



Use of Simple Information Communication Technology to Manage the Epilepsy Challenge at a Community Cottage Hospital in the Niger Delta Area of Nigeria

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SUMMARY

Epilepsy is a worldwide problem associated with stigmatization. In Nigeria many of these patients do not access adequate care, drop out of school or employment and many die at home. To help ameliorate this problem, the Obio Cottage Hospital, a Community Cottage Hospital in the Niger Delta of Nigeria, runs a seizure clinic for these patients. In addition simple ICT based video recording of attacks by mobile phone and sending the videos to the clinic by WhatsApp application is used to reach distant patients who may otherwise not access adequate care. Three vignettes demonstrating the use of this cheap, simple-to-use and widely available ICT to successfully manage epilepsy is reported. It is concluded that this can be employed to effectively manage epilepsy as well as similar health challenges in people who would otherwise not access adequate care in developing countries. Recognition of electronic signature for prescription drugs in this kind of circumstance is recommended.

INTRODUCTION

Epilepsy is a common neurological condition worldwide.¹ Nearly 80% of people living with epilepsy live in low and middle income countries². In Nigeria epilepsy has been reported to constitute about a quarter of neurological disorders seen in children in a tertiary hospital in the south-south geographical region of the country. Stigmatization of people with epilepsy, which appears to be worldwide, is particularly rampant in Nigeria.^{1,3}

Even highly educated people, including teachers, have misconceptions about the cause and treatability of this condition and stigmatize these patients.⁴⁻⁶ In addition many of these patients have no access to adequate care, partly because of the general belief in Nigeria that epilepsy is not amendable to western medicine⁴⁻⁶ and also because the facilities and qualified manpower to treat this condition are lacking in the country. As at 2011 it was reported that there were only fifty

neurologists in the country of more than 170 million people.⁷ Many of such affected children are given inappropriate care including herbal concoctions, enemas, home remedies, prayers in spiritual houses and traditional healers' remedies.^{4,5} Many of the children suffering from epilepsy in Nigeria are reported to die at home.⁸

In an effort to help ameliorate the problem of epilepsy in Nigeria, the Obio Cottage Hospital (OCH), a Community Cottage Hospital supported by Shell Petroleum Development Company in the Niger Delta region of Nigeria, has established a seizure clinic dedicated to the management of people of all ages with epilepsy. In order to reach patients in faraway places from the hospital who cannot otherwise access care, the center has introduced the use of simple, cheap and widely available information communication technology to manage this condition. We believe that this can be a model for the management of epilepsy and similar health challenges in this environment, and present here three vignettes on this management modality.

VIGNETTES

Vignette 1

Five year old master M.A living in a rural part of south-south Nigeria who had up to 30 seizure attacks a day for one year and received inappropriate treatment in many facilities including churches, herbal homes, pharmacies and even regular health facilities. Child had dropped out of school because of frequent attacks of seizure. Below is the whatsapp conversation between OCH seizure clinic and the mother published *verbatim* with the consent of both parents.

WhatsApp exchange between Mrs X, the mother of one of the children and the clinic.

Mrs. X: ok sir

Mrs. X: thanks for calling

Mrs. X: u r rili a God sent

Clinic: when did it start?

Mrs. X: Last yr August

A little touch on his head he will start shaking

Afta (After) sometime minutes or secs it will stop

He does it more dan (than) 30 times a day

Clinic: this can be handled. Is he able to walk?

Mrs. X: yes

Clinic: good. I am in Portharcourt currently. Is he in school?

Mrs. X: he was going to sch(school) but has since stopped school. he speaks and eat very well

Clinic: ok

Mrs. X: we took him to hospital dey(they) said its seizure

Different churches too

Yet no improvement

Hw (How) is ur(your) family sir

Clinic: it can be solved. Please stop doing churches for that. Any good pastor knows there are drugs for it

Mrs. X: sir pls I try to send it but network waz(was) so bad. These r (are) d (the) drugs.

Dolo-neurobian suspension, touvephaboid suspension

Clinic: those are useless for the condition. Did you get it from a doctor?

What is the weight of the child?

Mrs. X: last month dat (that) I took him to the hospital, the weight waz(was) 11 or 12.

Clinic: can you take a video of the attack and send it through whatsapp

Mrs. X: yes

The video of typical attacks was made and sent to the clinic via WhatsApp. Analysis of the video suggested complex partial seizure with automatism or focal seizure with impaired awareness. Child was placed on carbamazepine at 10mg/kg daily. Monitoring continued via WhatsApp. Dose was adjusted every week until seizure attacks decreased to three per day, at which point child returned to school. Further increase in dose resulted in dose related side effects of drowsiness and giddiness. Child was left at the maximum tolerated dose of carbamazepine and levetiracetam added at a dose of 250mg 12 hourly. Zero attack was then achieved and maintained. Regular review is continuing via

WhatsApp chats. Several months after parents were able to bring the child to the facility. CT scan showed normal brain study.

