seizures analyzed. Of this group a total of 572 seizures in 282 of the patients were evaluated on vEEG to verify suspected diagnosis. Phase I: participants were encouraged to record videos of	Questionnaire of 29 different semiological features administered on findings of home video The questionnaire was developed by two epileptologists based on the commonly encountered semiological features in clinical practice, with different levels of accuracy ascribed to various semiological features. The QOV scale for assessing video quality was developed for this study by one of the co-authors Manjari Tripathi	Agreement on semiological signs was measured between the questionnaire completed on the basis of medical history and home videos and on the basis of vEEG (gold standard)	The mean number of signs of semiology recorded after analysis of the home videos was 3.3 ± 2.2, and from the caregiver medical history was 2.1 ± 1.1 ($P < 0.01$). Bilateral generalized clonic movements of limbs, motor movement around mouth, fear, visual phenomena, hemisensory phenomena, and post-ictal unilateral weakness had the highest accuracy (greater than 85% sensitivity, specificity and accuracy). The overall agreement of semiological signs inferred from medical history versus vEEG was 0.75 and between home video recordings versus vEEG was 0.92.	A larger number of patients were correctly categorized into the focal epilepsy group when home videos were used to classify compared to when medical history was used. The study concluded that home videos were more reliable in picking up semiological signs and classifying

	limited repertoire of descriptive terminologies in a population with low education restricts the seizure description narrative. Prospective observational study.	events which were then assessed by the developer of the QOV scale and the 29 point questionnaire was also filled for each recording by the assessors based purely on the video recording provided and a diagnosis made Phase II: The 29 point questionnaire was administered to the subjects caregivers by a trained epilepsy resident and an attempt made at arriving at a diagnosis based on caregivers descriptions Phase III: Subjects underwent vEEg and semiology analysed by	(an epileptologist) and has been utilized in other studies subsequently			epilepsy type than history provided by caregivers of PWEs.
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		epileptologist using the 29 point semiology questionnaire and a diagnosis made. The vEEG aided diagnosis was deemed gold standard				
Goodwin <i>et al</i> ¹⁹ United Kingdom 2014	Assessed if patients on ambulatory EEG could match events with home video recording. Carers were tasked with recording events when they occurred and noting the time of occurrence for subsequent analysis alongside the ambulatory EEG Prospective study	Total of 130 patients offered a camcorder but only 45 patients (35%) accepted. Adults and children age range 13 days to 59 years. N=45	Caregivers who agreed to record events if they occurred during the study	No control group	34 (76%) had an event of which 17 (50%) were adequately/satisfactorily recorded. The main reasons for failure were that attacks were too brief, or machine error. Attacks were captured with greater success in children (14/23, 61%) than adults (3/11, 27%). Of the 17 video recordings, 14 (82%) aided interpretation of the ambulatory EEG.	n=130 were invited to participate but only 35% accepted. Main reason for saying "no" was that the events were too brief to capture. Study also highlights the importance of appropriate patient selection for take home interventions
Samuel and Duncan ²⁰	The role of hand held video camcorder in the evaluation of seizures	22 consecutively filmed patients with undiagnosed	Events recorded on camcorder reviewed for ability to assist differentiating between	No comparator	Videotapes assisted the diagnosis of non-epileptic attacks in nine of 22 patients (41%), and of epileptic attacks in eight of 22 patients (36%). 8	Interactions with patients during filming were particularly helpful.

United Kingdom 1994	Prospective study	events had events recorded via hand – held video camcorder on the ward by the nursing staff and subsequently, the video tapes were reviewed by medical staff	epileptic and non-epileptic events. The aim of filming was initially to provide a global picture of the event as soon as possible after the onset and then to further concentrate on eyes, mouth, cyanosis, breathing patterns, speech and sounds. The camera was able to work at low levels of illumination thus permitting recordings of nocturnal events. During the filming, a member of staff would interact with the patient including; response to commands, menace, pain, plantar reflexes and attempts to open eyes to assess resistance and direction of gaze. Serum prolactin levels were also measured and all patients underwent interictal eEEg and continuous EEG where feasible and the final diagnostic classification of seizures was based on the combined evidence		failed to generate useful video information. In two patients (9%) a confident diagnosis of non-epileptic seizures could be made from the videotapes alone. Seven patients subsequently required video-EEG telemetry. In the 10 patients with non-epileptic attacks, several features were filmed including: Resistance to attempted eye opening or avoiding eye contact in eight (8), elaborate and prolonged rigidity, opisthotonos, arm waving or leg kicking in seven (7), facial grimacing to menace or to testing plantar reflexes in four (4) voluntary salivation in two (2) patients directly interacting with camera on realising that they are being filmed (2) and self- restraint with the arms during falling in one patient.	It was concluded that the hand - held video camera is a useful and inexpensive tool to provide accurate seizure descriptions, but it should be used in conjunction with other evidence to classify seizures
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Chapter 2: Main report (publication ready)

THE UTILITY OF MOBILE TELEPHONE RECORDED VIDEOS AS ADJUNCTS TO THE DIAGNOSIS OF SEIZURES AND PAROXYSMAL EVENTS IN CHILDREN WITH SUSPECTED EPILEPTIC SEIZURES

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Word count:

Abstract: 249

Main text: 3951

Figures / tables: 4

Declarations of interest: none.

This research did not receive any specific grant from funding agencies in the public, commercial, or
not-for-profit sectors.

Highlights

- Good quality video, expert clinician review and history aids event differentiation.
- Caregivers should be advised of optimal video technique.
- The Quality of Video tool should be used to assess video quality.
- Ethics of transfer of information on internet domains should be considered.

Abstract

Epilepsy is often diagnosed through clinical description, but inter-observer interpretations can be diverse.

Objective: To assess the utility of mobile device videos in the diagnosis of paediatric epilepsy.

Methods: The literature was reviewed for evidence to support the use of home videos inclusive of advantages, ethical practice and potential disadvantages. An existing quality of video (QOV) scoring tool was adapted for use in children. A convenience sampling of videos from 25 patients were reviewed to assess the viability of the adapted QOV tool against the subsequent diagnosis for the patients with videos. Referral mechanism of the videos was reviewed for the source and consent processes followed.

