IMAN community-based epilepsy treatment gap intervention model in a rural area in Kano: the Kumbotso experience

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Abstract

Background: Epilepsy is a common chronic noncommunicable brain disease affecting all age groups. It is noted with different and debilitating comorbidities, challenges of treatment side effects, poor quality of life (QoL) and even early death in some. More burdensome is the fact that about three in every four individual with epilepsy do not have access to evidence-supported treatment, especially in low income countries. Meeting up with the treatment needs of people living with epilepsy (PLWE) is a worrisome dilemma. This study provided the analysis of a model that bridged the treatment epilepsy gap in a rural treatment center with good epilepsy management plan.

Methods/Results: The paper presented the analysis of the strategic treatment gap measure, practiced by Islamic Medical Association of Nigeria (IMAN), Aminu Kano Teaching Hospital Chapter, Kano-State. The framework is tagged the Kumbotso Model, comprise the giving free antiepileptic drugs (AEDs) to the indigents who are the larger part of PLWE, publication of a handbook titled "111 questions and answers on epilepsy" in Hausa language for education, improving awareness through some Radio/TV programs, the training of patients relations and members of the public on first aid measures for seizures, as well as in economic empowerment to ease the affordability challenge and improve medication adherence and follow-ups.

Conclusion: The Kumbotso model provided a strategic framework for bridging the AEDs treatment gap for PLWE. This marked a revolution in providing more than AEDs by reducing stigma and discrimination against PLWE, changing seizure-associated misconceptions, alleviating related poverty a little and contributing to the sufferers' improve QoL. It demonstrated further how epilepsy might be better managed in the rural community and advocated for why epilepsy should be integrated into the Primary Health Care Centers services.

Key words: Epilepsy, Treatment gap, Kumbotso Model, IMAN, PLWE.

Introduction:

According to World Health Organization (WHO)[1], epilepsy is one of the most common chronic noncommunicable brain disease affecting all age groups. Epilepsy is a recurrent seizures often associated with unconsciousness with(out) loss of bowel or bladder control functions. In addition, epilepsy has been noted with different and debilitating comorbidities, challenges of treatment side effects, poor quality of life (QoL) and even, early death in some[2].

Nearly 50 million individuals have been estimated to be suffering from epilepsy globally. Out of these, about four out of every five persons with epilepsy live in low and middle income countries. Despite the success rate associated with treatment, high level of stigma and discriminations are being experienced by people living with epilepsy (PLWE) globally. More burdensome is the fact that about three in every four individual with epilepsy do not have access to evidence-supported treatment, especially in

low income countries. This poor access to treatment by PLWE can be due to several issues including, living in rural areas, which are several distance to the treatment facilities, need to walk these long distance due to poverty, high community stigma and discriminations, poor epilepsy management plan in Primary Health Care Center that might be close by etc. A fall out of having to pay from pocket in obtaining health services in most part of Nigeria is the worrisome dilemma of not being able to afford anti-epileptic drugs (AEDs). This is especially for the teaming epilepsy population now reaching out to rural centers with good epilepsy management plan[1-3]. A study in southeast Asia provided two strategies involving the use of health workers volunteers, one visiting villagers with epilepsy and the other living with the villagers[4]. This study provided the analysis of another strategy, different from the above two models and was started about 13 years ago. This strategy framework, or the Kumbotso Model, was brought up from the treatment intervention provided by the Islamic Medical Association of Nigeria, Aminu Kano Teaching Hospital (IMAN-AKTH) Chapter, as a way to bridge the treatment gap on access to AEDs for PLWE and receiving treatment at the Kumbotso Comprehensive Treatment Center.

Methodology/Results

Kumbotso and Epilepsy

Kumbotso is a village and the headquarters of Kumbotso Local Government Area in Kano State, Nigeria. It is about 20km away from Kano metropolises. It has an area of 158 km² and a population of 295,979 according to the 2006 census. The people are predominantly peasant farmers and cattle rearers, Muslim and Hausas. Kumbotso also house the Comprehensive Health Centre, a primary care facility providing health services to its inhabitants and environs.

In Kumbotso and among other Hausa speaking people, epilepsy is locally referred to as “farfadiya”. It is believed to have been caused by evil spirit and it is contagious in nature. This belief is still pervasive in parts of Africa and the world. Hence, the locally preferred place of treatment, and across some parts of Africa is with the traditional healers and spiritualists. Due to this belief, PLWE may attend hospital mainly for the treatment of secondary injuries like burns and bruises, from recurrent seizures, and often not for the treatment of the epilepsy. Epilepsy is seen as a hope lost, known by all, and nobody wants to be associated with it.

