



Epilepsynews africa

Issue 1

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Epilepsynews africa is a publication of ILAE Commission on African Affairs. Comments, News of epilepsy and related topics are welcome. For further information contact nigeriaepilepsy@hotmail.com, or the editor at nigeriaepilepsy@hotmail.com our website @ www.Africaepilepsy.org



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Issue 2

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Features *I am Hurting.. The Secret place of Epilepsy*

Anyone who has ever looked a little closer into the life of people with epilepsy or has ever asked some extra questions about the lives of our brothers and sisters with epilepsy will be shocked about the burden and secrets these people carry. In this discourse I will only highlight two groups of people with epilepsy – women and those with associated psychiatric disorders.

Women are confronted with numerous challenges. These problems are compounded by the lack of basic knowledge of epilepsy by the sufferers themselves and the level of unwillingness of patients to continue with orthodox treatment due to cultural and religious beliefs. There is a thick cloud of ignorance and hallow psychology/philosophy/religion that has been passed over the generations hovering around some of these women.

Women-related-issues in epilepsy may be divided into 2. Medical and psychosocial. Most difficult medical issues usually come during pregnancy, delivery or while nursing. Seizures may be exacerbated during pregnancy, reduce in frequency or even stop. Increase in seizure frequency in a pregnant woman is a nightmare not only to the woman but also to her close associates. Prolonged seizures and indeed any seizure may cause severe hypoxia and consequently damage the fetus. The frequency of seizures may also be related to a woman’s menstrual cycle (catamenial seizure). The worst and the most feared moment in the life of these women is the possibility of having a seizure while nursing their new born babies. Drowning while bathing babies and other home accidents may occur and endanger both mother and child or even the marriage. Fear of such moments hunt young women with epilepsy.



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The other aspect of women-related-issues is psychosocial.

Stigma and exploitation are more likely to occur in women. In African societies as in many other societies, stigma in epilepsy is wide spread and has strong cultural and religious roots. Women and children are probably the most beautiful things in any society. Women are not only our sisters and mothers they make life worth fighting for.

The psychosocial consequences of the stigma are most evident in women of marriageable age. In a society where getting married is a thing of great pride, a young woman with epilepsy consider themselves disadvantaged because they do not believe they will get married. Men are less likely to marry women with epilepsy. Seizure exacerbation is more likely to lead to divorce especially if the sufferer is the woman. In most instances women suffer more from divorce especially those who are economically dependent.

‘Doc, if not for this problem, by this time I would have at least gotten married. My mother suffered for me because of this sickness but now she is dead. My brother sent me away because I became a financial burden to him.

The President's Column

It is a great pleasure to welcome all of us into the new year. Our goals and objectives if anything has not only remained the same but are getting bigger. Last year a lot was achieved by our various chapters in training, awareness creation and facilitating access to care at different levels. Undoubtedly, the greatest achievement for us all was the great convention— African Epilepsy Congress in Nairobi, Kenya. It was such a huge success and inspired many of us. However, as we bask in that euphoria there is the need for us to prepare for next year's congress which will likely come up in South Africa. In that congress hope to encourage each chapter to present some details of their activities. This was done in Nairobi, but we need to pay more emphasis on this. Furthermore, the new congress should focus on epilepsy in the rural African communities. We know of the experience presented by Sanofi in Mozambique. There are other experiences and scattered works here and there but there is need to do a more comprehensive work in this area. Most epilepsy patients in the continent dwell in rural areas, have little or no access to care. Rural Africa is almost synonymous to poverty and lack of basic infrastructures which has taken its toll on people living with epilepsy.

In accordance with our aspirations for the next AEC is the need to increase the number of chapters in the continent. We have made some progress in that area but we need to do more. We need ideas how to facilitate this work. Some of the challenges we have faced included the lack of man-power. The few available are involved in so many activities from teaching, training and clinical services to even politics. As the continent keeps growing in all spheres we hope that more and more doctors will come on board. Our collaboration with IBE has so far yielded so much fruit and needs to be continued. Epilepsynews Africa is one way of creating not only awareness but interest in this area. I encourage every one who will receive this bulletin to forward it to as many doctors and non doctors as possible.

Over the past year some training programs were planned and carried out. The 1st AEC in Nairobi incorporated in it training in epilepsy care (English Language). Unfortunately the events in Mali made us to shift the French

Language Course to go Senegal. We believe that the event will finally come to fruition.

What are our aspirations for the forth coming IEC conference in Montreal. Hopefully, many of us from the continent will attend, this will help us create some awareness for the need for new chapter and greater commitment in epilepsy related issues and research in the continent. We also hope that the organizers will create time to talk to our African brothers on this issue. I hope that some copies of this news letter will be available to raise and establish our profile.

Knowledge grows. It is cross fertilized by constant interactions. There is now need for our European/American/Oceania/Asian friends to consider collaborative work with the young and upcoming doctors from Africa. The work that is done through Virepa is great and should be encouraged and upgraded to help young Africans gain some certification in the area of epilepsy care. Finally, as in Rome this conference will be a huge success and go a long way in promoting knowledge and awareness in the field of epileptology.



*Pr Amadou Gallo DIOP, MD, PhD Chair,
Commission on African Affairs of the
International League Against Epilepsy*

Features **I am Hurting....Please I need Help.**

I left my first job as receptionists in a hotel because of the things that were going there. Now that I have a new job my salary is barely enough to feed me and pay for my accommodation. I once shared a room with a friend but she sent me away because of this problem. I do not have any meaningful education and cannot get married. This sickness has destroyed my life'

Another (an undergraduate) with tears in her eyes asked me if vaginal examination is part of the treatment of Epilepsy. She has been having seizures since infancy and the father did everything possible to help her. She was taken to a 'big doctor' who has always inserted his fingers into her private part as a modality of the treatment. She became suspicious when she noticed he would not do so in front of her father and will tell her to dress up hurriedly if someone is coming. Now she wanted to hear from me.

Yet another was made pregnant by a 'brother' who has always been there for her but swore to have nothing to do with her as soon as she got pregnant. She eventually lost the baby. A lady came to the clinic with a baby. When I found out she was not married she told me the parents of the boyfriend did not accept her because of her illness. It is interesting that all these people have been lost to follow up despite repeated pleas to keep coming to the clinic.

Being unemployed because of epilepsy is important for a woman with epilepsy, as it makes her economically dependent, as well as dependent in making personal decisions. Unmarried adult females with epilepsy are vulnerable to sexual exploitation, physical abuse, and extreme poverty making epilepsy a possible risk factor for HIV/AIDS. I personally know of two ladies who were told by their brothers that they are nothing but a drain pipe for the family. In African societies because women do most of the cooking, they are more likely to have burns and other heat related injuries. A young lady was seen in the clinic with extensive scars from burns sustained when she poured a pot of hot boiling rice on herself while cooking. Epilepsy related stigma may be extended to female members of the nuclear family even when the primary sufferer is a man.

Traditional healers perpetuate or even indeed profit from stigmatizing beliefs about spiritual causes of epilepsy. Women have been made to work for their treatment or even marry owners of these healing centers. A lady was told to bring a sacrifice each time she wants to plait her hair or else the seizures would come back. Superstitious beliefs lead to scarifications on the body and faces as well as sacrifices and unnecessary public prayers. These factors as well as certain complications of seizures such as burns, injuries and drowning all contribute to the stigma and burden of epilepsy on women. Over time these women become timid, depressed and unwilling to enter into any relationship because of epilepsy.



Every talk and discussion should include these people who suffer silently.

The other group of patients with epilepsy who are hurting are those with psychiatric co-morbidities. Psychiatric co-morbidities are relatively frequent in patients with epilepsy (PWE) and grossly under recognized even in countries with well developed health facilities. In Africa, the paucity of qualified personnel as well as the socio-cultural coloration of mental health issues brings this problem to the fore. It has been suggested that close to 30% of people living with epilepsy have experienced a psychiatric disorder in the course of his / her life [Tellez-Zenteno et al.].

Depression and anxiety disorders are common. Psychogenic non epileptic seizures, Attention Deficit Hyperactivity Disorders (in children) as well as psychosis are also relatively commoner in epilepsy. There is an association between psychiatric disorders and a worse response to a pharmacologic and surgical treatment of the seizure disorder. Furthermore there is a significantly increased suicidal risk in the presence of mood, anxiety and psychotic disorders. Thus, under recognition of these disorders on the part of clinicians may have important consequences in the overall management of PWE.

Several problems will immediately confront a non psychiatrist treating epilepsy. The most daunting one is how to make a reliable diagnosis and where to refer the patient to in case of treatment failure. There are few local neuropsychiatric instruments for making such diagnosis. I have personally tried using some of these batteries but always get stuck especially if the patient does not have a very good knowledge of English. There is a need for simple and brief cross-cultural neuropsychological screening instruments to be introduced for use in the continent with so many languages.

The next challenge is how to treat, how far will one go and who and to whom to refer to. The biggest challenge of all is response of patients to treatment. Most patients with epilepsy will be lost to follow-up especially if there is an associated psychiatric disorder. The last challenge is referral. What to do when and where there is no neurologist or psychiatrist.

Making a diagnosis and encouraging doctors to look for these co-morbidities should be encouraged. There is a need to disseminate information on management guidelines for mild to moderate cases and referral in severe ones. Psychiatric co-morbidities impact on the quality of life of PWE, including the increased economic burden on the patient, family and on society as a whole. Every discussion about CARE should include these disorders. PWE with these co-morbidities suffer silently but otherwise could have cried out-**I am hurting**

The Fight Against Epilepsy Ghana Initiative was launched on 26 September 2012 in the Northern Region of Ghana in the Tolon-Kumbungu district which is one of the implementation sites.

The Ghana Initiative is a 4-year project and is a collaboration between WHO/MOH/GHS with the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) as partners and funded by Sanofi Espoir Foundation. The initiative in the first year was piloted in 2 districts in Ghana, one in the northern region and the other Ashiedu-Keteke sub-metro in the Greater Accra Region. Three more districts from three regions will be enrolled in the second year.

The national launch had the theme “Scaling up epilepsy services to bridge the treatment gap in Ghana”. The objective of the launch was to improve awareness of community groups to decrease stigma and increase demand for epilepsy care



The launch was attended by representatives of the Minister of Health, Northern Regional Minister, Regional Director Health Services, WHO representative Headquarters, Geneva, WHO representative, country office, Managing Director, Sanofi Espoir Foundation, Representative, Sanofi Africa, DCE, Kumbungu, District Director Health Services, Tolon-Kumbungu, Headmaster, Kumbungu Senior High School, Traditional Rulers, Basic Needs – Ghana and the National Coordinating Committee members. The chief psychiatrist, Dr. Akwasi Osei gave an overview of the initiative.

The main goal of the initiative is to improve access to care which will be achieved through the training of general health care providers, increase awareness to reduce stigmatization and monitoring and evaluation of project activities.

The key messages were: Epilepsy is not contagious, Epilepsy is treatable, and People with epilepsy can live a normal life. There were messages from WHO country office, Sanofi Espoir Foundation and a patient and his father.

A representative of the Minister of Health delivered the keynote address and officially launched the initiative. The Minister reaffirmed government support for the project and said the major challenges for epilepsy in the African region were: Bridging the treatment gap, preventing symptomatic epilepsies which are mainly public health problems, promoting human rights issues for people with epilepsy by empowering individuals and communities with appropriate knowledge and skills, advocacy and provision of appropriate support and care.

