

Health service provision for people with epilepsy in sub-Saharan Africa: a situational review

Musa M. Watila ^{a,b}, Mark R. Keezer ^{b,c,d}, Samuel A. Angwafor ^b, Andrea S. Winkler ^{e,f},
Josemir W. Sander ^{b,d,g}

- a. Neurology Unit, Department of Medicine, University of Maiduguri Teaching Hospital. PMB 1414, Maiduguri, Borno State. Nigeria.
- b. NIHR University College London Hospitals Biomedical Research Centre, UCL Institute of Neurology, London WC1N 3BG, UK.
- c. Centre hospitalier de l'Université de Montréal (CHUM), Hôpital Notre-Dame, Montréal, Québec, H2L 4M1, Canada.
- d. Stichting Epilepsie Instellingen Nederland (SEIN), Achterweg 5, 2103 SW Heemstede, Netherlands.
- e. Centre for Global Health, Institute of Health and Society, University of Oslo, Kirkeveien 166, 0450 Oslo, Norway.
- f. Department of Neurology, Technical University Munich, Ismaninger Strasse 22, 81675 Munich, Germany.
- g. Epilepsy Society, Chalfont St Peter SL9 0RJ, UK.

Correspondence to:

Professor Ley Sander

Box 29, UCL Institute of Neurology, Queen Square, WC1N 3BG, London.

l.sander@ucl.ac.uk

ABSTRACT

Background: Epilepsy is a public health issue in sub-Saharan Africa (SSA) where many people with the condition receive no treatment. Healthcare services for epilepsy in this region have not been comprehensively assessed. We examined key features of epilepsy health services provided in SSA.

Methodology: This was a scoping review conducted using pre-specified protocols. We implemented an electronic search strategy to identify relevant citations using PUBMED, EMBASE, Web of Science, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), African Index Medicus (AIM), Open Grey, Cochrane database, and Google Scholar. Articles eligible for full-text review were screened and data of interest reported.

Result: The search identified 81 eligible articles, forty-nine from East Africa, 19 from West Africa, 8 from South Africa, and 5 from Central Africa. A variety of care services were identified, with reporting of rural epilepsy care in 75% of retrieved articles mainly from East and South African countries. The majority of the rural epilepsy clinics were health worker- or nurse-led, reporting a good seizure control in about two-third of patients using phenobarbital as the most commonly prescribed antiepileptic drug. Funding for rural epilepsy care came mainly from external donor agencies.

Conclusion: We attempted to provide a 'snapshot' of epilepsy care services in SSA. The successes achieved in some of the centres are due to the use of existing primary health care system and employing non-physician health-care personnel. The true picture of epilepsy care coverage is not apparent due to the lack of data and proper health system structure in most parts of SSA. As more individuals begin to receive care, the long-term funding for epilepsy care in African countries will depend on the commitment of their respective governments.

Keywords: Epilepsy, sub-Saharan Africa, Treatment, Programme, Phenobarbital, Rural.

1.0 INTRODUCTION

Epilepsy is a public health problem causing physical and psychosocial burdens on those affected as it interferes with educational attainment, professional goals, and social integration [1]. It contributes about 7 million disability adjusted life years (DALYs) to the global disease burden and more than 20% of the total global DALYs for neurological disorders [2], with an estimated 85% of this burden falling on low- and middle-income countries (LMICs) [3]. People with epilepsy often die prematurely [4] and despite the paucity of disease-specific data seems to be a major issue in sub-Saharan Africa (SSA) particularly when compared to other parts of the world [5, 6]. Studies from rural Kenya and South Africa reported that about three-fourths of the total epilepsy DALYs were due to premature mortality [7, 8].

A diagnosis of epilepsy comes with enormous physical, economic, and social consequences [9, 10]. Epilepsy is not generally perceived to be a health issue in traditional African cultures. The resultant lack of awareness is an important issue that limits access to health care and contributes to the high epilepsy treatment gap [11, 12]. Inefficient health-care systems, high costs of treatment, long distances, geographic difficulties, and poor transportation negatively impact access to treatment [13]. Even where functional health-care facilities exist, they are more likely to benefit the more affluent urban inhabitants than the rural poor. This inequality increases the complexity of managing epilepsy in resource-poor countries [14]. A multivariable analysis of risk factors for the treatment gap in rural Kenya reported that individuals living more than 30 km from health facilities were four times less likely to access health care and those who had to pay for antiepileptic drugs (AEDs) were three times less likely to take it [12]. It was suggested that public education, easy access to basic care and making AEDs freely available are essential in addressing the treatment gap.

The WHO Mental Health Gap Action Programme (mhGAP) has attempted to scale-up services for mental, neurological, and substance-misuse disorders in LMICs. The programme asserts that with proper care, psychosocial assistance, and medications the majority of currently underserved individuals could be treated [15]. An understanding of existing epilepsy care and what is obtainable in SSA will provide background information for

the development of appropriate health policies and interventions in Africa. Our objective was to identify, extract, and discuss information relating to epilepsy health care services available in SSA; specifically focusing on the rationale and nature of services, the diagnostic facilities available, and the sources of funding. We also looked at hindrances to optimal healthcare and identified research gaps.

2.0 METHODOLOGY

2.1 Protocol

The methodology employed followed the modified six-stage framework for conducting scoping reviews [16, 17] (Table 1).

Table 1: Epilepsy healthcare provision in sub-Saharan Africa: methodological framework [16].

Stages	Framework	Brief Description of Steps Taken
Stage 1	Identifying the research question	What is known about epilepsy health care provision in SSA? Types, nature of services, diagnostic facilities, funding sources and hindrances to optimal healthcare.
Stage 2	Identifying relevant studies	Searching databases, reference lists, hand-searching journals by manual page-by-page examination of entire content of journal references, and from websites and news reports of related organisations.
Stage 3	Study selection	All available articles reporting any form of epilepsy health service provision in SSA.
Stage 4	Charting the data	Reviewing information of the selected literatures, recording the information on the type of care programme and interventions. Reviewing the uniqueness, successes and outcomes of each programme.
Stage 5	Collating, summarizing and reporting results	Summarising findings and reporting results. Stratifying results according to geographic regions and countries, stating care recipients, and population type (e.g. rural or urban). Commenting on details of interests.
Stage 6	Consultations with stakeholders	A stakeholders meeting was not conducted, but we had communication with contact persons who provided additional information about studies included in the review.

2.2 Identifying relevant studies/Search strategies

An online search of PUBMED, EMBASE, Web of Science, Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), African Index Medicus (AIM), Open Grey, the Cochrane database and Google Scholar was conducted. Initially, an experienced librarian helped refine the review questions by testing several combinations using the PubMed medical subject headings (MeSH) and Emtree for Embase to develop the most appropriate search strategy (See Supplement 1 for search details). A backward search from the reference list of key publications and review articles was also done. Due to the peculiarity of retrieving publications from Africa, a search of grey literature sources like National Guidelines, the ILAE/IBE, and reports from NGOs was conducted by searching Google scholar. An initial study screening was made by scanning each search result using the title and abstract. The full texts of the selected articles were then read and screened for eligibility. The latest search was performed on the 30th of July 2016.

2.3 Study selection

All available articles reporting any form of epilepsy health service provision or intervention for any age group in SSA were included. These included original articles, news reports, webpages of organisations, reports from international organisations/associations like the WHO, International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE). There were no restrictions on language, year of publication, sample size or duration. Articles such as single cases, case series, and articles on special sub-populations, like febrile seizures and cerebral malaria were excluded.

2.4 Charting the data and summarising report

The data of interest included epilepsy healthcare services available in SSA: focusing on the type and nature of epilepsy services, the diagnostic facilities available, and the sources of funding. The results were stratified by geographic regions and countries.

(<http://unstats.un.org/unsd/methods/m49/m49regin.htm>) stating the care recipients and population type (e.g. rural or urban). All the countries in SSA are either low- or middle-income countries (LMIC), apart from Angola, Botswana, Gabon, Namibia, and South Africa

who are in the upper middle-income countries (<http://data.worldbank.org/income-level/LMY/UMC>).

