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Diagnosis of epileptic seizures by community health workers using a mobile app: A comparison with physicians and a neurologist

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ABSTRACT

Purpose: The World Health Organisation (WHO) strategy for non-physician health workers (NPHWs) to diagnose and manage people with untreated epilepsy depends on them having access to suitable tools. We have devised and validated an app on a tablet computer to diagnose epileptic episodes and now examine how its use by NPHWs compares with diagnosis by local physicians and a neurologist.
Methods: Fifteen NPHWs at Jan Swasthya Sahyog (JSS) a hospital with community outreach in Chhattisgarh, India were trained in the use of an epilepsy diagnosis app on a tablet computer. They were asked to determine the app scores on patients in their communities with possible epilepsy and then refer them first to their local JSS doctors and then to a visiting neurologist. With the neurologist's opinion as the "gold standard", the misdiagnosis rate from the NPHWs was compared with that of the local physicians.
Results: There were 96 patients evaluated completely. The NPHWs misdiagnosed eight and the physicians seven. There were more uncertain diagnoses by the NPHWs. In the 22 patients who presented for the first time during the study, the NPHWs misdiagnosed three and the physicians five.
Conclusions: NPHWs using an app achieved similar misdiagnosis rates to local physicians. Both these rates were well within the range of misdiagnosis in the published literature. These results suggest that task-shifting epilepsy diagnosis and management from physicians to NPHWs, who are enabled with appropriate technology, can be an effective and safe way of reducing the epilepsy treatment gap.

1. Introduction

Untreated epilepsy causes people with it very serious problems including death, disfigurement and social disgrace [1,2]. Untreated epilepsy is treatable with drugs with the expectation that about two thirds of people will be free of epileptic seizures [3]. But identifying people with untreated epilepsy is a problem because they are reluctant to attend health camps [4] and do not always admit to their problem on door-to-door surveys [5]. It is likely that raising community awareness of epilepsy may make identification easier and it is also likely that there will be local knowledge in a community about who may have epilepsy.

But once identified people needed diagnosed and treated. Indeed there is little point identifying them if they are not going to be treated. In many parts of the world however, especially in rural areas, there are no doctors to diagnose and treat [6–9]. It has been suggested by the World Health Organisation (WHO) that non-physician health workers (NPHWs) could diagnose and manage patients if they were given suitable tools [10], and there are of course many more NPHWs[1] than doctors. The first stage of the process of diagnosis is the determination about whether episodes of loss or alteration of consciousness are epileptic or non-epileptic in nature, and a tool in the form of a phone app for this purpose has been developed in Nepal [11]. This was derived using Bayesian principles by starting with the pre-test probability of episodes being epileptic and then calculating the likelihood ratios (LRs) of episodes being epileptic for each of 40 variables. The eventual algorithm asks the most eloquent 11 questions (those with LR > 3) about the episodes (Table 1), weights the answers based on the LR, and arrives at a probability score of the episodes being epileptic or not. The algorithm was converted into an app which can be used on

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Table 1
Variables with Likelihood Ratios > 3 of episodes either being epileptic seizures (F) or not epileptic seizures (A).

Prior to the episode	Male Gender (F) Predisposing factors excluding family history (F)
During the episode	Colour change to red or blue (F) Stiffness (F) Shaking (F) Tongue bitten (F) Incontinence of urine (F) Head turning to one side (F) Eyes closed (A) Able to communicate (A)
After the episode	One-sided weakness (F)

From Ref. [11] with permission.

both Android and IOS devices (NetProphets Cyberworks Pvt, Noida, India) [12].

The app was subsequently validated in Nepal and India [13]. The NPHWs who participated in this validation study were computer-literate but in the real world many NPHWs may have a very incomplete formal education and no experience of smartphones or tablet computers, although most possess basic mobile phones. We have since shown that a group of computer-naïve NPHWs had no difficulty in the technological aspects of using an app on a tablet computer [14]. The study below reports how these computer-naïve NPHWs, using the app, can diagnose episodes as epileptic or not, and how their accuracy compares to local physicians, with the neurologist's diagnosis as the "gold standard". In other words how safe and effective is this method of diagnosis.

2. Methods

2.1. Location

Jan Swasthya Sahyog (JSS) is a unique hospital in Ganiyari near Bilaspur, Chhattisgarh. It is a non-governmental organisation with a community health care model which trains and supports local villagers as NPHWs. Government health services are effectively non-existent in the area and JSS provides the only medical support for this community of about one million people. The population is mostly tribal and has been described in detail [15].

