

Case studies in Kenya

**KENYA ASSOCIATION FOR THE WELFARE
OF PEOPLE WITH EPILEPSY(KAWE)**

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**Providing Sustainable Mental Health
Care in Kenya – A Workshop**

Villa Rosa Kempinski

Nairobi, Kenya

Global context

- **Epilepsy is a common chronic neurological disorder affecting around 70 million people world wide**
- **Close to 80% of the affected are found in developing regions**
- **Epilepsy responds to treatment about 70% of the time yet about 75% of the affected people in developing countries do not get the treatment they need.**
- **The estimated proportion of the general population with active epilepsy at a given time is 4-10 per 1000 people. (0.4-1%)**
- **In developed countries annual new cases are between 40-70 per 100,000 people in the general population, in developing countries the figure is often twice as high,**

Studies by Kemri (2013) on Active Convulsive Epilepsy in 5 sub-Saharan countries shows that

- 1. At least 7.8 people in 1000 live with epilepsy at any given time**
- 2. Also approximately 77 new cases in 100,000 are reported every year**
- 3. More children are diagnosed with epilepsy than adults yearly which is attributed to childhood event including illnesses, accidents and abnormal ANC period.**

The Treatment Gap

- **While 80% of the potential market for AEDs is in the developing world, up to 90% of people with epilepsy in developing countries receive no treatment at all.**

WHO, Fact sheet , 2012 N°999

- **In Kenya today, an estimated 1 million people suffer from epilepsy. 18.2 per thousand prevalence.**

Kaamugisha and Feksi (1988. Neuro-epidemiology)

- **Only about 36% of the affected are receiving AEDs. Lesser percentage of the above are adherent.**

Symon Kariuki M. Epilepsia. 2013. 12392

Factors contributing to the treatment gap

- **Stigma**
- **Misconceptions surrounding the disease**
- **Traditional beliefs**
- **Ignorance**
- **Poverty**
- **Role of traditional and faith healers**
- **Lack of adequate medical personnel**
- **Inadequate professional training**
- **Inadequate drug availability and affordability**
- **Inefficient and unevenly distributed health care systems**





KAWE



- **IBE Affiliate**
- **Founded in 1982**
- **Non-government organization (NGO)**
- **Non-profit making**
- **Head office in Nairobi**

KAWE Team

7 board of directors (volunteers)

Program Co-ordinator

**Assistant program
Co-ordinator**

**Medical
Manager**

Accountant

**Clinic
Administrator**

**Community
Development
Officer**

**Part time paid
staff and
volunteers**

Vision

- ❖ **A society in which people with epilepsy are free from stigma and are able to access quality epilepsy care from government and other public health facilities**

Mission

- ❖ **To improve the quality of life of people with epilepsy so that they may realize their full potential**

KAWE Programmes; Bridging the Gap

Education, awareness training

- **Training of Primary Health Workers**
- **Awareness Creation e.g. community dramas, Community Health workers, Phone services Mass media**
- **Publications e.g. posters, flyers, books, videos**

Medical provision and social support

- **Running 3 epilepsy model clinics within Nairobi**
- **Supporting affiliated epilepsy clinics countrywide**
- **Counselling**
- **Patient support groups**

Lobbying and advocacy

- **Working with the Ministry of Health, e.g.**
- **Developing the National Epilepsy Guidelines,**
- **Curriculum development**
- **Advocate for policies**
- **Increased access to AEDs**
- **Advocacy to equal rights for employment, education etc.**

KAWE PROGRAMMES

I. EDUCATION, TRAINING & AWARENESS CREATION

Objectives

- A. Task shifting to the grass root level by training Health care workers; this will improve access to better epilepsy care
- B. Development of a curriculum to be used in Kenya Medical Training Colleges; to guarantee production of skilled workers with technical competencies.
- C. Raise awareness in the community to improve knowledge, reduce stigma and ensure suspected cases are referred to the clinics
- D. Increase access to epilepsy information via phone services, mass media, awareness materials and publications

KAWE PROGRAMMES

I A: Task Shifting by Training

- KAWE runs a training program for Primary Health Care workers mainly Clinical officers, Nurses and Community Health Workers (CHWs)**
- CHWs are trained as point persons to create awareness, identify, refer suspected cases, and make appropriate follow up.**
- The Clinical Officers and Nurses are trained to manage cases of epilepsy using affordable and available medication**

This increases access to epilepsy care at the primary Health care level.

