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Literature Review

Status Epilepticus in Sub-Saharan Africa: A Literature Review on Epidemiological Challenges, Socio-Cultural Barriers, and Public Health Impact

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Abstract: This literature review delves deeply into the epidemiology, structural and cultural challenges, and management strategies of status epilepticus (SE) in sub-Saharan Africa (SSA). Incidence rates of SE vary significantly between countries, with notable disparities associated with socio-economic contexts, healthcare infrastructures, and cultural perceptions of epilepsy. The management of SE in this region is often hindered by constraints in medical infrastructure, inadequate access to specialist diagnostics such as electroencephalogram, and limited availability of essential anti-epileptic drugs, which are frequently out of reach for rural populations. These challenges are further exacerbated by the social stigma and cultural beliefs surrounding epilepsy, impeding access to care and widening inequalities. Moreover, the scarcity of qualified medical personnel undermines the efficient and prompt management of this neurological emergency. The review underscores the pressing need to enhance healthcare infrastructures, boost the capabilities of healthcare professionals, and conduct community awareness initiatives to destigmatize epilepsy and lessen prejudice. Additionally, practical recommendations are put forward for enhancing local capacity, fostering equity in care access, and mitigating regional health disparities in SSA.

Keywords: Status Epilepticus; Sub-Saharan Africa; Neurological Emergency Management; Healthcare Infrastructure; Epilepsy Stigma

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1. Introduction

Status epilepticus (SE) is a severe neurological emergency characterized by an epileptic seizure that persists long enough or recurs at short enough intervals to create a fixed and lasting epileptic condition [1].

SE is a complex and common neurological emergency in sub-Saharan Africa, where access to care and medication remains limited. Although SE is globally recognized as an emergency condition requiring prompt intervention, its characteristics and management vary according to regional contexts, influenced by cultural, socio-economic, and health factors [2]. In sub-Saharan Africa, the management of SE faces significant challenges, particularly due to infrastructure constraints and the lack of trained healthcare professionals. Additionally, the prevalence of epilepsy in sub-Saharan Africa is twice as high as in other parts of the world, further escalating the burden of SE [2]. The objective of this literature review is to investigate the incidence and risk factors associated with SE in sub-Saharan Africa, pinpoint gaps in management strategies, and propose recommendations for sustainable improvements in care.

2. Definition of status epilepticus in sub-Saharan Africa

The Defining SE in sub-Saharan Africa can pose challenges due to limited access to timekeeping devices and the potential influence of cultural norms on time perception. Evaluating the duration of seizures before hospital admission is often complex [2]. Simple seizures typically last less than two minutes, but if they persist for 5 to 10 minutes, they only terminate spontaneously in approximately 50% of instances, prompting the adoption of a 5-minute threshold to define generalized tonic-clonic seizures [3].

The definition of non-convulsive status epilepticus (NENS) remains ambiguous in the literature. Although it is described as an alteration in basic neurological status associated with continuous epileptic activity visible on the electroencephalogram (EEG), the clinical manifestations are very diverse. They may include alterations in consciousness, behavioural changes, or sensory, non-convulsive motor, dysautonomic or cognitive symptoms [4]. The duration required to classify a non-convulsive seizure as an SE has also varied considerably over time (from 5 to 30 minutes). Thus, the French Formalised Recommendations of Experts operationally define generalized tonic-clonic status epilepticus (GTCSE) as a seizure with motor manifestations lasting more than 5 minutes, or as seizures (at least two) recurring at short intervals without regaining intercritical consciousness, i.e., without responding to simple commands [5].

3. **Classification of status epilepticus**

There are two main types of status epilepticus, each with distinct characteristics: convulsive seizures, manifested by seizures with visible and prolonged muscular movements, and non-convulsive seizures, characterized by altered consciousness or abnormal behavior without apparent convulsive movements.

3.1. Convulsive epileptic seizures

Convulsive states of epilepsy are characterized by seizures with prolonged and violent muscular movements. Several subtypes are distinguished.

3.1.1. Generalized convulsive seizures

- Generalized convulsive states can be categorized as primary or secondary tonic-clonic, characterized by sustained, bilateral, symmetrical or asymmetrical, continuous or intermittent tonic or clonic activity, with varying degrees of impairment of consciousness. They can initiate directly (primary malignant state) or ensue a partial seizure (secondary generalized malignant state) [6].
- Myoclonic seizures are characterized by continuous myoclonic jerks and are specific to epileptic patients suffering from idiopathic generalized epilepsy or progressive myoclonic epilepsy [1]. It is important to distinguish them from encephalopathies with myoclonus [7].
- Tonic seizures are characterized by the repetition at very short intervals of tonic seizures with vegetative manifestations, and are typical of epileptic encephalopathies such as Lennox-Gastaut syndrome [8].

3.1.2. Focal convulsive seizures

- Partial somatomotor seizures, with or without Jacksonian march, are characterized by a series of partial motor seizures without altered consciousness, with or without propagation (Jacksonian march) [1].
- Continuous partial epilepsy, also known as Kojewnikow syndrome, is characterised by serial partial motor seizures alternating with permanent segmental myoclonus, resistant to any treatment, affecting the same body region [9].

