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Epilepsy Alliance Africa (EAA)'s pan-African model of epilepsy management, education, awareness, advocacy and capacity building

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ABSTRACT

There are an estimated 10 million people with epilepsy in Africa, meaning that 0.9% or 1 per 1000 people live with epilepsy on the continent. Of these, only about 25% (2.5 million) are on medical treatment, giving a treatment gap of 75% (7.5 million). Out of those 2.5 million who are on medical treatment, we estimate that only about 25% (625 000) have access to medicines and 5% (125 000) have access to specialist treatment. The major reason behind the huge treatment gap is the knowledge gap, which stands at about 70%, meaning only about 30% view epilepsy as a neurological disorder that can be managed medically or surgically. The medication gap and specialist access gap are huge because of financial resources required to buy medicines, consult doctors including specialists and transport. The care of people with epilepsy implies not only the correct diagnosis and treatment, but also the management of its main sociocultural consequences such as misconception of the disease, the persistence of stigma and access to resources. Further, it implies effective management of comorbid conditions such as physical, social, psychopathological, psychiatric, behavioral, and emotional disorders and all the problems which have a profound impact on quality of life. It also implies putting in place effective policies at national and continental level and building stronger organizations, again at both national and continental level, and effective policies. For that, the Epilepsy Alliance Africa (EAA) was created in 2019 in order to accelerate awareness and education; coordinate advocacy; and to strengthen the capacity of organizations in Africa. The EAA has pan-African objectives driven by the need to recognise African knowledges and solutions as the basis for a sustainable solution to the problem of epilepsy. In this article, we provide the background of the EAA, describe its ongoing contribution, discuss the challenges and proffer suggestions to make the alliance model more effective. At the end, roles of social, community and development workers are outlined.

KEY TERMS: Africa, care, capacity building, education, epilepsy, Epilepsy Alliance Africa (EAA), pan-Africanism, stigma

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INTRODUCTION

There are an estimated 10 million people with epilepsy in Africa, meaning that 0.9% or 1 per 1000 people live with epilepsy on the continent (Awolabi et al, 2020). Of these, only about 25% (2.5 million) are on medical treatment, giving a treatment gap of 75% (7.5 million). Out of those 2,5 million who are on medical treatment, we estimate that only about 25% (625 000) have access to medicines and 5% (125 000) have access to specialist treatment. The major reason behind the huge treatment gap is the knowledge gap, which stands at about 70%, meaning only about 30% view epilepsy as a neurological disorder that can be managed medically or surgically. The medication gap and specialist access gap are huge because of financial resources required to buy medicines, consult doctors including specialists and transport. Epilepsy affects both males and females, people from all races, children and adults, rich and poor, educated or not. For that, the Epilepsy Alliance Africa (EAA) was created in 2019 in order to accelerate awareness and education; coordinate advocacy; and to strengthen the capacity of organizations in Africa. The EAA has pan-African objectives driven by the need to recognise African knowledges and solutions as the basis for a sustainable solution to the problem of epilepsy. In this article, authors provide the background of the EAA, describe the model it uses and its ongoing contribution. At the end, roles of social, community and development workers are outlined.

BACKGROUND INFORMATION

Epilepsy

Epilepsy can be an annihilating and chronic condition, however, with basic treatment, more than 70% of cases can be controlled with one drug World Health Organization (WHO) (2003). The challenge Africa faces is that of misunderstanding of epilepsy, it's stigmatized, severely underfunded, or even ignored by the healthcare systems. Rural communities suffer more because they are often marginalized with limited health and social support services. Over 75% of people with epilepsy in Africa live in rural and suburban areas where treatment is almost non-existent. People with epilepsy still suffer, even currently when there is an existence of affordable and effective drugs and low-cost programs (Newton and Garcia, 2012).

