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Epilepsy field workers, a smartphone application and telephone telemedicine: Safe and effective epilepsy care in rural Nepal



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ABSTRACT

Purpose: Most people with epilepsy live in low- or middle-income countries (LMICs) where there are relatively few doctors. Over 50% of people with epilepsy in these countries are untreated so other models of care are needed. In this report we evaluate a novel model of care.

Methods: We trained four residents of Myagdi, a rural district in Nepal as epilepsy field workers (EFWs). They provided epilepsy awareness to their communities. When they identified someone with possible epilepsy they used a smartphone application (app) to determine the probability score for an episode being epileptic and contacted an epilepsy specialist by phone. If the specialist thought treatment was indicated this was arranged by the EFW. We recorded mortality, change of diagnosis at face-to-face consultation and drug-related events as measures of safety. Seizure frequency and general wellbeing were also recorded, and a questionnaire was devised to measure satisfaction.

Results: 112 patients with app scores suggesting epileptic seizures were identified and managed in 18 months, of whom 15 had provoked seizures. Forty-three percent of epilepsy patients were untreated. At follow-up one had died of a cause other than epilepsy. Diagnostic agreement at face-to-face assessment was 93%. Overall 5% had side-effects of medication. Seizures were stopped in 33% and reduced in 57%. Ninety-six percent of patients preferred this service to travelling to other doctors.

Conclusion: This novel service met all criteria of safety and was effective in reducing frequency of seizures. Patients preferred it to conventional services. It should be transferable to other LMICs.

1. Introduction

The majority of people with epilepsy in the world live in low or middle income countries (LMICs) [1]. These countries have high treatment gaps – the percentage of people with epilepsy not on treatment. These range from 50 to 90% and are larger in rural areas than in cities [2]. One of the reasons for large treatment gaps is an absence of doctors to treat and manage epilepsy [3–5]. This is much worse in rural areas where the great majority of these people live and where doctors generally neither live nor visit. For the same reasons those patients with epilepsy already on treatment often receive a sub-optimal service.

So other methods of care are needed if both the epilepsy treatment gap is to be reduced and epilepsy care improved. The World Health Organization (WHO) has realized this [6] and has called for non-physician health workers (NPHWs) to be involved in the care and

management of people with epilepsy. There have been successful reports of this strategy from China [7] and Zimbabwe [8] but both have involved in-person involvement of local doctors.

But if NPHWs are to assume a greater role in epilepsy management they will need tools to help them. Over the last few years we have developed an aid for separating epileptic seizures from other causes of paroxysmal neurological events. This has been presented as a smartphone application [9] (app) which, in response to a series of questions, generates a probability score of the episodes being epileptic or not. The algorithm underlying the app uses a Bayesian approach and was developed in a Nepalese population [10] and validated in India and Nepal [11]. This app, presented on a tablet computer, can be used easily by computer-naïve NPHWs [12] and, when compared to the diagnosis of a neurologist, can generate similar agreement to that of local doctors [13]. The sensitivity of this app was 92% and 86% in two previous

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studies [11,13] with specificities of 100% and 33%. More importantly its misdiagnosis rate was 8% compared with 25% for the tool designed in South Asia by Anand et al. [14]. Also the use of the telephone by specialists to deal with epilepsy patients has been well-documented in many different settings [15–18].

In setting up an epilepsy service for a rural district of Nepal we wanted to identify, diagnose and treat people with possible epilepsy at a single encounter because other studies have shown a drop-out of patients between initial identification and later treatment [19,20]. We chose a combined approach incorporating local NPHWs using an app, and a remote epilepsy specialist, connecting the two by telephone. We did not have easy access to fully-trained NPHWs so instead we trained local people with little health background as epilepsy field workers (EFWs) in both clinical aspects of epilepsy and use of the diagnosis app. An epilepsy specialist (HR), based in Kathmandu, the capital city of Nepal, spoke to the EFWs by telephone and passed on a treatment plan to be delivered locally. We report an evaluation of the safety and effectiveness of this unique way of delivering epilepsy care.