3.2. Non-convulsive status epilepticus

Non-convulsive states of epilepsy encompass various seizure types that do not exhibit overt convulsive movements. These include:

1. Absence status epilepticus is characterized by fluctuating mental confusion of varying severity (ranging from simple obnubilation to a stuporous state), sometimes associated with discrete limb myoclonus that is difficult to observe. This condition may occur in patients with idiopathic generalized epilepsy (often triggered by inadequate antiepileptic treatment) or, more rarely, appear de novo in adults undergoing benzodiazepine withdrawal [10].
2. Frontal or temporal complex partial malignant state: manifested by a more or less marked and fluctuating confusional state, associated with behavioral disorders (in frontal malignant states) or subtle eating, gestural, or verbal automatisms (in temporal malignant states) [11].
3. Partial malignant states with elementary symptoms are rare. They are characterized by elementary symptoms of deficit or persistent positive symptoms with no change in consciousness, such as aphasia, hallucinatory states, pure sensory or somatosensory states, vertigo, etc.
4. Tardive malignant states represent the ultimate evolution of an untreated, inadequately treated, or refractory tonic-clonic or tonic malignant state, marked by a state of obnubilation with significant neurovegetative disorders [12]. Clinical symptoms then become extremely attenuated and may be limited to a simple tonic axial contraction or ocular revulsion.

4. Global epidemiology of status epilepticus

4.1. Worldwide incidence and prevalence

The incidence of SE varies significantly from region to region. It is reported as 10.7 cases per 100,000 people per year on the island of Funen in Denmark [13], 9.9 cases per 100,000 people per year in the canton of Vaud, Switzerland [14], 13.1 cases per 100,000 people per year in Bologna, Italy [15], 15.0 cases per 100,000 people per year in the Emilia-Romagna region [16], and 27.2 cases per 100,000 people per year in Ferrara [17]. In Germany, the incidence is 15.0 cases per 100,000 people per year [18], while in La Réunion, France, it is 8.52 [19]. A recent study in Salzburg, Austria, using the new 2015 ILAE definition, provided similar data [20]. In the US, an initial study found a rate of 41 cases per 100,000 people per year [21], while a retrospective study in Rochester estimated the figure at 18.3 cases per 100,000 people per year [22].

In Asia, Thailand reported an incidence of 5.2 cases per 100,000 people per year, and in Taiwan, it was 4.61 per 100,000 people per year between 2000 and 2011 [23]. In Japan, it is 38.8 per 100,000 people per year [24]. In Auckland, New Zealand, the age-adjusted incidence was 15.95 per 100,000 people per year for seizures lasting ≥30 minutes [25].

4.2. Impact on mortality and morbidity

SE is associated with a high risk of mortality and morbidity. The overall mortality rate varies according to the etiology and prompt management of seizures. The main causes of death include prolonged seizures, cardiorespiratory complications, central nervous system (CNS) infections, and underlying conditions such as stroke and head injury [21]. Prolonged or refractory seizures significantly increase the risk of long-term complications, particularly in terms of quality of life and functional ability, with long-term psychiatric and cognitive impairment in many patients [26,27].

Morbidity is also high, with frequent cognitive, motor, and behavioral sequelae, especially in children and the elderly. Full recovery is often hampered by neuronal damage resulting from prolonged seizures that are not treated in time [28]. These

complications can lead to an inability to regain previous levels of functioning, highlighting the importance of rapid intervention to minimize neurological damage [29].

Other causes include remote CNS damage and underdosing of anticonvulsant drugs [30]. The study conducted by Sebastián Sánchez et al. revealed that the risk factors for SE depend largely on its etiology and vary considerably between age groups. In children, infection with fever but no CNS involvement is the main cause of SE [30]. In London, in addition to epilepsy, SE can be accompanied by focal neurological deficits, cognitive impairment, and behavioral problems, although specific and consistent risk factors for these side effects have not been clearly identified [31]. In Germany, Mevius et al [32] demonstrated that the mortality rate after 12 months was 39.8% overall (with 19.4% after 30 days and 28.2% after 90 days), while it was 30.4% in PWEs. In Lima, the mortality rate for GTCSE (also called a *grand mal* seizure) was 8.47%, falling within the range reported in the literature (3-40%). This figure aligns with previous studies conducted in Peru, which noted mortality rates of 7.3% and 8.5% [34]. In contrast, a study by Outin et al. [12] in France reported a mortality rate of 10% for GTCSE.

