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. 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 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].

<table>
<thead>
<tr>
<th>Stages</th>
<th>Framework</th>
<th>Brief Description of Steps Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>Identifying the research question</td>
<td>What is known about epilepsy health care provision in SSA? Types, nature of services, diagnostic facilities, funding sources and hindrances to optimal healthcare.</td>
</tr>
<tr>
<td>Stage 2</td>
<td>Identifying relevant studies</td>
<td>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.</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Study selection</td>
<td>All available articles reporting any form of epilepsy health service provision in SSA.</td>
</tr>
<tr>
<td>Stage 4</td>
<td>Charting the data</td>
<td>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.</td>
</tr>
<tr>
<td>Stage 5</td>
<td>Collating, summarizing and reporting results</td>
<td>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.</td>
</tr>
<tr>
<td>Stage 6</td>
<td>Consultations with stakeholders</td>
<td>A stakeholders meeting was not conducted, but we had communication with contact persons who provided additional information about studies included in the review.</td>
</tr>
</tbody>
</table>

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).
Records identified through electronic databases $n = 2,159$
[Pubmed = 1197, Web of Science = 316, Embase = 126, CINAHL = 239, Scopus = 234, AIM = 47, Open Grey = 0, Cochrane = 0, Google scholar = 2]

Number of duplicates removed ($n = 1276$)

Records excluded after rapid review based on title and abstract ($n = 667$)

Number for initial screening based on title and abstract ($n = 883$)

Papers excluded not pertinent to health service provision ($n = 102$)

Full text articles assessed for eligibility ($n = 216$)

Potentially useful articles excluded (not reporting health service provision, papers on special sub-populations, and from North Africa ($n = 55$))

Potentially useful articles after full text review ($n = 114$)

Studies eligible for inclusion in scoping review ($n = 73$)

Google search for websites and news reports of international organisations and NGOs ($n = 8$)

Studies eligible for full scoping ($n = 81$)

Eastern Africa = 49
Southern Africa = 8
Western Africa = 19
Middle Africa = 5

Figure 1: Review process flowchart
Table 2: Summary of health service provision and resources available for people with epilepsy in sub-Saharan Africa