The care of people with epilepsy implies not only the correct diagnosis and treatment, but also the management of its main sociocultural consequences such as misconception of the disease, the persistence of stigma and access to resources (Obeid, 2008). Further, it implies effective management of comorbid conditions such as psychopathological, psychiatric, behavioral, and emotional disorders and all the problems which have a profound impact on patients' quality of life (Newton and Garcia, 2012). It also implies putting in place effective policies at national and continental level and building stronger organizations, again at both national and continental level. and effective policies (Mugumbate and Nyanguru, 2013).

The Alliance

On 10 December 2019, the EAA, a pan-African alliance of individuals, groups, organizations and health instructors averting and addressing challenges instigated by epilepsy was formed. The EAA was founded to unite all associations, groups and every person working to defeat epilepsy in Africa (EAA, 2020). At the time of its formation, the Alliance was made up of 11 associations and 30 individual members. Applications and nominations for leadership positions ensued, and the first council began working on a two-year term on December 12, 2019. The Alliance has an Executive Council and committees for research, planning, awareness and education. It has different categories of members: associations, individuals (professionals, people with epilepsy and advocates) and partners.

The idea of forming an African alliance for epilepsy had been in the making for several years. Back in 2017, African professionals attending the International Epilepsy Congress in Barcelona, Spain, started a forum of professionals interested in epilepsy. Other meetings followed during epilepsy congresses in 2019 in Bangkok, Thailand and Entebbe, Uganda. The attendees at the congress in Uganda adopted a Call to Action that called for initiatives and solutions to ease the battle against epilepsy in Africa.

After one year of its formation, the Alliance had 28 associations and over 90 individual members from 33 countries around Africa, still, welcoming new members from different fields (EAA, 2021). The Alliance introduced several continental programs as described in the next section.

Pan-African objectives

Pan-Africanism is a way of thinking about African challenges and solutions (Mulemfo, 2000). It promotes using African ideas and knowledges to address African challenges. This way of thinking has been promoted by pan-Africanists like Kwameh Nkrumah, Julius Nyerere, Kenneth Kaunda, Jomo Kenyatta, Léopold Senghor, Robert Mugabe, Nelson Mandela, Samora Machel, Patrice Lumumba, Gamal Abdel Nasser, Muammar Gaddafi, Du Bois, Thabo Mbeki and many other unsung heroes and heroines (Malisa, and Nhengeze, 2018). Today, pan-Africanist permeates every level of African society. Pan-African objectives are available at village level, community level, national level and are used when Africans engage with the international world. Pan-African institutions like the African Union (AU), are at the forefront of promoting pan-African ideals (Okhonmina, 2008). It is viewed as the most sustainable solution to African problems because it recognizes capacity within, supports a bottom-up approach and promotes participation. It builds confidence, unity and self-reliance (Mulemfo, 2000).

MODELS TO ADDRESS EPILEPSY AT REGIONAL LEVEL

To address epilepsy at regional or continental level, a number of models have been tried globally. These are: The models are described in turn.

African governments intervention

The first model is where governments work together to address epilepsy on the continent, usually coordinated by the regional health organization such as World Health Organisation (WHO) or a continental body such as the African Union. However, there is a limitation in that the governments often have numerous other health priorities such that epilepsy is not prioritized.

Interventions by people with epilepsy, professionals or advocates in Africa

The second model is where people with epilepsy, professionals or advocates in different countries collaborate in addressing epilepsy. The advantage of this model is that individuals can act quickly as they are not affected by the bureaucracy of organizations. The disadvantage is that individuals cannot achieve quite much as they can be limited by availability of resources.

Interventions by associations in different African countries

The third model involves associations in different countries working on their own or with other associations to improve epilepsy at a regional level without a formal alliance. The disadvantage is that plans and programs are not sustained, they happen for a short period and there are no formal structures to ensure that programs are sustained.