KAWE PROGRAMMES
IA(i): Medical and Community Health workers trained

	Medical training	CHWs training
2014	128	201
Total trained (2000-2014)	1814	3095

KAWE PROGRAMMES

IA(ii): Training Session



KAWE PROGRAMMES

I B: Curriculum Development



- In addition to trainings KAWE has joined hands with KMTCC the largest provider of medical trainings aiming at producing a curriculum on epilepsy; this will guarantee production of adequate numbers of skilled workers with technical competencies

KMTCC-Kenya Medical Training College

KAWE PROGRAMMES

I C: Awareness Creation

Aims at educating and empowering the public on matters pertaining to epilepsy causes, first aid, availability of treatment, dispelling myths and misconceptions etc.

Ways of creating awareness.

- i. Mobile Phone Health awareness project; FAFANUKA**
- ii. Oral presentations at public gatherings, churches, schools, institutions etc.**
- iii. Community Drama Groups**
- iv. Public Events e.g. Agricultural Society of Kenya Show, Road Shows etc.**
- v. Distribution of Educational and Information Material.**
- vi. Mass media campaigns.**

KAWE PROGRAMMES

I C(i): Mobile Phone Health Awareness Project



- ❖ **'FAFANUKA'** in partnership with Safaricom Mobile Service Co.
- ❖ Started in November 2013 and officially launched in April 2014
- ❖ **CONTENTS INCLUDE**
 - Directions to epilepsy clinics in the country.
 - Basic facts on epilepsy including causes, treatment
 - **1ST AID** for seizures

KAWE PROGRAMMES

I C(ii): Oral Presentations



KAWE PROGRAMMES
I C(iii): Oral Awareness (Public Education)

Total reached in 2014	106,163
Total reached (2010-2014)	254,029
Reached Via Mass Media	Estimated over 3million people reached
Materials distributed (2010-2013)	Approximately 80,000 pieces of Booklets, flyers, brochures, newsletters etc.

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I C(iv): Community Drama in Session



KAWE PROGRAMMES

I C (vi): Educational materials published and distributed by KAWE



KAWE PROGRAMMES

II. MEDICAL PROVISION & SOCIAL SUPPORT

Objectives;

- Provision of quality, affordable and accessible services to persons with epilepsy
- Offer counselling to patients and their families
- Provision of regular supply of anti-epileptic drugs
- Providing a platform where patients can form support groups.

KAWE PROGRAMMES

II A: KAWE CLINICS

- **KAWE runs 3 weekly clinics within Nairobi in partnership with the NCC**

Services offered

- 1. Consultations;** to new and follow up patients
 - 2. Counselling;** as part of the supportive treatment
 - 3. Drugs;** Regular supply of low cost drugs
 - 4. Clinic support;** to 17 affiliated clinics in different parts of the country
- **We are planning to support 5 more epilepsy clinics to be run by NCC in the near future**