<table>
<thead>
<tr>
<th>Country</th>
<th>Project name/Location</th>
<th>Author(s)/Date</th>
<th>Population Type</th>
<th>Type of epilepsy care</th>
<th>Resources available</th>
<th>Funding/support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>×</td>
<td></td>
</tr>
<tr>
<td>Tanzania</td>
<td>The Mahenge Epilepsy Clinic/ Muhimbi epilepsy project</td>
<td>Aall-Jilek, 1965 [25]; Jilek-Aall and Rwiza, 1992 [26]; Jilek-Aall et al., 1997 [27]; Rwiza, 1994 [28]</td>
<td>Rural</td>
<td>✓</td>
<td>PB, PHT, PRI</td>
<td>IDRC, University of British Columbia, EPICADEC, Private donations</td>
</tr>
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<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Epilepsy clinic Hai district demographic surveillance system (DSS)</td>
<td>Burton et al., 2012 [29]; Hunter et al., 2012 [30]</td>
<td>Rural</td>
<td>✓</td>
<td>×</td>
<td>Wellcome Trust, DfID</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td>×</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Haydom Lutheran Epilepsy Clinic (HLEC)</td>
<td>Winkler et al., 2008 [31]; Winkler et al., 2009 [32]; Winkler et al., 2009 [33]; Blocher et al., 2011 [34]</td>
<td>Rural</td>
<td>✓</td>
<td>×</td>
<td>Savoy Epilepsy Foundation Canada, Centre for International Migration Germany</td>
</tr>
<tr>
<td></td>
<td>Tanzanian Epilepsy Association</td>
<td>Kok, 1998 [35]; Rwiza, 1994 [28]</td>
<td>Rural &amp; Urban</td>
<td>✓</td>
<td>×</td>
<td>British Columbia Epilepsy Society</td>
</tr>
<tr>
<td>Malawi</td>
<td>Embangweni Hospital, plus other rural clinics for treating epilepsy. Malawi Epilepsy</td>
<td>Watts, 1989 [36]; Watts, 1990 [37]; Watts, 1992 [38]; IBE, 2014 [39]; Amos and Wapling, 2011 [40]; (Amos</td>
<td>Rural</td>
<td>✓</td>
<td>PB, PHT</td>
<td>Sue Ryder Foundation, non-governmental organisations</td>
</tr>
<tr>
<td>Location</td>
<td>Programme</td>
<td>Lead Organisation</td>
<td>Type</td>
<td>Funding</td>
<td>Description</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Ethiopia</td>
<td>Gondar NCD project, nurse-led epilepsy clinics</td>
<td>Berhanu et al., 2002 [41]; Berhanu et al., 2009 [42]</td>
<td>Rural</td>
<td>PB</td>
<td>Tropical health education trust, Government funded NCD project.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Amanuel Mental Specialized Hospital (AMSH), Addis Ababa</td>
<td>Tegegne et al., 2015 [43]</td>
<td>Urban</td>
<td>PB, PHT, CBZ, VPA</td>
<td>Financial support from Gondar University and AMSH</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jimma University Specialized Hospital (JUSH)</td>
<td>Kifle et al., 2011 [44]; Tsegabhrhan et al., 2014 [45]</td>
<td>Urban</td>
<td>PB, PHT, CBZ</td>
<td>JUSH</td>
<td></td>
</tr>
<tr>
<td>Uganda</td>
<td>Rural epilepsy treatment at Kabende Parish</td>
<td>Kaiser et al., 1998 [46]</td>
<td>Rural</td>
<td>PB</td>
<td>Local community</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mulago National referral and teaching hospital in Kampala</td>
<td>Kaddumukasa et al., 2013 [47]; Nabukenya et al., 2014 [48]; Nazziiwa et al., 2014 [49]; Settumba et al., 2015 [50]; (Kakooza A, Personal communication)</td>
<td>Urban</td>
<td>PB, PHT, CBZ</td>
<td>Ugandan Government, Belgium Technical Cooperation, other international organisations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hope for Human (Nodding syndrome)</td>
<td><a href="http://hopeforhumans.org">http://hopeforhumans.org</a> (Gazda, Suzanne, personal communication)</td>
<td>Rural</td>
<td>PB</td>
<td>Donations from individuals, Geneva Global</td>
<td></td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Epilepsy Support Foundation (ESF) and Murambinda Mission Hospital</td>
<td>Mugumbate and Mushonga, 2013 [51]; (Kadzitii, Taurai, personal communication) <a href="http://www.epilepsyzimbabwe.co.zw">www.epilepsyzimbabwe.co.zw</a></td>
<td>Rural</td>
<td>PB</td>
<td>ESF, ILAE</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Management of PWE by nurses at Chitungwiza and ESF</td>
<td>Adamolekun et al., 1997 [52]; Adamolekun et al., 2000 [53]</td>
<td>Rural</td>
<td>PB</td>
<td>W.K. Kellog Foundation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Zvimba health district and ESF</td>
<td>Adamolekun et al., 1999 [54]</td>
<td>Rural</td>
<td>PB</td>
<td>ESF of Zimbabwe, ILAE educational grant.</td>
<td></td>
</tr>
<tr>
<td>Country</td>
<td>Project Details</td>
<td>Eligible Treatment</td>
<td>Eligibility</td>
<td>Region</td>
<td>Funding Sources</td>
<td></td>
</tr>
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<td></td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>Hwedza demonstration project, Global Campaign Against Epilepsy, 2012 [55]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Zimbabwe Committee of the Global Campaign Against Epilepsy, WHO, ILAE, and IBE</td>
</tr>
<tr>
<td>Zambia</td>
<td>University of Zambia's Teaching Hospital and Chikankata mission hospital plus affiliated area clinics, 2012 [56]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>NIH USA</td>
</tr>
<tr>
<td>Rwanda</td>
<td>Gikonko Health Center, Kabutare District Hospital, and Butare University Teaching Hospital, 2013 [60]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>German Federal Ministry for Economic Cooperation and Development via the ESTHER programme</td>
</tr>
<tr>
<td>South Africa</td>
<td>Agincourt Health and Demographic Surveillance Site (HDSS), 2012 [61]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Wellcome Trust, Flora Hewlett Foundation USA, NIH, INDEPTH Network, CSIR SA, Rockefeller Foundation</td>
</tr>
<tr>
<td>South Africa</td>
<td>Mamre Community Health Project, 1995 [64]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Centre for Science Development, University of Cape Town</td>
</tr>
<tr>
<td>South Africa</td>
<td>The NCD service Hlabisa Hospital, 1998 [65]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Government health services</td>
</tr>
<tr>
<td>Nigeria</td>
<td>Red Cross War Memorial Children's Hospital (RCWMCH), 1950s to 1970s</td>
<td>Urban</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>RCWMCH, Epilepsy South Africa Western Cape Branch (ESA-WCB)</td>
</tr>
<tr>
<td>Nigeria</td>
<td>Epilepsy clinic at University College Hospital (UCH), Ibadan 1950s to 1970s.</td>
<td>Rural &amp; urban</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Government hospital.</td>
</tr>
<tr>
<td>Mali</td>
<td>RARE (Re ‘seau Action-Recherche), 2002 [72]</td>
<td>Rural</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>Sanofi-Aventis, Sante´-Sud, Institut Rhone-Poulenc Rorer.</td>
</tr>
<tr>
<td>Country</td>
<td>Program Description</td>
<td>Authors/Year(s)</td>
<td>Location(s)</td>
<td>Available AEDs</td>
<td>Antiepileptic Drugs</td>
<td>Program/Funding Agency</td>
</tr>
<tr>
<td>---------</td>
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</tr>
<tr>
<td>Senegal</td>
<td>Demonstration project at Pikine Health District</td>
<td>Reynolds, 2001 [76]; Sow and Gueye, 2003 [77]; Ndoye et al., 2005 [78]; Fall et al., 2015 [79]</td>
<td>Rural &amp; Suburban</td>
<td>✓</td>
<td>✓</td>
<td>PB</td>
</tr>
<tr>
<td></td>
<td>Mobile epilepsy clinics</td>
<td>Boissy, 2005 [80]; Boissy, 2008 [81]</td>
<td>Suburban &amp; rural</td>
<td>✓</td>
<td>✓</td>
<td>PB</td>
</tr>
<tr>
<td>Gambia</td>
<td>Demographic surveillance Medical Research Council</td>
<td>Coleman et al., 2002 [82]</td>
<td>Rural</td>
<td>✓</td>
<td>✓</td>
<td>PB</td>
</tr>
<tr>
<td></td>
<td>Royal Victoria Hospital (RVH)</td>
<td>Burton and Allen, 2003 [83]</td>
<td>Urban</td>
<td>✓</td>
<td>✓</td>
<td>CBZ, PB, PHT</td>
</tr>
<tr>
<td>Togo</td>
<td>Community-based care for epilepsy at six pilot districts</td>
<td>Guinhouya et al., 2010 [85]</td>
<td>Rural</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Guinea-Bissau</td>
<td>Community-based rehabilitation (CBR) at Buba</td>
<td>Otte et al., 2013 [86]</td>
<td>Rural &amp; Urban</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Cameroon</td>
<td>Essential NCD health intervention project (ENHIP)</td>
<td>Unwin et al., 1999 [87]; Kengne et al., 2008 [88]; Kengne, 2009 [89]</td>
<td>Rural</td>
<td>✓</td>
<td>✓</td>
<td>PB, PHT, CBZ</td>
</tr>
<tr>
<td></td>
<td>Epilepsy clinics Mbangassina area</td>
<td>Dongmo et al., 2003 [90]</td>
<td>Rural</td>
<td>✓</td>
<td>✓</td>
<td>PB, CBZ, PHT</td>
</tr>
</tbody>
</table>

