

Reducing Epilepsy Treatment Gap in Zimbabwe

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Epilepsy in the LMIC: The Treatment Gap (TG)

- “The difference between the number of people with active epilepsy and the number whose seizures are being appropriately treated in a given population at a given point of time, expressed as a percentage. This definition includes diagnostic and therapeutic deficits”.

ILAE.

- Estimated number of people living with epilepsy in Zimbabwe is 500 000. (ESF)
- The prevalence of epilepsy in Zimbabwe is unknown- no data.
- The true estimate using prevalence data from other African studies^{***} is between 85 000-240 000 people living with epilepsy.
- Epilepsy TG is estimated at 85% in Zimbabwe.

Tekle-Haimanot R et al, Epilepsy Res, 1990

Osuntokun BO et al, Epilepsia, 1987

Birbeck GL et al, Epilepsia, 2004

The Treatment Gap: The Zimbabwean Experience- Social Stigma

- Cultural myths, perceptions and incorrect information is prevalent in Zimbabwe.
- Epilepsy is:
 - caused by supernatural powers and evil spirits.
 - contagious.
 - a mental illness.
 - a demon
- Patients with epilepsy are hidden from society.
- A study in a rural district in Zimbabwe identified 32 types of myths, perceptions and incorrect knowledge related to causes, prevention & treatments of epilepsy.*

* *Mugumbate J, Mushonga J. Epilepsy & Behavior, 2013.*

Treatment Gap: The influence of cultural beliefs.



- Most patients in Zimbabwe with epileptic seizures will seek care with a traditional healer (TH) first.
- Regardless of socio-economic and educational status.
- Deep seated belief that seizures are caused by evil spirits.
- TH provide culturally acceptable explanations & remedies.
- Herbal remedies are widely used.

Treatment Gap: The influence of religious beliefs on epilepsy treatment.



- Zimbabwe has seen a phenomenal rise in Pentecostal Prophetic Movement since 2009.
- Led by flamboyant predominantly young men with the gift of prophecy, healing and deliverance.
- Congregants, mostly urban, are drawn by the new miracle performing prophets.
- They provide spiritual diagnoses and remedies in patients with ailments, epilepsy included.
- Epilepsy is mentioned in the Bible in 3 of the 4 Gospels (Matthew 17:14-18, Mark 9: 14-29, Luke 9:38-42).
- “Epileptic ” was translated from the Greek word for “lunatic”.

The Treatment Gap

The Zimbabwean Experience.

- 1 dedicated Epilepsy Clinic at Parirenyatwa Hospital, Harare, Zimbabwe.
- Run concurrently with the Neurology Clinic.
- Run once a week by two neurologists.
- Paediatric Neurology/Epilepsy Clinic at Parirenyatwa in Harare
- Run weekly by 1 paediatric neurologist.

The Treatment Gap: The Zimbabwean Experience.

- Other patients with epilepsy access care from various health cadres:
 - Specialist Physicians (80 total in Zim: 9 in Bulawayo, 2 in Gweru, Mutare 3, Chinhoyi 1, rest in Harare).
 - Neurosurgeons (historically the original epileptologists in Zim: The late Prof Laurence Levy).
 - Currently 12 neurosurgeons in Zim, 11 in Harare and 1 Bulawayo).
 - Psychiatrists (Epilepsy is under the Mental Health Act which then enables free access to health care including medications).
 - There are 15 psychiatrists in Zim, 2 in Bulawayo, 1 Gweru, 1 Chitungwiza, rest in Harare)

***2018 Statistics

The Treatment Gap: The Zimbabwean Experience

- General Practitioners: 1623 on the MDPCZ register (02/05/2019).
- Provincial hospitals- 8 :Medical officers and specialists
- District hospitals: 63 district hospitals with about 3-5 doctors and Mental Health Nurses (1 per district hospital), Clinical Officers (1 per district Hospital).
- Local Clinics: 1162 (Gvt, mission clinics, polyclinics)

***2019

The Treatment Gap: Human Resource Training.

- Lack of local neurology training at all levels:
- Training is available in South Africa, West Africa, Europe etc.
 - Neurologists.
 - Specialist physicians with an interest in neurology/epilepsy
 - General practitioners with an interest in neurology/epilepsy.
 - Epilepsy Specialist Nurses.

Treatment Gap: Equipment. EEG Machines.



- 3 EEG machines in the public sector. (2 in Harare, 1 in Bulawayo). Breakdowns are frequent.
- Cost of an EEG is about US\$60-80.00
- 4 EEG recording technicians (3 in Harare, 1 in Bulawayo).
- 1 EEG technologist in the whole of Zim (Only survivor in the plane crash that killed Prof Mielke). Retired from the public sector in 2019.
- 3 EEG machines on the private sector. All based in Harare.
- Cost of a routine EEG is US\$100-150.