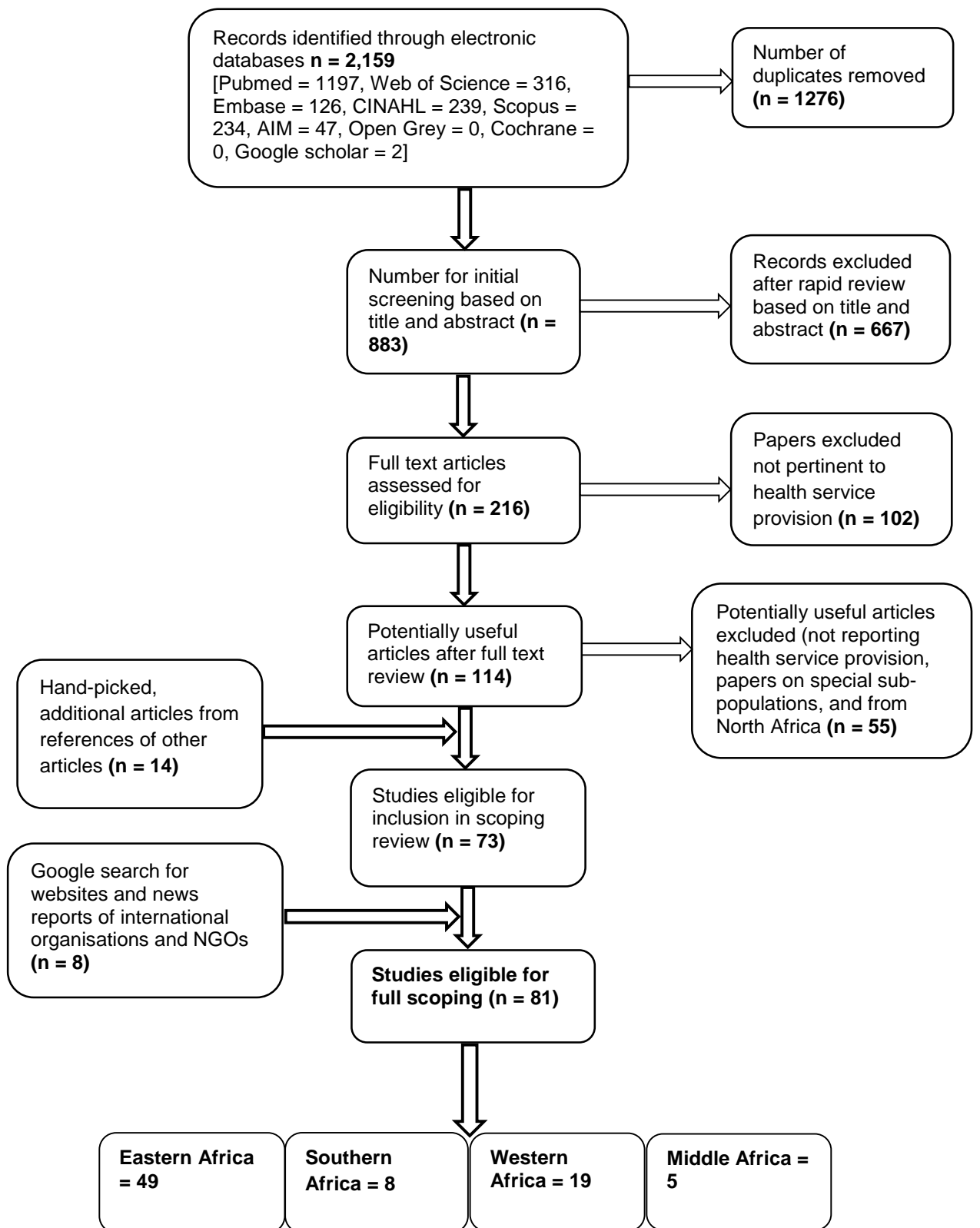


Figure 1: Review process flowchart

Table 2: Summary of health service provision and resources available for people with epilepsy in sub-Saharan Africa

Country	Project name/Location	Author(s)/Date	Population	Type of epilepsy care		Resources available				Funding/support
				Nurse/health-worker-led	Physician supervised	AED available	EEG	Neuro-imaging	Psycho-social supports	
Kenya	Nakuru ICBERG project, Nakuru district	Feksi et al., 1991 [18]; Feksi et al., 1991 [19]; Feksi, 1993 [20]	Rural & Semi-urban	✓	✓	PB, CBZ	x	x	✓	Ciba Foundation, UK National Society for Epilepsy,
	Kilifi Health and Demographic Surveillance System (KHDSS)	Scott et al., 2012 [21]	Rural	✓	✓	PB, CBZ, PHT, VPA	✓	✓	✓	Wellcome Trust, KEMRI, University of Oxford
	Kenya Association for the Welfare of People with Epilepsy (KAWE)	Dekker, 1993 [22]; Dekker-de Kieffe, 1994 [23]; ILAE, 2012 [24] http://www.kawe-kenya.org	Rural & Urban	✓	✓	PB	x	x	✓	Netherlands Epilepsy Fund, personal donations and run by volunteers
Tanzania	The Mahenge Epilepsy Clinic/ Muhimbili epilepsy project	Aall-Jilek, 1965 [25]; Jilek-Aall and Rwiza, 1992 [26]; Jilek-Aall et al., 1997 [27] Rwiza, 1994 [28]	Rural	✓	✓	PB, PHT, PRIM	x	x	✓	IDRC, University of British Columbia, EPICADEC, Private donations
	Epilepsy clinic Hai district demographic surveillance system (DSS)	Burton et al., 2012 [29]; Hunter et al., 2012 [30]	Rural	✓	✓	✓	✓	✓	✓	Wellcome Trust, DfID
	Haydom Lutheran Epilepsy Clinic (HLEC)	Winkler et al., 2008 [31]; Winkler et al., 2009 [32]; Winkler et al., 2009 [33]; Blocher et al., 2011 [34]	Rural	✓	✓	✓	✓	✓	✓	Savoy Epilepsy Foundation Canada, Centre for International Migration Germany
	Tanzanian Epilepsy Association	Kok, 1998 [35]; Rwiza, 1994 [28]	Rural & Urban	✓		✓			✓	British Columbia Epilepsy Society
Malawi	Embangweni Hospital, plus other rural clinics for treating epilepsy. Malawi Epilepsy	Watts, 1989 [36]; Watts, 1990 [37]; Watts, 1992 [38]; IBE, 2014 [39]; Amos and Wapling, 2011 [40]; (Amos	Rural	✓	✓	PB, PHT	x	x	✓	Sue Ryder Foundation, non-governmental organisations

	Association (MEA), Federation of Disability Organisations in Malawi (FEDOMA)	A, Personal communication)									
Ethiopia	Gondar NCD project, nurse-led epilepsy clinics	Berhanu et al., 2002 [41]; Berhanu et al., 2009 [42]	Rural	✓			PB	x	x	x	Tropical health education trust, Government funded NCD project.
	Amanuel Mental Specialized Hospital (AMSH), Addis Ababa	Tegegne et al., 2015 [43]	Urban	✓	✓		PB, PHT, CBZ, VPA	✓	x	✓	Financial support from Gondar University and AMSH
	Jimma University Specialized Hospital (JUSH)	Kiflie et al., 2011 [44]; Tsegabrhan et al., 2014 [45]	Urban	✓	✓		✓	✓	x	✓	JUSH
Uganda	Rural epilepsy treatment at Kabende Parish	Kaiser et al., 1998 [46]	Rural	✓	✓		PB	x	x	x	Local community
	Mulago National referral and teaching hospital in Kampala	Kaddumukasa et al., 2013 [47]; Nabukenya et al., 2014 [48]; Nazziwa et al., 2014 [49]; Settumba et al., 2015 [50]; (Kakooza A, Personal communication)	Urban	✓	✓		PB, PHT, CBZ	✓	✓	✓	Ugandan Government, Belgium Technical Cooperation, other international organisations
	Hope for Human (Nodding syndrome)	http://hopeforhumans.org (Gazda, Suzanne, personal communication)	Rural	✓	✓		✓	x	x	✓	Donations from individuals, <u>Geneva Global</u>
Zimbabwe	Epilepsy Support Foundation (ESF) and Murambinda Mission Hospital	Mugumbate and Mushonga, 2013 [51]; (Kadziti, Taurai, personal communication) www.epilepsyzimbabwe.co.zw	Rural	✓	✓		PB	✓	x	✓	ESF, ILAE
	Management of PWE by nurses at Chitungwiza and ESF	Adamolekun et al., 1997 [52]; Adamolekun et al., 2000 [53]	Rural	✓	✓		PB	✓	x	✓	W.K. Kellogg Foundation.
	Zvimba health district and ESF	Adamolekun et al., 1999 [54]	Rural	✓	✓		PB	✓	x	✓	ESF of Zimbabwe, ILAE educational grant.