2. Methods

2.1. Location

Myagdi is a district in the Western Region of Nepal with a population of about 115 000 people. Its principal town, Beni, is at the extreme south of the district and contains the only hospital. There are very few doctors outside Beni but there is a network of government health posts which however do not generally advise on epilepsy. There are also many traditional healers.

Myagdi has few roads and the only way to travel is walking but it takes more than two days to walk from the most northerly villages to Beni. From Beni it is about 10 h by bus to reach the nearest epilepsy specialist in Kathmandu. Mobile phone coverage however is fairly good even in remote areas.

2.2. Epilepsy field workers

Initially we trained two local residents from separate villages to cover the south of the district. Training consisted of a three-day intensive course in which they were taught on important clinical and social aspects of epilepsy based on the mhGAP program of the WHO [21]. They were provided with the diagnosis app on a smartphone or tablet. As well as support from a project manager in Kathmandu (SM) by telephone and intermittent in-person visits. They also attended some in-person clinics by HR. After 12 months two additional EFWs were recruited to cover the northern part of the district.

EFWs had two main roles: first they provided epilepsy awareness to their communities by talking for example to individuals, community groups, schools and village committees, explaining to them that epilepsy was a treatable medical condition and dispelling the myths surrounding it. Through this, and because they lived in the community, they were able to identify individuals with possible epilepsy and assess them for treatment.

2.3. Medical opinion

When the EFWs identified someone with possible epilepsy they straightaway used the diagnosis app to determine the probability score of the episode being epileptic. If an epileptic seizure was likely they then contacted an epilepsy specialist (HR) by phone in the presence of the person. HR was able to talk directly to both the patient and the EFW and decide if treatment with an anti-epileptic drug (AED) was indicated. If medication was required this was supplied from local stocks held by the Nepal Epilepsy Association.

2.4. Supply of anti-epileptic medication

The Nepal Epilepsy Association [22] is a Kathmandu-based epilepsy charity and a member of the International Bureau for Epilepsy. It was able to acquire AEDs at bulk prices and distribute these to patients at no cost. Distribution was done by one of the EFWs in conjunction with the local District Medical services.

2.5. Safety

2.5.1. Mortality

Eighteen months after the start of the study we invited all the participants to a face-to-face clinic in Beni. We offered patients a subsistence allowance and free accommodation to induce them to attend. For those who did not attend we contacted them by telephone in the next six months. If we could not establish contact or there was no contact number we contacted a local person and asked them. If this was unsuccessful the EFW visited the village.

2.5.2. Change in diagnosis

This was recorded at face-to-face consultation by a neurologist not previously involved (VP) and who was unaware of the diagnosis – epilepsy, provoked seizures, not epilepsy or uncertain – and who was also unaware of the app scores. Seizures were classified as convulsive or non-convulsive [21] and epilepsy type according to the International League Against Epilepsy [23].

2.5.3. Possible drug-related side-effects

These were recorded at the follow-up consultations whether FF or by telephone.

2.6. Effectiveness

At follow-up consultations it was recorded whether seizures were stopped or less frequent or the same or worse, and, as a measure of general wellbeing, whether the person felt better, the same or worse.

2.7. Satisfaction

A questionnaire was devised to assess satisfaction and administered by a Nepali speaker who was independent of the study (SJ). There were nine questions based loosely on the dimensions of quality as defined by the Institute of Medicine in the USA [24]. The answers were recorded using a 5-point Likert scale. We also asked patients at follow-up whether they were seeing other doctors for their epilepsy.

2.8. Governance

The project had the consent and cooperation of the Nepal Government Social Welfare Council and the Myagdi District Medical Officer.

2.9. Funding

The project was funded by a grant from Sathi Nepal with additional resources from the Nepal Epilepsy Association and the participating doctors.