2.2. Community health workers

Villages in the area served were arranged in three clusters serving a population of about 35,000 people. A sub-center served each cluster. Local health workers in these clusters participated in the study. Only two had previous experience of computers or smartphones but 11 of the 13 had a conventional mobile phone. They adapted well to using this unfamiliar technology [14].

2.3. Hospital

Patients with epilepsy attending the hospital Emergency Department (ED) were also eligible for inclusion. The ED was staffed by two NPHWs who were trained in using the app which they completed before the patient was seen by a doctor.

2.4. Local doctors' clinics

Clinics were held at the main hospital three days per week and at each sub-center once weekly. The doctors attending the sub-centres were postgraduate residents in family medicine. If they were uncertain of the diagnosis they could refer the patient to a more experienced doctor at the hospital.

2.5. Neurologist visits

A neurologist (MBS) from the All India Institute of Medical Sciences (AIIMS) in New Delhi visited two to three times per year to advise on patients with epilepsy and other neurological conditions.

There had been two previous visits to JSS by MBS and on one occasion she had been accompanied by PJ and VP. Epilepsy self-help groups had previously been started in three clusters of villages.

2.6. Tablet computer hardware

Tablet computers (Penta T-pad™, Pantel Technologies Pvt Ltd) were supplied to the participating NPHWs who were given responsibility for their care. They were encouraged to familiarize themselves and use the other features of the tablet at home.

2.7. Software

The tablets ran Android™ version 4.4.2. The mobile application Epilepsy Diagnosis Aid (NetProphets Pvt Ltd) was installed on each tablet. The language used was Hindi. The algorithm underpinning the app had been developed in a study of epilepsy patients in Nepal [11] and had been validated in an English version in a previous study in 132 patients in India and Nepal [13].

2.8. Health worker training

The participating NPHWs were given 11 h of training delivered in Hindi which covered the nature of epilepsy, causes, treatments, first aid, education of patients, neurocysticercosis, its effects and social aspects. The course included a three-hour practical session on the use of the tablets and use of the app. The course was presented by three of the authors (VA, PJ and VP)

2.9. Study inclusion criteria

Patients were included if they had ever had intermittent episodes lasting up to two hours of either loss of consciousness or alteration of consciousness or shaking or abnormal behavior with return to normality afterwards. Patients who had been previously seen for this symptom at JSS or its sub-centres or had been seen elsewhere and then referred to JSS were included. We included patients of any age even though those less than nine years of age had not been studied in the development and validation phases of the app.

2.10. Identification of suitable patients

NPHWs identified patients in a number of ways. First through members of the self-help groups who brought along someone who they thought might have epilepsy. Second by self-presentation of such patients to the NPHW. Third by the NPHW's knowledge of someone in the community who fitted the criteria and finally by people who had presented to the local doctors either at the hospital or the sub-centres.

2.11. Ethics

The study was approved by the Ethics Committee of AIIMS, New Delhi.

2.12. Study design

When a potential patient presented the NPHW checked against the inclusion and exclusion criteria that they were suitable for the study. The NPHW then explained the study, obtained written consent and gave the patient an information sheet about the study in Hindi. Each patient was given a unique identifier consisting of a letter, denoting the NPHW, and a number which was allocated by that NPHW consecutively starting at one. That is *C4* was the fourth patient seen by the NPHW who was designated *C*. The NPHW then recorded the patient's name, village, age and sex and how they had been identified. With the help of an eyewitness to the episodes if possible the app score was determined and recorded. It was saved on the tablet and when the NPHW was next at the hospital the record was uploaded on to a secure server.

In accordance with the validation study app scores of 80 or greater were recorded as *epileptic* and below 31 as *non- epileptic* with the rest being *uncertain*. The NPHW did not make any comment to the patient about the app score. All identified patients were referred to a local doctor for further diagnosis and management. The doctor had no access to the app score.

In addition to normal documentation of the consultation the doctor recorded on a special sheet using the patient's unique identifier the diagnosis of the episodes as to whether epileptic seizures or not. If not epileptic, the nature of the episodes was specified. If the episodes were thought to be epileptic, it was noted whether the person was currently on treatment and if not whether they had ever been on anticonvulsant treatment. The types of epileptic seizure were recorded. The doctor instituted management as thought appropriate.