Results: Eight studies were identified. Methodologies varied, only three included videos of children and quality of the videos was formally scored in two. Studies found that home videos of good quality assisted the differentiation of epilepsy from non-epileptic events, especially with accompanying history and with more experienced clinicians. Studies did not focus on the ethics or risks of home videos. The adapted QOV tool correlated with videos of moderate and high quality and subsequent diagnostic closure.

Conclusions: Data relating to the role of mobile device video of events in children is lacking. Guidelines for caregivers to acquire good quality videos is not part of routine practice. The ethical implications of transfer of sensitive material have not been adequately addressed for this group. Prospective multicentre studies are needed to formally assess the viability of the adapted QOV tool for paediatric videos.

Key words: mobile device videos, quality of video, differentiation, seizures, paroxysmal events

INTRODUCTION:

Epilepsy is largely a clinical diagnosis based on the semiology of the seizures.²⁴ The motor, sensory and behavioural signs are key in describing seizure semiology and subsequently, seizure type. However, health care workers rarely witness seizures so the events are often relayed by verbal accounts to physicians during subsequent consultations. The physician makes deductions from caregiver descriptions, who may not have witnessed the events. The perceived anxiety and potential risks of not treating an affected child with possible epilepsy may result in misdiagnosis and mismanagement. Some 20–30% of those referred to tertiary centres with refractory epilepsy do not in fact have epilepsy,²⁵⁻²⁸ hence the need for accurate descriptions of seizure events.²⁹

The gold standard to confirm a diagnosis of epilepsy is to capture an ictal event whilst performing an EEG with video running (video EEG telemetry).^{30, 31} However, video EEG telemetry (vEEG) is a scarce resource, and seizures or paroxysmal events cannot always be guaranteed to occur during the recording.³²

The increasing use of telemedicine and mobile phone/ device technology (smartphones) illustrate use of newer technologies which play a valuable role in the management of epilepsy and should be integrated into existing clinical pathways. The current coronavirus pandemic has highlighted that telehealth enables patients to gain access to healthcare, being exclusively used by 24.7% of child neurologists to manage their epilepsy patients during the early period of the pandemic³³.

This study undertakes a literature review, puts forward an adapted video screening tool and assesses the efficacy of the home videos through a convenience pilot study. The study aims to outline the accuracy of home videos in the diagnosis of paediatric epilepsy.

METHODOLOGY

Literature review:

Search terms and methodology are summarized in supplement 1. Figure 1 illustrates the PRISMA flow diagram for the identified papers. After removal of duplications, 193 articles were screened via abstracts and 21 identified for full review.

The included studies were reviewed for the current body of knowledge and guidelines for the use and assessment of home video to delineate seizures and paroxysmal events. The studies were further explored for the advantages and disadvantages of home video. Aspects which are necessary for optimal

recommended models for the intervention encompassing safe ethical practice related to the use of confidential data were noted.

Development of a Quality of Video scoring tool for children to grade assessment of video submitted material

An existing quality of video (QOV) tool^{18, 21} designed for use in adult patients was adapted for paediatric use and incorporated into a pilot study.

Retrospective convenience study and assessment of viability of the adapted QOV tool.

The Red Cross War Memorial Children's Hospital (RCWMCH), Cape Town, is a public paediatric teaching hospital in the Western Cape of South Africa. The paediatric neurology department receives frequent referrals of children with paroxysmal events into its dedicated epilepsy service. New patients are referred via in-patient and emergency services, primary and secondary healthcare facilities, and private clinicians. Referrals are via telephonic request, fax or a video recorded event of a child suspected to have an epileptic seizure, occasionally with some explanatory text message. A proportion of referrals from emergency or out-patient clinic, by convenience present with a captured video event, whilst others follow instructions and subsequently record events ready for the follow-up consultation. To delineate and understand this group more, a convenience sample of video recordings from 25 children referred to the service were reviewed by the authors. The reviewers were blinded to the referral background. The adapted QOV tool was assessed for use and viability in this setting. The study population and inclusion criteria were children under 18 years of age referred via videos to the neurology service, who were suspected to have epileptic seizures or in whom there was diagnostic uncertainty, children who were reviewed for the first time with suspected seizures, and children with undefined seizures where the type of event could not be delineated based on clinical history. Parents had given consent and where appropriate, children had given assent for the video recordings.

The study excluded children in whom a definite diagnosis of epilepsy was already made.

Data collected included the source of the video (parent, clinician), patient demographics, whether a presumptive diagnosis was made, if clinical history accompanied the recording, the QOV score, and how the video changed the care for the child. The video diagnoses were reviewed by specialist paediatric neurologists in the service and records of any discrepancies kept.

The study outcome was to understand the evidence to support the use of home videos to delineate seizures and paroxysmal event and to generate a recommendation for clinicians and caregivers to optimise mobile phone / device video recording of events in children.

The study was conducted following approval of the research committee at RCWMCH and ethics approval from the Faculty of Health Sciences Research and Ethics Committee, UCT (HREC 402/2020).

RESULTS:

Available literature on home video recordings for seizures and paroxysmal events in children

Figure 1 PRISMA chart summarises the literature search flow. Table 1 summarises the eight studies using PICO criteria (population, intervention, comparator and outcome).

Population: Large numbers of clinicians were recruited by Tatum *et al* with 530 epileptologists and trainees, and Huang *et al* who engaged with 452 paediatricians^{14, 15}. Other studies recruited small numbers of clinicians. Ojeda *et al* used three epileptologists, Ramanujam studied competency of “the epilepsy fellow”, Goodwin referred to clinicians only and Samuel and Duncan to “medical staff”^{16, 19-21}. Wasserman and Herskovitz recruited 26 neurologists and 20 non-neurology practitioners, inclusive of nursing staff¹⁷. Dash *et al* used a different model recruiting 312 caregivers and patients to record videos¹⁸.