3. Results

3.1. Patients seen

One hundred and twelve patients with app scores suggesting epileptic seizures were identified and managed. Provoked seizures occurred in 15, alcohol being the cause in 13 and febrile episodes in two. The 97 patients ranged in age from 6 years to 77 years with a mean of

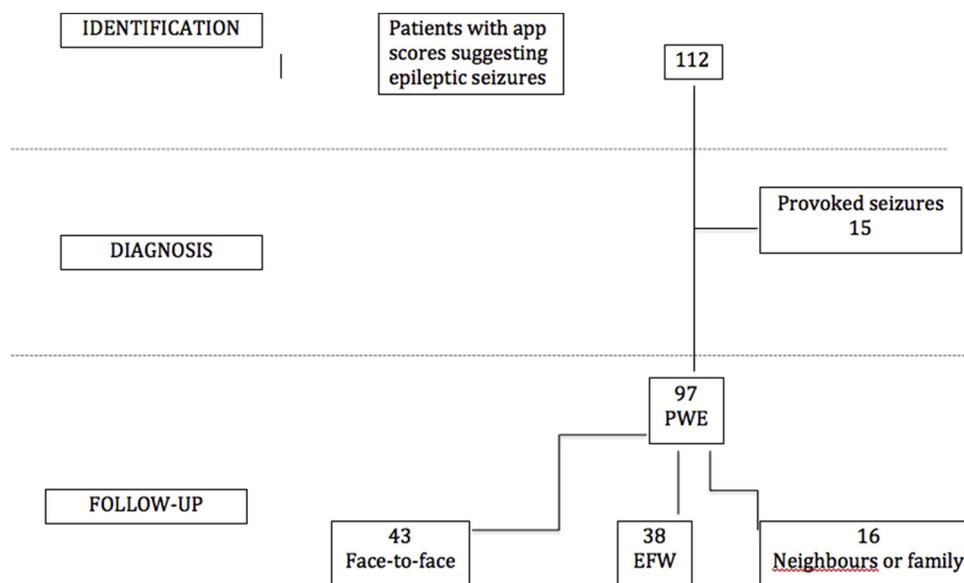


Fig. 1. Flowchart of identification, diagnosis and follow-up of patients. (PWE patients with epilepsy, EFW epilepsy field worker).

31. Fifty two percent were male. (Fig. 1)

Forty-three percent of the patients with epilepsy were not on anti-epileptic medication. Six patients with epilepsy declined to go on treatment as did three who had coexistent psychotic illness. Treatment initiated was generally with carbamazepine, valproate, levetiracetam or phenytoin. Phenytoin was not used.

3.2. Safety

3.2.1. Mortality

All of the study population was traced: 43 by face-to-face examination by a neurologist, 38 by the EFWs and 16 by ascertaining whether they were alive or dead from neighbours or family. A single person died during the study period. This was a 77 year-old woman whose death, according to family members, was due to problems other than seizures.

3.2.2. Change in diagnosis

Forty-three patients attended for FF consultation with a different neurologist (VP). Mean age was 30 years, range 12-72. There were 58% males

Thirty-two patients had only tonic-clonic seizures, six had non-convulsive seizures and five had both. All had a focal epilepsy according to clinical epilepsy classification [25] – neuroimaging and EEG are not easily available in Myagdi and few patients had ever had them performed.

Most people were taking a single drug with 33% taking two and 9% three.

Most commonly used drugs were carbamazepine (44%), levetiracetam (35%), valproate (28%) and clobazam (26%).

Forty patients were diagnosed FF as epilepsy and three as uncertain. Two had been previously treated and one was untreated at presentation. None had provoked seizures. As all the patients were diagnosed as epilepsy by the telephone system this constitutes a diagnostic agreement of 93% and a misdiagnosis rate of 0%.

3.2.3. Side effects

At the FF clinic two patients had side-effects of medication (5%). One had gum hypertrophy on phenytoin and the other had squinting vision on valproate. Overall side effects were reported in three of 66 patients in whom information was available (5%). (Table 1)

Table 1

Safety and effectiveness indicators at follow-up.