	Hwedza demonstration project	Global Campaign Against Epilepsy, 2012 [55]	Rural	✓	✓	PB	✓	×	✓	Zimbabwe Committee of the Global Campaign Against Epilepsy, WHO, ILAE, and IBE
Zambia	University of Zambia's Teaching Hospital and Chikankata mission hospital plus affiliated area clinics	Birbeck, 2000 [56]; Atadzhanov et al., 2010 [57]; Elafros et al., 2013 [58]; Elafros et al., 2014 [59]	Urban & Rural	✓	✓	PB CBZ, PHT	✓	✓	✓	NIH USA
Rwanda	Gikonko Health Center, Kabutare District Hospital, and Butare University Teaching Hospital	Rottbeck et al., 2013 [60]	Rural & Urban	✓	✓	PB, CBZ, VPA, PHT	×	×	×	German Federal Ministry for Economic Cooperation and Development via the ESTHER programme
South Africa	Agincourt Health and Demographic Surveillance Site (HDSS)	Ngugi et al., 2013 [61]; Wagner et al., 2014 [62]; Wagner et al., 2015 [63]	Rural & Suburban	✓	✓	✓	✓	✓	✓	Wellcome Trust, Flora Hewlett Foundation USA, NIH, INDEPTH Network, CSIR SA, Rockefeller Foundation
	Mamre Community Health Project	McQueen and Swartz, 1995 [64]	Rural & Urban	✓	✓	PB, CBZ, PHT, VPA	×	×	✓	Centre for Science Development, University of Cape Town
	The NCD service Hlabisa Hospital	Coleman et al., 1998 [65]	Rural	✓	×	PHT, CBZ, PB	×	×	×	Government health services
	Red Cross War Memorial Children's Hospital (RCWMCH)	Williams et al., 2015 [66]	Urban	×	✓	✓	✓	✓	✓	RCWMCH, Epilepsy South Africa Western Cape Branch (ESA-WCB)
Nigeria	Epilepsy clinic at University College Hospital (UCH) Ibadan 1950s to 1970s.	Dada et al., 1969 [67]; Osuntokun and Odeku, 1970 [68]; Osuntokun, 1972 [69]; Osuntokun, 1979 [70]; Lagunju et al., 2009 [71]; (Ogunniyi AO, Personal communication)	Rural & urban	×	✓	PB, PHT, CBZ, VPA	✓	×	×	Government hospital.
Mali	RARE (Re´seau Action-Recherche	Nimaga et al., 2002 [72]; Farnarier et al., 2002 [73];	Rural	✓	✓	PB	×	×	×	Sanofi-Aventis, Sante´-Sud, Institut Rhone-Poulenc Rorer.

	sur l'Epilepsie) program	Genton et al., 2003 [74]; Bruno et al., 2012 [75]									
Senegal	Demonstration project at Pikine Health District	Reynolds, 2001 [76]; Sow and Gueye, 2003 [77]; Ndoye et al., 2005 [78]; Fall et al., 2015 [79]	Rural & Suburban	✓	✓	PB	x	x	✓	ILAE, IBE. WHO	
	Mobile epilepsy clinics	Boissy, 2005 [80]; Boissy, 2008 [81]	Suburban & rural	✓	x	✓	✓	x	✓		
Gambia	Demographic surveillance Medical Research Council	Coleman et al., 2002 [82]	Rural	✓	✓	PB	x	x	x	Gambian government and General medical council of Gambia	
	Royal Victoria Hospital (RVH)	Burton and Allen, 2003 [83]	Urban	x	✓	CBZ, PB, PHT	x	x	x	Gambian Government	
Togo	Batamariba project at the Nadoba health centre	Balogou et al., 2007 [84]	Rural	✓	x	PB, CBZ	✓	x	x	WHO	
	Community-based care for epilepsy at six pilot districts	Guinhouya et al., 2010 [85]	Rural	✓	✓	✓	x	x	✓	WHO/AFRO, NPMH supply of AEDs	
Guinea-Bissau	Community-based rehabilitation (CBR) at Buba	Otte et al., 2013 [86]	Rural & Urban	✓	✓	✓	x	x	✓	CBR programme	
Cameroon	Essential NCD health intervention project (ENHIP)	Unwin et al., 1999 [87]; Kengne et al., 2008 [88]; Kengne, 2009 [89]	Rural	✓	x	PB, PHT, CBZ	x	x	✓	UK Government's DfID Health in the Next Millennium' programme.	
	Epilepsy clinics Mbangassina area	Dongmo et al., 2003 [90]	Rural	✓	x	PB, CBZ, PHT	x	x	x	Efforts of medical personnel	

✓available, x not available or not sure, AED – antiepileptic drug, EEG – electroencephalography, PB – Phenobarbitone, PHT – Phenytoin, CBZ – Carbamazepine, VPA – Valproate, PRIM – Primidone, ICBERG – International Community-based Epilepsy Research Group, KEMRI – Kenyan Medical Research Institute, IDRC – International Development Research Centre, EPICADEC – The Foundation Epilepsy Care Developing Countries, DfID – Department for International Development, NCD – Non-Communicable Disease, ESF – Epilepsy Support Foundation, ILAE – International League Against Epilepsy, IBE – International Bureau for Epilepsy, WHO – World Health Organisation, NIH – National Institutes of Health, ESTHER – Ensemble pour une Solidarite Therapeutique Hospitaliere en Reseau, CSIR – Council for Scientific and Industrial Research, NPMH – National Program for Mental Health, ENHIP – Essential NCD health intervention project

Table 3: Epilepsy surgery experiences in sub-Saharan Africa

Country	Location	Population	Authors (Date)	Epilepsy Surgery	Diagnostic investigations available			Funding/support
					Video EEG	CT	MRI	
South Africa	Johannesburg Hospital	Urban	Krynauw, 1950 [91]	Surgery of 12 children with epilepsy from Infantile hemiplegia	✓	✗	✗	✗
South Africa	Epilepsy surgery in South Africa.	Urban	Butler, 2005 [92]	The review observed the outcomes of 250 epilepsy surgery procedures for medically intractable seizure.	✓	✓	✓	Various hospitals
Kenya	Epilepsy surgery in Kenya	Urban	Ruperti, 1997 [93]	An account of operating on 97 cases with intractable epilepsy	✗	✗	✗	✗
Uganda	CURE Children's Hospital Uganda (CCHU) Epilepsy surgery	Urban	Boling et al., 2009 [94] http://www.cureinternational.org	CCHU is dedicated to paediatric neurosurgery offering epilepsy surgery to children with intractable epilepsy.	✓	✓	✗	CURE International

✓available, ✗ not available or not sure, EEG – electroencephalography, CT – computerised Tomography, MRI – Magnetic Resonance Imaging,

3.0 RESULTS

3.1 Characteristics of the publications retrieved

Eighty-one relevant journal articles, newsletters and webpages were identified (Figure 1). The 39 services, resources available, funding sources and collaborators are summarised in Tables 2 and 3. The distribution of care centres is shown on a map (Figure 2). Most of the programmes (75%) target rural or suburban populations. Even where care was based in tertiary care centres, they also served rural and community outposts [45, 49, 59]. Some of the rural care programmes recruited individuals for treatment following epidemiological surveys, community engagements or after recognising particular needs.