5. Epidemiology of status epilepticus in sub-Saharan Africa

5.1. Incidence and prevalence

There are few epidemiological studies of SE in SSA. There are several obstacles to assessing the incidence of SE, including the variable quality of prospective data collection, differences in the definitions used and the diversity of study populations. It is important to emphasise the risk of overestimating the number of cases of SE if postanoxic comas are included in the studies. It is now recognised that the vast majority of these comas are in fact non-convulsive encephalopathies, although they may often be accompanied by clonus. Conversely, nonconvulsive SEs are sometimes difficult to identify, which may lead to an underestimation of incidence rates [34]. A study conducted in Kalifi on the coast of Kenya recorded a minimum incidence of GCTSE of 35 cases per 100,000 per year in children aged 0-13 years based on hospital admissions [35]. Compared with epilepsy, its prevalence in SSA is twice as high as in other continents such as Europe, Asia, and North America [36]. It is thought that the greatest burden results from an increase in risk factors such as perinatal lesions and parasitic diseases [37]. A study by Kariuki et al [38] in three different sites (Agincourt in South Africa, Iganga in Uganda and Kilifi in Kenya) revealed prevalences of 0.9, 1.4 and 1.1 per 1000 inhabitants respectively. In Senegal, in a study conducted in a pediatric hospital, Lamine et al [39] reported an incidence of 4.1%. In Nigeria, in Ilesa, Olubosede et al [40] recorded a prevalence of 18% in a series of 880 children aged 3 to 6 admitted. Rajaonarison et al [41] in Antananarivo found a prevalence of SE of 16.9%. This compares with a prevalence of 1.3% in Nigeria in the study by Akpan et al [42]. The average age of patients presenting with SE varies according to the populations studied. For example, in the study by Kariuki et al [38], the average age of patients was 26. In Senegal, in the study conducted by Lamine et al [39] in a pediatric hospital, the average age of patients was 48 months. In Cameroon, in the study conducted by Nguefack et al [43], the average age of patients was 3 ± 2.6 years. In Antananarivo, Madagascar, the study conducted by Rajaonarison et al [41] revealed an average patient age of 43.09 years. In South Africa, the study by Reddy et al [44] found an average patient age of 15 months, ranging from 6 to 37 months. Wilmshurst et al [45] in Cape Town found an average age of 3.4 years. These variations in average age across studies reflect the differences in the populations studied, such as pediatric versus adult populations, regional healthcare access, and the varying prevalence of risk factors associated with status epilepticus in each context.

With respect to gender, multiple African studies have indicated a male predominance among SE patients [38]. This trend was notably evident in the research by

Rajaonarison et al [41] in Antananarivo, where males accounted for 56.6% of patients, resulting in a sex ratio of 1.30 favoring males. Similarly, studies by Lamine et al [39] in Senegal and Nguefack et al [43] in Cameroon reported a sex ratio of 1.2 favoring males.

5.2. Specific risk factors

In the study conducted by Rajaonarison et al [41] in Madagascar, the factors associated with SE were as follows: 54.7% of cases involved patients living with epilepsy (PWEs), 9.43% of cases were linked to a shortage of anti-epileptic drugs, and 18.8% were attributed to sleep deprivation. In Senegal, factors associated with SE included 24% of cases in PWEs, 32% in those with delayed psychomotor development, and 75% of PWEs admitted after a delay of more than 30 minutes [39]. In Cameroon, the factors associated with neurological sequelae were seizure duration of more than 60 minutes and abnormal prior neurological status. Death was associated with meningitis [43]. In Nigeria, the study by Akpan et al [42] showed that mortality and morbidity were associated with the duration of seizures before presentation to the hospital. In Kenya, important risk factors were perinatal complications, parasitic infections, a family history of seizures, neurological deficiencies, and consultation with traditional healers [38].

In the study by Bugeme et al [46] in Lubumbashi, Democratic Republic of the Congo (DRC), stroke and CNS infection were the factors most frequently associated with status epilepticus. In Ethiopia, factors associated with status epilepticus included stroke, systemic infections including HIV/AIDS, and traumatic brain injury [47]. In Nigeria, in 82.1% of cases, the cause of status epilepticus was cerebral malaria, while other causes included febrile convulsions, meningitis, seizure disorders and head trauma [40]. SE is an emergency that is often poorly managed in developing countries due to a lack of qualified staff, inadequate medical equipment and limited availability of essential medicines [48]. In the majority of developing countries, treatment is limited to injectable diazepam and/or phenobarbital, with variable efficacy [49]. Lack of access to and/or availability of assisted ventilation and intensive resuscitation are often major factors in morbidity and mortality. In Mali, socio-cultural factors strongly influence the management of PWEs, both individually and collectively. As a result, many PWEs go into hiding because of the social stigma associated with their illness [50]. The study by Karfo et al [51] in Dakar shows that PWEs are never totally excluded, whatever the social context. They are tolerated in society, but often find themselves without an active role in it [51]. Non-compliance with treatment remains a major problem, largely because the majority of patients do not seek help, believing that the illness is linked to supernatural causes. In Guinea, for example, epilepsy is still too often stigmatized, due to ignorance of the disease and supernatural or mystical beliefs [52]. In SSA, the social and cultural repercussions of epilepsy are profoundly detrimental to people with epilepsy (PWEs). The condition is often perceived as a curse or divine punishment, affecting not only the individual but also their descendants, perpetuating stigma across generations [53]. This rejection frequently extends to the family, where PWEs, though rarely expelled from their homes, are often relegated to sleeping in separate quarters. While this may not constitute outright exclusion, it represents a form of marginalization where they are tolerated but stripped of an active role within society [54].

In some SSA communities, the discrimination can be even more severe, as traditional funeral rites are sometimes denied to PWEs. They may be buried at the site of their death or outside designated cemeteries, further reinforcing their social exclusion even in death [55]. This marginalization takes a heavy emotional toll, leading many PWEs to experience shame, a diminished sense of self-worth, and a tendency to conceal their diagnosis from others. As a result, they often become symbols of collective anxiety and social scrutiny within their communities.