Vignette 2

Thirteen year old adolescent who had repeated epileptic attacks reportedly for one year and had dropped out of school. A video of the epileptic attack was sent to the seizure clinic by the parents via WhatsApp application. Analysis of the video showed generalized seizure disorder clonic type.

Child was placed on tablet of carbamazepine 200mg 12 hourly. Seizure control was achieved within a month and child has since returned to school. Regular review continues via WhatsApp chat.

Vignette 3

The video of a sixteen year old adolescent managed unsuccessfully in another hospital in a neighboring state was sent to us at the clinic. Analysis of the video showed violent hyperextension of the trunk and thrashing of the head from one side to the other with hyperventilation. A diagnosis of pseudoseizure was made and the hospital advised to involve a psychotherapist and a counselor, in the management of the adolescent.

DISCUSSION

These vignettes demonstrate the well-known problems of patients with epilepsy in resource limited environments. The child in vignette 1 had to withdraw from school because of frequent seizure attacks. The well-known poor knowledge and attitude of teachers to pupils with epilepsy may have contributed to this withdrawal.⁴⁻⁶ School dropout in children with epilepsy is particularly rampant in underdeveloped countries and represents serious setback to the education and development of these children.¹⁰⁻¹² In addition this child had presented to a variety of places for care, including herbal homes and spiritual houses with expectedly poor outcome. Child also presented at orthodox health facility but was poorly managed

and placed on drugs that have no bearing on the management of seizure disorders. That could only reinforce the widely held belief in our environment that epilepsy is not amendable to orthodox medication¹³ and confirms the poor knowledge of health practitioners on the diagnosis and management of epilepsy.¹⁴ While poor knowledge and attitude toward epilepsy is widespread, it is particularly problematic in rural settings in Africa.¹⁵ Successful management of patients in a rural setting as this through the deployment of ICT could help demystify the condition and put it in a modern context.

The second vignette illustrates again the perceived hopelessness in the management of epilepsy and the tendency for these children to drop out of school. This child lived in an urban environment yet could not access adequate care. The parents could not afford the time and fare to transport the child to our clinic, which they heard about from a nurse working in our cottage hospital. Fortunately they could make a video of a typical attack and send to us through WhatsApp application and the child has since achieved adequate seizure control and returned to school.

The third vignette illustrates the potential for collaboration between health facilities through the use of simple information communication technology for the better management of patients with seizure problem particularly in a country like Nigeria with very few trained personnel⁷

The WHO has identified telemedicine as an important modality for the provision of equitable, qualitative, accessible and effective health care services for both developed and less economically developed countries using modern information and communication technology.¹⁵ The elements germane to telemedicine include provision of clinical support, overcoming geographical barriers and connecting users who are not in the same physical location, using various types of ICT, with the overall goal of improving health outcomes. Barriers to telemedicine have been reported to include the perception that it is expensive to implement, underdeveloped infrastructure and

legal issues such as patient confidentiality.¹⁶ As at 2015 more than 50% of the over 181 million population of Nigeria was reported to have access to the internet, with triple digit growth rate of mobile phone usage almost every year since 2001.¹⁶ With such a large access to internet and wide use of mobile phones, telemedicine is undoubtedly feasible in Nigeria. Telemedicine has been considered a revolutionary mode of health care delivery that can improve equity of access, quality of care and the efficiency by which it is delivered.¹⁸ It has been argued that countries with inadequate health care have to incorporate telemedicine into their health care system through volunteer efforts of doctors globally.¹⁹ It has been shown effective in delivering services in developing countries such as Bangladesh, Nepal and the Solomon Islands.^{20,21}

A major type of telemedicine is interaction between the client and the expert through data, text, still images and video pictures.¹⁸ WhatsApp application is cheap, easy to operate and widely available in Nigeria and can store and transmit data, messages, and still images and video pictures. These vignettes show the large potential of this cheap information and communication technology in managing epilepsy and other similar challenges in Nigeria. Epilepsy at all ages can be reliably diagnosed by careful history and reports of observers.²² This simple ICT gives opportunity for good history and observation even from the most remote areas in Nigeria and similar environments. The confidentiality of these patients was not anymore compromised as it would have been in a regular neurology clinic. However virtually all drugs for the management of epilepsy are prescription drugs. The patients still had to present to a qualified doctor for review and transcription of our prescriptions. This may not always be easy for patients in all parts of Nigeria, particularly in the rural areas. This raises the need for a clear policy on the recognition of electronic signatures.

CONCLUSION

Epilepsy, and similar health problems, can be effectively managed by used simple ICT, such as WhatsApp application, in resource-limited environments. The privacy of such patients would be no more compromised as in regular clinics. The acceptance of electronic signature for prescription drugs in such areas is recommended.

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