The majority of rural care facilities were led by non-physician health workers trained and supervised by physicians or foreign collaborators. The AED most readily available and used was phenobarbital, provided free or at subsidized rate. The Nakuru project reported seizure freedom in 53%, with a further 26% having significant seizure reduction in the initial six months, with a compliance rate of 82% [19]. The Tanzanian cohort showed that 52% were seizure free and 36% had reduced seizures [26]. The Malian programme reported an 80% seizure-freedom and an additional 16% had significant seizure reduction [72]. A similar follow-up programme in Mali observed that 60% of those followed-up for a year were seizure-free [75]. The Togolese programme reported over 90% being seizure free for over 2 years [84]. A non-physician-led clinic at the rural Mbangassina area of Cameroon, using management algorithm reported that 70% went into remission, while 16% had partial improvement [90]. The programme at the Kabende parish in Uganda observed that about a third of subjects became seizure free [46]. Non-governmental organisations (NGOs) like Kenya Association for the Welfare of People with Epilepsy (KAWE), Hope for Humans, the Epilepsy Support Foundations, Malawi Epilepsy Association, and the Federation of Disability Organisations in Malawi in addition to providing free treatment or at cheaper rates, are involved in community engagement, counselling and education of patients and families, they also lobby for equal opportunities for schooling and

income generation. These NGOs coordinate with urban healthcare facilities to form outreach programmes and train allied health workers to render services in rural areas using epilepsy protocols

Four articles reported on experiences of epilepsy surgery conducted in South Africa [91, 92], Kenya [93], and Uganda [94]. Apart from CURE Children's Hospital of Uganda (CCHU) for Epilepsy surgery [94] and the Red Cross War Memorial Children's Hospital [66] all of the care facilities served adults and children. Almost all of these facilities are fully or partly funded by organisations and institutions from the US and Europe.

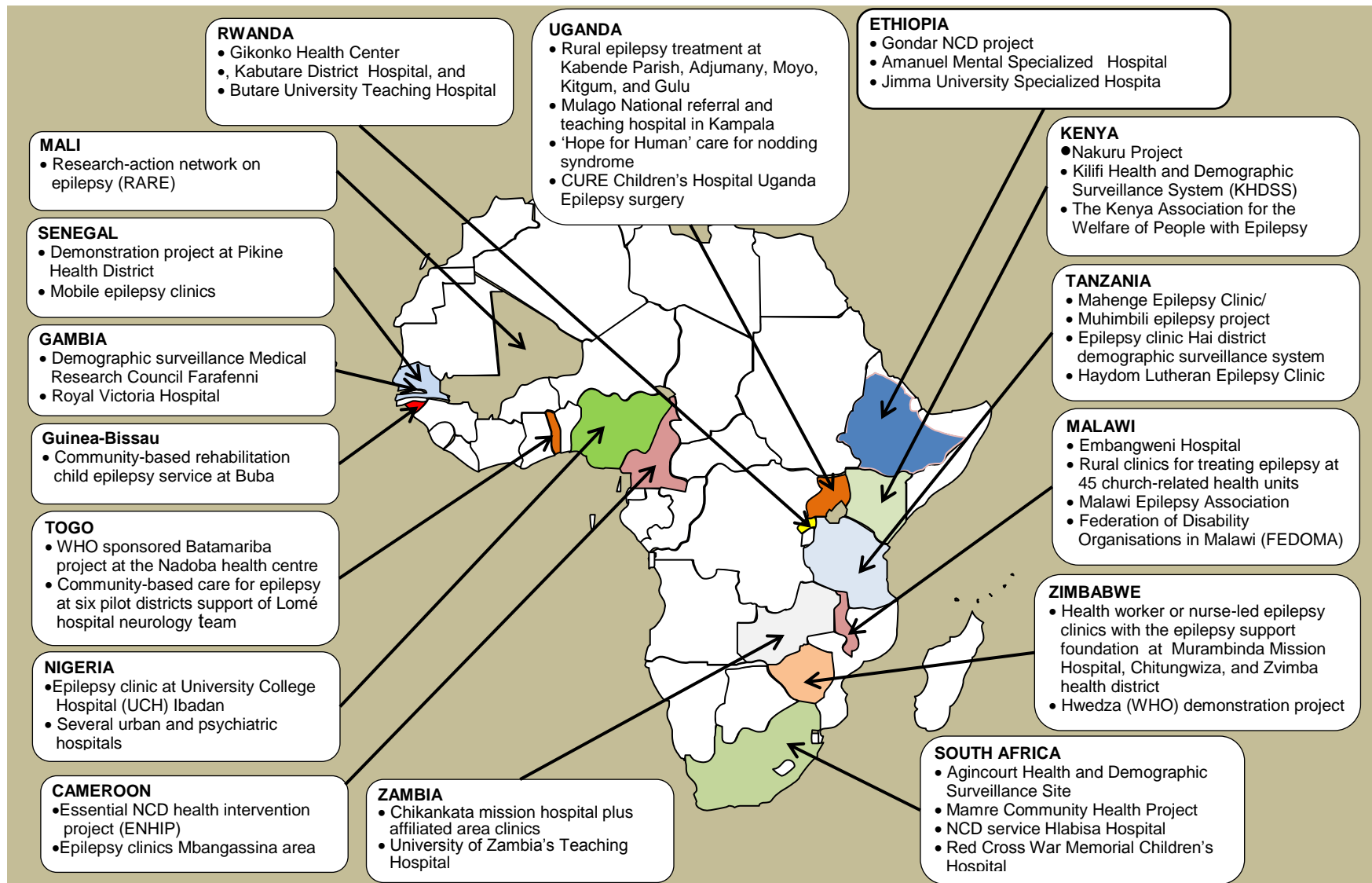


Figure 2: Map showing health care centres for people with epilepsy in sub-Saharan Africa

4.0 DISCUSSION

We wanted to explore the range of epilepsy services or programmes available in SSA and to present our perspectives on potential options to improve access to care in the continent. This review was undertaken as the first step towards developing a better understanding of the nature and scope of the literature related to epilepsy care provision in SSA. A scoping approach was preferred over a systematic review as an initial method for reviewing existing health research evidence in order to understand the range of services available rather than the quality of individual studies [95]. The most notable finding is that the overwhelming majority of African epilepsy care services are provided through centres based in rural areas. Three reasons can explain why rural programmes are popular and could represent the best model to reduce the treatment gap in Africa. Firstly, people in rural areas particularly need assistance because they are economically disadvantaged and can hardly afford most AEDs and the specialised epilepsy services often concentrated in major urban conurbations. Secondly, programmes that are run in rural centres are usually integrated within existing primary health care systems and are so more sustainable. Thirdly, most programmes in rural areas do not need sophisticated diagnostic technology and non-physician health workers can easily be trained to diagnose and provide quality care [18, 27, 36, 72, 75, 90].

It has recently been shown that community-based approach to providing care for chronic medical conditions is cost effective and sustainable [96]. With adequate training, people in allied medical professions can provide quality care in areas where access to physicians is limited and as a result, significantly reduce the treatment gap [97]. The efficiency of such community-based rural programs can sometimes be reinforced by the existence of a strong referral and counter-referral system with specialist centre. In Zambia [98] and Ethiopia [44] for example, rural clinics were linked with tertiary hospitals for the referral of those needing specialist assessment and further investigations. Some have proposed a care model for a national epilepsy programme where 60% of individuals can be successfully managed in the rural community, while 30% may be

referred to a secondary facility, with only 10% ever reaching tertiary care [98]. Apart from reducing the treatment gap, it is possible that establishing a well-coordinated rural health programme would reduce the total cost of epilepsy care provision in SSA, although this requires further research.

Community engagement and education seem critical in improving access to care and compliance. A Zimbabwean study reported that educating community health workers in epilepsy care improved recruitment and drug compliance [54]. It was observed that educating community leaders was useful in improving health seeking behaviour amongst people [99]. Psychosocial issues associated with epilepsy have been recognised as one of the most important determining factors causing the high treatment gap in Africa [12]. While the myths and stigmas surrounding epilepsy appear to be changing in many of these rural care facilities as a result of the favourable outcome of treatment, providing epilepsy care to people in rural settings in Africa remains challenging due to the considerable knowledge gap [51, 100]. Support groups have been shown to be useful in dispelling social stigma, improving treatment compliance, enhancing social acceptance and integration [27, 53, 66]. Support groups have also been shown to improve psychosocial indicators such as: positive self-management, social outlook, better coping strategies and quality of life (QOL)[101, 102]. The work by KAWE in rural Kenya illustrated how community-based NGOs can coordinate with the nurse-led system to cover more of the population especially with regards to aspects of education and social support (<http://www.kawe-kenya.org>). More studies are needed on the role of support groups and the influence of community education in improving public perception, social integration and the quality of life for people with epilepsy.