The patient was then seen by a neurologist (MBS) at her next visit. As well as conventional management she recorded on a special sheet using the patient's unique identifier the diagnosis of the episodes as to whether epileptic seizures or not. If not epileptic, the nature of the episodes was specified. The types of epileptic seizures and the type of epilepsy were recorded. Patients in whom the neurologist was not certain were not analyzable and so were excluded from analysis.

2.13. Statistics

The "gold" standard was taken as the neurologist's opinion as to whether the episodes were epileptic or not. This was compared with the app score (>79 for epileptic episodes (E), <31 for non-epileptic episodes (NE), otherwise uncertain (U)) and with local doctors' diagnoses – E, NE, U. After taking statistical advice we expressed the results as misdiagnosis rate, sensitivity and specificity, rather than using kappa statistics to measure agreement.

3. Results

3.1. Demographic details

One hundred and eighty seven patients were recruited into the study. We had complete information – consent form, app score, neurologist's form, and local physician's form – in 101 patients (Table 2). The remaining 86 patients were not included because one or more of the above were missing, most often the neurologist's opinion.

The demographic details of the patients are as follows (Table 2):

Table 2
Details of 101 patients.

		Number of patients
Gender	Male	61
	Female	40
Age (years)	<10	22
	10–20	38
	21–30	17
	31–40	15
	41–50	5
	>50	4

3.2. Agreement between neurologist and others

The neurologist was uncertain about the diagnosis in five cases (5%) and these were excluded from the analysis leaving 96 evaluated cases. Agreement between the neurologist and the physician and the NPHW/app combination is shown in Table 3.

Thus the app disagreed with the neurologist on eight out of 96 cases (8%) with physicians disagreeing on seven (7%); there was also more uncertainty, nine cases as against four. Sensitivities and specificities are in Table 4.

Of the patients less than age 10 where the app had not been used in the previous studies it agreed with 17 of 19 patients all of whom had epilepsy according to the neurologist. The remaining two had uncertain scores. The physician agreed with all 19.

3.3. Analysis of cases not seen by the neurologist

For logistic reasons many patients had difficulty coming to see the neurologist. There were 24 such consented patients. Their NPHW/app diagnosis classified them as not epilepsy in four, uncertain in two and epilepsy in 18. On the basis of Fisher's Exact Test, his group was not significantly different from the patients seen by the neurologist ($p = 0.114$).

3.4. Seizure classification

For the patients seen by the neurologist, 87% had tonic-clonic seizures and the remainder a variety of non-convulsive seizures. In the patients not seen by the neurologist, 75% had tonic-clonic seizures.

3.5. Patients previously unknown to JSS

There were 22 such patients with a mean age of 29 years (range 5–70). Ten had been presented from within the community and 12 had been seen by outside doctors. The neurologist rated 19 as epilepsy and three as non-epilepsy. The physicians judged the diagnosis as uncertain in two and made five misdiagnoses. The NPHW/app had four uncertain diagnoses but only three misdiagnoses.

3.6. Individual analysis of discordant patients

The eight patients in whom there was disagreement between the NPHW/app and the neurologist were analysed in more detail. Four were mistakenly diagnosed as epilepsy and four as non-

Table 3
Comparison of misdiagnosis and uncertainty rates by physicians and the NPHW/app combination in different age groups using the neurologist's diagnosis as the "gold standard".

		Physician Diagnosis		NPHW/App Diagnosis	
	Number	Uncertain	Misdiagnosis	Uncertain	Misdiagnosis
Age ≥ 10 yrs	72	2	7	7	8
Age < 10 yrs	19	0	0	2	0
Total	96	2	7	9	8

Table 4
Sensitivities and specificities compared to neurologist.

	Sensitivity %	Specificity %
Physician	93	50
NPHW/App	86	33

epilepsy. Three of those misdiagnosed as epilepsy were from a single NPHW; in one, neither neurologist nor physician felt that the episodes were paroxysmal so that they should probably not have been included in the study. Of the four patients misdiagnosed as non-epilepsy one had a focal seizure without impairment of consciousness and in another the neurologist commented that the history was difficult.