Treatment Gap: Equipment: CT scans.



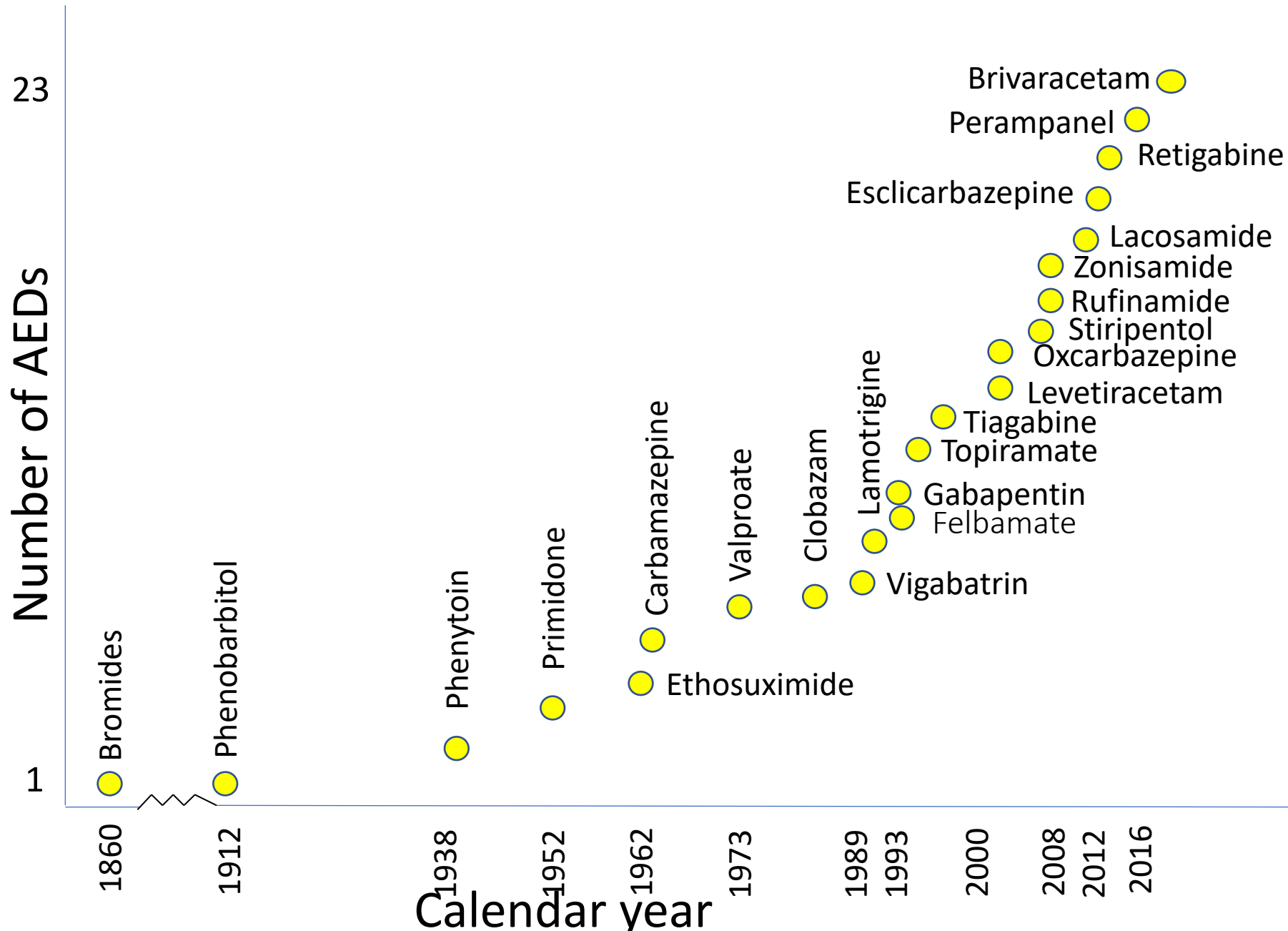
- 5 CT scans in the public sector. (1 in Harare, 2 in Bulawayo and each 1 in Masvingo, Mutare, and 1 at a district hospital).
- No full-time public sector radiologists.
- 16 CT Scans in the private sector (12 in Harare, 2 in Bulawayo, 1 each in Mutare and Gweru).
- 13 private sector radiologists (12 in Harare and 1 in Bulawayo).
- Cost: US\$300-500

Treatment Gap: Equipment: MRI scans.



- 3 public sector MRI machines at SMCH, Parirenyatwa and UBH.
- 6 MRI machines in the private sector (5 in Harare, 1 in Bulawayo).
- Cost: US\$500-800.