An important observation is the role of mobile epilepsy care including home visits to provide drugs and support. This has been shown to be helpful in improving compliance in rural communities in Malawi [36], Senegal [80], Mali [72], Togo [84], and by KAWE [22, 23]. The long-term feasibility and value of mobile care needs to be examined in larger longitudinal studies. It

has been suggested that healthcare centres located within a convenient walking distance would substantially reduce out-of-pocket expenses and may be of better long-term usefulness [12, 82, 103].

Phenobarbital was the cheapest and most readily available AED used in majority of rural areas. In the Nakuru project, phenobarbital had similar efficacy and tolerability compared to carbamazepine [19]. Based on the success of trials and the cost advantage of phenobarbital in India [104], Brazil [105], and China [106], WHO has suggested the use of phenobarbital as a drug of choice for treating epilepsy in resource-poor settings [107, 108]. This cost-effectiveness has been observed in the Malian [72] and Zambian studies [98, 109], where the overall cost of epilepsy management is between US\$15 and US\$25 per person per year, which is substantially less than the expenses of treating other chronic health conditions. A recent study assessing the expected resource needs for scaling up mental health care plans, also reported that the cost of epilepsy care packages is significantly lower than the cost of treating psychosis [110]. The renewed interest in the use of barbiturates as a cost-effective option for epilepsy treatment in Africa, calls for further research to verify the sources and the quality of these drugs available in African health facilities.

One important aspect of treatment in SSA is adherence. A Ugandan study found that almost 80% of people reported being adherent to AED, but only about a quarter were adherent when serum drug levels were checked [49]. Good adherence to AED is associated with better seizure control, improved job prospects, increased productivity, reduced road traffic accidents and a better overall QOL [111]. Studies on how to reduce the adherence gap could be an important future research. Even though serum drug monitoring is rarely used in Africa as cost may be a hindrance, its use may help reduce the adherence gap, but this is not established and needs to be further investigated [12, 112].

The majority of people with epilepsy can be diagnosed clinically without the support of investigations as suggested by our review. The diagnostic gap in SSA requires improvement by

providing access to EEG and neuroimaging. The diagnostic gap, the cost, and possibly the lack of skilled manpower have limited the use of epilepsy surgery [113]. A few centres reported performing surgery on a small subset of children with hippocampal sclerosis. A separate review on epilepsy surgery will be imperative to understand its utilization in Africa.

Collaborations between epilepsy care facilities in African countries and European and North American countries, with regard to funding, provision of drugs, diagnostic facilities, and transfer of technical and intellectual skills are common. They are helpful in reducing the treatment gap, but are vulnerable to economic and political changes. African governments must take the responsibility of setting up proper primary health care services [114].

Epilepsy care provisions are more concentrated in East and South Africa compared to West and Central Africa. This difference could be due to several factors: publication bias; under-reporting of epilepsy care programs; disproportionate exposure to research partnerships and funding from international donor agencies; and differences in the commitment of the local Ministries of Health.

In many countries in SSA, health insurance is poorly developed and payment for health services is out-of-pocket, making long-term management of people with chronic conditions challenging. In Nigeria, the National Health Insurance Scheme (NHIS) covers only 3% of the population mainly living in urban areas [115]. A robust health insurance scheme to cover the basic needs of the rural populace of Africa will probably improve access to epilepsy care and should be a priority for SSA. The WHO has recommended the policy of Universal Health Coverage (UHC) where citizens can access health care without incurring financial hardship; this could alleviate the burden of epilepsy and contribute to greater equality in access to care, by reducing the out-of-pocket expenses that exacerbate poverty [116].

This review has limitations. Firstly, there is clearly a bias for reporting rural epilepsy care compared to urban care, which may reflect the rapidly growing weight of literatures reporting model rural care. Rural epilepsy care programmes are more likely to be publicly or

internationally funded, and therefore more likely to be published. Secondly, we may have excluded information as only scientific articles and few grey literatures were retrieved. The potential for researchers to be unwilling to publish unfavourable results, and the inequalities of SSA studies to be published in indexed journals should be recognised. Thirdly, epilepsy services are often provided as an adjunct to mental health services [117, 118], and may not have been reported. Fourthly, a stakeholders' meeting, as recommended for most scoping reviews [16], was not performed, due to limited resources. Such meeting would have provided an avenue where information on the true situation on sites may have been further elucidated. We recognise that this is a challenging process in SSA, and could be a possible area for future research. Lastly, we acknowledge that the description of epilepsy services presented here may not reflect all care available in all of SSA as it is unlikely to be recorded in the literature.

5.0 Conclusions

We have provided a broad view of epilepsy care provision in SSA to inform health policy. The main finding highlights the usefulness of rural epilepsy care in meeting the health care needs. This success was attributed to using the existing primary health care system and employing community nurses and health workers in epilepsy care. This practice of using allied health workers in providing primary healthcare needs, despite the lack of modern diagnostic facilities, is noteworthy and could be replicated. Epilepsy care should be integrated into established health systems if possible and modelled after successful model care programmes [119]. Phenobarbital is effective in over 60% of people and remains the cheapest most readily available AED. We recognise the usefulness of community engagement and education in improving access to epilepsy care and compliance. The long-term sustainability of epilepsy care will ultimately lie in the hands of the government of these countries.

Acknowledgements

This work was carried out at UCLH/UCL Comprehensive Biomedical Research Centre, which receives a proportion of funding from the UK Department of Health's National Institute for Health Research Biomedical Research Centres funding scheme. We are grateful to Kate Brunskill, librarian at UCL Institute of Neurology for her expert assistance with the literature search. MMW is a Commonwealth Scholar funded by the UK Department of International Development.

Disclosures:

JWS receives research support from the Marvin Weil Epilepsy Research Fund and the UK Epilepsy Society endows his current position.

JWS has received research funding from Eisai, GSK and UCB, personal fees from Eisai, UCB Lundbeck and Teva, outside the submitted work.

Author Contributions

MMW, MRK and JWS conceptualised and designed the study. MMW and SAA collected the data. MMW drafted the manuscript. ASW provided intellectual content to the manuscript. All approved the final version. JWS is the guarantor.

SUPPLEMENT 1

Details of Literature Search

1. Preliminary search terms developed is shown below, and was used for PUBMED, EMBASE and Web of Science databases.

(((((epilepsy) OR epilep*)) AND ((healthcare OR neurologic services OR primary health care OR primary care OR tertiary care OR treatment program OR support OR service))) AND ((Africa OR Africa south of the sahara OR SSA OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cabo Verde OR Cameroon OR Central African Republic OR Chad OR Tchad OR Comoros OR Congo OR Republic of the Congo OR Democratic Republic of congo OR Cote d'Ivoire OR Djibouti OR Equatorial OR Guinea OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Sao Tome and Principe OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR South Sudan OR Sudan OR Swaziland OR Tanzania OR Togo OR Uganda OR Zambia OR Zimbabwe)))

2. For Scopus and Cumulative Index to Nursing and Allied Health Literature (CINAHL)

"Epilepsy" and "Africa" and "Health care service"

3. For Open Grey and the Cochrane database

"Epilepsy" and "Africa"

4. For African Index Medicus (AIM)

"epilepsy"