NCC - NAIROBI CITY COUNTY

KAWE PROGRAMMES

II A(i): Mathare Clinic in Session



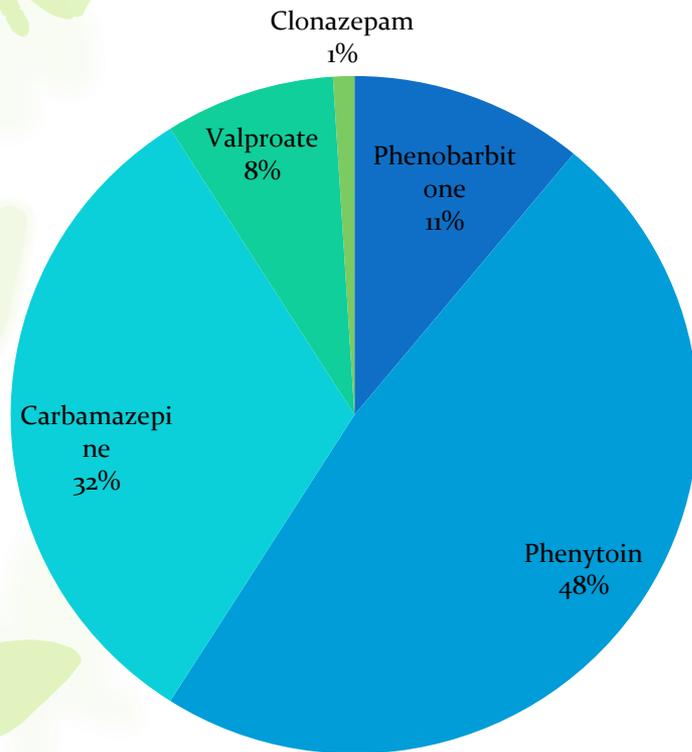
KAWE PROGRAMMES

II A(ii): Overall Clinic Attendance

	Total Registered patients	Total patients seen in 2013
Nairobi (3 Clinics)	13,887	7,728
Affiliate Clinics (17 Clinics)	12,423	Data not available

KAWE PROGRAMMES

II A(iii): Drug Use Analysis Jan –May 2012



- 84% of patients are well controlled on monotherapy.
- 15% are on two drugs .
- 1% are on three drugs.
- Majority are on phenytoin and Carbamazepine.
- Most drugs are generic.

KAWE PROGRAMMES :

II A(iv): Cost of Drugs

	Unit per tin	Buying price per tin	Buying price per tablet	Selling price to patients KAWE	Market price
Phenobarbitone 30mg tabs	1000tablets	320ksh	0.32ksh	1.00ksh	3ksh
Phenytoin 100mg	1000tablets	850ksh	0.85ksh	1.25ksh	1.5ksh
Cabamazepine 200mg tabs	1000 tablets	1500ksh	1.50ksh	2.5ksh	3.59ksh
Encorate 200mg tabs	100tablets	600ksh	5.6ksh	10ksh	27ksh
Epilim 200mg	100tablets	500ksh	5ksh	10ksh	30ksh
Epilim Syrup 5mls/200mg	300mls	784ksh	784ksh	1000ksh	1200ksh
Epilim Chrono 500mg	100tabs	2556ksh	25.56ksh	30ksh	45ksh
Rivotril 2mg	30tabs	644ksh	21.1ksh	25ksh	30ksh
Lamotrigine 100mg	50tabs	1250ksh	25ksh	30ksh	35ksh

KAWE PROGRAMMES

III: LOBBYING AND ADVOCACY:

Objectives

- **To develop national standards for epilepsy management**
 - National Guidelines on Epilepsy Management launched
- **To have Anti-epileptic drugs in the essential drug list**
 - Epilepsy is now listed in the MOH morbidity sheet
 - Anti-epileptic drugs included in the essential drug list
- **To improve epilepsy care at the primary health care level**
 - In the process of developing a training curriculum for the National Medical Training College
- **To position epilepsy on the national agenda**
 - Annual Epilepsy Walk
 - Participation in World Health Days