6. Impact of status epilepticus on public health

6.1. Morbidity and mortality associated with status epilepticus

Mortality rates due to seizures are higher in SSA compared to developed countries, attributed to factors such as delayed access to hospital care, challenges in promptly administering appropriate treatment, lack of certain anti-epileptic drugs, insufficient clinical and etiological management, especially for severe yet treatable causes, and overall low awareness of the disease, all contributing to increased morbidity and mortality [56,57]. Kariuki et al's research in Kenya revealed mortality rates related to status epilepticus of 2.5%, 5.5%, and 11.41% in the three examined sites respectively [38]. In Guinea, Cissé et al's study reported a mortality rate of 43.33%, with factors like patient age, poor positioning, refractory status epilepticus (RSE), and extended hospital stays linked to mortality. Charles et al noted a hospital mortality rate of 15%, with 21% of patients passing away post-discharge [2]. In Cameroon, 9.8% of children with SE succumbed, while 17.4% experienced neurological sequelae [43]. A study in Cape Town, South Africa by Wilmshurt et al. documented a 20% mortality rate in adults with status epilepticus [45]. Akpan et al's study in Nigeria found a mortality rate of 19.2% among patients with SE [42].

6.2. Direct and indirect economic costs.

The duration of SE and the speed at which it is properly managed directly impact healthcare costs outside the hospital setting. Conversely, the illness's etiology and complication development are key factors in hospitalization costs for SE. Treating SE linked to acute illness and lacking a prior epilepsy diagnosis typically incurs higher expenses. In SSA, deficits in skilled healthcare workers (HCWs), diagnostic tools, AEDs, cultural beliefs, and social stigma widen the treatment gap [45]. Scarce resources in developing nations contribute to the elevated mortality and morbidity rates tied to SE [44]. Marshall et al.'s study [59] highlighted challenges in care access and limited EEG exam availability. Moreover, inadequately equipped intensive care units hinder effective SE management. Within the same research, 81% of patients cited cost or drug scarcity as barriers to compliance [59]. Economically and socially, three-quarters of PWEs in developing countries go untreated for various reasons [60].

7. Diagnosis and management of status epilepticus

7.1. Recognizing the signs and symptoms of status epilepticus

All forms of epileptic seizures have the potential to progress to status epilepticus (SE), with generalized tonic-clonic SE (GTCSE) being the easiest to diagnose and the most clinically critical [61]. Studies across sub-Saharan Africa (SSA) consistently report a predominance of generalized epilepsy among SE cases. For example, Kariuki et al. [38] identified generalized epilepsy as the leading clinical presentation. In Madagascar, Rajaonarison et al. [41] observed that the majority of patients presented with generalized convulsive seizures. Similarly, Cissé et al. [58] in Guinea reported that 52.22% of SE cases were generalized seizures. In the DRC, Bugeme et al. [46] found that 71.16% of SE cases were generalized seizures, including tonic-clonic, tonic, and clonic types. Wilmshurst [45] in South Africa and Nguefack et al. [43] in Cameroon also highlighted a predominance of generalized seizures, with the latter reporting 66% of observed cases as generalized.

From a paraclinical perspective, electroencephalography (EEG) is the most frequently used diagnostic tool in SE cases. Kariuki et al. [38] noted that most EEG results were normal in their cohort of SE patients. In contrast, Lamine et al. [39] in Senegal reported pathological EEG findings in 72% of cases. In Madagascar, Rajaonarison et al. [41] confirmed non-convulsive SE in 1.88% of cases through EEG, underscoring the importance of this diagnostic modality in detecting less overt forms of SE.

7.2. Importance of differential diagnosis

The diagnosis of SE can be incorrectly made in a variety of situations [62]. Non-epileptic pseudo-seizures of psychogenic origin and certain abnormal movements may mimic a convulsive status epilepticus [63]. Encephalopathies of post-anoxic, metabolic, drug-induced or Creutzfeldt-Jakob disease origin may be misinterpreted as non-convulsive confusional seizures, mainly due to misinterpretation of the EEG [64]. In these encephalopathies, the existence of (non-epileptic) myoclonus and the disappearance of EEG abnormalities after injection of a benzodiazepine (without correction of the confusion) are additional sources of diagnostic error [65]. Combined analysis of the clinical data and the EEG usually makes it possible to confirm or rule out the diagnosis of SE. Non-epileptic abnormal movements may be mistaken for status epilepticus. These include myoclonus (which is usually isolated or may be repeated irregularly and discontinuously, which distinguishes it from clonus during a seizure, consisting of regular, repetitive muscle activity) [10], asterixis, characterized by negative myoclonus, choreic movements (defined by a disordered succession of repeated contractions causing exaggerated contortions), as well as dystonia, manifested by involuntary, slow and prolonged muscular contractions, may all be included in the differential diagnosis with a SE [66]. Tremors, in their various forms [67], and hemiballismus, which are large movements of rotation and extension of the limbs on the side opposite the lesion, often stereotyped unlike chorea, can sometimes be mistaken for SE [68]. Other symptoms may be confused with SE, such as the pyramidal syndrome, which can cause spasms that are sometimes clonic in response to stimulation (epileptoid foot tremor). It is crucial not to confuse these with partial motor seizures [5], diffuse spasms [69] and tics, which are stereotyped movements that can sometimes be temporarily controlled by the patient's will [70]. All these difficulties underline the importance of performing an EEG quickly. However, this examination can also be difficult to interpret because of certain misleading differential diagnoses, such as toxic, metabolic or postanoxic encephalopathies, which present generalised periodic paroxysmal abnormalities [10]. It should be noted that in the presence of an obvious diagnosis, EEG should not be waited for before starting antiepileptic treatment, but should be performed as soon as possible. The EEG is indicated as an emergency measure in the presence of a GTCSE without delaying treatment, in cases of suspected non-convulsive confusional seizures or in cases of doubt about a pseudo seizure [71].