References

- [1] De Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. *Epilepsy Behav.* 2008;12: 540-546.
- [2] Murray CJ, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, Ezzati M, Shibuya K, Salomon JA, Abdalla S. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 2013;380: 2197-2223.
- [3] Newton CR, Garcia HH. Epilepsy in poor regions of the world. *Lancet* 2012;380: 1193-1201.
- [4] Gaitatzis A, Johnson AL, Chadwick DW, Shorvon SD, Sander JW. Life expectancy in people with newly diagnosed epilepsy. *Brain* 2004;127: 2427-2432.
- [5] Preux P-M, Druet-Cabanac M. Epidemiology and aetiology of epilepsy in sub-Saharan Africa. *Lancet Neurol.* 2005;4: 21-31.
- [6] Ngugi AK, Bottomley C, Fegan G, Chengo E, Odhiambo R, Bauni E, Neville B, Kleinschmidt I, Sander JW, Newton CR. Premature mortality in active convulsive epilepsy in rural Kenya Causes and associated factors. *Neurology* 2014;82: 582-589.
- [7] Ibinda F, Wagner RG, Bertram MY, Ngugi AK, Bauni E, Vos T, Sander JW, Newton CR. Burden of epilepsy in rural Kenya measured in disability-adjusted life years. *Epilepsia* 2014;55: 1626-1633.
- [8] Wagner RG, Ibinda F, Tollman S, Lindholm L, Newton CR, Bertram MY. Differing Methods and Definitions Influence DALY estimates: Using Population-Based Data to Calculate the Burden of Convulsive Epilepsy in Rural South Africa. *PLoS one* 2015;10: e0145300.
- [9] Baker GA. The psychosocial burden of epilepsy. *Epilepsia* 2002;43: 26-30.
- [10] Winkler AS, Mayer M, Schnaitmann S, Ombay M, Mathias B, Schmutzhard E, Jilek-Aall L. Belief systems of epilepsy and attitudes toward people living with epilepsy in a rural community of northern Tanzania. *Epilepsy Behav.* 2010;19: 596-601.
- [11] Dillip A, Alba S, Mshana C, Hetzel MW, Lengeler C, Mayumana I, Schulze A, Mshinda H, Weiss MG, Obrist B. Acceptability—a neglected dimension of access to health care: findings from a study on childhood convulsions in rural Tanzania. *BMC Health Serv Res* 2012;12: 1.
- [12] Mbuba CK, Ngugi AK, Fegan G, Ibinda F, Muchohi SN, Nyundo C, Odhiambo R, Edwards T, Odermatt P, Carter JA. Risk factors associated with the epilepsy treatment gap in Kilifi, Kenya: a cross-sectional study. *Lancet Neurol.* 2012;11: 688-696.
- [13] Meinardi H, Scott RA, Reis R, Sander JWAS, ILAE Commission on the Developing World. The treatment gap in epilepsy: the current situation and ways forward. *Epilepsia* 2001;42: 136-149.
- [14] Radhakrishnan K. Challenges in the management of epilepsy in resource-poor countries. *Nat. Rev. Neurol* 2009;5: 323-330.
- [15] World Health Organization. The World Health Report 2001: Mental health: new understanding, new hope: World Health Organization; 2001.
- [16] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol.* 2005;8: 19-32.
- [17] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5: 1.
- [18] Feksi AT, Kaamugisha J, Gatiti S, Sander JWAS, Shorvon SD. A comprehensive community epilepsy programme: the Nakuru project. *Epilepsy Res* 1991;8: 252-259.
- [19] Feksi AT, Kaamugisha J, Sander JWAS, Shorvon SD, Gatiti S, For ICBERG (International Community-based Epilepsy Research Group). Comprehensive primary health care antiepileptic drug treatment programme in rural and semi-urban Kenya. *Lancet* 1991;337: 406-409.
- [20] Feksi AT. Epilepsy. A community approach. *Trop Geogr Med* 1993;45: 221-2.

- [21] Scott JAG, Bauni E, Moisi JC, Ojal J, Gatakaa H, Nyundo C, Molyneux CS, Kombe F, Tsofa B, Marsh K. Profile: the Kilifi health and demographic surveillance system (KHDSS). *Int J Epidemiol* 2012;41: 650-657.
- [22] Dekker N. Community approach in epilepsy treatment: the KAWE experience. Comment and discussion. *Trop Geogr Med.* 1993;45: 248-252.
- [23] Dekker-de Kieffe P. The Kenya association for the welfare of epileptics. *Trop Geogr Med.* 1994;46: S20-S21.
- [24] ILAE. Commission on African Affairs, KAWE: An example to emulate. 2012.
- [25] Aall-Jilek LM. Epilepsy in the Wapogoro Tribe in Tanganyika. *Acta Psychiatr Scand* 1965;41: 57-86.
- [26] Jilek-Aall L, Rwiza HT. Prognosis of Epilepsy in a Rural African Community: A 30-Year Follow-Up of 164 Patients in an Outpatient Clinic in Rural Tanzania. *Epilepsia* 1992;33: 645-650.
- [27] Jilek-Aall L, Jilek M, Kaaya J, Mkombachepa L, Hillary K. Psychosocial study of epilepsy in Africa. *Soc Sci Med* 1997;45: 783-795.
- [28] Rwiza HT. The Muhimbili epilepsy project, a three pronged approach: assessment of the size of the problem, organization of the an epilepsy care system and research on risk factors. *Trop Geogr Med.* 1994;46: S22-S24.
- [29] Burton KJ, Rogathe J, Whittaker R, Mankad K, Hunter E, Burton MJ, Todd J, Neville BG, Walker R, Newton CR. Epilepsy in Tanzanian children: association with perinatal events and other risk factors. *Epilepsia* 2012;53: 752-760.
- [30] Hunter E, Rogathi J, Chigudu S, Jusabani A, Jackson M, McNally R, Gray W, Whittaker RG, Iqbal A, Birchall D. Prevalence of active epilepsy in rural Tanzania: a large community-based survey in an adult population. *Seizure* 2012;21: 691-698.
- [31] Winkler AS, Blocher J, Auer H, Gotwald T, Matuja W, Schmutzhard E. Anticysticercal and antitoxocaral antibodies in people with epilepsy in rural Tanzania. *Trans R Soc Trop Med Hyg* 2008;102: 1032-1038.
- [32] Winkler AS, Blocher J, Auer H, Gotwald T, Matuja W, Schmutzhard E. Epilepsy and neurocysticercosis in rural Tanzania—An imaging study. *Epilepsia* 2009;50: 987-993.
- [33] Winkler AS, Schaffert M, Schmutzhard E. The pattern of epilepsy in a rural African hospital—an approach adapted to local circumstances. *Trop Doct* 2009;39: 44-47.
- [34] Blocher J, Schmutzhard E, Wilkins PP, Gupton PN, Schaffert M, Auer H, Gotwald T, Matuja W, Winkler AS. A cross-sectional study of people with epilepsy and neurocysticercosis in Tanzania: clinical characteristics and diagnostic approaches. *PLoS Negl Trop Dis* 2011;5: e1185.
- [35] Kok P. Epilepsy in practice. *Trop Doct* 1998;28: 68-72.
- [36] Watts AE. A model for managing epilepsy in a rural community in Africa. *BMJ* 1989;298: 805-807.
- [37] Watts AE. Treating epilepsy in Malawi: lessons learned. *Trop Doct* 1990;20: 52.
- [38] Watts AE. The natural history of untreated epilepsy in a rural community in Africa. *Epilepsia* 1992;33: 464-468.
- [39] IBE. International Epilepsy News. A Malawian dream. Newsletter of the International Bureau for Epilepsy 2014: 3-5.
- [40] Amos A, Wapling L. Epilepsy in Malawi: Report for Federation of Disability Organisation in Malawi in Partnership with Sue Rider Foundation in Malawi. 2011.
- [41] Berhanu S, Alemu S, Asmera J, Prevett M. Primary care treatment of epilepsy in rural Ethiopia. *Ethiop. J. Health Dev.* 2002;16: 235-240.
- [42] Berhanu S, Alemu S, Prevett M, Parry E. Primary care treatment of epilepsy in rural Ethiopia: causes of default from follow-up. *Seizure* 2009;18: 100-103.
- [43] Tegegne MT, Mossie TB, Awoke AA, Assaye AM, Gebrie BT, Eshetu DA. Depression and anxiety disorder among epileptic people at Amanuel Specialized Mental Hospital, Addis Ababa, Ethiopia. *BMC psychiatry* 2015;15: 1.

