An Overview of The Harmful Cultural Practices on Epilepsy in Sub-Saharan Africa and Their Impact on Its Clinical Management

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Abstract

Epilepsy remains a significant non-communicable disease with global health relevance. The World Health Organization (WHO) estimates that between 4 and 10 per 1000 people worldwide suffer from active epilepsy, with the African population having the highest associated morbidity and mortality.

This review highlights the prevalence of epilepsy in sub-Saharan Africa using data collected via online resources, including Google Scholar and PubMed. It aims to highlight the various harmful traditional practices used in this part of the world to abort seizure attacks, as well as the common clinical examination and investigative findings noticed at the presentation after such traditional interventions have been applied, to better guide clinicians towards a more thorough management of such dynamic presentations.

Harmful cultural beliefs and practices on the interventions of epileptic conditions are common in many developing countries across Africa, many of which have been found to cause more harm than good. Healthcare providers must be aware of these interventions and provide tailored and individualized care in their management.

Keywords: Harmful practices, Epilepsy, Seizure, intervention, Africa

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Introduction

Epilepsy is a chronic disorder of the brain characterized by an enduring disposition towards recurrent unprovoked seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. The diagnosis of epilepsy requires at least two unprovoked seizures occurring greater than twenty-four hours apart (1).

The WHO estimates that 25 million people in Africa suffer from epilepsy, with two-thirds living in low and middleincome countries (2). Despite this significant epidemiological burden, the management of epilepsy in Africa has remained inadequate (3).

Epilepsy has also remained a highly stigmatized disease condition, especially across Africa, and is historically believed to be a sacred disease that results from the invasion of the human body by a god or spirit (4). Unfortunately, these myths have been carried on from one generation to another among several communities and ethnic groups in Africa, resulting in stigmatization, and carrying out of harmful cultural and

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Figure 1.0. Illustration of the impact of harmful cultural practices on the management of epilepsy.

traditional interventions, many of which eventually cause more harm than good, making it a dreaded disease of public health importance (5).

Many individuals with epilepsy can live seizure-free with appropriate management (2). However, most individuals with epilepsy in Africa do not get the needed and timely intervention that is required (Treatment gap), as the condition of seizure disorders across Africa is often shrouded by various myths and misconceptions (3, 4). This is due to the community's lack of awareness and education and the lack of access to the required standard healthcare.

This article aims to highlight the various misconceptions and harmful practices associated with the interventions of epilepsy across various African communities and the impact on its clinical management, to further guide clinicians towards providing a holistic and comprehensive approach to its management. It aims to raise awareness of the negative impacts of cultural beliefs and practices on epilepsy while promoting safe, effective, and evidence-based management in treating people with epilepsy.

Epidemiology of Epilepsy in Africa

Epilepsy affects more than 50 million individuals worldwide, with a substantial number residing in Africa. Nearly 80% of people with epilepsy live in low-income and middle-income countries (1). It remains a non-communicable disease of public health significance in Africa, with a high prevalence and incidence rate across various African countries (6). The epidemiology of epilepsy in Africa varies widely across countries and populations studied. Several studies have reported that the prevalence of epilepsy ranges from 0.5% to 10% in various African countries (7). The burden of epilepsy in Africa has also been found to have a bimodal distribution, higher among children and elderly individuals. A higher prevalence and incidence rate have also been found in rural areas compared to urban areas of low- and middle-income countries, due to a lack of access to needed healthcare services as well as a lack of awareness of the disease conditions (8).

The epidemiology of epilepsy in Africa varies widely across countries and populations studied. Several studies have reported that the prevalence of epilepsy ranges from 0.5% to 10% in various African countries (9). However, it is believed that the actual prevalence of epilepsy in Africa may be underreported.

In Nigeria, the estimated prevalence of epilepsy was reported to be approximately 8 per 1000 people⁽⁹⁾, similar to findings in Uganda, with a slightly higher prevalence of 10.3 per 1000 (10). Tanzania has a relatively higher prevalence rate of 10% than Ghana, with an estimated prevalence of 7.9% (8). Mozambique, however, has one of the lowest prevalence rates of epilepsy in Africa, at 1.6% (11).

In terms of incidence, studies have reported rates ranging from 20 to 50 per 100,000 people per year in different African countries. For example, Ghana has an estimated incidence of 40 per 100,000 people per year, whereas Ethiopia has an estimated incidence of 30 per 100,000 people per year (8). Nigeria and South Africa have close-range estimated incidence rates of 27 and 25 cases per 100,000 people per year, respectively (8).

There are disparities in the prevalence and incidence of epilepsy in rural areas compared to urban areas, which is due to the limited awareness of the signs and symptoms of epilepsy and lack of access to healthcare and diagnostic tools in rural areas (8). Notably, studies have revealed a higher prevalence and incidence of idiopathic epilepsy (epilepsy with no known cause) in Africa than in symptomatic epilepsy (epilepsy caused by an underlying condition) (8).