7.3. Medical care

7.3.1. First-line and second-line treatments

The pharmacological management of status epilepticus (SE) presents significant challenges in SSA. In many hospitals across the region, the availability of AEDs is often limited to diazepam and injectable phenobarbital, which significantly restricts treatment options [45,48]. In Madagascar, Rajaonarison et al. [41] used diazepam as the first-line treatment, followed by carbamazepine as the second-line therapy. Similarly, Reddy et al. [44] in South Africa administered midazolam as the first-line agent, followed by thiopental for refractory cases. In Nigeria, diazepam was the preferred first-line treatment, with phenobarbital used as a second-line option [42]. Lamine et al. [39] in Senegal employed a similar approach, administering diazepam first, followed by phenobarbital. In the DRC, Bugeme et al. [46] also reported the use of diazepam as the initial treatment, followed by phenobarbital for cases that did not respond to first-line therapy. In Côte d'Ivoire, diazepam was the first-line drug of choice, while valproic acid was used as the second-line treatment [72]. In Madagascar, Rajaonarison et al. [41] detailed a protocol involving an initial bolus of 10 mg diazepam, followed by a continuous infusion (0.5 to 1 mg/kg/24h), with oral carbamazepine administered via a nasogastric tube as a second-line intervention. In Cameroon, Gams et al. [73] reported that first-line management typically

involved either diazepam alone or a combination of diazepam and phenobarbital, while second-line treatment options included clonazepam or phenobarbital.

These findings underscore the heavy reliance on a limited range of AEDs in SSA and highlight the need for broader access to alternative therapies to improve SE management outcomes.

7.3.2. Recommended treatment protocols.

SE is both a diagnostic and therapeutic emergency. If not promptly treated, it can lead to severe neurological complications and death [74,75]. To prevent brain damage, it is crucial to halt seizures as quickly as possible and prevent their recurrence. Intensive treatment must begin immediately, as metabolic decompensation of the brain typically starts after about 30 minutes of continuous seizures. The longer the seizure persists, the higher the risk of progressing to RSE and chronic epilepsy [76]. Treatment for SE is guided by numerous recommendations from expert societies, increasingly informed by large-scale studies comparing available drug options. These guidelines generally propose a structured therapeutic algorithm, starting with a first-line benzodiazepine, followed by second-line treatments, and management of RSE [77].

- **First-line treatment,** The efficacy of benzodiazepines as first-line treatment has been thoroughly evaluated in high-quality clinical trials. These studies have consistently shown that benzodiazepines offer rapid onset of action, good tolerability, and are as effective as other therapeutic classes. In cases of initial treatment failure, a second dose can be administered after 5 to 10 minutes with promising results [10,77].
- **Second-line treatment: 20 to 40 minutes after onset of seizures,** Several randomized, prospective studies have compared the efficacy of different second-line drugs to optimize patient management [10]. In these studies, sodium valproate was generally found to be as effective as, or even slightly more effective than, phenytoin and levetiracetam, though it did not significantly impact patient prognosis at discharge. The American guidelines classify valproate, phenytoin, and levetiracetam as second-line treatments, without specifying a preferred order. Fosphenytoin is favored due to its better venous tolerance compared to phenytoin, while phenobarbital is suggested as an alternative if the other drugs are unavailable. Notably, high bolus doses are recommended [78]. The 2018 French Formalised Recommendations of Experts treatment protocol ranks valproate, phenytoin, and phenobarbital equally, with a slight reservation for levetiracetam [5].
- **Third-line treatment: refractory status epilepticus,** Approximately 20% of SE cases progress to RSE, and 13% to intractable SE [79]. The management of RSE, whether convulsive or delirious, involves general anesthesia, intubation with mechanical ventilation, and meticulous hemodynamic monitoring [74]. Current SE treatment guidelines are largely based on studies conducted in developed countries. However, in SSA and other tropical regions, these recommendations face substantial barriers. These challenges include limited medical resources, ineffective treatments, and frequent stock-outs or unavailability of antiepileptic drugs [75].

8. Specific challenges in managing SE in SSA

8.1. Economic challenges and limited access to care

The cost of care represents a significant burden for the families of people living with epilepsy (PWE). In the Ituri region of the DRC, the cost of caring for a patient with epilepsy can consume nearly half of a household's income, leaving minimal resources for daily needs. This situation worsens the vulnerability of families and perpetuates a cycle of poverty [80]. It creates a cycle of poverty. In comparison to other developing countries,

the annual cost of epilepsy in the DRC is lower than in Nigeria [81], but higher than in South Africa [82] and Burundi [83]. This difference is due to the fact that in South Africa, anti-epileptic drugs (AEDs) are provided free of charge, and indirect costs are not considered, while in Burundi, the expenses related to traditional medicine are not factored in. This situation is exacerbated by the inadequate health infrastructure and insufficient training for health professionals, along with the lack of funding for health systems. Medical facilities and services are often inaccessible or too expensive for many families. While there may be some reporting subject to recall bias, given the chronic nature of epilepsy, regular expenditure is generally well known and accurate in households [80,84].