He stressed epilepsy is not only a medical condition, but also a social and public health issue which requires multi-disciplinary and multi-level intervention. Self-help and social awareness among the patients and the public are critical to enhance the quality of lives of patients and promote a more inclusive society. Even though management of epilepsy is simple and effective there are inadequate human resources for care of people with epilepsy.

The Ministry of Health is happy to collaborate with the WHO to address the lack of care in Ghana as in other developing countries. The programme to train non-specialist health personnel within first and second level health institutions to provide care and serve as first point of contact was most laudable and Ghana is prepared to own this project and scale it up to all ten regions of the country.

He said the expectation of government was that there will be marked improvement in access to quality care and services for people with epilepsy and epilepsy will be raised as a priority in the national health agenda. The involvement of non-specialist providers in epilepsy care and services will be integrated in the primary health care system.

He said the government hoped the initiative will reduce the treatment gap, enable more children with epilepsy to go to school and more adults employed, thereby improving the quality of life of our people for a positive social and economic impact.

In the chairman’s closing remarks, he thanked all for coming and being part of such a laudable programme and encouraged parents and care givers to continue supporting people with epilepsy in the district and hoped they will help reduce the treatment gap and burden of the disease in the district and in Ghana as a whole.



Training of Health Care Providers

One of the objectives of the Fight Against Epilepsy Ghana Initiative is to promote training of all professional health care providers, making them competent in the diagnosis and treatment of epilepsy and integrate provision of care and services for epilepsy in the primary health care system. training manual on epilepsy using WHO mh Intervention Guide was adapted for Ghana.

January 27th 2011: Meeting of the General Assembly of the CLAE in Yaoundé at the Cameroon National Medical Council, from 2:00 to 5:00 PM.

Election of Dr Jacques DOUMBE, neurologist at the Douala Laquintinie Hospital as 2nd vice president of the league to replace the late Dr NDO BELINGA. Dr Victor SINI, neurologist at the Yaoundé Central Hospital was also elected as vice chair of the scientific committee of the CLAE.

Admission of new members: Dr Faustin YEPNIO NJONDA (last year neurology training at Limoges, France), Dr Francis NNANGA (specialist in internal medicine with neurology as option, Military Hospital Yaoundé) and Dr Godwin TATAH (last year training in internal medicine with neurology as option, France), Dr Joseph FONDOP (neurosurgeon, Douala Laquintinie Hospital).

Set up of two discussion group, one in Douala (chair: Dr DOUMBE Jacques) and other in Yaoundé (chair: Pr NJAMNSHI) for the organization and implementation of the 2011 action plan.

February 10th 2011 and 12th March 2011: Meeting at Douala for the elaboration of the 2011 action plan. Many propositions were made and sent to the Executive for further discussions, adoption and implementation.

August 28th to September 1st 2011: International Epilepsy Congress, Rome, Italy.

General Assembly of the ILAE: final adoption of the candidature of Cameroon as a national chapter of the ILAE. Our league was represented in this meeting by the president (Pr Elie MBONDA), the secretary general (Dr Callixte KUATE) and the vice chair of the scientific commission (Dr Victor SINI). Meeting of the ILAE commission on African affairs: The 2012 action plan of the African commission was discussed and the budget adopted. Preparation of the 1st African Epilepsy Congress, Nairobi, Kenya.

30th January to 2nd February 2012, Marseille, France: Participation to the congress of the French Society for Paediatric Neurology (Dr Séraphin NGUEFACK).

2nd to 4th february 2012, Antebe, Uganda: participation to the International congress on Paediatric neurology (Pr Elie MBONDA).

3rd March, 2012, Douala, Cameroon: General Assembly of the CLAE.

Amendments of the constitution. An amendment was voted by 100% of 13 members present, on article 6 for the suppression of the mention "in charge of international relations" for the 1st vice president and "in charge of national relations" for the 2nd vice president.

Admission of new members : New members have been admitted to the CLAE:

Dr Kamdem Fokam Aimé (consultant neurologist, Bafoussam Regional Hospital),

Dr Djouakep Noël (consultant pediatrician, Douala Laquintinie Hospital)

Dr Ndensi Jean Paul (consultant pediatrician, Bafoussam EEC Hospital)

Adoption of the CLAE 2012 Action plan.

5th and 6th December 2012: Sensitization campaign and consultation of 103 patients with epilepsy in three health centers in economic capital Douala: District Hospital of Nylon, Bonassama District Hospital and Hôpital Saint Albert Legrand of Bonaberi.



REPORTS FROM CAMEROON

Summary of Activities in Relation to Global Campaign in 2011 and 2012

September 15th, 2011: Dr Samuel ELONG NGONO, treasurer of the Cameroonian League has participated on a radio program on epilepsy in an international German radio Deutsche Welle. http://www.dw-world.de/dw/article/0,,6618001,00.html?maca=fra-podcast_sante-1858-xml-mrss

Educational Activities

May and June 2011: Activities in Mbam area, Centre Cameroon, under supervision of the Ministry of Public Health: sensitization campaign against epilepsy, recruitment of patients and organization of training session in the Mbam area.

4th December, 2012: Training session for 10 general practitioners at the District Hospital of Nylon. Subject for discussion was semiology of seizures (Dr Jacques DOUMBE) and Medical treatment of epilepsy (Dr Callixte KUATE).

4th December, 2012: Training session for nurses and paramedics at the Bonassama District Hospital on Clinical diagnosis of seizures and treatment of status epilepticus (Dr Joseph FONDOP)

Activities in conjunction with local IBE Affiliate

5th and 6th December 2012: Sensitization campaign and distribution of more than one thousand prospectus on definition, clinical sign, aetiologies of epilepsy, and care for people with epilepsy.

Elaboration of prospectus and posters in collaboration with SANOFI-AVENTIS for sensitization campaign of the CLAE.

Future Plans

Choose a National Epilepsy Day,

Organize a sensitization campaign in elementary and primary schools in Douala and Yaoundé,

Organization of a sensitization campaign in two national companies, and training of health personnel of these companies in the diagnosis and treatment of epilepsy.

Organize the 1st Cameroonian Epilepsy congress

Officer Election Date : Yet to be stated. Probably end of year 2013

Report By: Dr Callixte KUATE TEGUEU, secretary General of CLAE

Three planned training sessions of 2 days in management of epilepsy for health personnel; nurses, community psychiatric nurses, medical assistants, doctors, pharmacists were conducted during the first year of the project; one in Tolon-Kumbungu and two in Ashiedu Keteke districts. In all 87 health personnel were trained; 28 from the Northern Region and 59 from the Greater Accra Region.

Participants had a pre and post-test. Test scores for the post test improved significantly over that of the pre-test in all the groups. For Northern Region test scores for the pre-test ranged from 3-8 over a total of 10 with an average of 5.68 and that for the post-test 7-10. The average score for the post test was 9.76. Participants completed a post training evaluation form. Most participants said the training was good. Some suggestions from participants to improve the training were:

- increase training period to 4-5 days
- training of more staff and general public on the disease
- more clinical videos
- follow up visits to assess the effectiveness of training
- more continuous training workshops
- there should be clinical sessions during training

- improve availability of drugs
- a role play should be introduced so participants can act

Participants received certificates of participation at the end of the training and were encouraged to practice what they have learnt.

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FACES OF GHANA FIGHT AGAINST EPILEPSY LAUNCH

*Cape Town: 10-13 February 2013
Dr Kirsty Donald and Prof Jo Wilmhurst*



The Cerebral palsy Association its 2013 conference in the beautiful city of Cape Town SouthAfrica. Prof Jo Wilshurts presents the highlights of the conference.

There were representatives from 22 different countries. Sponsorship was offered to one delegate from each country, but a number of countries chose to pay for additional delegates to attend. A total of 60 people attended the 2 days (including the local delegates). There was a strong representation from the Francophone countries in Africa. This was a significant strength of the meeting and Professor Shevell made an additional contribution of skillfully integrating the post-lecture discussions across English and French representatives. As such languages were not a barrier.

Programme summary:

The scientific programme consisted of a range of topics spanning advances in the understanding of the neurobiology underlying the cerebral palsies, clinical and functional classification systems, theories around the relationship between different factors in the causal cascade of this group of conditions, thoughts on the different spectrum of causes in resource-poor countries, management priorities and cost-effective management strategies as well as addressing specific topics such as vision, seating, interventions in Cerebral Palsy (CP) (with associated discussion on guidelines and appropriateness of different strategies in the African context). A range of delegates representing different geographical areas across the continent were invited to give brief presentations on a situational analysis/specific challenges for their country/region.

Workshop summary

On the second afternoon a series of facilitated group discussions were held around 4 key focus areas:

Definitions (facilitator: Prof L Jacklin, RSA Dr K Donald, RSA; Prof Majnemer, Canada)

Aetiology/epidemiology (facilitator: Dr P Follet, USA, Prof R Wammanda, Nigeria)

Services/Capacity (facilitators: Prof Singhi, India, Dr A Kakooza, Uganda)

Education and research (facilitators: Prof Wilmhurst, RSA, Dr D Beardon, Botswana/USA)

Take home points from group discussions:

CP is a term often used in African contexts to describe all motor disability syndromes.

Delegates reported that in many countries CP is considered synonymous with birth asphyxia.

Internationally accepted consensus definitions are relevant in resource-poor countries but the lack of diagnostic facilities makes excluding some of the “non-CP” conditions/mimics more difficult. Also the “ceiling” age at which one can call a post-natal insult CP may be more important in this group?

Some groups include children who acquired brain injury up to the age of 5 years. After the discussion it was felt that using the international consensus definition age of 2 years is probably the most useful way to achieve consistency in the discussion of the topic.

The spectrum of aetiologies is different to the well described European and North American cohorts. There seems to be a greater proportion of post-natal aetiologies (Infections/post-infectious/Traumatic brain injury), based largely on anecdotal evidence. There is very little published data either on prevalence or aetiology in African countries. Published reported to date are largely discreet cohorts often drawn from hospital clinics and therefore not population based studies.

Delegates reported seeing a larger proportion of Gross Motor Functional Classification System (GMFCS) IV and V children in their services compared to European and North American cohorts. This was postulated to be due to a combination of selection bias (hospital cohorts vs community); lack of access to medical services (resulting in only the most severe children who really need medical input to survive being brought to medical attention) and **powerful stigma against disabled children (resulting in children being “hidden” when medical attention not considered essential).** Delegates felt that there may be overall a greater proportion of children with more severe disability in resource poor countries because of delayed presentation of a range of disorders as well as the lack of early intervention services. However, this hypothesis needs to be tested across population based epidemiological studies. This was identified as a key research priority going forward.



There was a robust discussion

on whether certain acquired conditions should be included in the CP group. The consensus was that congenital infections such as cytomegalovirus and rubella should be included, as well as traumatic brain injury and neurological sequelae of meningitis (<2 years of age), providing they also met the other inclusion criteria for the diagnosis (especially motor disability). **Conditions which are included by some centres such as HIV encephalopathy (progressive) and Spinal muscular atrophy (i.e. lower motor neurone disorders) should be excluded.** A discussion about the inclusion of these conditions in “motor disability” rather than “CP” clinics for service purposes was discussed. This was the rationale for including a talk on HIV Encephalopathy in the programme. It is clear that there is **inadequate training at both undergraduate and postgraduate levels** in paediatric neurology in most Medical schools across the African continent.