Intervention: All studies were prospective. Tatum *et al* showed a small number of carefully selected videos (n=44) to a large number of epileptologists and trainees, Huang *et al* used 12 also carefully selected videos of infants with paroxysmal events to show to paediatricians who were initially only supplied with a description of the events. Likewise, Wasserman and Herskovitz used 10 videos of five epileptic seizures and five psychogenic non-epileptic seizures (PNES) to show to neurologists and non-neurologists^{14, 15, 17}. These researchers were exploring the competency of clinicians to differentiate events based on selected videos with or without clinical information. Ramanujam *et al* also carefully selected better quality videos (n=269) to show to a blinded epilepsy fellow to assess ability to differentiate PNES¹⁶. In a similar study Ojeda *et al* recruited n=135 home videos which were scored for quality and shown to 3 epileptologists to assess accuracy in differentiating of events²¹. Dash *et al* recruited 624 video events which were screened by epilepsy trainees and neurology specialists using a 29 point questionnaire¹⁸. Goodwin *et al* and Samuel and Duncan encouraged patients to undertake home videos which were reviewed for diagnostic use in small cohorts (n=45 and 22 respectively)^{19, 20}.

Comparator: Tatum *et al* explored the validity of smartphone video to differentiate events based on the experience of the reviewer (epileptologist versus trainee), similarly Wasserman and Herskovitz assessed the ability of different practitioners from neurologists to emergency medicine nurses^{14, 17}. Huang *et al* explored how the addition of video after the description added to the subsequent ability to accurately differentiate events¹⁵. Ramanujam assessed the accuracy of the home video events compared to vEEG¹⁶. Ojeda *et al* also explored features captured in the videos that experts found useful in differentiation of events as scored via the Quality of Video tool, they then explored whether the original diagnosis was revised by the process²¹. Dash *et al* used their 29 point questionnaire which was completed by caregivers and clinicians against history and video, with final diagnosis verified by vEEG¹⁸. Samuel and Duncan, and Goodwin *et al* did not have a comparator group^{19, 20}.

Outcome: Tatum *et al* found that experts were more accurate in predicting diagnosis and residents were less accurate but tended to have greater confidence¹⁴. Motor signs and additional history increased diagnostic yield. They supported use of the tool to aid diagnosis of PNES and to triage urgency of patients awaiting vEEG. Huang *et al* found that use of home video was a cost effective tool and useful to diagnose paroxysmal events in infants, the more senior the clinician the more accurate the diagnostic yield¹⁵. Ramanujam *et al* concluded that good quality home videos can be used to differentiate PNES from epileptic seizures and can complement vEEG in diagnosing PNES in a cost effective manner. The group critiqued and assessed useful and important clinical markers to note during the video. Wasserman and Herskovitz found that more experienced neurologists were statistically more effective in correctly diagnosing events compared to general physicians¹⁷.

Knowledge gained through accompanying the neurologist was hypothesized to explain why the emergency medicine nurses performed better than the general physicians. Ojeda *et al* found that non-epileptic events had better QOV scores than epileptic seizures, of the recruited group videos could be recorded in about half of the patients²¹. The group suggested that training and guidance is needed for caregivers to attain optimal videos. Dash *et al* found that focal seizures were likely to be correctly diagnosed in patients with a home video, compared to if only history was available¹⁸.

Assessment of the home videos detected significantly more semiological signs than the history alone. The group devised the scoring system referred to as the Quality of video (QOV) scale with 11 items. The study concluded that home video aided epilepsy diagnosis and PNES differentiation. Goodwin *et al* noted that selection and recruitment of the correct patient is important for the best results¹⁹. Samuel

and Duncan concluded that home videos were useful differentiating aids, the researchers noted that interaction with patients during events was useful.

Limitations in the studies included bias where only the fair and good quality videos were included^{16, 19}. Some patients and caregivers declined joining studies or failed to capture adequate quality videos, inclusive of when events were too short to record¹⁹⁻²¹. The studies varied as to whether caregivers were trained or guided for optimal videos^{18, 21}. Only three studies included child or adolescent home videos for review¹⁵⁻¹⁷. There were variances in the directness and consistency of the studies such that some recruited large numbers of clinicians who reviewed a small number of carefully selected videos to verify their ability to differentiate epileptic from non-epileptic seizures. Other studies selected large numbers of home videos and showed them to small select groups of clinicians. Some of these videos were selected following screening for the best quality videos after direction was given to caregivers for best quality, whilst others were random selections as presented by caregivers^{16, 21}. Some studies provided additional information such as history or verified outcomes when compared to vEEG telemetry^{14, 16}. Three of the studies (2 from the same group) used the QOV tool^{16, 18, 21}.

Studies established that home videos are useful to aid differentiation between epileptic and non-epileptic seizures, especially when viewed by a more experienced clinician and if accompanying history was provided^{14, 15, 17, 18}. Overall, all the studies supported use of home videos to aid assessment of patients with undiagnosed paroxysmal events. All emphasised that videos can be challenging to capture and optimal with fair to good QOV scores^{16, 18, 21}. Whilst the QOV scoring system has some important points it focused on analysis of events in adults.

Recommended Quality of Video tool for children to assess video submitted material

Based on the elements analysed in the literature, a grading system was adapted from the tool developed for adult QOV to critique the quality of a submitted video of a child (Table 2)^{18, 21}. Key elements included in the adapted scale for children were whether the caregiver interacted with the child, if the event could be interrupted by touch, and whether level of awareness could be gauged from the video. In-line with Dash *et al* recommendations, the maximum score for the QOV scale was 10 and a score of 1–4 was considered poor quality, 5–7 moderate quality, and 8–10 good quality¹⁸.

Results of convenience sample

The 25 recordings were sent consecutively to the “neurology team WhatsApp” group (June 2019 - January 2020). Parents recorded the videos and provided verbal permission for the files to be sent for assessment via their referring clinicians, or clinicians made the recordings themselves with verbal consent from the carer. Similar to other studies, the main question was to determine if the recorded event was an epileptic seizure or not and to further define focal seizures in a number of cases. Table 3 summarises the key findings.