4. Discussion

The misdiagnosis rate of the NPHW/app combination is similar to that of local physicians when measured against a neurologist. This is important because in the vast swathes of the world there are neither epileptologists nor neurologists and the local doctor (if there is one) is the *de facto* "gold standard". Compared with physicians the NPHW/app combination had more uncertain diagnoses – nine against three – but similar numbers of incorrect diagnoses – eight against seven. In the 22 patients either newly diagnosed or diagnosed by outside doctors the app did better – three misdiagnoses compared with five for the physicians

There are many published papers about misdiagnosis rates for epilepsy and these have recently been reviewed [16]. But most of them are from rich countries and most are about mistaken diagnosis of non-epilepsy episodes as epilepsy rather than the other way round. The latter has been less well-described [17,18]. In this study misdiagnosis by both the physician and the app was split evenly both ways. The misdiagnosis rate – 8% for the app and 7% for the physician – compare well with the recent systematic review of false-positive diagnosis where rates vary from 2 to 71% [16].

In 2005 a tool was devised for NPHWs in Asia to diagnose tonic-clonic seizures [19]. When used by physicians in South Asian countries it achieved a sensitivity of 72.1% and a specificity of 100% in a population of 223 of which 197 had tonic-clonic seizures. This equates to a misdiagnosis rate of 25%, considerably worse than that of the present study.

The low specificity in this study was not found in previous studies of the app and may reflect the small numbers of people with non-epileptic events in the study and the fact that they were not recalled and included by the NPHWs as they were not on any community register. In India epilepsy accounts for over 90% of presentations to epilepsy clinics. In a survey of patients presenting to the Lifeline Express, a mobile epilepsy clinic, only 20 out of 334 (1.8%) did not have epilepsy [20]. Similarly in a recent study of over 70,000 schoolchildren in Sudan only 9% of children presenting with "seizures" did not have epilepsy [21]. Non-epileptic presentations are much higher in "richer" countries [22]; over 30% of people attending a first seizure clinic in Canada had non-epileptic events, most commonly syncope [23]. Perhaps this is because there is a reservoir of untreated epilepsy in poorer countries which does not exist in richer ones. But because the frequency of epilepsy presenting to clinics is much greater than that of non-epilepsy, reduced specificity results in far fewer misdiagnosed patients than reduced sensitivity. We did not collect information on exact diagnosis in non- epilepsy cases but psychogenic non-epileptic attacks were much commoner than syncope, something also found in the two studies above and in our previous validation study [13].

Uncertainty exists at all levels of diagnosis, whether by epileptologists or NPHWs [24]. This is because all the information from the history may not be available if the episodes are not witnessed independently. It remains a dilemma how such patients should be managed as doing investigations or arranging follow-up is often impractical in poor rural communities.

This is the first time that the app has been tested on people under nine years old. It identified 17 of 19 cases where the neurologist was certain of the diagnosis. Presumably these seizures were convulsive and since the semiology of convulsive seizures is not different in children and adults this result is perhaps not surprising.

This study was carried out in a real-life rather than an artificial setting and so there are inevitably potential biases. There was a single neurologist as the gold standard. To lessen this the neurologist used standard guidelines about the diagnosis of seizures and epilepsy and we sought follow-up evidence of diagnosis change by reviewing the charts looking for any later change in diagnosis; 30 patients had been seen subsequently by the same neurologist and six by a different neurologist (VP); there were no changes in the neurologist's original diagnosis. There was also the possibility of bias from doctors and neurologists being aware of the app score (even though we did everything possible to avoid this) and there were the difficulties in obtaining full follow-up of recruited patients. The last may be in part to do with patients having more important things to do in their life than make hospital visits. The struggle for day-to-day survival is not far below the surface for many people in this part of rural Chhattisgarh. These patients had made their first contact with health services but they had difficulty coming again. This phenomenon has been observed repeatedly before. In a study in a tribal community from Jharkand similar to that studied here only 453 of 787 people with possible epilepsy identified by NPHWs came to a subsequent medical camp [4]. It emphasizes the need to diagnose and start treatment for epilepsy, and indeed other diseases, at the first patient contact.

5. Conclusion

This is the third study on the use of this seizure diagnosis app. It is clear that its use by NPHWs has the potential to be effective and indeed to replace some doctor's time, making available a scarce resource in poorer parts of the world. It provides evidence that supports the plan of the WHO to devolve much of epilepsy care to NPHWs. Episode diagnosis, is however only one part of epilepsy management and a more comprehensive tool is required. But this study indicates how the combination of task shifting and technology has the potential to change things for the better for this neglected group of people.

Conflict of interest statement

VP developed the app used in this study and holds the intellectual property rights.

The other authors have no conflicts of interest.

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