Intervention by international organizations outside Africa

The fourth model is where international organizations create committees, commissions or taskforces for a continent or a region. While this model can expose the region to resources it has numerous disadvantages. For example, the committees involve only a few people, usually one to five, and they usually find it difficult to reach many countries. The committees are usually underfunded. Another challenge is that projects or plans for the region are created from the top, creating a top-down approach. Interests of the international organization are often prioritized at the expense of interests of the region. Committees usually run for a short term, and lack continuity and the projects they usually implement are short term in duration, lacking sustainability. Yet another challenge with the fifth model is that the international organizations neglect to work with governments and continental bodies, they prioritise working at international level. This creates a gap where issues are dealt with at the local level by country associations and at the international level but with no work being done at the regional level.

Alliance of associations in the African region (the integrated model)

The fifth model is where associations in the region form an alliance or regional association. The disadvantage is that commitment is required from the members but there are several advantages. Organizations can pool their resources together and come up with bigger programs that they can sustain by setting up formal structures. Another advantage is that an alliance can accommodate all types of members including organizations, associations, partners, professionals, advocates and people with epilepsy. It can also accommodate governments and international organisations.

From the five models described above, the Alliance adopted this fifth model. The model integrates the first four models. Using this model, the Alliance formed a regional committee (executive council) made up of representatives from each of the African regions: North Africa, West Africa, East Africa, Central Africa and South(ern) Africa. After forming the committee, associations from different countries were asked to apply for membership without a limit per country. The executive council is led by a President, Vice-President from each region, Secretary General, Treasurer and additional committee members.

THE WORK OF THE ALLIANCE

The Alliance was founded for several reasons, including but not limited to engaging the African Union, engaging the WHO Regional Office for Africa, engaging other African institutions, unite African forces against epilepsy and promote pan-African solutions and homegrown advocacy. Another reason was to have a unified voice when working with continental and international organizations like the WHO, International League Against Epilepsy, the International Bureau for Epilepsy and disability organisations. In the following subsections, the work of the Alliance is described.

Specialist treatment through weekly free virtual clinic

After realizing that some people with epilepsy were in immediate need of specialist services, yet these services were not available in their countries, the EAA started a free virtual clinic in 2020. The clinic runs once a week for two hours. The clinic has three, these are specialist centre staffed by a senior neurologist based in Morocco; a country centre run the epilepsy association in each country that has patients who require specialist support and a virtual meeting room. This virtual model allows for specialists to volunteer their services across borders and decreases the cost of epilepsy health care for the patients. However, the cost of internet on the part of the virtual centre, has been a disadvantage.

Awareness

Public knowledge and attitudes towards epilepsy have been repeatedly investigated in developed and developing countries. Large gaps have been found in awareness of the causes of the disease, and, even worse, widespread negative attitudes were documented. We support our members with easily adaptable posters, ideas and documents to strengthen their national awareness activities. The awareness targets various groups including decision makers, professionals, people with epilepsy and their families, teachers, and primary health care workers, police and the general public. This helps to reduce the stigma related to the condition and also sensitize policy makers about the need to prioritise the condition.

One area of awareness in 2019 and 2020 has been coronavirus disease 2019. The Alliance published posters and shared information with members about best practices. Research was and developments was shared through social media.

Education and training of health and social service workers

Training health care workers is essential if people with epilepsy are to be correctly diagnosed and appropriately treated. Improving local competence at primary and secondary health care levels is a necessity. As part of education, we have introduced an annual conference where speakers from different countries present their work. The first conference was held in September 2020 with a guest from the African Union. The EAA organizes monthly webinars to create a platform to meet, discuss the latest developments in basic and clinical research, and built a network with fellow researchers, clinicians and other health care practitioners from all Africa. To date, 12 regional webinars have been organized and one interregional webinar. In all webinars there is interaction between participants, people with epilepsy, their families, health workers professors and new neurologists. Our training uses the tele-health approach which delivers training using the internet. While this is innovative, the downside is that many of our members do not afford the cost of internet.

Epilepsy research and publishing

Epilepsy research is imperative especially in the African countries, through medical research; we generate new ways in the management of epilepsy. The EAA encourages young African neurologist to publish their experience and their cases. EAA creates research partnerships and working arrangements with organizations in Africa and beyond, including universities. We arrange monthly webinars for this research to be shared.