Of the 25 recordings sampled, 14 (56%) were male patients, while 11 (44%) were female, ranging in age from 2 months old to 11 years old, with a median age of 18 months. The quality of video recordings for clarity and capturing of the onset/early manifestations was adequate and correlated with QOV scoring in 19 of the 25 videos (76%). Clinicians could make a correct diagnosis in 18 out of the 19 (95%) with high certainty often without requiring the accompanying history. Patient 10 had a video supplied directly by a caregiver, which demonstrated myoclonus and facilitated urgent referral for a more detailed assessment as accompanying history was inadequate. Of the 18 confirmed cases, 11 were epileptic events and seven were non-epileptic.

The remaining 6 video recordings (24%) were of poor quality due to the onset not being captured in 5 videos (83%), the face not being visible in three (50%), and the carer not stimulating the patient in two videos (33%). The quality issues often overlapped. The adapted QOV scale was less than 3 for all. In the videos where a diagnosis was possible, management and appropriate referrals were made, with the majority commenced on anti-seizure medication or existing anti-seizure medications switched to a more appropriate one. Urgent medical intervention was enabled where relevant e.g. admission and steroids commenced for epileptic spasms (patients 7,18 and 22).

A brief history supplied for 15/25 (60%) of the videos was associated with improved diagnostic accuracy. A definitive diagnosis was possible in 11 out of the 15 videos (73%) with a history. In comparison, a definitive diagnosis was possible for only three of the remaining nine videos (33%) which lacked an accompanying history.

Consent was obtained verbally by the referring clinician from the parent in order to share the recording with a specialist. It emerged however, that details of sharing video recordings across online platforms was not always discussed with the carers from the outset.

DISCUSSION

Epilepsy is the commonest neurological condition with an estimated 50 million people affected in the world, of whom up to 75% live with little to or no access to medical services or treatment especially video EEG telemetry^{32, 34-36}. Moreover, the current global coronavirus pandemic has further disrupted access to medical care with limitations on movement and health resource reallocations, making telemedicine an increasingly attractive and useful resource to improve access to clinical services especially in the management of epilepsy.

The literature search revealed gaps in data which assessed the use of mobile/home video recordings in the diagnosis of paroxysmal events, especially for the paediatric population. No studies were conducted in the African setting. Studies are needed to address the role of mobile video recordings in epilepsy diagnosis especially across ethical, diagnostic, management, educational and research areas. The ethics of sharing mobile video recordings and the importance of consent/assent were not adequately addressed, highlighting the issue of safety, ownership and regulation of sensitive patient information shared across internet platforms among vulnerable populations. However, the tool has the potential to support existing infrastructure and facilitate established referral and communication networks in the clinical assessment of remote patients. Further, there are potential educational and research benefits emanating from the collection of large amounts of data used for characterizing paediatric seizures.

The accuracy of seizure descriptions by witnesses, including medical professionals is highly variable³⁸. Neurologists are better at the diagnosis of epilepsy than non-specialists (mistake rate 5.6% vs 18.9%)³⁹. The misdiagnosis rate of epilepsy is high, reported at 23 -71% depending on the population group sampled and the methodology of screened patients^{26-28, 39, 45}.

The accuracy of seizure documentation and description by patients varies over time⁴⁰. Witnesses tend to inaccurately describe movements misleading medical professional away from focal events⁴¹. Subtle features such as automatisms, lip movements or staring episodes are more difficult to identify not just for lay persons but also by health care professionals⁴². Different semiologies can be associated with different levels of reporting accuracy, with non-convulsive semiologies being less accurately described than convulsive events⁴³. Facial appearance and vocalisations were most accurately

described whilst limb movements and post ictal behaviour are least accurately recalled and described⁴⁴.

Mobile phone technology plays an integral part in our daily livelihoods with evolving roles beyond a communication device^{7, 46-53}. However seizure detection methods are considered to be in the early stages of development⁵⁴.

Mobile technology is easy to use and does not require special training, it is also becoming increasingly accessible in low and middle income countries (LMICs)⁵⁵. Smart phone ownership/social media utilisation averages 42% in LMICs and 72% in high income countries⁵⁶.

The use of mobile technology in the description of seizures serves as an adjunct to the diagnosis and should not substitute a good clinical history and examination. The incorporation of mobile technology to facilitate epilepsy diagnosis requires access to mobile phones and electricity, as well as reliable internet connectivity to relay video recordings which may be challenging in rural areas in some LMICs. Socio-cultural barriers may also exist for sharing of information relating to epilepsy, and this may influence carers negatively. Witnesses may not be available to record events or they may be pre-occupied and worried about the safety of the patient. In other instances, seizures may be very brief, and / or subtle and therefore not easily captured by video recording. Nocturnal events and events occurring in poorly lit areas may also not be picked up and recorded. Additionally, the beginning of the event may be difficult to record especially if seizure evolution is very fast, occurs with little warning or if there are behaviours or somatosensory auras not recognised as ictal.

Based on the literature review and the convenience sample findings the following aspects are important to document in the setting of a home video referral: presence of accompanying history from referring source, level of experience of the referring clinician (in instances where the source is a clinician) and whether the caregiver was given instructions of how to take an optimal home video. The outcome of the videos should be graded according to the QOV (Table 2) and the confidence of the specialist to make a diagnosis which should fall into the following categories namely: certain, possible, or not possible. Children in whom the diagnosis remains unclear will be the group directed for more extensive interventions from further history, additional videos and potentially vEEG.

The use of online media platforms for sharing or conveying video material also carries the risk of security breach of the patient's private information. Concerns about information privacy on mobile platforms carries a high litigation risk for all parties involved and can also be a deterrent for patients to use the services. There are also emerging concerns on the proprietary ownership of information that is shared on online platforms considering that a permanent data record is held in custodial trust by internet domains and as such is not entirely owned by the person who made the recording. Data records are also vulnerable to other cyber threats such as infiltration/corruption of stored electronic records by computer viruses etc.

STUDY LIMITATIONS

The existing studies lacked consistency in study methodology and directness in study question which limited comparison of findings. To our knowledge we identified all studies relevant to the study question but the search terms may have been too narrow and missed some reports. Further, use of videos is common, and the structured studies may not have represented real clinical practice. The convenience sample was small and limited to clinicians/carers with access to a paediatric neurology service and may not adequately represent the breadth of paroxysmal events in the wider population. This assessment was undertaken to assess the viability of the QOV tool rather than to understand the complete range of video cases referred to the service.

