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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.