



Review

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



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ABSTRACT

Background: Epilepsy is a public health issue in sub-Saharan Africa (SSA) where many people with the condition receive no treatment. Health-care 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 were 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 good seizure control in about two-thirds 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 centers are due to the use of existing primary health-care systems 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.

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1. 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

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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 program 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 health care and identified research gaps.

2. Methodology

2.1. Protocol

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

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 organizations, and reports from international organizations/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 summarizing report

The data of interest included epilepsy health-care 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>).

3. Results

3.1. Characteristics of the publications retrieved

Eighty-one relevant journal articles, newsletters, and webpages were identified (Fig. 1). The 39 services, resources available, funding sources, and collaborators are summarized in Tables 2 and 3. The distribution of care centers is shown on a map (Fig. 2). Most of the programs (75%) target rural or suburban populations. Even where care was based in tertiary care centers, they also served rural and community outposts [45,49,59]. Some of the rural care programs recruited individuals for treatment following epidemiological surveys, community engagements or after recognizing 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 program in Mali observed that 60% of those followed-up for a year were seizure-free [75]. The Togolese program reported over 90% being seizure-free for over 2 years [84]. A non-physician-led clinic at the rural Mbangassina area of Cameroon, using a management algorithm, reported that 70% went into remission, while 16% had partial improvement [90]. The program at the Kabende parish in Uganda observed that about a third of subjects became seizure-free [46].

Non-governmental organizations (NGOs) like Kenya Association for the Welfare of People with Epilepsy (KAWWE), Hope for Humans, the Epilepsy Support Foundations, Malawi Epilepsy Association, and the Federation of Disability Organisations in Malawi, in addition to

Table 1
Epilepsy health-care 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 health care.
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 organizations.
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 program and interventions. Reviewing the uniqueness, successes, and outcomes of each program.
Stage 5	Collating, summarizing and reporting results	Summarizing 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.

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