CONCLUSION:

The available literature supported that home video recordings of good quality, reviewed by experienced clinicians with accompanying history can be beneficial to differentiate between epileptic and non-epileptic seizures, thus improving reliability and diagnostic accuracy. This could lead to earlier, more targeted care, avoid unnecessary invasive and costly interventions and risk of inappropriate antiseizure medications. The studies varied for consistency and directness in their methodologies. Few formally critiqued the quality of the submitted videos using the Quality of Video scale. Only three studies included children. The ethical issues of transfer of private information on internet domains were not categorically addressed in these studies.

Based on the findings of the retrospective convenience sample coupled with the paucity of similar studies in children, there is need for a prospective study to delineate if the growing practice of using mobile video recordings, particularly in a current and post pandemic context, is an appropriate tool to add to the management of people with epilepsy and to understand how this should be implemented

for optimal ethical and management outcomes. A multicenter prospective study would further enable protocol development for seizure diagnostic aids utilizing mobile video technology. The ethical concerns of conveying sensitive information across internet platforms also need to be highlighted. Liaison between referring and receiving clinicians on video captured events will further define the knowledge gaps amongst health care practitioners on identification of paroxysmal events and target education needs. It will also help inform parental education needs regarding seizure identification.

Legends:

Figure 1: PRISMA flow diagram for the identified papers.

Table 1: Summary of the literature on use of home videos to differentiate seizures from other paroxysmal events. Delineated via PICO analysis (Population, Intervention, Comparator, Outcome)

Table 2: Quality of the video will be graded as follows: (adapted from Dash *et al* and Ojeda *et al*)^{18, 21} * notes areas novel for videos of children. Key LOA = level of awareness.

Table 3: Summary of convenience group demographics, QOV score and outcome.

Supplement 1: Summary of the literature review search terms and process.

Figure 1: PRISMA Flow Diagram for literature assessing the role of home videos

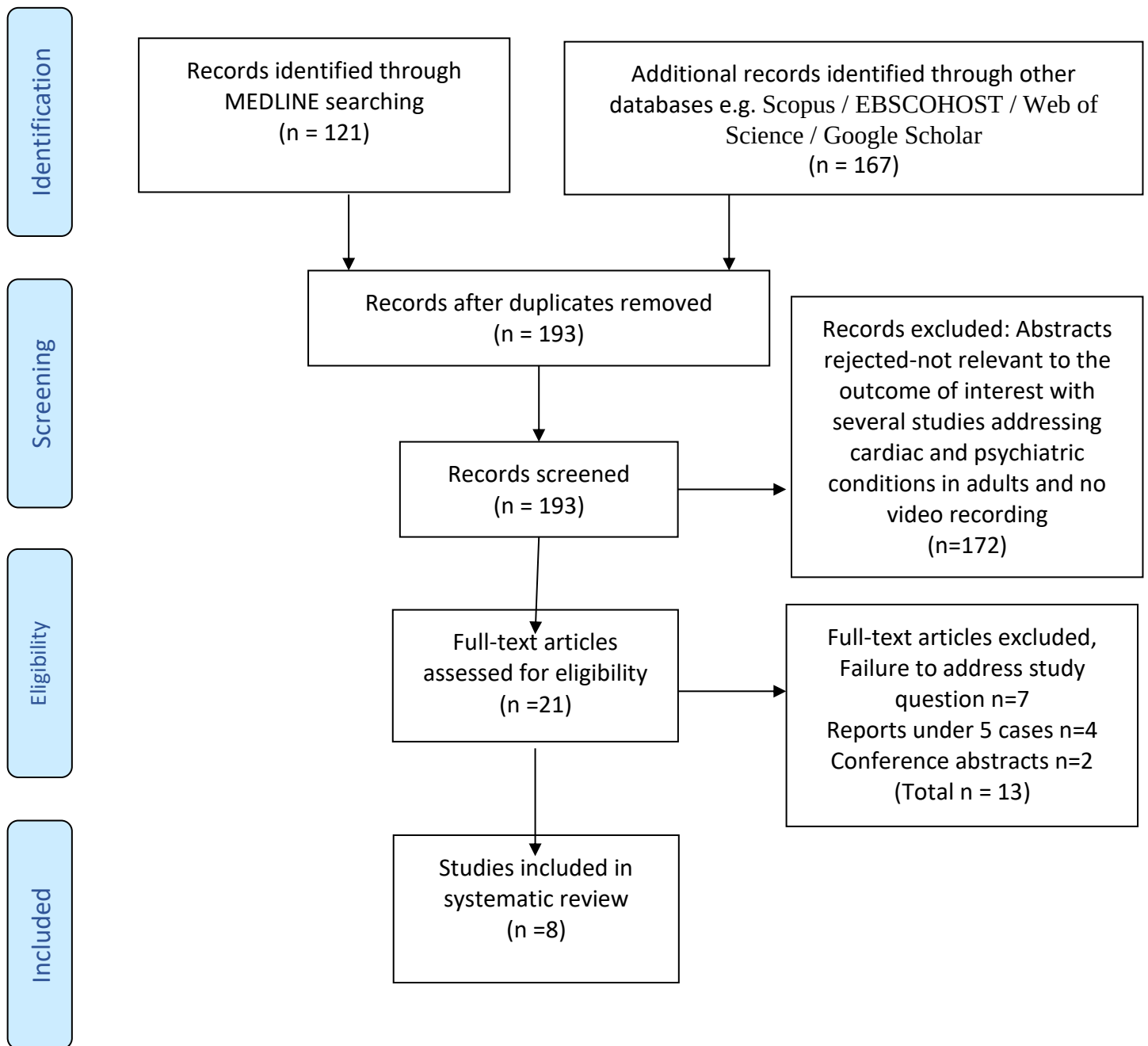


Table 1: Summary of the literature on use of home videos to differentiate seizures from other paroxysmal events. Delineated via PICO analysis (Population, Intervention, Comparator, Outcome)