- [44] Kiflie Y, Jira C, Nigussie D. The quality of care provided to patients with chronic non-communicable diseases: a Retrospective multi-setup study in Jimma zone, Southwest Ethiopia. *Ethiop J Health Sci.* 2011;21: 119-130.
- [45] Tsegabrhan H, Negash A, Tesfay K, Abera M. Co-morbidity of depression and epilepsy in Jimma University specialized hospital, Southwest Ethiopia. *Neurol. India.* 2014;62: 649.
- [46] Kaiser C, Asaba G, Mugisa C, Kipp W, Kasoro S, Rubaale T, Kabagambe G. Antiepileptic drug treatment in rural Africa: involving the community. *Trop Doct* 1998;28: 73-77.
- [47] Kaddumukasa M, Kaddumukasa M, Matovu S, Katabira E. The frequency and precipitating factors for breakthrough seizures among patients with epilepsy in Uganda. *BMC Neurol* 2013;13: 1.
- [48] Nabukenya AM, Matovu JK, Wabwire-Mangen F, Wanyenze RK, Makumbi F. Health-related quality of life in epilepsy patients receiving anti-epileptic drugs at National Referral Hospitals in Uganda: a cross-sectional study. *Health Qual Life Outcomes* 2014;12: 1.
- [49] Nazziwa R, Mwesige AK, Obua C, Ssenkusu JM, Mworozi E. Adherence to antiepileptic drugs among children attending a tertiary health unit in a low resource setting. *Pan Afr Med J.* 2014;17.
- [50] Settumba SN, Sweeney S, Seeley J, Biraro S, Mutungi G, Munderi P, Grosskurth H, Vassall A. The health system burden of chronic disease care: an estimation of provider costs of selected chronic diseases in Uganda. *Trop Med Int Health.* 2015;20: 781-790.
- [51] Mugumbate J, Mushonga J. Myths, perceptions, and incorrect knowledge surrounding epilepsy in rural Zimbabwe: A study of the villagers in Buhera District. *Epilepsy Behav.* 2013;27: 144-147.
- [52] Adamolekun B, Mielke J, Ball D, Mundanda T. An evaluation of the management of epilepsy by primary health care nurses in Chitungwiza, Zimbabwe. *J Epilepsy* 1997;10: 294-297.
- [53] Adamolekun B, Mielke J, Ball D, Mundanda T. An evaluation of the management of epilepsy by primary health care nurses in Chitungwiza, Zimbabwe. *Epilepsy Res* 2000;39: 177-181.
- [54] Adamolekun B, Mielke J, Ball D. An evaluation of the impact of health worker and patient education on the care and compliance of patients with epilepsy in Zimbabwe. *Epilepsia* 1999;40: 507-511.
- [55] Global Campaign Against Epilepsy. Demonstration Project on Epilepsy in Zimbabwe. 2012.
- [56] Birbeck GL. Seizures in rural Zambia. *Epilepsia* 2000;41: 277-281.
- [57] Atadzhanov M, Haworth A, Chomba EN, Mbewe EK, Birbeck GL. Epilepsy-associated stigma in Zambia: what factors predict greater felt stigma in a highly stigmatized population? *Epilepsy Behav.* 2010;19: 414-418.
- [58] Elafros MA, Sakubita-Simasiku C, Atadzhanov M, Haworth A, Chomba E, Birbeck GL. Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia. *Int Health* 2013;5: 288-294.
- [59] Elafros MA, Bui E, Birbeck GL. Medication side effects among people with epilepsy taking phenobarbital in Zambia. *Epilepsy Res* 2014;108: 1680-1684.
- [60] Rottbeck R, Nshimiyimana JF, Tugirimana P, Düll UE, Sattler J, Hategekimana J-C, Hitayezu J, Bruckmaier I, Borchert M, Gahutu JB. High prevalence of cysticercosis in people with epilepsy in southern Rwanda. *PLoS Negl Trop Dis* 2013;7: e2558.
- [61] Ngugi AK, Bottomley C, Kleinschmidt I, Wagner RG, Kakooza-Mwesige A, Ae-Ngibise K, Owusu-Agyei S, Masanja H, Kamuyu G, Odhiambo R. Prevalence of active convulsive epilepsy in sub-Saharan Africa and associated risk factors: cross-sectional and case-control studies. *Lancet Neurol.* 2013;12: 253-263.
- [62] Wagner RG, Ngugi AK, Twine R, Bottomley C, Kamuyu G, Gómez-Olivé FX, Connor MD, Collinson MA, Kahn K, Tollman S. Prevalence and risk factors for active convulsive epilepsy in rural northeast South Africa. *Epilepsy Res* 2014;108: 782-791.

- [63] Wagner RG, Bottomley C, Ngugi AK, Ibinda F, Gomez-Olive FX, Kahn K, Tollman S, Newton CR, Wagner R, Twine R, Connor M, Collinson M, Masanja H, Mathew A, Kakooza A, Pariyo G, Peterson S, Ndyo-mughenyi D, Odhiambo R, Chengo E, Chabi M, Bauni E, Kamuyu G, Odera VM, Mageto JO, Ae-Ngibise K, Akpalu B, Akpalu A, Agbokey F, Adjei P, Owusu-Agyei S, Kleinschmidt I, Doku VC, Odermatt P, Neville B, Sander JW, White S, Nutman T, Wilkins P, Noh J. Incidence, Remission and Mortality of Convulsive Epilepsy in Rural Northeast South Africa. *PLoS One* 2015;10: e0129097.
- [64] McQueen AH, Swartz L. Reports of the experience of epilepsy in a rural South African village. *Soc Sci Med* 1995;40: 859-865.
- [65] Coleman R, Gill G, Wilkinson D. Noncommunicable disease management in resource-poor settings: a primary care model from rural South Africa. *Bull. World Health Organ.* 1998;76: 633.
- [66] Williams N, Nefdt WM, Wilmshurst JM. Epilepsy South Africa: Turning obstacles into true potential. *Epilepsia* 2015;56: 184-187.
- [67] Dada T, Osuntokun B, Odeku E. Epidemiological aspects of epilepsy in Nigeria; a study of 639 patients. *Dis Nerv Syst* 1969;30: 807-813.
- [68] Osuntokun BO, Odeku EL. Epilepsy in Ibadan, Nigeria. A study of 522 cases. *Afr J Med Sci* 1970;1: 185.
- [69] Osuntokun BO. Epilepsy in the Developing Countries The Nigerian Profile. *Epilepsia* 1972;13: 107-111.
- [70] Osuntokun BO. Management of epilepsy in developing countries. *Niger Med J* 1979;9: 1-11.
- [71] Lagunju IA, Fatunde OJ, Takon I. Profile of childhood epilepsy in Nigeria. *J Pediatr Neurol.* 2009;7: 135-140.
- [72] Nimaga K, Desplats D, Doumbo O, Farnarier G. Treatment with phenobarbital and monitoring of epileptic patients in rural Mali. *Bull. World Health Organ.* 2002;80: 532-537.
- [73] Farnarier G, Nimaga K, Desplats D, Doumbo O. [Treatment of epilepsy in rural areas in Mali]. *Rev. Neurol. (Paris)* 2002;158: 815-818.
- [74] Genton P, Togora A, Nimaga K, Desplats D, Farnarier G. Recherche-action en réseau sur l'épilepsie (RARE) au Mali: l'expérience d'un séminaire de formation de médecins de campagne. *Epilepsies* 2003;15: 201-205.
- [75] Bruno E, Nimaga K, Foba I, Vignoles P, Genton P, Doumbo O, Gérard D, Preux P-M, Farnarier G. Results of an action-research on epilepsy in rural Mali. *PLoS One* 2012;7: e44469.
- [76] Reynolds EH. ILAE/IBE/WHO Global Campaign "Out of the Shadows": global and regional developments. *Epilepsia* 2001;42: 1094-1100.
- [77] Sow AD, Gueye CSK. Use of various methods of social mobilisation to increase awareness of epilepsy at pikine (Senegal) in the context of the demonstration project of the global campaign against epilepsy. In: *Epilepsia: Blackwell Publishing Inc 350 Main St, Malden, MA 02148 USA; 2003. p. 195-195.*
- [78] Ndoeye NF, Sow AD, Diop AG, Sessouma B, Sene-Diouf F, Boissy L, Wone I, Toure K, Ndiaye M, Ndiaye P. Prevalence of epilepsy its treatment gap and knowledge, attitude and practice of its population in sub-urban Senegal an ILAE/IBE/WHO study. *Seizure* 2005;14: 106-111.
- [79] Fall M, Touré K, Seck LB, Ndiaye M, Diop AG, Ndiaye MM. Epidemiological and socio-economic support patients living with epilepsy in dakar, senegal. *Tunis Med.* 2015;93: 101-103.
- [80] Boissy L. Action in communities against epilepsy in Senegal. In: *Epilepsia: Blackwell Publishing 9600 Garsington Rd, Oxford OX4 2DQ, Oxon, England; 2005. p. 345-345.*
- [81] Boissy LG. Itinerant experience of fight against the epilepsy in Senegal. *Epilepsies* 2008;20: 92-96.
- [82] Coleman R, Lopyy L, Walraven G. The treatment gap and primary health care for people with epilepsy in rural Gambia. *Bull. World Health Organ.* 2002;80: 378-383.