Even for particularly prevalent conditions such

Cont'd p10

LIVING WITH EPILEPSY

WE THOUGHT SHE HAD A DEMON....Alumona, Christian Obiajulu

Final year medical student,
University of Nigeria, Enugu Campus. 07030585247

Once again Auntie Agnes was having another of those “attacks”. While she lay helplessly on the ground shaking terribly under the palm fronds she was carrying on her shoulders before she fell, no one seemed in a hurry to come to her aid. Though the adults tried so hard to make their own escape appear passive, we the children practically took to our heels and fled with our hands clutching tenaciously on our noses as though a chemical weapon just detonated. From a safe distance, we would then watch as the “demon took hold of her and shook the life out of her”. During this period she drivels saliva and sometimes inflicts serious bite injuries on her tongue which would prevent her from enjoying a decent meal for a significant while.

After this convulsive episode, she would remain unconscious for some minutes and it was during this time that she was supposed to release the “highly contagious flatus” that is capable of transferring the “affliction” to anyone who was “foolish” enough to come around her.

Later on I was to discover that what we taught was a demonic attack indeed had a scientific explanation and that auntie Agnes had what is called **Grand Mal Seizures Disorder**. However, this was because I entered medical school. Meanwhile all the other kids who remained in the village continued in this misconception about epilepsy. They would later grow up into adults and pass on the same belief to the next generation thereby perpetrating the stigma that followed Auntie Agnes and all the others like her in the village.

Epilepsy is probably one of the most stigmatised diseases in the world today. The attitude of people towards **People with Epilepsy (PWE)** is shaped to a very great extent by ignorance about the aetiopathogenesis of the disease. It was this same ignorance and the belief that epilepsy was both demonic and contagious that made us to avoid Auntie Agnes. No kid went close to her house let alone sit to eat anything she cooked. On an occasion, she fell into the fire while cooking and before she was rescued part of her face and hands got burnt leaving her with a big scar. The general attitude with which both relatives and neighbours treated her forced her to withdraw into a world of her own. This all the more made Auntie Agnes to look so weird especially to us kids.

PWE face various degrees of **Epilepsy Stigma (ES)** all over the world.

It is expected that stigmatization would be more severe in the developing countries as awareness about the disorder is least in these regions

Also with about 80% of **PWE** living in developing nations¹, the majority of **ES** would occur in the developing nations. The spectrum of **ES** ranges from simple rejection to historical atrocities such as burning at the stakes². Even though the later belongs to history, the stigma forms prevalent to our society today have been classified into three types viz; **Perceived ES, Enacted ES and Courtesy ES**³.



Perceived ES: This is a self-inflicted stigma. It refers to a feeling of shame of being epileptic. The person feels that he/she will be devaluated and discriminated hence he adopts as a result of such misleading notions negative strategies like social withdrawal and secrecy that would impact on their quality of life³.

This is very common and my auntie Agnes had it too. It can preclude educational or career pursuit. **PWE**

cannot totally be blamed for this because it is their society that forces them into this miserable state. The existence of this form of stigmatization requires that any programme aimed at fighting **ES** should be geared not only towards the perpetrators but also the victims.

Enacted ES: This form of **ES** is inflicted by uninformed relatives, friends, neighbours and the general society on **PWE**. It represents actual episodes of discrimination against **PWE** for no other reason besides the fact that they have epilepsy. It is compelled by ignorance and prevails in developing countries. Auntie Agnes suffered this too in our hands.

Courtesy ES: This is experienced by parents, friends and family or people associated with **PWE**. It is characterised by a feeling of shame and **PWE** may be kept indoors in other to hide the diagnosis. Maybe we did not experience this stigma because we were still kids at the time auntie Agnes lived but I remember vividly that her two daughters could not find suitors until at advanced ages.

Cont'd p 17

Medical schools across the African continent. Even for particularly prevalent conditions such as epilepsy and cerebral palsy, which constitute a significant burden of disease amongst the paediatric population, there is very little formal training in many centres.

Outcomes: The way forward

This meeting gave an excellent body of both academic and practical content around the topic of Cerebral Palsy in the African context. Discussion was far ranging and enthusiastic across the full range of topics and revisited in the facilitated discussion groups.

All the lectures were recorded and will be available as podcasts (and pdf's) on the ICNAPAedia website shortly. Links will be individually sent to delegates and will also be widely and freely available as a resource for people to refer to. Discussions following the didactic lectures will be included in the material available.

Longer term training programmes which foster both clinical training and research collaborations is a key priority. Existing networks already exist to a limited extent

The African Paediatric Fellowship Program based in the Department of Paediatrics, University of Cape Town, has formally trained medical and nursing practitioners from across Africa since 2008. Collaborations are formed with other tertiary institutes who identify key health care challenges where developing a skilled work force will influence child health outcomes. This program is training doctors in all disciplines including paediatric neurology and neurodevelopment. <http://www.scah.uct.ac.za/apfp/>

Research priorities must include some multicenter collaborative studies looking at the prevalence, spectrum of CP and main aetiologies in the African context. This is vital in order to motivate not only for services for children with existing disabilities, but also in order to effectively target the main aetiologies to develop preventative strategies for the continent.

The value of this meeting included getting a group of individually, often isolated professionals (as they they may be the only such specialist in the country), driving the care of children with CP in their region/country together to address challenges which in many respects are similar across the continent. This is a forum which can be grown and expanded in order to focus the needs of children with neurodisability in Africa.

Epilepsy workshop:

On the final day of the workshop the delegates attended a session relating to Updates on Epilepsy in Children. Speakers at this workshop were Prof Helen Cross (The Prince of Wales's Chair of Childhood Epilepsy, and recently elected Secretary of the International League Against Epilepsy), Associate Prof Jo Wilmshurst (HOD Paediatric Neurology, Red Cross Children's Hospital) and Prof Pratibha Singhi (Chief Pediatric Neurology and Neurodevelopment, Chandigarh, India and President of the Child Neurology Society of India).

Prof Cross presented the basic concepts of epilepsy through to the relevance of molecular genetic testing – especially the implications to therapies. Further presentations on co-morbidities and medically intractable epilepsy syndromes generated much discussion. Prof Singhi presented the latest approaches to status epilepticus with relevance to capacity to follow guidelines in RPC and safe practical approaches relevant to the African context based on her extensive experience in India. Associate Prof Wilmshurst showed a collection of video clips of paroxysmal events which the audience were asked to differentiate from seizures and commit to the underlying aetiologies. The meeting closed with a summary of the updated information on services and capacity to treat seizures across Africa from a total of 34 African countries. This data has recently been accepted for publication in the Journal of Child Neurology. Access to this article will be made open for health care workers from low income countries. This interactive workshop was attended by 129 delegates both from the ACNA group but also South African paediatricians who were attending as part of a Paediatric Refresher course which occurred over the subsequent days.

This was a valuable opportunity for practitioners from diverse situations to interact and forge collaborations. A number of the ACNA group elected to remain on for the remainder of the refresher course program.

The next focus area identified by the ACNA delegates for this ICNA educational outreach programme is **Autism**. This will be held in Ghana in 2014



News from SENEGAL:

The Board of Senegalese League against Epilepsy has been received by the Minister of Health, Pr Awa-Marie Coll Seck on March 12 2013. The activities and projects have been presented to her. She gave instructions for the organization of a workshop which purpose will be to set up a National Plan of action against Epilepsy in Senegal.

PSYCHOSOCIAL ISSUES IN EPILEPSY

Epilepsy is a chronic medical disorder characterized by repeated, unprovoked episodes of seizure. Seizure is a transient behavioural manifestation due to abnormal electrical discharge from the brain. Approximately 1% of the world populations suffer from the disease whose onset could be from childhood or adulthood. Several conditions such as head injury, meningitis, fever, substance abuse, pregnancy, brain malformation, etc. have been associated with seizure. Persons with Epilepsy are treated with Antiepileptic drugs (AED) and should visit their doctors on appointment for evaluations.

The major problem of persons with epilepsy is not occasional recurrent seizure episodes that occur for few seconds but the **PSYCHOSOCIAL** consequences, unfortunately many attending physicians may only assess seizure control in clinical visits. With the introduction of newer Antiepileptic drugs, many assessing treatment have good seizure control but the issue that may linger is stigmatization, isolation or other psychological sequelae that may follow a single episode, especially if it happens in a public place. In addition, financial burden and regular hospital visits are added stress.

Young females with epilepsy may find it difficult to marry due to stigmatization and discrimination. Seizure frequency and severity vary during menstrual cycle due to hormonal changes, hence the need to adjust doses of AED. The female sex hormone, Estrogen, increases the risk of seizure while progesterone reduces the risk, and the concentrations of these two hormones vary during menstrual cycle. Epileptic females are likely to give birth to children with the defects, although premedication with folic acid are beneficial against these defects. Studies have shown that women with epilepsy have low fertility and are more likely to Have cycles without ovulation.

Persons with epilepsy, especially intractable type, are stigmatized, Isolated, sometimes retrenched from work, divorced or driven away from marital homes, etc become unhappy, loose interest on pleasurable events, sleep poorly at night and many eventually fulfill criteria for diagnosis of Depressive episode. Unrecognized and untreated depression may lead to Suicide.

He or she develops fear of possible seizure episode, even on medication and may then begin to avoid public places, places of worship, stops going to work or drop out of school. Subsequently meets guideline for diagnosis of Anxiety disorder such as social phobia, Panic attack, specific phobia or Agoraphobia. Repeated episodes of seizure impair cognitive function such as memory, language, executive functioning etc.

Sometimes altered mental state with presence of either or combinations of Hallucinations, delusions or

disorganization, impairing their ability to function may occur. This is known as psychosis.

Persons with intractable or untreated seizure episodes for years may be dependent on relations, unable to marry or sustain employed job.

In view of the above briefly outlined psychological and social sequelae of epilepsy, there is need not only to focus on seizure control especially among young females. Seizure control constitutes about 20% of Biopsychosocial care, hence the need to engage mental health experts in the management of persons with epilepsy.