Paper / Location / year	Study Question Study Type	Population group	Intervention	Comparator:	Outcome:	Comment
Tatum <i>et al</i> ¹⁴ USA 2020	Assessed usefulness of OPD smartphone videos to diagnose epileptic seizures from 44 convenience samples of non-consecutive adult outpatients presenting for the first time who presented with good quality videos (as assessed by epileptologists) and were subsequently delineated with vEEG. Prospective, masked, diagnostic accuracy study	Epileptologists and trainee doctors from 8 academic epilepsy centers n=530 (530 total physician reviews)	Epileptologists and trainees reviewed studies to state opinion of diagnosis (ES or PNES). Measures of performance (accuracy, sensitivity, specificity, positive predictive value, and negative predictive value) for smartphone video-based diagnosis by experts and trainees (the index test) were compared with those for history and physical examination and video EEG monitoring (the reference standard)	Validity of the tool (smartphone video) based on level of experience.	About 80% of recorded videos were ranked by reviewers as having adequately good quality. Smartphone video was accurate in predicting diagnosis of epileptic seizures by experts 89.1% (95% CI, 84.2%-92.9%) of the time, with a specificity of 93.3% (95% CI, 88.3%-96.6%). Resident responses less accurate, despite greater confidence. Motor signs during events increased accuracy. Addition of history and examination to video, diagnoses rose from 78.6% to 95.2%. A correct diagnosis was 5.45 times greater when smartphone video accompanied history and examination (95% CI, 1.01-54.3; P = .02).	Expert review of outpatient smartphone video has predictive and additive value for diagnosing epileptic seizures. Smartphone videos may reliably aid PNES in some settings. Recommended greater interactivity, longer recordings and optimal views. 30 of the 44 subjects had PNES making generalization difficult. Promoted triage for patients at

	(the OSmartViE study).					greatest need for vEEG.
Huang <i>et al</i> ¹⁵ China 2019	Three steps: 1. role of home videos for diagnosis on the patients' first visit, 2. the cost savings of video online consultation, 3. what type of doctor is optimal. Prospective study	452 practitioners from six centers attending pediatric academic conferences.	Practitioners asked for diagnoses from descriptions alone of 12 infants with paroxysmal events	Same group was re-questioned after watching the corresponding home videos of the episodes	301/ 452 met the criteria (66.6%) for analysis. The mean correct diagnoses with and without videos was 8.4 (SD 1.7) of 12 and 7.5 (SD 1.7) of 12, respectively. For epileptic seizures, mobile phone videos increased the mean accurate diagnoses by 3.9% (p= 0.006); for nonepileptic events, it was 11.5% (p<0.001). More senior paediatric neurologists had higher diagnostic accuracy.	Home videos are a cost-effective tool and useful for the diagnosis of paroxysmal events in infants. Recommended video infants with paroxysmal events and consult online a senior neurologist.
Ramanujam B, et al. India 2018	Role of mobile phone videos to diagnose Psychogenic Non-epileptic Seizures (PNES).	Videos from n=783 Patients suspected with PNES Hospital based study Prospective study of consecutive patients aged 10-50 years of age	Selected 269 videos out of the 783 screened. Of the 269, 155 had fair quality (QOV 5-7) and 114 had good quality (QOV 8-10) Videos of all recruited subjects were reviewed by the epilepsy fellow (single reviewer, blinded to clinical history; step 1) the label of PNES was assigned if at least three of the semiological features reported by *LaFrance et al. as having "good evidence from primary studies" or by **Lazarus et al. as 'ictal characteristics'	Compared to video EEG telemetry recordings	The diagnosis at step 1 was epileptic seizures in 71.4% and PNES in 27.1%. Diagnosis at step 2 was PNES in 25.3%, other physiologic events in less than 1% and epileptic seizures in 73.6%. There was a concordance between the diagnoses in steps 1 and 2 of 97.2% of subjects with no statistically significant difference between the diagnoses of steps 1 and 2. PNES diagnosis sensitivity of 95.4% (95% CI: 87.2%-99.1%), specificity of 97.5% (95% CI: 94.3%-99.2%), positive and negative predictive values of	Concluded that good quality home-videos may be used to differentiate PNES from epileptic seizures and can complement vEEG in diagnosing PNES in a cost-effective way. Utilised "Quality of Video scale" ¹⁸ . Note significant proportion of videos could not be used.

			were noted in the videos^{22, 23} (Criteria were provided for labelling events as PNES using specific features such as eye closing/resistance to eye opening), ictal crying, jaw clenching, hyperventilation, pelvic thrusting, side to side head and body movements, memory recall. All patients subsequently underwent vEEG which were reviewed by an epileptologist (blinded to the diagnosis formulated by the epilepsy fellow); step 2 and concordance between their diagnoses noted in each case		92.65% (95% CI: 84.1%-96.8%) and 98.5% (95% CI: 95.6%-99.5%) respectively. The most commonly noted semiological features on home videos pointing to diagnosis of PNES were: Eye closure; accuracy of 96.2% (95% CI: 92.3%-98.45%) Crying or shouting; accuracy of 89.6% (95% CI: 83.1%-93.2%) Hyperventilating; accuracy 89.1% (95% CI: 83.7%- 93.2%) Wild, uncoordinated movements; accuracy 71.74% (95% CI: 64.6%-75.7%) Lying still/no movements; accuracy 81.6% (95% CI: 75.3%-86.8%)	
Wasserman and Herskovitz¹⁷ Israel 2017	Compared capacity of clinicians of different levels of experience to diagnose PNES from ES based on 10 videos (5 PNES and 5 ES) to reduce diagnostic delay	46 participants, 26 non-neurological and 20 neurological personnel.	Ability of neurologists to differentiate between PNES and ES in a cohort of videos from adolescents and adults.	Ability of non-neurologists to differentiate between PNES and ES	Epileptologists diagnosed correctly 87.5% of cases, General neurologists 72.8%. Neurology nurses 69.8%, ER nurses 58%, Internal Medicine physicians 54.1% and ER physicians 44.4%. Statistically significant difference between the general physicians to all neurology group professions was >0.05.	Neurologist ability to recognize seizures using semiology alone was found to be higher than other medical personnel. The group encouraged the need for video