Starting Epilepsy Clinic in Kumbotso

In 1998, the story began, when the Hungarian, Neuro-psychiatrist and Head, Department of Psychiatry, Aminu Kano

Teaching Hospital, Kano, Dr Istivan Patkai, led the opening of a community epilepsy clinic in Kumbotso Comprehensive Health Centre. The clinic is managed by doctors and nurses in Department of Psychiatry, AKTH Kano. The clinic took off as a bi-weekly clinic and presently, it is weekly (and on Mondays).

The visionary opening of a community epilepsy clinic in Kumbotso was a welcome idea to few, but to many, it was a misplacement of priority. The later might be due to lack of awareness on the rising number of PLWE in Kumbotso and surrounding environs. From inception, focus was on the establishment of a sustainable program. Thus, a dialogue took place between the Department of Psychiatry, AKTH Kano and the Kumbotso community stakeholders, leading to community participation. The clinic started with no patient, and 20 years later it has registered more than 7000 PLWE. The clinic is patronized by the forty four local government areas of Kano state, neighboring states and also the far away Niger Republic. The epilepsy clinic has facilitated AKTH Kano, to take over the running of Kumbotso Comprehensive Health Centre, and to open more clinics, both general and specialty, running on all days of the week.

Running the epilepsy clinic now

Patients and relations start arriving at the clinic as early as 6.00am from far and near. Some patients come on foot walking for an average of 2 to 20km, few on bicycle, fewer on motor bike and commercial transport buses. While those from very far distance or neighboring state and the Niger Republic come a day earlier and pass the night in the Hospital or in the Kumbotso village. After consultation, most patient still could not afford AEDs. This treatment gap leads to the effort of some clinical staff of the Department of Psychiatry AKTH-Kano to start providing free AEDs. However, the treatment gap is still huge and then come the more supply of free AEDs from IMAN-AKTH chapter. This kick-start the Kumbotso Model of giving free AEDs to the indigents who are the larger part of PLWE.

The drug of choice is based on the epilepsy treatment plan and may range from mostly phenorbabitone, then carbamazepine and phenytoin, and rarely sodium valproate and leviteracetam. Appointment is given from 2 to 12weeks depending on level of seizures control, distance of client's village to the clinic, availability of free medications and affordability to buy drugs. And with the provision of free drugs, optimal medication compliance and seizure control are often achieved. At times, the patients might enjoyed some assistance for other basic needs, in addition to AEDs.

Next addition to the growing model is on education and awareness, that soon start to receive remarkable attention on epilepsy.

Henceforth, on first day of visit to the clinic, patient is given a handbook titled: "111 questions and answers on epilepsy" written in Hausa language i.e. "tambayayo dari da sha daya akan ciwon farfadiya". This handbook, written by the first author of this work, is produced to provide a practical knowledge and skills to PLWE, their family members, and members of the public. This awareness on epilepsy soon received booster with some Radio/TV programs on epilepsy by experts (also from the clinic) and occasionally the clients themselves, where myths, ignorance and discrimination against epilepsy and PLWE are roll backward. Another feature contributing to reducing treatment gap in the clinic now is in the training of patients relations and members of the public on first aid measures for seizures, as well as in economic empowerment to ease the affordability challenge and improve medication adherence and follow-ups. All these, or the Kumbotso Model, have contributed to improve understanding, attitude, and care, for PLWE and in transforming the wrong perception of the public.

Some specific outcomes of the Kumbotso Model noted in PLWE

The following are some of the noted Kumbotso Model outcome that are specific to PLWE:

- Controlled seizures, contributed to mental stability among clients, and enhanced their social acceptance and involvement in social decision making.
- Children with epilepsy now seizure free have been privileged to be enrolled in schools or go back to school in the case of those who dropped out because of the illness.
- Many destitute, beggars and divorcees as a result of the illness are able to go back to their homes to reunite with their children, relatives and society.
- The socio-economic burden for people with epilepsy and their families has drastically reduced.
- With seizure controlled, employment becomes a necessity, many patients are able to start work or go back to work either on their farms, paid jobs or other productive activities.
- They become very knowledgeable on safety at places of work and the need to avoid jobs that are hazardous to self and others.
- Some were able to control, own or recover their lost or inheritable properties.
- Many who have earlier lost hope in marriage were able to realize their dreams.