Dr. Onyebueke Godwin
MBBS, FWACP (Psychiatry)

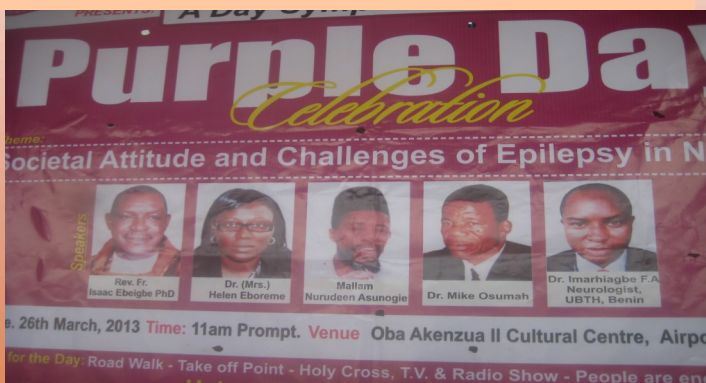


Angie Epilepsy Foundation

Where we are coming from

Angie epilepsy foundation was born out of passion for those living with epilepsy. The passion came from pain and frustration I experienced when my son first started showing signs and symptoms of epilepsy. Initially I didn't know that what my son was suffering from was epilepsy. I was totally ignorant of what he was going through. As at this time he was not falling, in the night he would scream, stretch, twist and gnashed his teeth and we would struggle with him out of ignorance, at the end of each traumatic struggle, the entire household would end up in frustration. This became very frequent and I began seeking the help of prophets, spiritualists and herbalist. I went to different churches where we were subjected to different kinds of fasting this ranges from three days to seven days as in the custom of the particular church. He was given all kinds of concussion to drink all to no avail. This night mare lingered on for years, we his immediate family began to wear off. Almost at the point when all hope seemed to be dropping I had a dream. In this dream a man in a white suit driving a white car almost knocked me down on the road as I was running to buy drugs for my son. He was very furious because I ran into the road without watching; I had to apologize to him and told him it was as a result of my rush to procure drugs for my son who was having a seizure. I was amazed at how furious this man was because I thought he would be sympathetic instead be blew up and called me a selfish woman because he said to me in that dream, I quote *'YOU WANT TO DIE BECAUSE YOUR SON HAS EPILEPSY? WHO DIES FOR THOSE OUT THERE WITH NO ONE TO CARE FOR THEM?'* Worse still he continued *'WHO DIES FOR THOSE WHO ARE TOTALLY UNAWARE THAT WHAT THEY ARE SUFERING FROM IS EPILEPSY'*

When I woke up from this 'day time' dream, I was frightened and worried. The next morning I went to see my Parish Priest and narrated the dream to him. My Parish Priest Rev. Fr Alfred Agbonlahor who had told me before now that my son's illness will bring about many testimonies, asserted that surely what I had was a revelation of great testimonies to come and charged me to be ready to do the will of God.



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*A*ngie Epilepsy foundation is committed to a worldwide awareness on the causes, early detection, dangers and management of epilepsy. Its main aims and objectives are as follows;

to reduce and gradually eradicate epilepsy in the society

To eradicate the stigma associated with persons suffering from epilepsy

To provide selfless and non discriminating service to them

To foster hope and boost the self esteem of the abandoned ones in the society

To foster hope and love amongst parents whose children are suffering from epilepsy

To help raise funds for those families who can no longer help their loved ones In procurement of drugs for treatment and control of this disease



So the journey began.....

When I left the office of the Priest, I told my catechist, Mr. Peter Ugbenyor that I wanted to have a foundation on epilepsy. Right away, he said to me 'I will introduce you to a lady who had worked with an NGO before. The next day the lady and I met. She introduced herself to me as Obehi Okpiabhele. She told me that I don't need any qualification to begin aside from PASSION. As long as there is passion the fire will keep burning. Passion I told her is the exact reason I was taking up this laudable project.

The passion to look and care for the children living with epilepsy besides my son, the passion to help reduce and eradicate epilepsy, the passion to help create awareness on epilepsy to the ignorant society and the world at large, the passion to LOVE and LIVE with persons living with epilepsy .

First of all I told Obehi that I wanted a sample test of the task ahead, so I started with my Parish (St Gabriel the Archangel Catholic Church sapele road ,Benin City Edo State). I decided to put a write up in the bulletin about epilepsy. After Mass on that same Sunday, over five people called my phone requesting to meet with me. The bulletin message was *"are you a parent or a guardian whose child or ward is having frequent fit and you don't know what to do? Do you know the best method or way to combat Epilepsy? If you are confused because your child is having seizures do well to call the following numbers 07033138244 or 07059306368"*

After my meeting with these people and seeing how anxious they were I told God that the project was really laudable and that it was going to be very challenging. After that we took the first dip by organizing the first seminar ever of the Angie Epilepsy Foundation in Benin City with the theme *"DISCOVERING THE SECRET HEALING AND MANAGEMENT OF EPILEPSY"* after the seminar which was a huge success with over 120 persons in attendance, there was the huge challenge of payment of debt. We needed money for the materials used at the seminar. In fact at the first seminar funding and communication were our major constraint.

It was with divine strength and encouragement we were able to organize our second seminar which took place in Mother of Redeemer Catholic Church Effuru. This seminar was an overwhelming success story because Catholics, Non Catholics and even Muslim men and women were present. We had a Muslim Guest speaker Mallam Nuroden Asorome.

We have been able to carry out seminar in several Places in Asaba, Onitsha, Sapele, Abuja, Auchilagos and in several Catholic communities in Warri.

Where we are going to....

According to the popular parable 'if you don't know where you are coming from you will not know where you are going to'. As it is we the members and workers of Angie Foundation have come a long way, we have so-journeyed rough long roads, journeys of been acquainted with disappointing faces, disapproving faces, journeys of rejection, no assistance.

By and large I think we have a focus, we have a sense of direction that is why a canoe that uses only passion as fuel is the vehicle taken us on this journey. We actually have a direction- *TO ERADICATE EPILEPSY IN NIGERIA. THIS IS OUR VISION STATEMENT.* But if we must do this, then our mission statement will be- *CREATING AWARENESS ON THE CAUSES, EARLY DETECTION, DANGERS, and TREATMENT AND MANAGEMENT OF EPILEPSY IS OUR PASSION.* However a lot remains to be done. We do not know how many people are not getting the help they need, help that is available, help that can be obtained at no great cost. Estimate suggests that over four million persons are living with epilepsy in Nigeria. Where are these people? over ten million Africans are suffering from some form of epilepsy, many of them suffer silently, many suffer alone. Beyond the sufferings and absence of care lie the frontiers of stigma, shame, exclusion and more often than we care to know death. Many people commend us every day we say thank you but we want you to do more. Knowing about the people living with epilepsy is not enough let us redefine our habits of giving. Let us give and learn not to ask for anything in return. We want those living with Epilepsy to be of good cheers, manage yourselves well and do something that will bring positive impact to the society. When we started we were managing over 17 persons but now we have affected 500 hundred person and we hope to do more. We however appeal to those living with epilepsy and their families to identify with this foundation. Please continue to spread awareness. It is so exciting to think just how big we will keep growing every year with all of us working together.

A.O ASEMOTA for
Angie epilepsy Foundation



Angie Epilepsy Foundation

2013 Purple Day

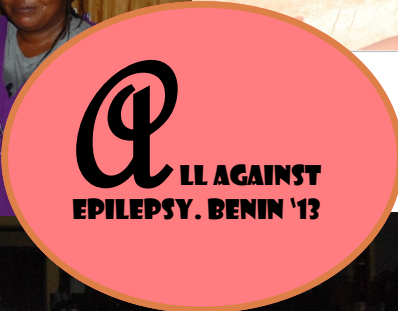


PURPLE DAY 2013 IN THE MIDWESTERN CITY OF BENIN, NIGERIA. THIS PROGRAM WAS ORGANISED AND CONDUCTED BY THE ANGIE EPILEPSY FOUNDATION



CROSS SECTION OF PARTICIPANTS AT 2013 ANGIE EPILEPSY PURPLE DAY CAMPAIGN





ANGIE EPILEPSY FOUNDATION



A Day Symposium to Mark

Purple Day Celebration

Theme:
Societal Attitude and Challenges of Epilepsy in Nigeria.

Speakers



Rev. Fr. Ebeigbe PhD



Dr. (Mrs.) Helen Eboreme



Mallam Nurudeen Asunogie



Dr. Mike Osumah



Dr. Imarhiagbe F.A. Neurologist, UBTH, Benin

Date: Tue. 26th March, 2013 Time: 11am Prompt.

Venue: Oba Akenzua II Cultural Centre, Airport Road, Benin City.

Activities for the Day: Road Walk - Take off Point - Holy Cross
T.V. & Radio Show - People are encourage to wear purple



The “Preying” Mantis

By Dr Biodun Ogungbo. FRCS, FRCS
(Neurosurgery)

She was pretty, petite, shy and introverted. Really, she was just a normal 16 year old Nigerian girl with a seizure disorder. Her story was engaging, her nature saddening as she told a story of seizures which has blighted her life from the age of 13 years. No warning. But, then she did have a bout of Malaria for which she was treated with Chloroquine for a whole month! Don't ask me why. The seizures make her stiffen up, lose consciousness, fall down and jerk like a fish out of water. Two minutes later, all quiets and she drowns in deep sleep, to wake up later, none the wiser of her ordeal.

Her mother took up the story. She has taken Beatrice (not her real name!) everywhere for treatment and the elusive cure. She has been to herbalists and numerous churches. She has drunk gallons of concoctions and performed many rituals, yet the seizures continue. In fact, it happened the morning of our consultation. “What investigations have been performed”, I asked? “Investigations?” she replied. “Is she on any medications now”, I asked. “Nothing o”, she replied. “I am tired of the problem”, she said. “It has drained me completely”, she added and started crying. Beatrice, the daughter, rummaged in her small hand bag and dug up a handkerchief which she gave to her mother, to use in wiping away the tears. I was touched by the simple act of kindness and love. Yet, she was actually the victim here.

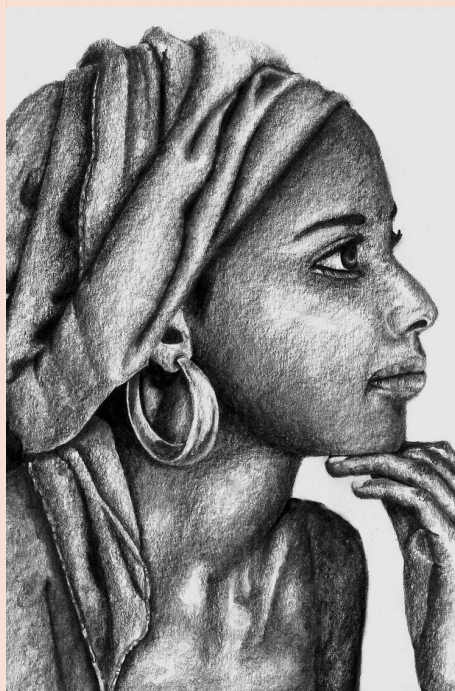
The mother carried on. Beatrice has not been properly diagnosed or treated. They did see a doctor once who showed keen interest in her problem and prescribed medications for her. It seems he also prescribed sex; for once, he invited her to a hotel to have fun. When she refused his advances, the treatment stopped.

The same prescription was offered by one of the pastors in the church. The mother had left her with the pastor for prayers and the ubiquitous olive oil anointing. She stayed overnight in the church. In the morning, on her way to the bathroom, the pastor appeared, naked, with the required ‘stick’ with which to drive out the evil spirits causing the epilepsy. The same prescription was offered by one of the pastors in the church. The mother had left her with the Once again, Beatrice refused and she was tossed out of the church. Obviously, this one cannot be cured!



Preying on the weak in our society. I was truly overwhelmed with the story and remembered the praying mantis. This tall, graceful insect with a big stomach has some of the fastest moves among insects.

Praying mantis is highly predacious and feed on a variety of insects, including crickets and grasshoppers. They lie in wait with the front legs in an upraised position intently



watching and stalking their prey. They will eat each other and often the adult female will eat the male after or during mating.