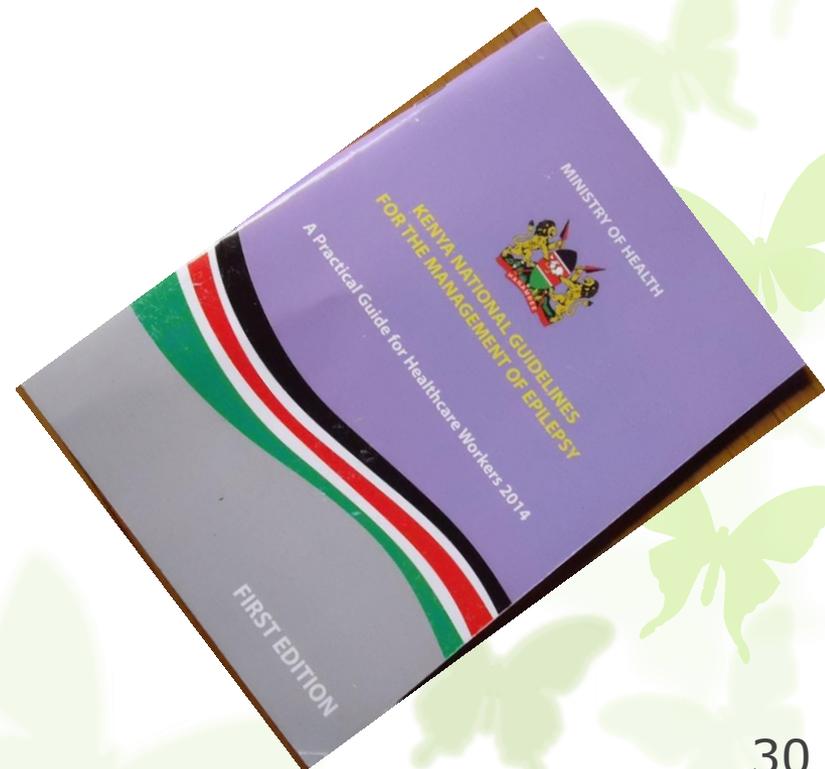
KAWE PROGRAMMES

III A: Launch of the National Epilepsy Management Guidelines

- On 26th March 2014 MOH, KAWE & other epilepsy stakeholders launched the National Epilepsy Guidelines which will be distributed to public health facilities.



Permanent Secretary, Ministry of Health, Prof Fred Segor presenting a copy of the epilepsy guidelines to Dr Miyanji