In Guinea, the study carried out by Camara et al [52] highlighted the limited number of health care facilities and the remoteness of existing facilities. These factors contribute to the lack of therapeutic management of epilepsy in Conakry and the rest of the country. The lack of infrastructure in SSA is a factor associated with mortality, as demonstrated by the study conducted by Newton & Kariuki [2]. This lack of medical equipment and facilities contributes to worsening health conditions and increasing mortality rates in the region. The study carried out in Cameroon by Kuate et al [85] also highlighted the lack of adequate infrastructure. It is also important to perform an EEG quickly when nonconvulsive SE is suspected. The EEG will also be fundamental in characterizing the type of nonconvulsive SE (generalized/focal, and its location, particularly temporal or frontal). Finally, EEG, particularly continuous EEG, is useful for checking the effectiveness of treatment [10]. In SSA, access to EEG examinations remains very limited, as few facilities have the necessary equipment to carry out these crucial paraclinical examinations [86]. This situation significantly reduces the possibilities for diagnosing and monitoring patients with epilepsy. For example, in Mali, according to the study by Maiga et al [87], only 53.8% of patients with epilepsy were able to have an EEG, due to difficulties in accessing this test. In the study by Lompo et al [88] in Burkina Faso, only 23.3% of patients had an EEG recording. In Madagascar, the study by Marshall et al [59] revealed that only 30% of patients had access to an EEG examination. Lamine et al [39], in Senegal, highlighted the difficulty for many children with status epilepticus in accessing an EEG examination, underlining a major obstacle in the diagnostic and therapeutic management of these patients.

8.2. Problems of geographical distribution of health centers.

In SSA, epilepsy care faces a number of major economic obstacles and limited access to care. Among these challenges is the uneven distribution of health centers, with a concentration in urban areas leaving rural regions largely underserved. This situation complicates access to care for PWEs and those presenting with SE, particularly with regard to essential diagnostic tools such as EEG and brain imaging [80]. As the majority of healthcare infrastructure is concentrated in urban areas, access to care in rural areas is often limited, which explains the difficulties encountered by rural populations in obtaining appropriate medical care. Even where functional health facilities exist, they generally benefit wealthier urban dwellers more than the rural poor. This inequality compounds the complexity of epilepsy management in resource-limited countries, where access to care remains largely inequitable between different regions [89].

According to the study by Mbuba et al [90], the primary challenge in the management of epilepsy in developing countries is the scarcity of qualified personnel. This deficiency of specialist staff poses a significant obstacle to the efficient care of patients with epilepsy. The median number of neurologists in SSA is estimated at 0.3 per million inhabitants, underscoring a severe shortage of specialists in this region [91]. The insufficiency of qualified human resources has been identified as a critical factor constraining the effective management of epilepsy [92].

In their study conducted in Mali, Maiga et al. [84] identified several factors impeding the effective management of epilepsy. These included a shortage of qualified personnel and diagnostic resources necessary for comprehensive diagnosis, patient and family refusal or non-compliance with treatment due to cultural beliefs, the high cost and limited availability of medications, and the substantial psychosocial impact of the disease.

The pharmacological management of SE in SSA faces numerous challenges. In many African hospitals, the available AEDs for treating SE are often limited to diazepam and phenobarbital. Furthermore, the supply of injectable phenobarbital is inconsistent in certain countries, complicating access to adequate treatment [2]. In developing nations, a large proportion of individuals with epilepsy do not receive proper treatment, primarily due to insufficient medical resources, limited drug availability, and uneven distribution of healthcare infrastructure [93].

The "epilepsy treatment gap", as defined by the International League Against Epilepsy, refers to the disparity between the number of individuals with active epilepsy and those who receive appropriate treatment for their seizures in a specific population at a given time. This gap includes both diagnostic and therapeutic shortcomings [94]. Notably, this treatment gap varies considerably between countries and even within regions of the same country. The discrepancy is particularly pronounced in rural areas, where access to healthcare is often more limited [95].

The inadequate supply of medications, especially in rural clinics and dispensaries, prevents many patients from maintaining adequate therapeutic levels. Moreover, there is an increasing concern about the proliferation of substandard and counterfeit medications, which disproportionately affect developing countries [96]. In a study by Ibanga et al. [92] in Gabon, it was reported that the majority of children with epilepsy lacked access to appropriate antiepileptic treatment, which significantly hindered their care and clinical management. The absence of proper treatment considerably worsens their health and exacerbates the challenges of managing their condition. Similarly, in Guinea, the lack of adequate emergency drug stocks severely compromised patient care, leading to a notable increase in mortality. This highlights the difficulties posed by insufficient medical resources, especially in critical situations [58].

8.3. Socio-cultural factors

8.3.1. Perceptions and stigma associated with epilepsy

In SSA, epilepsy is often perceived as a mystical manifestation rather than a medical condition requiring care. As a result, around 80% of people with epilepsy in this region do not have access to appropriate care, which exacerbates the situation for PWEs due to cultural beliefs and lack of medical resources [98]. The study by Ibanga et al [92] revealed that care for children with epilepsy remains limited, largely due to the persistence of prejudice and negative beliefs about epilepsy, which are widespread among teachers, school-age children, and the general population. These children are often a source of stress and disruption to the social, professional, and educational lives of their parents and siblings [92]. In low-income countries and sub-Saharan Africa, PWEs are marginalized, have a lower quality of life than other chronically ill patients, and a much shorter life expectancy [84]. Many people believe that there is a link between the onset of epileptic seizures and the phases of the full moon. These beliefs are often rooted in mystical or cultural explanations for the disease [98]. Erroneous beliefs about epilepsy vary from country to country and can have an impact on how individuals respond to available care options. These beliefs often influence behavior and treatment decisions, limiting access to appropriate medical care [99]. In many SSA countries, PWEs find it difficult to marry. Furthermore, in the African context, the schooling and social integration of children with epilepsy remain sensitive and often debated subjects, due to the stigma and cultural beliefs surrounding the disease [98,100].