Despite the paucity of data, various studies have shown that Africa contributes significantly to the prevalence of epilepsy worldwide. It is also important to note that there is a need for more in-depth studies to increase the data on the incidence and prevalence of epilepsy in every African country.

Myths Associated with Epilepsy and Harmful Cultural Practices

Gomutra

Cow urine concoction, also known as 'Gomutra' is an ancient practice believed to be a potent anti-seizure therapy. It originated in India in 1964 and is still used for therapeutic purposes by some caregivers as an unorthodox home remedy for seizure attacks in many countries, most notably India, Nepal, and Nigeria. Currently, cow urine use is prevalent in the Yoruba tribe in the southwestern region of Nigeria (12).

The components of the concoction have been noted to vary across countries, but the most consistent ingredients used include tobacco leaves, garlic leaves, basil leaves, lemon juice, rock salt, and the bulb of onions soaked in cow urine. The concoction is either forced down the mouth of the convulsing child or applied topically (12). It is usually used in children aged between six months and five years with a predilection for febrile seizures in this age group. It has been noted that the therapeutic effect of the cow urine concoction is a result of the tobacco component or a similar constituent in the concoction. Over 50 components have been identified in cow urine concoctions, and the major components are benzoic acid, phenylacetic acid, and nicotine.

According to existing studies, the use of 'Gomutra' has been attributed to certain traditional beliefs, including fear of death,

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fear of seizure recurrence, and fear of disability. Another important belief is that mothers think that if a child has seizures, their siblings will develop seizures later in life and that cow urine has the potential to prevent this, hence its widespread use (13). Other people attribute seizure attacks to supernatural forces, angry gods, and evil spirits, and they believe that cow urine provides spiritual protection (13, 14). Administration of a cow urine mixture to a convulsing child is a widespread practice that has always had a poor outcome (14). It has been noted to give rise to several clinical and biochemical findings, and it is quite easy to identify someone who has taken the concoction because it has a particularly pungent smell (15). Some clinical findings that have been attributed to the ingestion of 'Gomutra' include initial bradycardia followed by tachycardia, and a biphasic effect on blood pressure characterized by a fall followed by a rise has been noted. A short period of respiratory arrest and depression followed by tachypnea with associated hypoventilation, restlessness, and behavior disturbances is common (15). In addition to the clinical findings, the following biochemical findings have been noted: profound hypoglycemia, low CSF glucose level, ECG changes, deranged blood urea electrolyte and creatinine values (mainly hyperkalemia), and lymphocytopenia, particularly reduced neutrophil and monocyte count (15).

In most developed countries, seizure attacks resolve spontaneously. They are associated with little to no complications, whereas in countries like Nigeria, where the use of cow urine is common, many complications have been noticed over time. Some of these complications include fatal infections that occur because of the high bacterial load in cow urine and neurological sequelae such as generalized hypertonia, trigeminal and facial nerve palsies, cortical blindness, hemiplegia, sensorineural deafness, and death.¹⁵ Several efforts have been made to educate the population about the dangers associated with using cow urine concoction as an anti-seizure remedy, and mothers have been noted to constitute a good target group for specific health education.¹³

Burning patients' limbs

Intentional burning of patients' limbs is another practice reported in the literature (13). This is not advised because burns lead to full-thickness erosion of the entire epithelium covering the skin and may sometimes extend into the hypodermis and include subcutaneous fat. It also predisposes individuals to infections such as tetanus, a common soil organism.

However domestic accidents may occur in some people with epilepsy when neglected, as they carry out activities of daily living unsupported. For instance, while cooking with firewood they may fall into the fire thus sustaining burns and suffering head trauma from falls. This predisposes them to anoxic ischemic injury due to several causes, ranging from cardiorespiratory failure to impaired cerebral blood flow (16). Unintentional manifestations of the signs of epilepsy are the major reason a child can fall into fire. At other times, there is an intentional burning of the child's limbs, which increases the risk of dehydration, acute kidney injury, and death or sepsis from poorly healed wounds.

Hypovolemia from burns is a common cause of pre-renal acute kidney injury (AKI), which in turn is the most common form of AKI. The pathophysiology of pre-renal AKI involves renal hypoperfusion, which leads to decreased glomerular filtration rate (GFR) and decreased urinary output. Reduction in urine output is an early symptom of AKI after a child's limb is burnt.

Delayed wound healing is also a common finding in post-burn epileptic patients with a history of scarification, as keloid formation causes a delay in wound healing. Hypopigmentation is a major problem in deep dermal burns and no standard treatment is available for post-burn hypopigmentation disorder (17).