	and need for vEEG Prospective study					taking of episodes and education plan to first responders who were noted to have low diagnosing ability
Ojeda et al ²¹ Spain 2016	Explored the role of home video to assist epilepsy diagnosis in adults Prospective observational study	Of 317 consecutive adult patients with drug resistant epilepsy (established at least two years before) attending epilepsy service, caregivers instructed to record optimal home video. Instructions for good quality recordings were provided including turning on lights, using a steady hand, interacting with patient, asking questions to the patient, assessing the	Three neurologists/epileptologists watched the videos in clinical session, rated the quality of the recordings following some parameters (face or whole body recorded, environmental illumination, single or multiple events, early stage of event recorded) and made a clinical diagnosis.	In a second phase, previous diagnosis was revised.	87% had access to recording devices. From this group, 135 (50%) felt unable to record events. Reasons given: Low seizure frequency: 60%, seizures short duration: 80%. 50 events from 22 patients recorded. Previous epileptic syndrome diagnosed (based on description/neuroimaging/EEG): 15 focal temporal lobe epilepsy, 4 focal frontal probably symptomatic epilepsy, 3 epileptic encephalopathy. Regarding the QOV, the mean rating was 4.6 points out of a possible maximum of 8 and minimum of 3. (5 had excellent recordings, (QOV 8-10), 64% had medium quality recordings (QOV 5-6) and 27% had low quality recordings (QOV 3-4) In a second phase, there was agreement among neurologists in the clinical and semiological diagnoses but in one patient	Some bias as these patients were already in an epilepsy service and the caregivers were given instructions how to perform the video. Used different recording methods Photo camera: 100%, cell-phone: 100%, webcam: 10%, video camera: 30%). Only half of these able to capture event. Group recommended that homemade videos may be of diagnostic value in epilepsy management. Training in

		patient's awareness and memory, capturing face and whole body.			who had tremor: action tremors. Focal clonic seizure. 18 patients' diagnoses were confirmed, three patients were determined to have been misdiagnosed with temporal lobe epilepsy and they all had non epileptic seizures. It was also highlighted that non epileptic seizures were more likely to be recorded and yielded better QOVs than epileptic seizures, though no statistical conclusions could be drawn due to low numbers.	performing good-quality videos is necessary. Webcam long term recordings should be recommended as the best recording option. Also used a Quality of video rating score- the same as devised by Dash et al 2016 ¹⁸ .
Dash <i>et al</i>¹⁸ India 2016	To evaluate the yield of different semiological signs inferred from the descriptions provided by caregivers and to evaluate the role of home videos as independent tools to diagnose epilepsy by picking up seizure phenomenology and classifying epilepsy types in a resource poor setting, with the rationale that the	Home videos from 312 patients with a total of 624 seizures analyzed. Of this group a total of 572 seizures in 282 of the patients were evaluated on vEEG to verify suspected diagnosis. Phase I: participants were encouraged to record videos of	Questionnaire of 29 different semiological features administered on findings of home video The questionnaire was developed by two epileptologists based on the commonly encountered semiological features in clinical practice, with different levels of accuracy ascribed to various semiological features. The QOV scale for assessing video quality was developed for this study by one of the co-authors Manjari Tripathi	Agreement on semiological signs was measured between the questionnaire completed on the basis of medical history and home videos and on the basis of vEEG (gold standard)	The mean number of signs of semiology recorded after analysis of the home videos was 3.3 ± 2.2, and from the caregiver medical history was 2.1 ± 1.1 ($P < 0.01$). Bilateral generalized clonic movements of limbs, motor movement around mouth, fear, visual phenomenon, hemisensory phenomenon, and post-ictal unilateral weakness had the highest accuracy (greater than 85% sensitivity, specificity and accuracy). The overall agreement of semiological signs inferred from medical history versus vEEG was 0.75 and between home video recordings versus vEEG was 0.92.	A larger number of patients were correctly categorized into the focal epilepsy group when home videos were used to classify compared to when medical history was used. The study concluded that home videos were more reliable in picking up semiological signs and classifying

	limited repertoire of descriptive terminologies in a population with low education restricts the seizure description narrative. Prospective observational study.	events which were then assessed by the developer of the QOV scale and the 29 point questionnaire was also filled for each recording by the assessors based purely on the video recording provided and a diagnosis made Phase II: The 29 point questionnaire was administered to the subjects caregivers by a trained epilepsy resident and an attempt made at arriving at a diagnosis based on caregivers descriptions Phase III: Subjects underwent vEEg and semiology analysed by	(an epileptologist) and has been utilized in other studies subsequently			epilepsy type than history provided by caregivers of PWEs.
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		epileptologist using the 29 point semiology questionnaire and a diagnosis made. The vEEG aided diagnosis was deemed gold standard				
Goodwin <i>et al</i> ¹⁹ United Kingdom 2014	Assessed if patients on ambulatory EEG could match events with home video recording. Carers were tasked with recording events when they occurred and noting the time of occurrence for subsequent analysis alongside the ambulatory EEG Prospective study	Total of 130 patients offered a camcorder but only 45 patients (35%) accepted. Adults and children age range 13 days to 59 years. N=45	Caregivers who agreed to record events of they occurred during the study	No control group	34 (76%) had an event of which 17 (50%) were adequately/satisfactorily recorded. The main reasons for failure were that attacks were too brief, or machine error. Attacks were captured with greater success in children (14/23, 61%) than adults (3/11, 27%). Of the 17 video recordings, 14 (82%) aided interpretation of the ambulatory EEG.	n=130 were invited to participate but only 35% accepted. Main reason for saying "no" was that the events were too brief to capture. Study also highlights the importance of appropriate patient selection for take home interventions
Samuel and Duncan ²⁰	The role of hand held video camcorder in the evaluation of seizures	22 consecutively filmed patients with undiagnosed	Events recorded on camcorder reviewed for ability to assist differentiating between	No comparator	Videotapes assisted the diagnosis of non-epileptic attacks in nine of 22 patients (41%), and of epileptic attacks in eight of 22 patients (36%). 8	Interactions with patients during filming were particularly helpful.