But, the real issue is about pastors, preachers and charlatans who prey on the vulnerable in our society. Many of these fake people cannot cure epilepsy but they promise cure, “so long as you do as I say, not as I do”. The means of cure can be spiritual or even physical as demonstrated

here. Mrs Angela Asemota (Angie Epilepsy Foundation, Benin) chipped in that she herself had been propositioned by men in position of power when she goes out soliciting support for the foundation. An offer of help either materially or financially is conditional upon her satisfying this type of base and animalistic urge for domination. While talking about seizures, all the men think about is convulsing with pleasure.

Epilepsy

Epilepsy is not due to a spiritual attack and so pastors do not have to cast evil spirits out of the patient. Epilepsy is also not a mental illness but many sufferers are hidden away by families and friends in a warped protective manner. Seizures are mainly a symptom that there is a physical problem, like a scar, on the brain.

Some people with epilepsy are extremely clever, others are of average intelligence and some have learning difficulties. Big deal! Many of our leaders are actually like this as well. Epilepsy is therefore not a bar to success in life but the fact that many children do not go to school is what ends up blighting their future.

Epilepsy can affect anyone

I keep saying and impressing on people that epilepsy can affect anyone and we need to be more compassionate to sufferers. For as long as we are still alive, we all still have a risk of developing seizures in our lifetime. Secondly, people suffering from this disorder are highly stigmatised, dehumanised and ostracised.

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LIVING WITH EPILEPSY

These three forms of stigma work hand in hand to compromise on the quality of life, relationships, employment status, educational attainment, psychosocial attributes and the general health of PWE. Whereas the disorder itself can be effectively controlled with medications, the stigma can only be controlled with positive advocacy, awareness creation and public enlightenment in addition to efforts aimed at improving the self-worth and esteem of PWE through platforms such as support groups and the likes.

Each time I recall the part we played in the morbidity my aunty suffered, I feel a pang of guilt in my conscience. If it were possible to turn back the hands of time, then I would go back home and tell everybody not to be afraid of her anymore. I would explain to them that she has no demon; that what she has is only a mere disorder involving the brain and that this disorder is not contagious at all. I would teach them how to take care of her when she has a seizure. Then I would go on to counsel Aunty Agnes and tell her all she needed to know about her condition;

how to recognize when an attack is imminent and places and activities to avoid. Finally I would encourage her to present to a neurologist with a referral which I would personally sign. But this might not happen anyway; Aunty Agnes is dead. She died long ago after a status. She died in her own house. It was said she died with tears on her face. No one took her to hospital. We all taught she had a demon.

Even though my Aunty is dead and there is nothing I can do for her, there are still people living with epilepsy today who are passing through more severe forms of stigmatization than my aunt ever experienced. They leave in ignorance and misery. For these ones we can do a lot. It is what we do from now that would be the next and honest story about epilepsy.

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 Epilepsy and Seizures- A Historical Perspective- Myths and Misconception. www.science.jrank.org. Accessed on Feb. 28, 2013.
 Epilepsy: Stigmata and Management. www.scialert.net. Accessed on Feb. 28, 2013.

The “Preying” Mantis

It knocks their self confidence and destroys their self worth. They feel cursed and abandoned even by God. Many have committed suicide because of the shame and the dent in their potential. Beatrice does not go to school though she is highly sensitive and perhaps even very intelligent.



If we all do our job to the best of our limits and skills, then it is possible to keep patients seizure free and off the clutches of nasty people.

Attitudes need to change to make life a bit more bearable for sufferers. They are not and should not be seen as cannon fodder by pastors and even doctors. We have to actively protect sufferers from predators by

Epilepsy can be treated, controlled and rarely cured.

In over 50% of cases of epilepsy, we do not have a credible diagnosis and do not see any structural abnormality on the brain of the sufferer. In these types of cases, cure is also elusive and long term medical treatment is crucial. Doctors also have so much to offer with up to 20 different drugs available for patients with epilepsy.

The right drug for the right patient and at the right dose for the individual is what is important. Sometimes, it is even possible to tail off a medication and then stop completely once the person is seizure free. The Government (**You and I, the people**) must use Nigeria’s economic clout (**all 160 million of it**) to get drug manufacturers to make these drugs easily available and affordable for our people (remember, it maybe them today, it could be you tomorrow). Epilepsy due to an accessible, abnormal area of the brain such as a brain tumour

providing affordable and effective treatment centres. Please if you have read and understood this article, resolve to help sufferers today. Share this information and be more compassionate towards victims. Donate to the charity (Angie Epilepsy Foundation, Benin).

Remember, it could still affect you (though may it not be your portion, Amen).



By Dr Biodun Ogungbo. FRCS, FRCS Neurosurgery)

EPILEPSY CARE IN SUB-SAHARAN AFRICA

MANAGEMENT OF EPILEPSY IN NIGERIA

Challenges and perspectives.

In the African sub region epilepsy is the most common serious neurological disorder and one of the most prevalent noncommunicable diseases. Epilepsy can occur in all ages, but especially within childhood and adolescence. The prevalence in Nigeria reflects a worldwide pattern, although the number of new cases every year (incidence) is likely to be higher because of higher incidence of predisposing cerebral disorders such as communicable diseases, perinatal insults and other brain stressing factors. Violence, high rates of road traffic accidents as well as outdated cultural and religious practices all contribute to the high burden of epilepsy in the society.

This high prevalence also reflects the poor health conditions resulting in several public health-related diseases complicated by brain damage which may later result in epilepsy. It is easy therefore to conclude that most cases of epilepsy in Nigeria are symptomatic and preventable. For example good obstetric care and immunization would prevent many causes of epilepsy in children (the most exposed population to epilepsy).

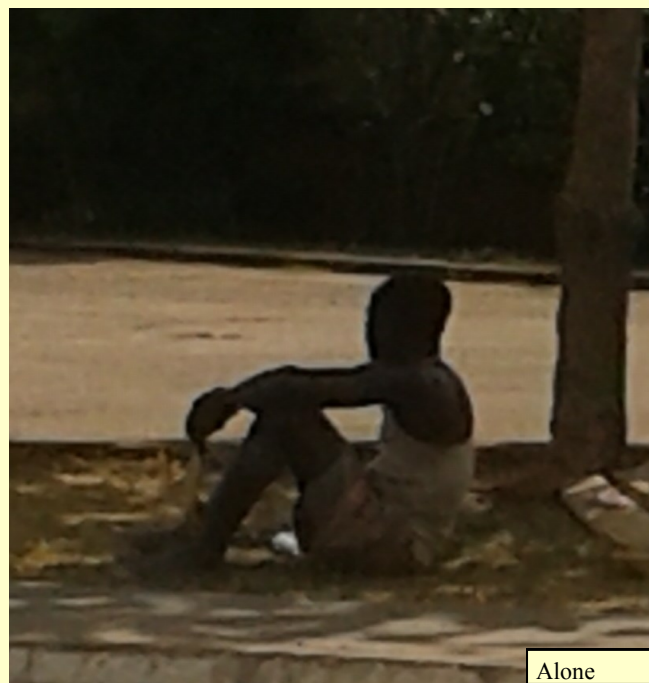
Febrile convulsions a major cause of seizures can be stopped by treating the most common causes of fever such as malaria and other infectious diseases such as meningitis, encephalitis and septicaemia. Increasing use of tobacco and increasing cardiovascular disorders as well as sedentary lifestyle are associated with stroke leading to increased incidence and prevalence of epilepsy in later life.

The long-term outcome, impact, prognosis and mortality of epilepsy has not been well documented in the country. Mortality data are scarce. In Cameroon the mortality was 3–4 times higher than the general population. This may also be true in Nigeria. Accurate mortality information is essential to place epilepsy correctly within the rank of public health disease context.

Challenges and Perspectives.

Cultural and religious beliefs are important issues in the country. They influence the value placed by society on chronic disorders including epilepsy. The presentation of symptoms, illness behavior, pathways to care, family and community response to illness, the degree of acceptance and support (and stigma and discrimination) experienced by the person with epilepsy may be colored by cultural and religious beliefs. Cultural beliefs vary between and within ethnic groups. People may not seek treatment with antiepileptic drugs if epilepsy is not seen as a condition that can be treated by orthodox medicine.

Commonly as in many less developed countries, epilepsy is perceived as a manifestation of supernatural forces such as evil spirits. In a northern Nigerian urban community 17.5% of the respondents believed that epilepsy is transmissible through physical contact, saliva and droplet infection. In Enugu, South east Nigeria about 39.3% of school children believed that epilepsy is due to spiritual attack, and close to 70% will advocate the use of herbal remedies for its treatment. Similar findings were reported from other parts of the country. When patients and/or their families hold supernatural beliefs regarding seizures, care seeking will be directed toward traditional healers rather than hospital or clinic-based care. Furthermore, seeking care from traditional healers may lead to serious implication especially for children who are more likely to develop irreversible brain injury.



Alone

Despite Western and Islamic cultures this problem is still widespread. It is only after several months or years of trial and error that the patient eventually is taken to hospital for proper care. It has been suggested that improving the cooperation with the traditional healers could lead to better referral but this has not been found to be true in my experience. The choice of method of prevention is also connected with religious inclination of the family involved. Hence, offering prayers and choosing spouses from families without epileptic members are common and these often reinforce stigma. The levels of literacy however influence cultural beliefs and choices.

Epilepsy is often perceived as a mental illness or contagious disease and often managed by psychiatrists. This leads to unacceptable responses towards people living with epilepsy.

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Death, drowning, burning and other injuries are common in people living with epilepsy and may reinforce stigma even within families and communities of people with epilepsy. Many patients are denied education, opportunity to learn trade and employment. Children with epilepsy often face discrimination and isolation at school. Side effects of antiepileptic drugs may cause drowsiness and poor academic performance hence reinforcing stigma. Hospital-based study indicate that people living with epilepsy of normal intelligence receive significantly less education than their sex matched siblings. Sometimes parents may deny their children education to limit injuries and stigma outside the home, in other cases it maybe a way to save money to educate other 'normal' siblings. The result is low self-esteem and under-achievement at school. Surveys conducted in schools revealed a high rate of social withdrawal among children with epilepsy.

Regulations regarding epilepsy generally does not exist and where they exist they are not well implemented. However, in general, there is little appreciation of the need to curtail some rights or where this exists such curtailments are unduly harsh and unsubstantiated. The results are avoidable accidents on one hand and low productivity on the other. Marriages may be terminated because of seizures and children separated from their parents. The psychosocial consequences of the stigma are most evident in women with epilepsy of marriageable age. Studies in rural southern Zambia has shown that in polygamous regions, People with epilepsy are less likely to marry than people without the disease. Seizure exacerbation may lead to divorce.

Being unemployed because of stigma is important for a woman with epilepsy, as it makes her economically dependent, as well as dependent in making personal decisions. Unmarried adult females with epilepsy may be vulnerable to sexual exploitation, physical abuse, and extreme poverty making epilepsy a possible risk factor for HIV/AIDS. Stigma may be extended beyond the individual to family members and other close associates 'Courtesy' stigma. Sometimes health workers may also attribute some seizures to supernatural causes, and such beliefs may influence their willingness to provide epilepsy care and the quality and content of that care.

Most patients because of cultural beliefs, visit traditional healers for care who also endorse a supernatural explanation for epilepsy in which the whole family unit maybe seen as the victim. This serves to foster protective feelings toward people living with epilepsy or alternatively rejection and ill treatment towards the individual or their families. Traditional healers perpetuate or even indeed profit from stigmatizing beliefs about spiritual causes of epilepsy.