Wasting of the muscles in the affected area becomes obvious in children whose limbs have been burnt. Contractures can develop if burns occur over a joint, as observed in third-degree burns. They are late complications of severe burns, which increase their risk of dependence on caregivers in the future. It usually occurs following maturation, thickening, and tightening of burn scars, which prevent movement of the affected joint. The complexity of these burns requires specialized treatment by a multidisciplinary group of foot and ankle professionals, burn reconstructive surgeons, and rehabilitative experts. The goal of reconstruction is to achieve smooth and painless ambulation by preserving limb length, function, and mobility. The most encountered issue with foot and ankle burns is contracture deformity, which often requires surgical release of scars, scarred tendons, tight joint capsules, correction of bony deformities, and coverage of soft tissue defects (18).

Severe contractures may involve tendon shortening secondary to scarring, in addition to capsular fibrosis of the interphalangeal and metatarsophalangeal (MTP) joints (18). Interviews with people with epilepsy in Burkina Faso suggested that they would resort to modern medicine only if complications such as burns, or other injuries associated with seizures occurred or if traditional medicine failed. It has also been noted that children with epilepsy in the urban areas of Burkina Faso are excluded from schools (19). To improve the quality of life of patients with epilepsy, the stigma of epilepsy should be addressed.

Scarification markings

This portrays the significant challenges of poverty and lack of access to healthcare for people with epilepsy in developing parts of Africa, whereby they rely on traditional healers who make minor cuts into the skin of body parts (scarification) affected by seizures. These cuts are sometimes used as depots for herbal medicine; in other cases, scarification itself represents the treatment. The cuts are usually set on the head and face but may be found all over the body (20). Scarification may lead to local dermal hypertrophy and atrophy.²¹ Scarification poses health risks to those who undergo it due to the use of unsterile tools and materials (21). These risks include local infections such as skin infections, and systemic

infections like sepsis, hepatitis B, hepatitis C, HIV, and even tetanus (21, 22). Traditional healers and scarification practitioners also face occupational risks due to repeated exposure to patient blood carrying blood-borne pathogens (22).

Current guidelines in the management of epilepsy

The management of patients with epilepsy sets out to find appropriate medications to control seizures, limit or avoid treatment-related adverse effects, and restore or maintain the patient's quality of life. Optimal treatment requires an individualized approach, correct diagnosis, documentation of the intensity and frequency of seizures, awareness of medication side effects, and updated knowledge of the available anti-seizure medications. Once the seizure type has been classified using the framework of the International League Against Epilepsy (ILAE), it can be decided when to start treatment and what the appropriate anti-seizure medication should be (23).

A first unprovoked seizure should be treated if the examination identifies signs of neurological deficit and the electroencephalogram (EEG) shows unequivocal epileptic activity or brain imaging shows a structural abnormality. For adults presenting with an unprovoked first seizure, immediate anti-seizure therapy, compared to no treatment, reduces the absolute risk of seizure recurrence within the subsequent two years. However, considering recurrence over a longer term (>three years) for an unprovoked first seizure, immediate antiseizure treatment as compared with treatment delayed until a second seizure occurs, is unlikely to improve the prognosis measured by sustained seizure remission. Therefore, treatment after the first seizure should be based on individualized assessments that weigh the risk of recurrence against the adverse effects of anti-seizure medication therapy (24).

According to the NICE guidelines, treatment of epilepsy should begin with the use of a single antiseizure medication whenever possible. If seizures continue despite an optimal dose of first-line anti-seizure medication, the diagnosis of epilepsy must be reviewed. If first-line monotherapy is unsuccessful and the diagnosis of epilepsy remains confirmed, monotherapy with another anti-seizure medication should be attempted with caution during the changeover period. Occasionally, monotherapy may be unsuccessful; thus, an add-on treatment should be carefully titrated and the treatment reviewed frequently, including monitoring for adverse effects, such as sedation. Overall, it is paramount that a discussion be held with the patient, their family, and caregivers on the benefits of taking as few medicines as possible to maintain seizure freedom or control as well as the long-term adverse effects of taking antiepileptic medications (25).

Addressing challenges in the management of epilepsy

In Sub-Saharan Africa, epilepsy management faces challenges like stigma, poverty, inadequate access to physicians, limited awareness, and misconceptions (26, 27). To tackle these limitations, strategies have to be implemented, such as conducting public education campaigns, engaging in community outreach, training healthcare professionals to deliver culturally sensitive care, and improving access to epilepsy care through insurance coverage.

Recommendation and conclusion

For many people living in low- and middle-income settings, the practice of alternative medicine, either in isolation or complementary to orthodox medicine is still common. Some herbal medicines and dietary supplements may have anticonvulsant effects, but very few have been tested in rigorous trials; thus, some may even have pro-convulsing effects. In addition, the use of alternative medications can affect and alter the levels of anti-seizure medications when taken, rendering them ineffective. Our cultural practices remain sacrosanct but should not be an obvious source of harm to the people it is meant to protect and heal.

The points listed above are not exhaustive; therefore, we advocate not just for more research into these harmful practices and the effect they have on the management of epilepsy, but also for a robust health education and awareness drive to dispel myths and provide optimum care.

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Ethical approval

Not applicable

Availability of data and material

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Consent for publication

This manuscript has been approved for publication by all authors.

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