Table 3: Epilepsy surgery experiences in sub-Saharan Africa

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

✓ 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

- **Ethiopia**
  - Gondar NCD project
  - Amanuel Mental Specialized Hospital
  - Jimma University Specialized Hospital

- **Kenya**
  - Nakuru Project
  - Kilifi Health and Demographic Surveillance System (KHDDS)
  - The Kenya Association for the Welfare of People with Epilepsy

- **Uganda**
  - Rural epilepsy treatment at Kabende Parish, Adjumany, Moyo, Kitgum, and Gulu
  - Muliago National referral and teaching hospital in Kampala
  - ‘Hope for Human’ care for nodding syndrome
  - CURE Children’s Hospital Uganda Epilepsy surgery

- **Rwanda**
  - Gikonko Health Center
  - Kabutare District Hospital, and Butare University Teaching Hospital

- **Tanzania**
  - Mahenge Epilepsy Clinic
  - Muhimbili epilepsy project
  - Epilepsy clinic Hai district demographic surveillance system
  - Haydom Lutheran Epilepsy Clinic

- **Kenya**
  - Nakuru Project
  - Kilifi Health and Demographic Surveillance System (KHDDS)
  - The Kenya Association for the Welfare of People with Epilepsy

- **Malawi**
  - Embangweni Hospital
  - Rural clinics for treating epilepsy at 45 church-related health units
  - Malawi Epilepsy Association
  - Federation of Disability Organisations in Malawi (FEDOMA)

- **Nigeria**
  - Epilepsy clinic at University College Hospital (UCH) Ibadan
  - Several urban and psychiatric hospitals

- **Cameroon**
  - Essential NCD health intervention project (ENHIP)
  - Epilepsy clinics Mbangassina area

- **Zambia**
  - Chikankata mission hospital plus affiliated area clinics
  - University of Zambia’s Teaching Hospital

- **South Africa**
  - Agincourt Health and Demographic Surveillance Site
  - Mamre Community Health Project
  - NCD service Hlabisa Hospital
  - Red Cross War Memorial Children’s Hospital
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 centres. 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 successful 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.
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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.
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"
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