Timescale of development of ASMs



ASM Availability in Zimbabwe: Central and Provincial Hospitals:29/05/2024

	Phenobarbitone	Carbamazepine	Phenytoin	lamotrigine	Sodium valproate	Levetiracetam	Diazepam IV	Lorazepam IV
Pari	✓	✗	✓	✓	✗	✓	✗	✗
SMCH	✓	✗	✓	✗	✗	✗	✓	✗
UBH	✓	✗	✓	✗	✗	✗	✗	✗
Mpilo	✓	✗	✓	✗	✗	✗	✗	✗
Chitungwiza	✗	✓	✓	✗	✓	✗	✓	✗
Gweru	✗	✓	✗	✓	✓	✗	✗	✗
Mutare	✗	✗	✗	✓	✗	✗	✓	✗
Masvingo	✗	✗	✗	✗	✗	✓	✗	✗

ASM Availability in Zimbabwe: Private sector: As of 29/04/2019

	Cost (US\$) per month	Minimum Dose
Phenobarbitone.	4.00	90mg nocte
Carbamazepine.	4.00	200mg nocte
Sodium valproate	7.00	200mg nocte
Gabapentin.	8.00	100mg nocte
Lamotrigine.	12.00	50mg nocte
Pregabalin.	12.00	75mg nocte
Phenytoin	15.00	100mg od
Levetiracetam.	17.00	500mg od
Lacosamide	39.00	100mg nocte
Oxcarbazepine	48.00	600mg nocte

ASM Availability in Zimbabwe: As of 29/04/2019: ASM & Special Populations.

- HIV and ASM
 - Zimbabwe & SSA have a high burden of HIV.
 - The recommended ASM in patients on ART are sodium valproate and lamotrigine. Not routinely available.
 - Private sector prices are prohibitive.
- ASM and WWE.
 - The recommended ASMs in pregnancy: lamotrigine and levetiracetam are not universally available in the public sector.
 - Private sector prices are again beyond the reach of many pts.

Reducing the Treatment Gap.

1. Epidemiological studies: define the true prevalence, aetiologies, perceptions. “Lets’ start counting numbers....accurately”. Gvts & Funding agencies require this information.
2. Appropriate training of more neurologists ... in country or regional centres, supported by centres of excellence, WFN, AAN, EAN etc. Overseas training has had little impact because of non-return by trainees.
3. Targeted upskilling/training in epilepsy : Specialist Physicians, Psychiatrists, Neurosurgeons, GPs etc: Epilepsy Training in Adult Medicine Course (ETAM): July 2024 in Zimbabwe.
4. Task shifting in terms of diagnosis & treatment of epilepsy. Masterclass programmes designed for GPs and nurses. (Successfully used in decentralization of ART in HIV programmes. “Nurse driven and Dr led programmes”).

Reducing the Treatment Gap.

1. Demystifying of epilepsy to reduce social stigma and misinformation: Course in Stigma in Epilepsy: Zimbabwe July 2024.
2. Constructive engagement with traditional healers and churches. These are the first port of call in epilepsy in most African settings.
3. Continue to engage governments and NGO through advocacy to ensure reliable availability of cheap and appropriate generic drugs. Pharmaceutical companies have a role to play.
4. Legislative : Section 76, sub-section 1-4 of the constitution of Zimbabwe affords every citizen the constitutional right to health care. Hold governments accountable through advocacy.

Reducing the Treatment Gap.

5. Ensuring a reliable supply of basic generic ASMs: Essential Drugs List in Zimbabwe: EDLIZ

- Phenobarbitone, phenytoin, carbamazepine.
- Appropriate medications for PLHIV/AIDS and WWE.
- Appropriate paediatric formulations.
- Global appeal to pharmaceutical companies to supply drugs at reduced cost. (an example : the Diflucan programme by Pfizer- supply free fluconazole to SSA since 2001 for treatment of cryptococcal meningitis & oesophageal thrush).

6. The innovative use of artificial intelligence and Apps to reach out to people with epilepsy for both diagnostic and therapeutic purposes: AGENDA (Prof Arjune Sen). This will improve access to care.

Reducing the Treatment Gap.

- The patients whom we serve are hidden by society & silenced!
 - We need to speak out on their behalf!
 - We need to shout on their behalf!

“Global Fund for Epilepsy”

(Chin JH. Afri Health Sci. 2012:12(2): 186-192)

Thank You

Acknowledgements

The Medical and Dental Practitioners Council of Zimbabwe.

Dr Chimudzi: MMed(Med(Registrar): Parirenyatwa

Dr Z Mutsemi: Consultant Physician: Mutare

Dr P Nyawayi: Consultant Physician: Masvingo

Dr Patience Maramba: Gweru

Dr S Pfumojena: Consultant Physician: Sally Mugabe Central Hospital,
Harare

Dr Patience Manyuchi: Consultant Physician: Chitungwiza Central

Dr Nothando Moyo: JRMO