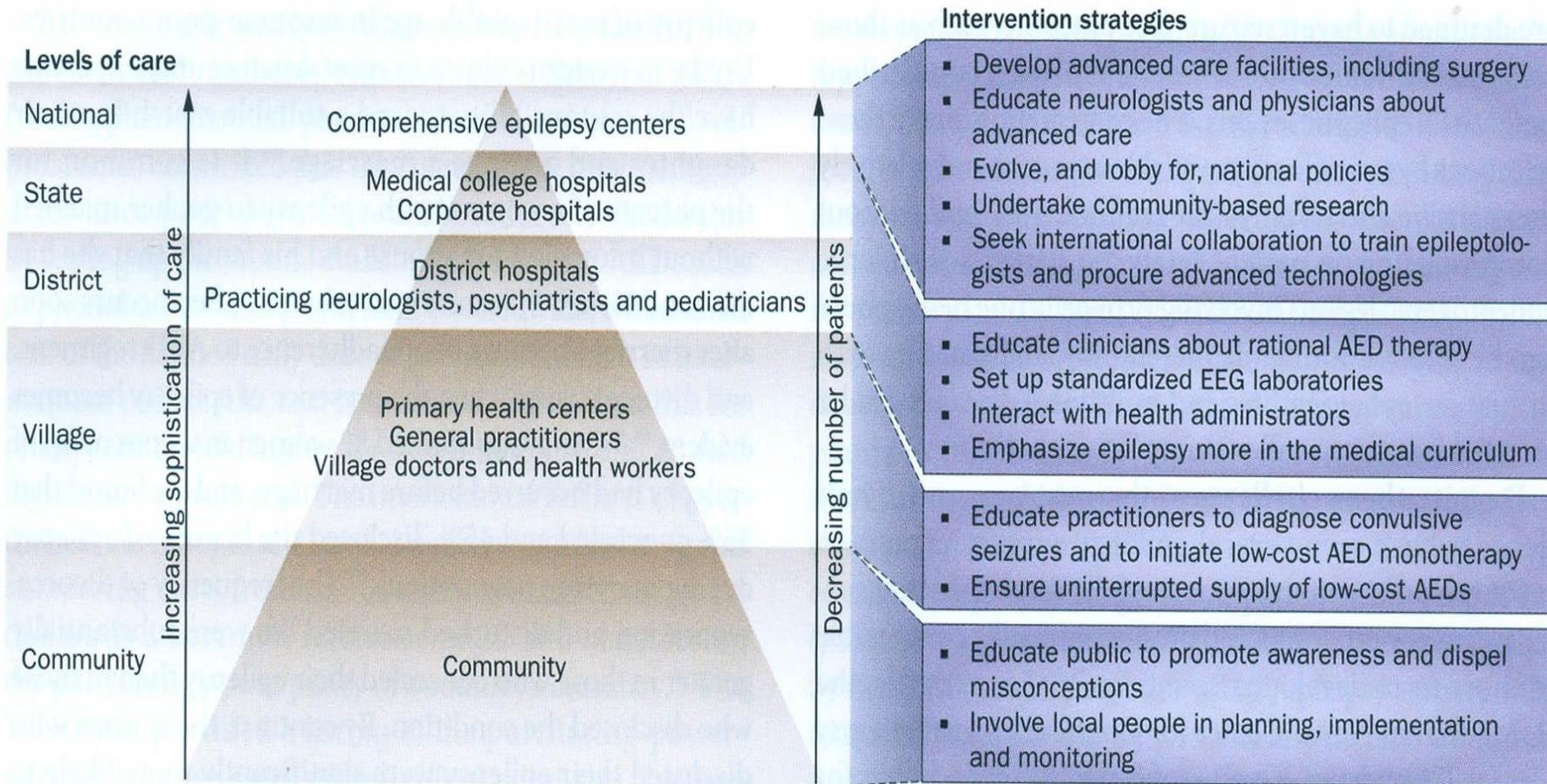


KAWE PROGRAMMES

III B: Annual Epilepsy Walk



The Epilepsy Care Pyramid



Summary of Achievements

- **Trained 1814 Clinical Officers and Nurses and 3095CHWs (2000-2014)**
- **Mobile phone awareness creation project launched**
- **Awareness creation reaching an estimated 254,000 people directly, over 3million through mass media and 80,000 information materials distributed nationwide (2010-2014)**
- **Registered more than 25,000 patients in and out of Nairobi clinics**
- **Provided a constant supply of drugs to patients**
- **Published Educational Materials in the form of books, brochures, leaflets, posters, videos etc**
- **Launched National Epilepsy Guidelines**
- **Developing a more comprehensive epilepsy curriculum for the medical training institutions**

Lessons Learnt

- **Public education is essential in addressing social stigma and reducing ignorance surrounding the disease.**
- **Training of health workers is key**
- **Patients can be treated with affordable drugs.**
- **Partnering with MOH is important**
- **Partnering with other like minded organizations e.g. NCC, low cost private and Mission facilities.**
- **It is important to establish ways to ensure financial sustainability.**
- **Monitoring and Evaluation is important**
- **Maintenance of records and data analysis is essential**

The background of the slide is white with several light green butterfly silhouettes scattered across it. The butterflies are of various sizes and orientations, some appearing to fly towards the center. The text is centered in a bold, dark brown font.

KAWE has demonstrated that we can reduce the treatment gap through viable and practical solutions which are affordable and achievable

Supporters and Donors

○The successful implementation of our projects was facilitated by the following donors, well wishers and partners;

- 1. Ministry of Health**
- 2. Nairobi City County**
- 3. Kenya Community Development Foundation**
- 4. Duncan Charitable Trust**
- 5. Kifafa Foundation**
- 6. Liliane Fonds**
- 7. Ms Caroline Pickering**
- 8. Peponi Preparatory School**
- 9. Sanofi Aventis Groupe**
- 10. Safaricom Foundation**
- 11. The Christmas Trust Fund**
- 12. Thika East Africa Women's League**
- 13. Other Local Donations**



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**FOR ASSISTING
IN PREPARING
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PRESENTATION**