United Kingdom 1994	Prospective study	events had events recorded via hand – held video camcorder on the ward by the nursing staff and subsequently, the video tapes were reviewed by medical staff	epileptic and non-epileptic events. The aim of filming was initially to provide a global picture of the event as soon as possible after the onset and then to further concentrate on eyes, mouth, cyanosis, breathing patterns, speech and sounds. The camera was able to work at low levels of illumination thus permitting recordings of nocturnal events. During the filming, a member of staff would interact with the patient including; response to commands, menace, pain, plantar reflexes and attempts to open eyes to assess resistance and direction of gaze. Serum prolactin levels were also measured and all patients underwent interictal eEEg and continuous EEG where feasible and the final diagnostic classification of seizures was based on the combined evidence		failed to generate useful video information. In two patients (9%) a confident diagnosis of non-epileptic seizures could be made from the videotapes alone. Seven patients subsequently required video-EEG telemetry. In the 10 patients with non-epileptic attacks, several features were filmed including: Resistance to attempted eye opening or avoiding eye contact in eight (8), elaborate and prolonged rigidity, opisthotonos, arm waving or leg kicking in seven (7), facial grimacing to menace or to testing plantar reflexes in four (4) voluntary salivation in two (2) patients directly interacting with camera on realising that they are being filmed (2) and self- restraint with the arms during falling in one patient.	It was concluded that the hand - held video camera is a useful and inexpensive tool to provide accurate seizure descriptions, but it should be used in conjunction with other evidence to classify seizures
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Table 2: Quality of the video will be graded as follows: (adapted from Dash et al and Ojeda et al)^{18, 21} * notes areas novel for videos of children. Key LOA = level of awareness.

Video activity	Adequate yes / no	score
Captured event from start		/2
Adequate lighting		/1
Visualized face		/1
Visualized relevant body parts		/1
Interacted with child (voice)*		/1
Touch child to demonstrate event could not be stopped*		/1
More than one event		/1
Possible to assess LOA*		/1
Captured all of event inclusive of postictal movement and speech		/1
TOTAL		/10

Table 3: Summary of convenience group demographics, QOV score and outcome.

Demo- graphy	Source	Brief history provided	Question/presumptive diagnosis	Epileptic seizure or not	Quality (as per assessor) Defined as clarity of video, capturing the onset of event and face	Adapted QOV score	Video could help answer question with diagnostic certainty	Final diagnosis
5 y.o male	Clinician Medical officer	Yes	Is this a focal seizure	yes	Good	6	Yes	Focal seizure
2 m.o Male	Carer	Yes	Is this a seizure	No	Good	7	Yes	Hyperkplexia
6 y.o female	Clinician Paeds registrar	Yes	Is it a focal seizure	yes	Good	7	Yes	Focal seizure
11 m.o male	Clinician Paeds registrar	Yes	Is this a seizure	yes	Good	6	Yes	Epileptic seizure
8 y.o female	Clinician Medical officer	Yes	Should I commence CBZ (by implication..Is this a focal seizure?)	yes	Good	6	Yes	Focal seizure
12 m.o female	Clinician Paeds registrar	No	Is this a seizure	No	Good	7	Yes	Infantile gratification
7 m.o male	Clinician Paeds registrar	Yes	Are these spasms?	yes	Good	7	Yes	Epileptic spasms
5 y.o male	Clinician Paeds registrar	No	Is this absence or focal seizure	Yes	Good	7	Yes	Focal seizure
3 m.o male	Clinician Paeds registrar	No	Is this jitteriness	Not certain	Poor- face and onset not captured	2	No	Undefined
13 m.o male	Carer	Yes	Is this a seizure	Not certain	Good	7	Yes	Definite myoclonus but further history recommended to delineate type of myoclonic syndrome.
9 m.o female	Clinician Medical officer	Yes	Is this a seizure	No	Good	7	Yes	Gratification
18 m.o male	Clinician Paeds registrar	Yes	Is this a seizure	yes	Good	5	Yes	Atonic drop

6 y.o female	Clinician Medical officer	Yes	Is this absence or focal seizure?	yes	Good	6	Yes	Focal seizure
4 y.o female	Clinician Medical officer	Yes	Is this a seizure	No	Good	7	Yes	Breath holding
10 m.o male	Clinician Medical officer	Yes	Are these spasms?	Not certain	Poor-face not captured	2	No	Cannot exclude spasms
7 y.o male	Clinician Paeds registrar	No	Are these focal seizures	Yes	Good	7	Yes	Focal seizure
17 m.o male	Clinician Paeds registrar	No	Are these myoclonic jerks	No	Good	6	Yes	Movement disorder
15 m.o male	Carer	Yes	Are these spasms?	Yes	Good	7	Yes	Epileptic spasms
6 y.o female	Clinician Medical officer	No	Is this absence or focal seizure	Yes	Poor----onset not captured/face not well visualised	2	No	Possible focal seizure, but cannot be certain
8 m.o female	Clinician Medical officer	No	Are these seizures	No	Good	5	Yes	Infantile Gratification
4 y.o female	Clinician Paeds registrar	No	Is this a focal seizure	yes	Poor----onset not captured/no interaction	1	No	Possible focal seizure
11 m.o male	Clinician Paeds registrar	Yes	Are these spasms?	Yes	Good	5	Yes	Epileptic spasms
8 y.o male	Carer	No	Is this a seizure	Not certain	Poor-onset and face not captured	2	No	Possible frontal lobe seizure vs conversion
11 y.o female	Carer	No	Is this epileptic	No	Good	5	Yes	PNES/conversion
8 y.o female	Clinician Paeds registrar	Yes	Is this absence or focal seizure	Yes	Poor- onset not captured/ poor lighting/no interaction	2	No	Possible focal seizure

Supplement 1: Summary of the literature review search terms and process.

Literature search was undertaken by the researchers with the assistance of the University librarian to assess data relating to the role and use of phone / mobile device videos to assist in the delineation of children with seizures and paroxysmal events. Pubmed, Scopus, EBSCOHOST, Web of Science and Google Scholar were searched. Search terms were “Neurology”; “home video OR home videos OR mobile video OR mobile videos OR smartphone videos OR smartphone videography”; “Diagnosis OR diagnose OR delineation”. With MeSH search headings included where available. Only human clinical studies published in English were included, case reports of under 5 patients were excluded. Review articles were screened for additional papers.

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