- [83] Burton K, Allen S. A review of neurological disorders presenting at a paediatric neurology clinic and response to anticonvulsant therapy in Gambian children. *Ann Trop Paediatr.* 2003;23: 139-143.
- [84] Balogou A, Grunitzky E, Belo M, Sankaredja M, Djagba D, Tatagan-Agbi K, Mandlhate C, Barakamfitye DG. Management of epilepsy patients in Batamariba district, Togo. *Acta Neurol. Scand* 2007;116: 211-216.
- [85] Guinhouya K, Aboki A, Kombate D, Kumako V, Apetse K, Belo M, Balogou A, Grunitzky K. [The epilepsy treatment gap in six primary care centres in Togo (2007-2009)]. *Sante (Montrouge, France)* 2009;20: 93-97.
- [86] Otte WM, Nhaga AA, Tchuda DL, Abna B, Sander JW, van der Maas F. Understanding of and attitudes towards people with epilepsy among community-based rehabilitation volunteers in Guinea-Bissau. *Epilepsy Behav.* 2013;28: 196-200.
- [87] Unwin N, Mugusi F, Aspray T, Whiting D, Edwards R, Mbanya JC, Sobgnwi E, Rashid S, Alberti KGMM. Tackling the emerging pandemic of non-communicable diseases in sub-Saharan Africa: the essential NCD health intervention project. *Public Health* 1999;113: 141-146.
- [88] Kengne AP, Fezeu LL, Awah PK, Sobngwi E, Dongmo S, Mbanya JC. Nurse-led care for epilepsy at primary level in a rural health district in Cameroon. *Epilepsia* 2008;49: 1639-1642.
- [89] Kengne AP, Sobngwi E, Fezeu L, Awah P, Dongmo S, Mbanya J-C. Setting-up nurse-led pilot clinics for the management of non-communicable diseases at primary health care level in resource-limited settings of Africa. *Pan Afr Med J.* 2009;3.
- [90] Dongmo L, Echouffo B, Njamnshi A, Kamdem P, Sini V, Pepouomi M. Difficulties faced in the management of epilepsy in rural Cameroon: the case of Mbangassina locality. *Afr J Neurol Sci* 2003;22.
- [91] Krynauw RA. Infantile hemiplegia treated by removing one cerebral hemisphere. *J. Neurol. Neurosurg. Psychiatry* 1950;13: 243-267.
- [92] Butler J. The role of epilepsy surgery in southern Africa. *Acta Neurol. Scand* 2005;112: 12-16.
- [93] Ruperti RF. Surgery of intractable epilepsy in Africa. *Afr. J. Neurol. Sci.* 1997: 16.
- [94] Boling W, Palade A, Wabulya A, Longoni N, Warf B, Nestor S, Alpitsis R, Bittar R, Howard C, Andermann F. Surgery for pharmacoresistant epilepsy in the developing world: a pilot study. *Epilepsia* 2009;50: 1256-1261.
- [95] Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier L, Kastner M, Moher D. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol.* 2014;67: 1291-1294.
- [96] Vaughan K, Kok MC, Witter S, Dieleman M. Costs and cost-effectiveness of community health workers: evidence from a literature review. *Hum. Resour. Health* 2015;13: 1.
- [97] Wagner R, Norström F, Bertram M, Tollman S, Forsgren L, Hofman K, Newton C, Lindholm L. A community health workers to improve adherence to anti-epileptic drugs in rural sub-Saharan Africa: Is it cost-effective? 2016.
- [98] Birbeck GL, Chomba E, Mbewe E, Atadzhanov M, Haworth A, Kansembe H. The cost of implementing a nationwide program to decrease the epilepsy treatment gap in a high gap country. *Neurol Int* 2012;4.
- [99] Ball D, Mielke J, Adamolekun B, Mundanda T, McLean J. Community leader education to increase epilepsy attendance at clinics in Epworth, Zimbabwe. *Epilepsia* 2000;41: 1044-1045.
- [100] Winkler A, Mayer M, Ombay M, Mathias B, Schmutzhard E, Jilek-Aall L. Attitudes towards African traditional medicine and Christian spiritual healing regarding treatment of epilepsy in a rural community of northern Tanzania. *Afr J Tradit Complement Altern Med* 2010;7.
- [101] Dilorio C, Hennessy M, Manteuffel B. Epilepsy self-management: a test of a theoretical model. *Nurs Res* 1996;45: 211-217.

- [102] Chung K, Liu Y, Ivey SL, Huang D, Chung C, Guo W, Tseng W, Ma D. Quality of life in epilepsy (QOLIE): insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). *Epilepsy Behav* 2012;24: 256-263.
- [103] Wagner RG, Bertram MY, Gomez-Olive FX, Tollman SM, Lindholm L, Newton CR, Hofman KJ. Health care utilization and outpatient, out-of-pocket costs for active convulsive epilepsy in rural northeastern South Africa: a cross-sectional Survey. *BMC Health Serv Res* 2016;16: 208.
- [104] Mani KS, Rangan G, Srinivas HV, Sridharan VS, Subbakrishna DK. Epilepsy control with phenobarbital or phenytoin in rural south India: the Yelandur study. *Lancet* 2001;357: 1316-1320.
- [105] Min LL, Sander JWAS. National demonstration project on epilepsy in Brazil. *Arq. Neuropsiquiatr* 2003;61: 153-156.
- [106] Wang WZ, Wu JZ, Ma GY, Dai XY, Yang B, Wang TP, Yuan CL, Hong Z, Bell GS, Prilipko L. Efficacy assessment of phenobarbital in epilepsy: a large community-based intervention trial in rural China. *Lancet Neurol.* 2006;5: 46-52.
- [107] Kwan P, Brodie MJ. Phenobarbital for the treatment of epilepsy in the 21st century: a critical review. *Epilepsia* 2004;45: 1141-1149.
- [108] Chisholm D. Cost-effectiveness of first-line antiepileptic drug treatments in the developing world: a population-level analysis. *Epilepsia* 2005;46: 751-759.
- [109] Chomba EN, Haworth A, Mbewe E, Atadzhanov M, Ndubani P, Kansembe H, Birbeck GL. The current availability of antiepileptic drugs in Zambia: implications for the ILAE/WHO “out of the shadows” campaign. *Am J Trop Med Hyg* 2010;83: 571-574.
- [110] Chisholm D, Burman-Roy S, Fekadu A, Kathree T, Kizza D, Luitel NP, Petersen I, Shidhaye R, De Silva M, Lund C. Estimating the cost of implementing district mental healthcare plans in five low-and middle-income countries: the PRIME study. *Br. J. Psychiatry* 2016;208: s71-s78.
- [111] Hovinga CA, Asato MR, Manjunath R, Wheless JW, Phelps SJ, Sheth RD, Pina-Garza JE, Zingaro WM, Haskins LS. Association of non-adherence to antiepileptic drugs and seizures, quality of life, and productivity: survey of patients with epilepsy and physicians. *Epilepsy Behav.* 2008;13: 316-322.
- [112] Winkler AS. Measuring the epilepsy treatment gap in sub-Saharan Africa. *Lancet Neurol.* 2012;11: 655-657.
- [113] Wieser HG, Silfvenius H. Overview: epilepsy surgery in developing countries. *Epilepsia* 2000;41: S3-S9.
- [114] Lu C, Schneider MT, Gubbins P, Leach-Kemon K, Jamison D, Murray CJ. Public financing of health in developing countries: a cross-national systematic analysis. *Lancet* 2010;375: 1375-1387.
- [115] Dutta A, Hongoro C. Scaling up National Health Insurance in Nigera: Learning from case studies of India, Colombia and Thailand. Washington, DC: Future group. Health policy project 2013;13.
- [116] Megiddo I, Colson A, Chisholm D, Dua T, Nandi A, Laxminarayan R. Health and economic benefits of public financing of epilepsy treatment in India: An agent-based simulation model. *Epilepsia* 2016.
- [117] Gureje O, Alem A. Mental health policy development in Africa. *Bull. World Health Organ.* 2000;78: 475-482.
- [118] Ofori-Atta A, Read UM, Lund C. A situation analysis of mental health services and legislation in Ghana: Challenges for transformation. *Afr J Psychiatry* 2010;13.
- [119] Chin JH. The global fund for epilepsy: a proposal. *Neurology* 2013;80: 754-755.