	FOLLOW-UP METHOD			Total %
	Face-to-face (FF) by neurologist (n = 43)	Telephone or FF by EFW (n = 38)	Contacting Neighbours or Family (n = 16)	
Deaths n = 97	0 (0%)	1 (3%)	0 (0%)	1
Diagnosis Change n = 43	3 (7%)	–	–	7
Misdiagnosis rate n = 43	0 (0%)	–	–	0
Drug Side-effects n = 66	2 (5%)	1 (4%)	–	5
Frequency of Seizures n = 81				
stopped	11 (26%)	16 (42%)	–	33
fewer	26 (60%)	20 (53%)	–	57
same	6 (14%)	2 (5%)	–	10
worse	0 (0%)	0 (0%)	–	0
General wellbeing n = 60				
better	28 (80%)	22 (88%)	–	83
same	7 (20%)	2 (8%)	–	15
worse	0 (0%)	1 (4%)	–	2

3.3. Effectiveness

3.3.1. Seizure control

In the 43 patients seen FF seizures had stopped in 11 (defined as no seizures for 12 months), were less in 26 and the same in six. Results in the whole group are shown in Table 1. There was no difference between previously treated and untreated groups. The group with both convulsive and non-convulsive seizures seemed to do less well than the other two groups – 3 out of five (60%) stopped or better compared with 28/32 (88%) in the convulsive only group and 6/6 (100%) in the group with non-convulsive seizures though obviously these numbers are small. There were three patients whose seizure control was inadequate on usually-effective doses of AEDs. They were referred to the All India Institute for Medical Sciences, New Delhi, India (AIIMS) for consideration of epilepsy surgery under the care of one of the authors (MS).

Table 2
Patient satisfaction questionnaire (n = 22).

Question	Not Applicable	Strongly agree	Agree	No opinion	Disagree	Strongly disagree
Q1. This service is better than I had before	2	7	11	2		
Q2. I would recommend this service to other people		1	18	2	1	
Q3. I found the EFW easy to contact	1	6	15			
Q4. Its easier for me than going to hospital or private doctor	1	12	9			
Q5. My seizures are better than they were		6	13	1	2	
Q6. Overall I feel better than before		1	17	2	2	
Q7. I feel less scared with this service than before		9	12		1	
Q8. I do not have to wait long to see the EFW and doctor	2	2	13	4	1	
Q9. Its easy to get advice on the phone wherever I am	2	15	5			

3.3.2. Wellbeing improvement

At FF examination this information was available in 35 patients of whom 28 (80%) felt better and seven the same. None felt worse. There was no difference between previously untreated and treated patients. Results in the whole group are shown in [Table 1](#).

3.4. Satisfaction

3.4.1. Questionnaire

This was administered to 22 patients attending a separate face-to-face clinic. Responses were overwhelmingly positive. Ninety-six percent agreed that the service was easier than going to a hospital or a private doctor (Q4). Eighty-two percent said that they would recommend this service to others (Q2). Ninety-one percent found it easier to get advice by telephone. (Q9). The questions and full results are shown in [Table 2](#).

3.4.2. Seeing other doctors

Of the FF group three of 43 were receiving care from other doctors for their epilepsy. Overall other doctors saw 18% of the 78 patients in whom this information was available.

4. Discussion

We have described how NPHWs can be involved to provide a model of care for epilepsy patients which is of high quality according to the IOM criteria [24] – safe, effective, patient-centred, timely and equitable. It also reduced the epilepsy treatment gap from 43% to 9% with the latter group remaining untreated by choice. Although the WHO have stated that NPHWs should be encouraged to take on the burden of diagnosis and management of epilepsy in poorer parts of the world they have not stated how this is to be done. The tool we have developed as an app to assist in the diagnosis of episodes as epileptic or not should help NPHWs but it needs to be incorporated into an overall system of delivering care. This paper has described one such system in which an EFW with no previous health experience uses the app and communicates by telephone with an epilepsy specialist to obtain a diagnosis and management plan. Knowing the app probability score greatly simplified the specialist's assessment.