In SSA, the social and cultural repercussions of epilepsy are particularly harmful for patients, often manifesting themselves in isolation and exclusion. These consequences can be summed up in one word: rejection, because the stigma associated with the disease leads to social estrangement and discrimination in many aspects of the daily lives of those affected [54].

8.3.2. Influence of traditional beliefs on management.

In SSA, misconceptions about epilepsy vary widely from country to country and often shape individuals' attitudes toward treatment options. Among the Dogon people in Mali, epilepsy is commonly viewed as a contagious disease, prompting certain precautions. For instance, family members and friends avoid sharing meals with PWEs and provide them with separate utensils for eating [84]. In Guinea-Conakry, persistent beliefs about the incurability and contagiousness of epilepsy continue to lead to the exclusion of PWEs from school and prevent them from marrying. At the same time, the widespread belief that epilepsy has a supernatural or evil origin contributes to significant stigmatization, discrimination, and further social exclusion of PWEs [52].

A study conducted by Polepole et al. [101] in Goma (DRC), on public knowledge of epilepsy found that approximately 88% of PWEs believed the illness was contagious, a mental disorder, or the result of demonic possession. Similarly, Bora et al. [102] in Lubumbashi (DRC), reported that most PWEs perceived the disease as having a spiritual or religious cause. In Abidjan (Côte d'Ivoire), a study by Kouassi et al. [97] revealed that some parents of children with epilepsy believed the illness to have a supernatural origin, which influenced both their perception of the condition and the care they sought for their children.

9. Strategies to prevent and improve care

9.1. Capacity building

9.1.1. Training for healthcare workers

Numerous studies have revealed a significant deficit in the knowledge of front-line healthcare staff regarding the management of epilepsy. These gaps can affect the quality of care provided to patients with epilepsy, underlining the importance of increasing training and awareness among healthcare professionals in this area [103,104].

The lack of knowledge about epilepsy is a major obstacle to the proper management of this condition, which remains poorly studied. Given the importance of this pathology, it is crucial to establish solid initial training, while reinforcing the ongoing training of healthcare professionals. According to the WHO, up to 80% of people with epilepsy in Africa are deprived of care because the public is poorly informed about the disease [95]. In Cameroon, with the aim of improving epilepsy care, the Cameroon Epilepsy League regularly runs awareness campaigns. It also organizes consultation caravans for people with epilepsy in various health centers, as well as training sessions for general practitioners, nurses, and teachers in schools and colleges. These initiatives aim to strengthen the medical and social skills needed to better manage epilepsy in the country [85].

9.1.2. Development of health infrastructures

The development of healthcare infrastructure is essential for improving the management of epilepsy in Africa, where specialized services remain scarce, particularly in rural areas. While urban centers may have well-equipped health facilities, they are often overcrowded and treatment costs can be prohibitively high. In contrast, rural areas are severely underserved, with few clinics offering essential diagnostic tools, such as EEG, which hinders the diagnosis and effective treatment of epilepsy [98, 105, 106].

To address this gap, significant investment is needed to build and equip specialized healthcare centers in rural areas, including improvements to transportation networks to facilitate access to care. Additionally, it is crucial to provide training for healthcare professionals, particularly in rural regions where knowledge of epilepsy is often limited [108]. There is also a pressing need for psychosocial support infrastructure, especially in rural areas where stigma is more deeply entrenched. Improving healthcare infrastructure will not only enhance access to care but also reduce the disparities between urban and rural regions. Such capacity-building efforts are vital to ensure that epilepsy care in Africa is both equitable and effective [85].

9.2. Access to medication

9.2.1. Policies to improve the supply of medication

In SSA, epilepsy continues to be a significant public health concern. Alongside the scarcity of resources in the healthcare sector, there is a substantial therapeutic gap in epilepsy treatment. Limited availability of first-line antiepileptic drugs persists, raising concerns about their quality [108].

Improving access to AEDs in SSA is essential if the thousands of people affected are to be treated effectively. Barriers such as high cost, poor infrastructure, and inadequate health policies persist. These obstacles, including stock-outs and duration of treatment, need to be identified in order to raise awareness and improve compliance and the quality of life for PWEs [92,109].

To address these issues, governments should implement policies to subsidize and reduce import taxes on anti-epileptic drugs to enhance accessibility. Moreover, enhancing logistical infrastructures is vital to prevent frequent stock-outs, which can have severe or fatal implications for PWEs, including SE. Therefore, it is crucial to ensure continuous access to these medications to prevent any treatment interruptions. Access to AEDs remains restricted in low-resource settings, with many governments yet to establish national programs or allocate resources for implementing strategies to combat the disease [110].

