



Validation of a phone app for epilepsy diagnosis in India and Nepal



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ARTICLE INFO

Article history:

Received 12 March 2015

Received in revised form 11 May 2015

Accepted 12 May 2015

Keywords:

Untreated epilepsy

Epilepsy treatment gap

Phone app

mHealth

Health workers

Bayesian

ABSTRACT

Purpose: Untreated epilepsy is a major global public health problem with more than 20 million people not being treated for an easily treatable disease. In part this is due to a lack of trained doctors. There are many more non-medical health workers than doctors and they could have an important role in diagnosis and treatment of epilepsy if they had some tools. We have previously described such a tool to distinguish epileptic episodes from other causes of altered consciousness and here present its validation in three new populations.

Methods: The tool was presented as a phone app where the answers to 11 questions provided a probability score which indicated whether episodes might be due to epilepsy or not. It was applied either by non-medical volunteers, health workers, or inexperienced doctors to 132 patients in three separate populations in India and Nepal and compared with the “gold standard” diagnosis of a neurologist with expertise in epilepsy.

Results: There was good agreement between the app score and the neurologists' diagnoses (weighted kappa = 75.3%). An app score of 90 or greater had a sensitivity of 88% and a specificity of 100% for diagnosing epilepsy. The app was easy to use with little training and took about 5 min to administer.

Conclusion: A tool presented as a phone app can be used by non-medical health workers to identify episodes as epileptic or not with good accuracy. It needs to be evaluated more widely but has the potential to play a part in reducing the epilepsy treatment gap.

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1. Introduction

Untreated epilepsy is a major problem in poorer countries where about three quarters of people with active epilepsy are not on treatment [1]. Yet treatment with relatively inexpensive medication can abolish seizures in about two thirds of such patients [2]. There are a number of reasons for this treatment gap one of which is lack of access to doctors of any sort let alone neurologists [3,4] – in many poorer countries most people live in the countryside whereas doctors usually live in cities.

Two broad solutions have been suggested to overcome this treatment gap: the first is to delegate functions of diagnosis and treatment to non-doctors such as nurses, paramedics or village health workers who are more numerous than doctors and who live

closer to the people with untreated epilepsy [5,6]. The second is to educate locally practising doctors and get them to take on a greater role in epilepsy care with support from specialists [7]. The exact operational details of these systems of care has not been fully documented but if either group is to take over a greater role in epilepsy care they will need some tools to help them. The World Health Organisation, as part of their Mental Health programme, have reviewed evidence on the specific question “*Can convulsive epilepsy be diagnosed at first level care by a non-specialist health care provider in low and middle income country settings?*” and concluded that there was a need for further studies to address this question [8].

Previously we have described a tool to enable non-doctors to diagnose episodes of altered consciousness as epileptic or not. This was developed in Nepal and was based on an analysis of the sort of questions which comprise routine history taking in this situation [9]. Questions with the highest likelihood ratios [10] of episodes being epileptic (E) or not epileptic (NE) were combined sequentially in the tool which then gave a post-test probability score of a particular episode being E. This mimics the way experienced

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doctors make the diagnosis. That tool showed initial promise in separating *E* from *NE* in a small population of 14 patients. The aim of the present study is to test its validity in a larger series of patients from India and Nepal.

2. Methods

2.1. Locations

Patients were studied at three separate locations. These were all special clinics for people with suspected epilepsy which had been advertised as widely as possible during the preceding weeks using local notices, newspapers, local radio and word-of-mouth. Patients were assessed clinically, in the usual way, by the authors shown in parentheses. The patients were all new attendances to the authors.

1. An epilepsy clinic on the Lifeline Express Hospital train based at Raipur India (MS).
2. Epilepsy camps at Dhulikhel Hospital Nepal (VP).
3. Epilepsy camps run by the Nepal Epilepsy Association at three places in Western Nepal (HR, VP).

2.2. Use of the diagnostic tool

The previously described tool was incorporated into a phone app to run on Android™ phones. This app was developed by NetProphets Cyberworks Pvt Ltd. Each record consisted of an identifying clinic number and the 11 questions which had been defined in the previous study. These are shown in Table 1 with the available answers.

Using the same algorithm as in the previous study a probability score for the episode being epileptic was then calculated. The pre-test probability of having epilepsy from the original study – 0.76 – was used giving pre-test odds of 3–1 in favour of having epilepsy. The odds were then multiplied by the likelihood ratio for having epilepsy of each of the 11 questions inputted sequentially. This final figure was then converted to a probability score which was displayed on the phone screen. The records were stored on the mobile phone and later uploaded to a secure server from which they could then be downloaded for analysis as a .csv file. No patient-identifiable information was stored on either the individual phone or on the server. The record was linked by a study number to the patient record which avoided duplicate entries.

The tool was used by non-doctors in location 1, by trainee doctors in location 3, and by a combination of the two in location 2. The health workers and trainee doctors were trained in using the phone app by being taken through it once by VP and being given a three-page set of guidelines. VP was available to answer specific questions if required. The average time to use the phone app was recorded on a sample of the patients at location 1.

At location 1 the tool was used in a separate session either before or after the clinical consultation. The order was pre-determined by randomizing study numbers to being assessed either before or after the clinical consultation. At locations 2 and 3 the tool was used in the course of the clinical consultation. The trainee doctor or health worker who entered the data also acted as translator for VP.

2.3. Clinical assessment

Only patients with episodes of loss of consciousness or awareness over nine years of age were included. Patients were seen by a neurologist and their episodes were categorized as epileptic (*E*), not epileptic (*NE*) or uncertain (*U*). This was done in the usual way based on a history from the patient and from an available eyewitness, obtained in person or by phone, followed by an examination of the patient. The neurologists came to their conclusion without reference to the phone app score.

2.4. Ethics

The study was approved by the Ethics Committee of the All India Institute of Medical Sciences.

3. Results

3.1. Patients seen

Details are shown in Table 2.

The final diagnoses in those who did not have epilepsy included a single case of parasomnia with the rest being either non-epileptic attacks or panic attacks. There were no cases of syncope. At Raipur it proved impossible to randomize patients into being tested before or after their clinical consultation as in practice they tended to disappear after their consultations with the doctor and then the epilepsy educators. So in practice most app testing was carried out before the clinical consultation.

3.2. Probability scores

The probability scores as determined by the phone app are shown in Fig. 1 for each patient in each of the three clinical groups displayed in ascending order of probability score – *E*, *NE* and *U*. In general there is near-complete separation between the groups. Three patients who were clinically uncertain achieved very low probability scores using the app because there was no eyewitness available to give an account of the seizure. In future the absence of an eye-witness combined with a low probability score will categorize the patient as uncertain. In general, those patients whom the app categorized as uncertain had less well-described

Table 1
Questions and possible answers used in the phone app.

	Questions	Possible answers		
Prior to the episode	Gender	Male	Female	
	Predisposing factors excluding family history	Yes	No	Not known
During the episode	Colour change to red or blue	Yes	No	Not known
	Stiffness	Yes	No	Not known
	Shaking	Yes	No	Not known
	Tongue bitten	Yes	No	Not known
	Incontinence of urine	Yes	No	Not known
	Head turning to one side	Yes	No	Not known
	Eyes	Open	Closed	Not known
	Able to communicate	Yes	No	Not known
After the episode	One-sided weakness	Yes	No	Not known

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