We have shown that this system is safe. Safety is one of the six dimensions of quality in the definition drawn up by the Institute of Medicine in The United States of America and is arguably the most important when assessing a new method of treatment. Assessing safety in non-surgical interventions is more difficult than in surgical ones but death, diagnosis change and side-effects of medication are the obvious markers which allow an assessment of safety. In this study there was a single death (in the oldest member of the study cohort) and importantly there was 100% ascertainment for this. The estimated number of deaths from this cohort of 97 patients with epilepsy followed for 12 months is similar to the recent study from China which found an all-causes death incidence of 11.23 per 1000 patient years [26]. The independent

assessment of diagnosis at face-to-face attendance showed a disagreement of 7% but only between epilepsy and uncertainty; the misdiagnosis rate – between epilepsy and not epilepsy - was 0%. Again this is well within the limits reported in the recent systematic review of misdiagnosis [27]. Only 43 of 97 patients attended this clinic and this is likely to be due to the considerable transport difficulties in rural Nepal which has a low population density and no roads so it may take two or three days to make the trip to a clinic. Most people are subsistence farmers and can ill afford to spend that amount of time. And a 5% rate of side-effects from AEDs is much less than that reported in a recent literature review of community-based epilepsy interventions where the average incidence of adverse events was 27% across 13 studies [28]. This may be because we did not use phenobarbitone which was used in most of the reviewed studies.

Effectiveness is another of the IOM's six dimensions of quality and we assessed this using first reduction in seizure numbers and second improvement in wellbeing, both self-reported. Ninety percent of patients had fewer seizures. The follow-up was not long enough to ascertain the total number becoming seizure-free. Also 83% of people reported that they had improved wellbeing. Those whose seizures were drug-resistant were referred to a tertiary centre in India (AIIMS, Delhi) for consideration of epilepsy surgery.

The satisfaction questionnaire which was administered to a sample of patients measured different quality dimensions, principally patient-centredness. Again the results were overwhelmingly positive for every question. Two questions (Q3,Q8) were about timeliness and they had positive ratings also. Equity is the quality dimension we did not test but it is self-evident that a locally-delivered service in place of one delivered many miles away is going to be more equitable. The overwhelming response to the statement "I would recommend this service to other people" suggests that the stigma of epilepsy in this part of rural Nepal may have been lessened. This model of care enables rural Nepalese patients to have a similar service to those living in urban Kathmandu.

But all this comes at a cost: medication, EFWs salaries and the time taken by HR (given freely) present sustainability challenges. However there are substantial savings in the time of a specialist; using the method in this study the specialist dealt with 97 people with epilepsy in about 10 min each. If the patients had been seen in a face-to-face clinic the specialist would have spent three days including travelling time to see 43 patients (the number attending the face-to-face review clinic in the study) as the remainder would not have attended. That amounts to 72 h for 43 patients, which equates to 100 min per patient. So the method in this study reaches over twice the number of patients with a 90% saving in specialist's time. We hope to publish a full health economic evaluation in the future.

As well as helping people whose epilepsy is untreated this system also benefits those with treated epilepsy who are likely to co-exist in any one region if the treatment gap is not 100%. These treated patients may be being managed suboptimally and will have difficulty accessing continuing care; their needs should be incorporated into any new model

of care.

There are a number of possible factors which might confound our conclusions such as the completeness of ascertainment of people with epilepsy by the EFWs, the outcome of people with low app scores and the less than 100% follow-up for all measures other than mortality. Reasons for the last have already been highlighted. There were less than five people with low app scores and these were not followed up. Because of the small number this is unlikely to have affected the overall results. We feel that the results of this study are much more likely to be valid than not.

5. Conclusion

There is unlikely to be a single solution to reducing the epilepsy treatment gap in LMICs because each country, or region of a country, has different resources available to it. This particular model of care involving EFWs without any formal health training takes into account absence of functioning local doctors, and indeed absence of trained health workers, both of which are problems in many parts of the world. Doctors are very reluctant to live in rural areas of any country so some sort of telemedicine is the obvious practical solution for rural epilepsy patients as long as there is a doctor somewhere willing to take on their care. As well as helping people whose epilepsy is untreated this model also benefits those with treated epilepsy who will have difficulty accessing continuing care; both are likely to co-exist in any one region. Having a local EFW also increases the awareness of epilepsy within a community, which should reduce the condition's stigma. So by delivering raised awareness, identification, diagnosis, treatment and review an EFW, in connection with a remote specialist, can provide outstanding epilepsy care to rural patients.

Declarations of interest

VP holds the intellectual property rights of the Epilepsy Diagnosis App.

The other authors have no interests to declare.

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