Human resources are the center around the health system of any country or society revolves. The number and the skill levels of health workers in the country are far below what is needed to reduce the disease burden. A country with a population of about 150 million with only 150 neurologists and less than 50 neurosurgeons is nothing but the definition of failure. Further challenges such as insecurity and other internal conflicts have adversely affected health infrastructure, services, and personnel retention. In the country, specialized diagnostic tools for brain disorders, are few. Though infrastructure has improved, but these challenge remains. Consequently, patients are not optimally treated, leading to over-diagnosis of epilepsy and unnecessarily prolonged antiepileptic drug therapy. In addition, there are large inequities within and across the country and income groups.



Closely related to the dearth of human resources is the limitation and challenges of research in Epilepsy in Nigeria. The case of epilepsy care in Nigeria can be correctly called 'Alone'. People with epilepsy truly has no voice. Health facilities and institutions are simply not interested. The society and politicians do not believe there is a problem. We go about with shallow religion and piety and are ready to kill one another when provoked. Managing our health and public institutions well will do more to reduce the burden of epilepsy than our shallow beliefs.

Another challenge in the management of epilepsy in Africa is poverty. The cost of epilepsy in the country includes the high cost of transport to distant hospitals as well as the direct and other indirect costs. The burden of care is easily appreciated when one remembers that more than sixty percent of our people live on less than US\$ 1.00 per day (UNDP, 2001). This in fact, explains the use of cheaper antiepileptic drugs despite their higher side effect profile. Modern antiepileptic drugs are not readily available and remain very expensive. Most patients may not afford the cost and therefore do not benefit from modern treatment or do not continue to seek treatment. Epilepsy provides the clearest example of a neurological disorder for which effective and cost efficient treatment is available. Studies both in the developing and in the developed world revealed that if properly

treated, up to 70% of people with this condition could live productive and fulfilling lives, free from seizures. Yet in Nigeria less than 10% the people who have this condition are on treatment. Consequently the rest remain in the shadow of this treatment gap. "Treatment Gap".

Out-of-pocket payment is the primary methods of health financing for epilepsy care in the country. Scarce epilepsy services coupled with high cost, results in inequity in the utilization of services. Disability benefits, such as monetary benefits, rehabilitation and health benefits, benefits at the workplace and other benefits including housing, transport, education and special discounts are nonexistent. In the country, health care vary from region to region and from state to state, as such patients' care may be compromised when they relocate from one place to another. It should also be stated that the government's structural adjustment programs hinder the health sectors making many health activities unaffordable

Inadequate training of primary health workers in the use of antiepileptic drugs has led to many patients with epilepsy receiving multiple and often expensive antiepileptic drugs simultaneously thereby increasing cost. Irrational drug use may cause drug side effects which are otherwise avoidable. Furthermore, a large proportion of patients with epilepsy, despite being initiated on treatment, soon discontinue the treatment (secondary treatment gap). The principal reasons include cost and lack of basic information about the consequences of medication nonadherence.

No center in Nigeria offers epilepsy surgery. Neurosurgeons do treat causes of secondary seizures such as tumors and post-traumatic scars, which cause seizures. The sophisticated diagnostic equipments required are no readily available. Ketogenic diet is expensive and may have limited application because of widespread poverty. Rehabilitation or re-socialization programs for people living with epilepsy are nonexistent.

Another major challenge in the management of epilepsy is the lack of a proper health policy on chronic neurological disorders such as epilepsy. Much of the focus has been on infectious diseases and maternal and child health issues. There is a poor awareness of the problems of epilepsy among decision-makers. To address this issue in the continent, one conclusion of the Marrakech meeting on the "Treatment Gap" in May 1999 was:

"A commitment to resources for epilepsy treatment must be gained from governments and international health organizations. Political patronage must ensure that epilepsy remains on the agenda and that essential drug supplies are assured."

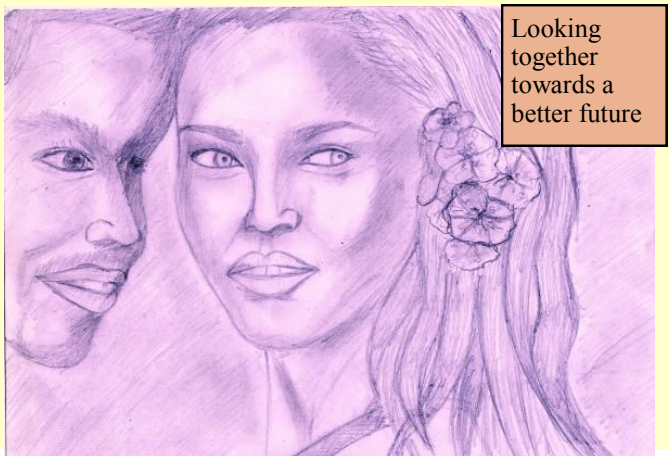
Every single person with epilepsy can contribute to the economy if he or she becomes seizure-free. Indeed the World Bank has prioritized epilepsy as a highly cost-effective condition to treat. Primary prevention of epilepsy must come to the fore and must be included as a component of the National Health Plan in the country.

Other important aspects to consider are: literacy, cultural beliefs, distance from modern healthcare facilities, restricting/regulating the practice of traditional healers in the continent. Efforts should be made to address the problem of the availability of know-how at the community health care level. Reasonable level of seizure control can be achieved by primary healthcare workers but sufficient back-up for all primary health care workers should be available in order to give epilepsy care its proper place.

Various groups (politicians and other decision makers as well as professionals, people with epilepsy and their families, teachers, and primary health care workers, police and the general public) have to be targeted. The use of modern education programs and information for professionals could benefit health care givers. In view of our heterogeneous sociocultural environment, intervention models should be tailored towards the local and regional scenarios and should be community based: what is applicable in one region may be totally unacceptable elsewhere.



**Dr Ezeala-Adikaibe
BA, FWACP
(neurology)**



Looking together towards a better future

Country Report Cameroon

REPORT OF A TRAINING SESSION AND SENSITIZATION CAMPAIGN ON EPILEPSY

Training of medical doctors: December 4th, 2012 from 1:00 to 2:30 PM.

Trainees : 17 MDS attend the training session.

Report for the consultations :

A total number of 103 patients were consulted with 60 female (58.3%) and 53 male (41.7%). Out of these patients, 89 (86.4%) were living on urban area (Douala town and around) and 14 (13.6%) in rural area. The mean age of the patients was 22.98 ± 13,70 years. The younger was 12 months old and the elder 70 years old. The distribution of patients by age is showed on table I.

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Table 1,

Duration of epilepsy	Frequency	Percentage (%)
Less than a year	14	13,6
1-2 yrs	9	8.7
2-3 yrs	5	4.9
3-4 yrs	11	10.6
4-5 yrs	3	2.9
5-10 yrs	26	25.2
10-15 yrs	20	19.5
15-20 yrs	9	8.7
More than 20 yrs	6	5.9
Total	103	100

Subject for discussion:
 semiology seizures (Dr Doumbe),
 Medical treatment of Epilepsy (Dr Kuate) ;

Training session for nurses: December 4th, 2012 from 1:00 to 2:30 PM.

Number of trainees: 20 nurses from public and private hospital in Douala.

Semiology of seizures (Dr Fondop),
 Care of patient with generalized tonic clonic seizures (Dr Fondop)

Sensitization campaign.

Conception and distribution of prospectus on epilepsy to patients and accompanying person in two district hospital (Bonassama and Nylon) and one private hospital (Albert Legrand of Bonassama). More than 1000 prospectus were distributed during the two days campaign, on 5th and 6th December 2012.

Medical consultations: December 5 and 6, 2012 from 8:00 am to 13:00 pm.

Nylon district Hospital: Dr Mapoure, Dr Fondop, Dr Doumbe, Dr Kamdem Aimé, Mme Yolet Pauline

Bonassama district Hospital:

Dr Kuate, Dr Jon, Mme Ngwa, Ngankou Stève, Kenmogne Marie

Albert Legrand Hospital of Bonabéri :

Dr Noubissi Gustave and Dr Tchaleu Clet



Occupation : The majority of patients 45 (43.7%) were pupils or students, 30 (29.1%) retired, 10 (9.7%) of liberal profession, 8 (7.8%) traders or craftsman, 4 (3.9%) were farmers, 3 (2.9%) civil servant and 3 (2.9%) working at home. For the level of education, 51 patients (49.5%) went to secondary school, 36 (35%) a primary school, 10 patients (9.7%) have not finish the primary school and 6 (5.8%) went to University.

Treatment (Table II) : A part for antiepileptic drugs, 43 (69.4%) patients were taking traditional medicine and 25 (40.3%) prayers with religion pastor **Frequency of seizures:** The frequency of seizures was monthly for 49 patients (47.6%), yearly for 22 patients (21.4%), weekly for 14 (13.6%), quarterly for 13 (12.6%) and every day for 4 patients (3.9%).

Duration of epilepsy (see Table III):

Table III: Distribution of patients according to duration of epilepsy.



Antiepileptic drugs	Frequency	%
Carbamazepine	36	35
Valproate	34	33
Phenobarbital	24	23,3
Phenytoine	7	6,8
Benzodiazepines	6	5,8
Aucun	8	7,7
Monotherapy	83	87,3
Bitherapy	11	11,5
Tritherapy	1	1%

Duration of epilepsy	Frequency	%
Less than a year	14	13.6
1-2 yrs	9	8.7
2-3 yrs	5	4.9
3-4 yrs	11	10.6
4-5 yrs	3	2.9
5-10 yrs	26	25.2
10-15 yrs	20	19.5
15-20 yrs	9	8.7
More than 20 yrs	6	5.9
Total	103	100

Report by :Dr Jacques DOUMBE, 2nd vice president of CLAE, Dr Callixte KUATE, Secretary General of CLAE.



Beautiful Indeed



CHALLENGES OF PAEDIATRIC EPILEPSY CARE IN NIGERIA

DR IGWE WC

CONSULTANT PAEDIATRICIAN/CHILD NEUROLOGIST,
NAUTH NNEWI

Epilepsy, the most common chronic neurological disorder in children affects about 10.5 million children world. Although about 80% of these children with epilepsy (CWE) reside in developing countries, epilepsy care in these areas is limited and the majority is left untreated. Nigeria, like other developing countries, is ill-equipped to tackle the medical, social and economic challenges posed by epilepsy care. The health care systems are weak, poverty is widespread and drug supply is limited with poor quality control of locally available anti-epileptic drugs (AEDs).

I will examine the challenges faced while managing children with epilepsy in our local setting and suggest practical solutions to overcome

Difficulties are in the areas of:

Epidemiologic Research

Diagnosis

Treatment

Social issues

Epilepsy is the most common childhood neurological disorder in Nigeria. From various studies in Nigeria, the prevalence rate range from 45.3-75.4%. Majority of these CWE belong to the low socio-economic class. However these studies being hospital-based, are not truly representative of burden of childhood epilepsy in our environment for many reasons. There are few epidemiological studies that focus on children with epilepsy. Lack of manpower, poor exposure in the field of epidemiological research as well as poor funding are some of the most common challenges. Social stigma, poverty, ignorance, socio-cultural beliefs and practices pose additional challenges to epidemiological study of epilepsy. Community-based studies are inevitable to correctly assess the true burden of childhood epilepsy.