Advocacy

The major challenges for epilepsy in the African region which the EAA try to overcome are bridging the treatment and knowledge gaps; preventing symptomatic epilepsies which are mainly public health problems; rights promotion for people with epilepsy by empowerment of individuals and communities with appropriate knowledge and skills, advocacy and self-representation and provision of appropriate support and care; knowledge generation and dissemination and development of effective partnerships. However, African governments seem not to prioritise epilepsy. As such, there is need for advocacy. The Alliance started its advocacy by approaching the African Union because it has the capacity and power to influence all government ministers of health and heads of governments. Besides, the Union is an African initiative of African governments with a mandate to improve the welfare of all people in Africa. The Union has been very receptive, and they have listened to the Alliance, offered suggestions and opportunities to partner in the long term.

Capacity building

One important work the EAA is doing is to build the capacity of epilepsy associations in Africa. The EAA publishes guidelines about forming groups and associations and how to run them. It also provides opportunities for associations to host webinars in their countries and provide them with technical support. The Alliance provides awards annually as a way of encouraging members and honoring their hard work. Another important function of the Alliance is fundraising and resource mobilization at continental level.

CHALLENGES

The major challenge faced by both associations and individuals within the Alliance is lack of internet resources required to successfully attend the virtual clinic, webinars and conferences. Other challenges include a lack of contact people in some countries and language barriers given that other countries in Africa use indigenous languages, Arabic, English, French and Portuguese. Suggestions include:

- Increase membership to cover all countries of Africa.
- Have programs in different languages suited to different regions of the continent.
- Find resources to support members to be able to effectively use internet based tele-health services.
- Promote harmonized epilepsy awareness, for example, epilepsy week in Africa.
- Working with universities, teaching colleges, nurse training colleges and other tertiary institutions.
- Establish a good tele-health program with the minimum technologies and expertise in epilepsy field.

THE ROLE OF SOCIAL, COMMUNITY AND DEVELOPMENT WORKERS

Social, community and development workers have an important role to play to improve the efficacy and the efficiency toward the fight against epilepsy. As Mugumbate, Riphagenn and Gathara (2017) noted:

Epilepsy remains an under-reported, under-recognised, under-treated, under-represented, under-resourced, and under-researched condition that presents multiple social challenges. Social workers have a role to deal with these 'u's in epilepsy. In managing these challenges, social workers must work with other professionals as part of a comprehensive developmental program that includes economic empowerment, medical therapy, psychosocial support, public education and awareness raising to reduce social stigma, increase treatment uptake, and promote treatment adherence. Further, they advocate and lobby for affordable and accessible treatment services, and research to inform public policy. A developmental approach that empowers people with epilepsy and addresses structural systemic factors that impede their potential to address the various medical, psychological, economic, cultural, and social challenges they face is thus needed.

These roles include:

- Non-stop advocacy to African governments and institutions to increase their involvement in epilepsy and for the development, adoption and implementation of epilepsy policies and programs at regional, sub-regional and national levels.
- Awareness to reduce the knowledge gap.
- Attend to needs of people living in rural communities, considering that the majority of Africans live in rural areas. These needs include access to public education, health workers and medicines.
- Setting up regular training programs on social issues of epilepsy for doctors, nurses and midwives, social workers, advocates, people with epilepsy, school teachers and police.
- Promote collection and processing of data and publishing and dissemination of literature.
- Psychosocial support and lifestyle management
- Enhancing service accessibility and resource mobilization
- Employment issues and income maintenance
- Promoting the inclusion and participation of people with epilepsy

CONCLUSION

Epilepsy, one of the most common neurological conditions, is under-resourced and undertreated in most African countries. The EAA's pan-African model presents an opportunity to sustainably address the challenges of epilepsy in Africa at continental level despite shortage of resources especially covering the cost of internet for virtual clinic centres and members attending webinars and conferences. Social, community and development workers have an important role to play to improve the efficacy and the efficiency toward the fight against epilepsy. The authors hope that other regions will find the model used by the Alliance adaptable to their situations.

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