Some generally noted successes of the Kumbotso Model

In the 20years under review, the singular role of IMAN-AKTH in bridging the treatment gap and the tireless efforts of the staff of the Department of psychiatry AKTH Kano, has been noted with the following overall successes:

- The quality of lives of Kumbotso clients living with epilepsy has improved remarkably;
- For most of them, the seizure is now under control and for few with residual symptoms, the frequency of seizures and injuries have reduced remarkably
- Despite the observation of minimal drug side effects reported, the overall level of independence is on the increase as their activities of daily living (ADL) improves, level with their productiveness and recreational activities enhanced;
- Most stigma or discriminations noted before are now replaced by care and understanding;
- The clinic has continued to function for more than 20years without any interruption, and it has never been closed, even when there is public holiday or health workers strike actions.
- It has provided a platform to increase awareness on facts about epilepsy, and reduction in misconception, stigma, discriminations and sudden death associated with epilepsy;
- It has provided a life purpose for staff, increased their team work, improved the health-worker-patient's relationship;
- It has led to the formation of PLWE association in the place of review. (This was inaugurated a year ago. After getting the Hospital Management approval, it was registered with Kano State Government as community development association and patrons, executives and members meet periodically to discuss issues concerning the members in accordance with the constitution);
- It has facilitated the running of more specialty clinics at the Kumbotso Comprehensive Health Centre i.e. it has facilitated more health services for more members of the rural community with(out) epilepsy.

Some challenges worth pointing out:

Despite the establishment of Kumbotso epilepsy clinic and the positive changes it has brought to the lives of PLWE and those who care for them, there are still few challenges. The following are worth bring forward:

- Awareness still needs to be intensified, as anecdotal report showed that about 40% of the PLWE in the Kumbotso area and environs are the ones using the facility's care plan and hence seizure free with relatively improved QoL. This might not be unconnected to the supernatural causation belief that evil spirit are responsible. This can be anecdotally inferred from more than 2 in 7 PLWE utilizing the Kumbotso Comprehensive Health Centre services still solicit for the service of herbalists/spiritualists.
- Despite the 20 years of providing epilepsy services and collaborating with community leaders, the Kumbotso Local Government Authority is yet to prioritize epilepsy as a public health challenge.
- Till the time of this analysis, no similar clinic has been set up by surrounding Local or State Government, even though their citizens travelled far to benefit from the current effort.
- Despite the attainment of being seizure free among PLWE utilizing the center's services, just a handful are able to get reintegrated into the community social

roles like gaining employment, getting re-married, living without disability etc.

- Caregiver burden which is relatively high among care providers of PLWE is yet to be addressed as part of the treatment package. Although, the free AEDs made available by IMAN-AKTH do appear to provide some of the relief expected.
- Transportation to clinic also remains a major constrain, either in terms of cost, safety or long distance. Hence, patients and/or relation might be easily worn-out as they trekked or cycled long distance, and/or the stress might provoke seizure that might lead to fall, fracture and other injury. Also, for some, money spent on transportation translate to less available for medication. The cost of transportation and medication might also meant missed appointments and follow-ups, which might hinder medication adherence.
- The cost of accompany patients to the clinics might also include foregoing opportunities that might contribute to family income and wellbeing.
- The mental health law in Nigeria is not in cognizance of the plight of PLWE, nor does any policy provides for limiting the stigma, segregation and discriminations faced by PLWE.
- When children with epilepsy are denied the rights to be enrolled in schools or adults denied employment, it increase the suffering faced by them and their perpetrators are never brought to book because of ignorance and poverty.
- A major constraint in the management of PLWE in the place of analysis is the occupation of some of them. Some work as taxi drivers, local fishermen, street hawkers etc. These occupations carry high hazard for PLWE for any bout of seizure while at work might come with life threatening consequences. Hence, the need for policy makers and job providers to provide safer jobs and opportunities for these group of people.

Sustaining the epilepsy clinic and care program

The primary role of providing AEDs by IMAN-AKTH chapter has been central to the successful running of this community care program for PLWE. This is very practical in helping to reduce the treatment gap faced by PLWE. The Kumbotso experience gives a vivid account of a sincere and accurate vision of improving the quality of lives of PLWE in their rural localities. This experience also shows how a group of committed health care team as the tireless financial and moral support of IMAN-AKTH Kano, brought health care to the door steps of PLWE in rural African societies. It demonstrates practical strategies towards fighting misconception and stigma and how they could be replaced with care and understanding. Despite its many challenges and constraints, this laudable project and model might serve as an example for more IMAN chapters and other community-based organizations to emulate. This model might fast track the integration of epilepsy services into existing Primary Health Care programs, as it provide an efficient system for procuring and supplying AEDs, as well as providing a format for caring for PLWE. It is also quite instructive for the ongoing BRIDGE Project on epilepsy in Africa.

Conclusion

Despite epilepsy, being a major chronic non-communicable disease with less than a quarter of PLWE having access to the needed AEDs, this experience in Kumbotso might provide a model for bridging the treatment gap. The Kumbotso experience and model, marked a revolution in providing more than AEDs by reducing stigma and discrimination against PLWE, changing seizure-associated misconceptions, alleviating related poverty a little and contributing to the sufferers' improve QoL. It demonstrated further how epilepsy might be better managed in the rural community and advocated for why epilepsy should be integrated into the Primary Health Care Centers services.

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Conflict of interest: Nil