Diagnosis

The diagnosis of epilepsy is a clinical judgment based on medical history. The accuracy of the diagnosis depends on the skill and experience of the physician and the quality and reliability of the information provided by the witnesses. The ease of identification is also dependent on seizure type and frequency. Some seizure types for example nocturnal and absence seizures may therefore be easily overlooked than the more obvious generalized tonic-clonic seizures.

In the few places that have EEG services, there are no



standards for EEG laboratory to ensure quality control. Consequently, EEG results are frequently misinterpreted leading to over-diagnosis. The need to educate healthcare providers about the role of EEG in epilepsy evaluation cannot be over-emphasized. Moreover, the knowledge of epilepsy and anti-epileptic therapy is limited among primary and secondary health staff that sees these patients before referral.

Treatment.

The successful management of CWE begins with establishment of an accurate diagnosis followed by treatment using an appropriate AED in a manner that optimizes efficacy. The goal should also be to use the single most effective AED that has the least adverse effects. Unfortunately, epilepsy is still considered by many as medically incurable; hence they resort to various traditional and spiritual remedies that offer no proven efficacy. Moreover, many of the misconceptions about epilepsy that are prevalent in the local population are also present among health professionals. The population and many health staff are not even aware of long-term treatment required in epilepsy care.

Cont'd p24

In many cases where AEDs are not administered properly. This may partly explain the poor response and thus lack of confidence the population place on medical treatment of epilepsy. Moreover, many CWE are treated with multiple AEDs simultaneously at the time of referral from primary and secondary health care. This results to significant adverse effects leading to patients discontinuing the treatment. Blood drug monitoring also helps in detecting and confirming poor compliance. This however is not readily available in many centers in Nigeria.

Ideally the choice of AED is based on seizure type/or syndrome. Unfortunately both the choice and supply of drugs are limited in our settings. Presently only few generics of AEDs are readily available locally (phenobarbitone, clonazepam, diazepam, carbamazepine, phenytoin, valproate and more recently levetiracetam). Many of these are not currently available in paediatric forms. Management is usually limited by the lack of paediatric formulations appropriate for different age groups. Sadly many of these generics are sub-standard and fake. Efforts aimed at availability of quality drugs will go a long way in achieving good seizure control.

Many CWE, despite being diagnosed and started on AEDs are soon lost to follow-up and thus discontinue treatment. These patients stop treatment immediately their seizures are controlled and only return whenever seizures recur. The usual reasons given for discontinuation of treatment were erroneous belief that they have been cured, high cost of drugs and lack of information on the consequences of discontinuing treatment.

Social issues.

Misconceptions about epilepsy and the resulting social stigma often cause more distress to persons with epilepsy and their families. Children with epilepsy often face discrimination and isolation at school. Side effects of antiepileptic drugs may cause drowsiness and poor academic performance hence reinforcing stigma. Parents may deny their children education to limit injuries and stigma outside the home or even to save money which will otherwise be useful in training other ‘normal’ siblings or for ‘better things’. These result in low self-esteem and under-achievement at school/trade. Surveys conducted in schools revealed a high rate of social withdrawal among children with epilepsy.

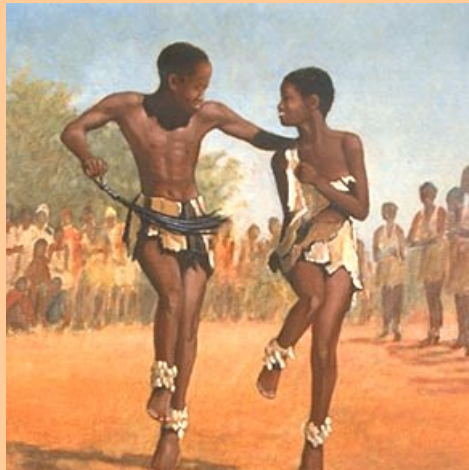
Public reluctance to disregard the myths and misconceptions still poses a great challenge to epilepsy care in our local settings. Because of misconceptions many CWE are brought for medical treatment much later than when the seizures actually started.

The way out

- Educate the public to promote awareness and dispel misconceptions.
- Ensure uninterrupted supply of newer AEDs with formulations appropriate for different age groups.
- Educate practitioners in the first and secondary levels of care to diagnose epilepsy and to initiate effective AEDs.
- Set up standardized EEG laboratories
- Educate neurologists about advanced epilepsy care
- Undertake community-based research on epilepsy

Conclusion.

CWE in our local settings are yet to benefit from the scientific, medical and social advances of meeting today’s goals of “no seizures, no side effects of treatment.” Global efforts should be dedicated to enable all CWE, irrespective of race, financial means or where they live, to achieve complete seizure control, thereby expanding the goals to “no seizures, no side effects, no comorbidities, and no stigma.” Making significant progress will require the scientific and lay epilepsy organizations to work together to: CWE in our environment are yet to benefit from



Making our children again

the tremendous progress in the social and clinical management of epilepsy achieved in advanced societies. Epilepsy still continues to present challenges to CWE and their families due to widespread poverty, illiteracy and inefficient health care systems. In addition, social stigma and misconceptions associated with epilepsy still pose barriers to effective epilepsy care.



BE-Beyond Epilepsy

Epilepsy Education and Advocacy in rural Tanzania

Tanzania-Laura Jurassek RN NP MN
Canada



An Education and Advocacy Program for frontline Healthcare Providers in Tanzania

Rural Tanzania, specifically the regions of Kilombero and Ulunga have been selected to pilot an epilepsy education and advocacy program for healthcare providers and key community members with the goal to increase

In June of 2012 I had the privilege traveling to Tanzania for the first meeting and planning session for the epilepsy education and advocacy program to be provided to frontline healthcare workers in low resource areas of Tanzania. The project was selected by the Council of African Affairs, with a travel grant supported by the North American Commission of the ILAE in an effort to improve the lives of people with epilepsy in Africa. This project is a collaborative effort of the Ministry of Health in Tanzania, Tanzania National Nurses Association (TANNA), Tanzania Training Center for International Health (TTCIH) and myself, Nurse Practitioner at the Stollery Childrens Hospital in Canada. I have also solicited a senior EEG technologist at the University Hospital to assist with program development and delivery.

During my time in Tanzania meetings occurred amongst the partners, local community leaders and interested stakeholders; as well as visits to the communities where the project will first be implemented in rural Tanzania. In depth discussions occurred with frontline health care providers, those living with epilepsy, their families and traditional healers. The information gathered was very rich in detail and cultural context and essential to the development of a sustainable educational intervention in Tanzania.



Two districts in Tanzania have been selected for this pilot project; Kilombero and Ulunga. These districts both have a high prevalence of epilepsy, many remote communities and close proximity to a central location at the TTCIH well equipped for conducting the course and accommodating those in attendance. In January of 2014 the 5 day pilot course will be implemented with 25 nurses, clinical officers and selected community members. Further dissemination of epilepsy information will continue by course participants in their local communities, in their local language; Swahili.

Written educational information and assessment tools are in development and will be translated to Swahili by partners working on program development in Tanzania. Further dissemination of epilepsy information will continue by course participants in their local communities, in their local language; Swahili. Written educational information and assessment tools are in development and will be translated to Swahili by partners working on program development in Tanzania.



Moving forward...

The **BE-Beyond Epilepsy** program will be offered across rural Tanzania by participants of our pilot program with support of Canadian partners. Future projects include modification of the the Nursing curriculum in Tanzania in collaboration with the Ministry of Health to include the **BE-Beyond Epilepsy** program and implementation in other African nations with changes made to reflect local culture and context.

where are we now?

Currently we are gathering donations and seeking sponsorships while developing our course and content. Our logo is in development and soon you will be able to follow us on Facebook and access our webpage! We are all very excited and passionate about this program and benefits it will bring to people with epilepsy.

The collaborative program in Tanzania has been an amazing undertaking with commitment and growth beyond my expectations! I am very grateful for my partners support and commitment and the opportunity to help people with epilepsy live well in their communities in Tanzania.

Eseigbe EE, Adama SJ, Eseigbe P. *Niger Med J* 2012

Febrile seizures in Kaduna, north western Nigeria.

Abstract

Background: Febrile seizure is the most common seizure of childhood and has a good prognosis. However its presentation is fraught with poor management, with grave consequences, in our environment. Thus a review of its current status is important. Objective: To review the status of febrile seizures in Kaduna metropolis.

Materials and Methods: A review of cases seen in the Department of Pediatrics, 44 Nigeria Army Reference Hospital, Kaduna between June 2008 and June 2010.

Results: Out of the 635 cases admitted in the department 17 (2.7%) fulfilled the criteria for febrile seizures. There were 11 Males and 6 Females (M: F, 1.8:1). Age range was from 9 months to 5 years with a mean of 2.2 years \pm 1.1 and peak age of 3 years.

Twelve (70.6%) were in the upper social classes (I-III). therapy were instituted, where indicated. All recovered and were discharged. Fever, convulsion, catarrh and cough were major presenting symptoms. Incidence of convulsion was least on the 1st day of complaint. Fourteen (82.4%) of the cases were simple febrile seizures while 3 were complex. There was a positive family history in 5 (29.4%) of the cases. Eleven (64.7%) had orthodox medication at home, before presentation, 5 (29.4%) consulted patient medicine sellers and 7 (41.7%) received traditional medication as part of home management. Malaria and acute respiratory infections were the identifiable causes. Standard anti-malaria and anti-biotic therapy were instituted, where indicated. All recovered and were discharged.

Conclusion: There was a low prevalence of febrile seizures among the hospitalized children and a poor pre-hospitalization management of cases. It highlighted the need for improved community awareness on the prevention and management of febrile seizures.

F T Nuhu, A J Yusuf, T L Sheikh, E E Eseigbe. *S Afr J CH* 2012

Poor academic performance among adolescents with epilepsy in Kaduna, Northern Nigeria: A case-control study.

Abstract

Background. Adolescents with epilepsy experience significant academic difficulties. However, little is known about the effects of epilepsy on the academic performance of adolescents with the disorder in Northern Nigeria.

Objective. To assess the academic performance of adolescents with epilepsy and factors associated with poor performance in this population in a Northern Nigerian setting.

Methods. The socio-demographic/clinical characteristics of 77 consecutive adolescents (aged 12 - 17 years) with epilepsy attending the Child and Adolescent Clinic of Federal Neuropsychiatric Hospital, Kaduna, North-West, between March 2008 and September 2010 and the socio-demographic characteristics of 76 controls (matched for age and sex) were recorded. Information concerning school attendance and academic performance of the subjects and the controls were obtained from the adolescents and their parents or caregivers.

Results. The mean ages of the subjects and the controls were 15.1 (standard deviation (SD) 2.1) and 14.7 (SD 1.7) years, respectively ($p > 0.05$), the mean duration of illness was 6.1 (SD 4.6) years, the mean seizure-free period was 16.8 (SD 15.6) weeks, and 64.9% of the subjects and 57.9% of the controls were males.

controls were males. Forty-six subjects (59.7%) and 12 controls (15.8%) had poor academic performance ($p < 0.001$). Long duration of illness, short seizure-free periods and irregular school attendance were significantly associated with poor academic performance ($p < 0.05$).

Conclusions. Poor academic performance is common among adolescents with epilepsy and is associated with early onset, poor seizure control and missing school. Efforts should be made to control seizures and educate society about the illness.