A long-term solution is to promote local production of generic AEDs via regional agreements, which would reduce import dependence and costs [111]. Policies on access to medicines in developing countries require consideration of both local regulations, which facilitate the implementation of public health policies, and global regulations, where health often struggles to be a priority. Access to medicines is often approached from the angle of accessibility, availability, and distribution, but a political perspective is essential to grasp the dynamics of the players and the existing obstacles. Working in partnership with international organizations could also provide financial support for these initiatives. By combining these strategies, it is possible to guarantee equitable access to AEDs in SSA and to improve care for people with the disease [110].

9.2.2. Subsidy programs and universal access

Various drug pricing policies have been introduced to make treatments more accessible and affordable. However, there is limited evidence regarding the practical implementation of these policies in sub-Saharan African contexts, leaving gaps as to their actual effectiveness [112].

Subsidy programs are crucial in enhancing access to epilepsy care in SSA, where the disease is frequently under-treated. The significant expenses associated with anti-epileptic medications, particularly in rural regions, pose a significant obstacle [112].

By reducing these costs and import taxes, governments, with the assistance of national and international non-governmental organizations, can enhance the affordability of healthcare. Subsidies should also aid in the training of healthcare professionals and enhancing distribution infrastructures to prevent stock-outs. Only a limited number of

sub-Saharan regions currently receive subsidies for anti-epileptic drugs, as outlined by Watila et al [113].

10. Education and awareness

10.1. Awareness campaigns to reduce stigma.

In SSA, epilepsy remains a disease surrounded by many erroneous beliefs, often perceived as supernatural, which leads to significant stigmatization of sufferers. This stigma has serious social consequences, including exclusion from school, work, and even family life, as well as difficulties in accessing care. To combat this phenomenon, awareness campaigns are essential [114]. These campaigns aim to demystify epilepsy by informing the public about its medical causes and available treatments [115]. They focus on dispelling preconceived ideas, such as those associating epilepsy with demonic possession or a curse. In SSA, a number of initiatives have been launched to raise awareness, involving local communities, religious authorities, and healthcare professionals to reduce discrimination against people living with epilepsy [116,117].

For example, some organizations collaborate with community leaders and traditional healers to modify perceptions and promote social acceptance of PWEs. Moreover, these awareness campaigns play a crucial role in enhancing fair access to healthcare and urging families to pursue proper medical treatment rather than turning to unconventional remedies [118].

10.2. The importance of community education on the causes and treatment of epilepsy

Community education on the causes and treatment of epilepsy is crucial to enhance the management of this disease in SSA, where it is often poorly understood. Epilepsy in many regions is surrounded by misconceptions attributed to supernatural causes like witchcraft or possession, leading to the stigmatization of individuals [119]. These false beliefs hinder the pursuit of proper medical care and foster an environment of social exclusion. This scenario has been evident in Sierra Leone, where the significant social stigma linked to epilepsy likely stems from insufficient community education. Effective intervention through education, coupled with competent clinical case management, is necessary to combat this stigma [119]. Community education serves to debunk these myths by providing scientific insights into the neurological origins of epilepsy. A deeper comprehension of the condition can motivate families and patients to seek healthcare professionals rather than resorting to ineffective traditional remedies [50].

With this in mind, in Zimbabwe, training has been organized for community leaders to enable them to identify and record cases of epilepsy, thereby facilitating their management. The aim of this initiative is to strengthen early detection and improve access to care for those affected, drawing on the key role of local leaders in mobilizing and educating communities [120]. A study by Watila et al. aimed to examine the main characteristics of epilepsy health services in SSA. It found that non-governmental organizations such as the Kenya Association for the Welfare of People with Epilepsy (KAWE), Hope for Humans, the Epilepsy Support Foundations, the Malawi Epilepsy Association, and the Malawi Federation of Disabled People's organizations play a key role. In addition to offering free or low-cost treatment, these non-governmental organizations are involved in community awareness-raising, counseling, and patient and family education. They also advocate for equal opportunities in education and employment, while collaborating with urban health facilities to train paramedics to deliver services in rural areas using epilepsy-adapted protocols [113].

11. Conclusion

Status epilepticus (SE) is a critical neurological emergency, and its effective management remains a substantial challenge in SSA. This literature review highlights the region's alarmingly high incidence of SE, exacerbated by the widespread prevalence of epilepsy and numerous barriers to effective treatment. Key factors such as inadequate infrastructure, a shortage of skilled healthcare professionals, limited availability of essential medications, and pervasive societal stigma contribute to the high morbidity and mortality associated with SE. Additionally, cultural norms and traditional beliefs significantly influence patients' willingness to seek care and adhere to treatment, underscoring the urgent need for targeted community awareness programs.

To improve SE management in SSA, it is essential to strengthen local diagnostic and therapeutic capabilities. This includes enhancing access to critical diagnostic tools such as EEG and ensuring a steady supply of high-quality antiepileptic drugs. Furthermore, ongoing education and training for healthcare providers, coupled with the development of appropriate infrastructure—particularly in rural areas—are fundamental to improving both access to and equity in healthcare services. Equally important, community awareness initiatives aimed at dispelling myths and reducing stigma are crucial to encouraging timely medical intervention and improving patient outcomes.

While progress has been made in understanding and treating SE, a concerted and sustained effort is required from governments, healthcare organizations, and local communities to address the complex challenges facing this region. Collaborative efforts are essential to meet the healthcare needs of individuals with SE and significantly improve their prognosis.

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