Epilepsy Congresses

Get more information on the congresses listed below at: www.epilepsycongress.org.



4-6 April, 2013
4th London-Innsbruck Coloquium on Status Epilepticus and Acute Seizures
 Salzburg, Austria

9-13 April, 2013
15th International Neuroscience Winter Conference
 Sölden, Austria

11-14 April, 2013
7th World Congress on Controversies in Neurology (CONY)

18-21 April, 2013
Epilepsy Surgery Course
 Basic principles and controversies in epilepsy surgery
 Sponsored by Cleveland Clinic (Ohio, USA), Neurology Clinic (Belgrade) and Association of Serbian Neurologists
 Mecavnik, Serbia

16 May, 2013
Recent Clinical and Research Advances in Childhood Epilepsy
 London, England

20 -24 May, 2013
6th International Epilepsy Colloquium
Epilepsy Across the Lifespan Cleveland, Ohio

25-28 September, 2013
European Paediatric Neurology Society (EPNS) Congress
 Brussels, Belgium

30 September - 6 October, 2013
5th Eilat International Educational Course: Pharmacological Treatment of Epilepsy
 Jerusalem, Israel
 Application & bursary deadline: December 2, 2012

23 - 26 October, 2013
24th International Symposium on the Autonomic Nervous System
 Sponsored by the American Autonomic Society
 Hawaii, USA

3 - 9 November, 2013
7th Migrating Course on Epilepsy
 ILAE Cyprus Epilepsy Society
 For specialists in neurology, psychiatry, neuropsychiatry, paediatric neurology, paediatrics, clinical neurophysiology and psychology
 Nicosia, Cyprus

21 - 23 November, 2013
3rd International Congress on Neurology and Epidemiology (ICNE)
 The use of academic research and neuroepidemiology in improving neurological health
 Abu Dhabi, UAR

CONFERENCES

23-25 May, 2013
BIT's 4th Annual Congress of NeuroTalk (NeuroTalk-2013)

25-27 May, 2013
European Forum on Epilepsy Research
 Sponsored by IBE and ILAE
 Dublin, Ireland

8-11 June, 2013
23rd Meeting of the European Neurological Society
 Barcelona, Spain

16 - 18 August, 2013
Colloquium on Drug-Resistant Epilepsy: Current concepts and future directions
 NIMHANS Convention Center, Hosur Road, Bangalore, India

21 - 26 September, 2013
XXIst World Congress of Neurology
 "Neurology in the age of globalization"
 Vienna, Austria





Title: Partnerships between North American Epilepsy Centers and Africa

This is an invitation to submit an application to this program from the North American Commission of the ILAE. The program seeks to promote and improve the care of persons in Africa living with epilepsy, through education, advocacy and research. It aims specifically to support and expand exchange programs between members of the North American Commission and African chapters of the ILAE, in order to significantly impact epilepsy care in that region. Based on our experience with the Latin American and Caribbean partnerships, the ILAE is confident that NAC members can significantly contribute to this mission.

The application should address program goals. This program supports travel between North America and Africa to perform one and preferentially of the following activities:

- 1) Education and training of epileptologists, neurologists, neurosurgeons, primary care physicians, health care extenders, and/or other professionals involved in epilepsy care.
- 2) Education (and advocacy) of local authorities and opinion makers, to enhance community awareness of epilepsy, treatment gap, access to care, cultural and other issues that impact delivery of care.
- 3) Improve the provision of locally-sustainable patient care.
- 4) Initiate and foster sustainable collaborative research related to epilepsy.

The Education Task Force of the North American and African Commission will evaluate applications & support multiple partnerships in 2013. There is no honorarium designated for the faculty member. Reasonable travel and accommodation expenses will be covered up to the maximum of \$5,000 (US dollars) per partnership. Applications to extend ongoing partnerships are accepted but priority will be given to new partnerships.

Deadline for reception for 2013 partnerships is May 31st 2013.

Application Form:

1) Name of Visitor:

Institution:

Address:

City: Country:

Chapter affiliation:

Email:

Phone Number

2) Name of proposed site/ program/ institution to be visited:

Address:

City: Country:

Chapter affiliation:

3) Describe the activities of this exchange program (300 words maximum).

4) Describe the expected outcomes and criteria used to evaluate outcomes including a timeline (300 words).

5) Describe how these activities will be sustained in the future beyond NAC support (200 words)

Signature of the Visitor & Date

Please submit applications electronically to

[Lionel Carmant](mailto:lionel.carmant@umontreal.ca): lionel.carmant@umontreal.ca (North American Commission of ILAE) before May 31st 2013.

Priority will be given to the following criteria:

Partners need to be from countries with an ILAE chapter.

NAC partner involved in one of the CAA teaching session

Sustainability of the partnership needs to be demonstrated

HEY! EPILEPSY ADVOCATE OUT THERE, CAN YOU HELP ME?

Dr. Kakooza Angelina (M.D)
President, Epilepsy Society Uganda
(EPISOU).

Often in my practice as a doctor taking care of patients with epilepsy you often listen to several caregiver anecdotes sharing their experiences of taking care of their relatives with epilepsy. Below is one excerpt of one such experience. (Names are altered to maintain respondent confidentiality)

Brenda is a young professional, single mother working for a busy corporate company in the capital city of low income country. She recently graduated from College and is looking at prospects of furthering her education however is hindered by personal commitments. She gets a fairly hefty salary compared to peers her age however most of it is spent taking care of her extended family. She looks after her parents (both retired), her family of two children and two other close elderly relatives. In the previous month she added on four more namely: her brother with epilepsy and his three children.

“Doctor, I am desperate I need your help. I do not know what to do. The disease is severe for Bando.... It started when he was thirty, now he is forty-four! He has no caregiver...I am the one helping him. He has three children I am taking care of, and yet I have a very big dependence burden! I want him to regain his life and work for his children! Imagine he is twice older than me, but I have bigger children than his who need more requirements! His are young and need much care! My brother can't do any work, he has lost memory, he is mentally disturbed, his wife boycotted him because she could not withstand him and she left him three young kids who are really putting me in a situation worse than ever before! My brother wants to commit suicide and he says; he has lost hope in his life. With whom can I share this problem Doctor?”

Brenda asserts that during this time Bando has mainly been on traditional medicines with poor response. No specific investigations have been carried out on him. His seizure



frequency is about 3-4 seizures a week and her description of the seizures fits a focal dyscognitive type. He has been staying in the village (four hours drive from the city) but she was now considering bringing him to the city to undergo further investigations and treatment.

This anecdote clearly shows the dilemma of this young lady who is obliged to help where she can but the current family responsibility is taking its toll on her. Notably her brother has had adult onset epilepsy for the past 14 years whose possible aetiology is more likely to be acquired rather than genetic or metabolic considering the late presentation and focal features. This however does not rule out these possibilities. If we entertain the former possibility, one calls to mind several possible risk factors: those related to cardiovascular disease (diabetes, hypertension and a history of stroke)^{1,2}, exposure to the parasites (*Taenia solium*, *Toxoplasma gondii*, *Toxocara canis* or *Onchocerca volvulus*)³⁻⁷, previous head injuries⁸ or presence of a slow growing benign brain tumour⁹.



Unfortunately help is only being sought now, 14 years after the onset of his symptoms because previously

Bando was not Brenda's direct responsibility since he had his wife and was fairly able to take care of himself. However now that the severity of the seizures has become disabling, he has developed personality changes, lost his job and most likely deteriorated in sexual function, his wife exits the scene and the crisis set in. Bando is plunged into a wave of anxiety and depression with suicidal ideation prominent in his mind.

The primary predicament Brenda, Bando and many of our readers face is that despite epilepsy having been around for several decades, the level of awareness regarding its cause and treatment in Low Income Countries is still overwhelmingly low with more than two thirds ignorant of its causes.¹⁰. This fact is eventually the root cause for the detrimental social effects that persons with epilepsy face in our communities. For this reason, communities especially those in the deep rural areas have not been educated about the causes and effects of epilepsy, let alone the presence of such a disorder. It is hence not surprising when they seek less effective alternative treatments for their epilepsy. Epilepsy presents quite a frightening experience

CAN YOU HELP ME? Anelina Kakooza

Epilepsy presents quite a frightening experience for the general public because of its unpredictable nature, characteristic wide range of symptoms, the patient's complete loss of self-control and its attribution with the devil, other supernatural spirits, and mental illness.¹¹ This shrouds it in mystery which contributes to the stigma attributed to epilepsy as well as serving as a channel for fuelling the existing attitudes and perceptions related to the disease. Persons with epilepsy hence become victims of extreme discrimination because they are viewed as "abnormal" and as such not assured of their basic human rights¹².

As health workers treating persons with epilepsy we should endeavor to give Epilepsy a face. It should be just as well known as HIV/AIDS, Tuberculosis, Malaria or any other major disease, because these patients equally face the same burden. Victims of epilepsy cannot be neglected simply due to the fact that they have changed personality, lost their jobs or cannot take care of their families. Thorough investigations where possible and warranted, need to be conducted to rule out the possibility of obtaining complete remission for the disorder.

These and similar situations can be avoided by raising awareness about epilepsy and offering support to persons with epilepsy. Awareness needs to be raised, much more urgently than before and individuals and communities should be empowered with appropriate knowledge and skills about epilepsy. This requires more investment in the use of appropriate mass media channels like local drama groups or local songs, development of more social support networks, advocacy with the governments and local nongovernmental organizations to solicit for financial support and the provision of community based health care using local resources raised from family and social groups. At an international level there is need to encourage more collaborative epileptic research on the potential of African traditional medicines, psychosocial community based rehabilitation, cost effective generic drugs for the region and applicable low cost holistic interventions. Action needs to be taken urgently to avoid forbidding situations like Bando's suicidal attempts. Only then will justice be served to the courageous patients who live with this disorder and their loving caregivers.

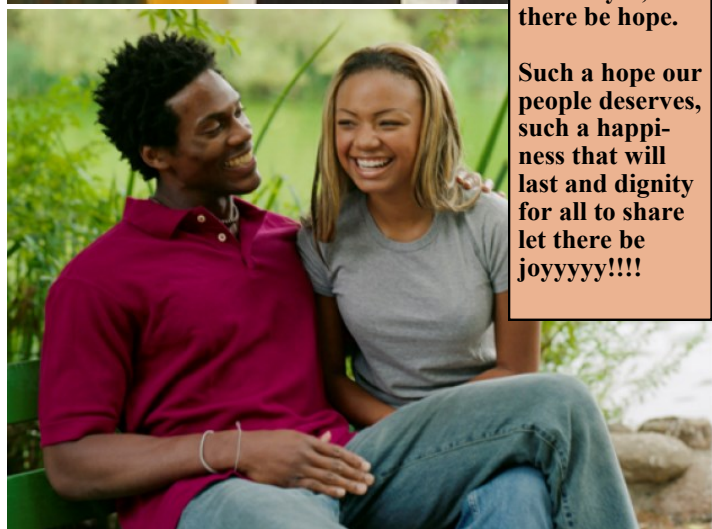
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Let there be joy
in our hearts,
let there be love
in our eyes, let
there be hope.



Such a hope our
people deserves,
such a happiness
that will
last and dignity
for all to share
let there be
joyyyyy!!!!