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Challenges Related to Epilepsy Management in Sudan, an Example of Low-Middle Income Country

Ismat Babiker, Awab Saad, Basil Ibrahim and Mohamed Abdelsadig

Abstract

Epilepsy is one of the most common neurological diseases that require long-term healthcare, although it has no racial, gender, or geographical boundaries, certain populations and demographics face different challenges regarding management of epilepsy. These challenges include patients' and communities' misconceptions of epilepsy nature, treatment and outcome, various use of traditional and spiritual therapy in management of epilepsy, stigma of epilepsy, shortage of neurology facilities and specialists and their aggregation in the capital, and collapse of the healthcare system in Sudan. This chapter aims to highlight some of the difficulties facing people with epilepsy in Sudan, an example of a low middle-income country.

Keywords: difficulties, seizures, developing countries, Africa, treatment

1. Introduction

Epilepsy is a global health challenge, one that is responsible for a social and economic burden worldwide, it is estimated to be twice as common in low-income countries than that in the high-income countries, especially in a poor country like Sudan, resulting in unfair treatment, prejudice and stigma [1], and overwhelming decrease in quality of life [2]. People with epilepsy (PWE) in Sudan suffer from a collapsing and deficient health care system, and a community falling behind and lacking enough understanding towards their affliction, with a cultural heritage and misconceptions, and an educational system contributing to make it only that much more difficult for (PWE) to live a normal life, sometimes weighing them down and preventing them from seeking professional medical help altogether. The resultant treatment gap causes a mortality rate dwarfing that of first world countries [3]. On top of that, Sudan is lacking sufficient research and infrastructure to develop satisfying estimates about the situation on the ground, and recent data are scarce [3].

1.1 Sudan: background and population

Sudan is the third largest country in Africa that occupies almost 728,000 square miles of northeast Africa. It sits along the sub-Saharan crossroads and along the

cost of the red sea that runs through its east-northern borders. In addition to Egypt, Sudan shares borders with six other countries, which are Ethiopia, Chad, Libya, Eritrea, Central African Republic, and lastly South Sudan that had its secession from Sudan by July 2011. Sudan is mainly formed of flat plains interspersed by mountain ranges, and due to its immense area, Sudan has different climates and several rivers coursing through the country, mainly the blue and white Niles that join together to form the river Nile in Khartoum the capital city of Sudan.

Although it's an enormously sized country, it is sparsely populated compared to some of the African countries as it has an estimated census of 43 million people, the majority of which are rural in comparison to the urban population that is mainly centered in the capital.

Sudan is vastly enriched with different races, cultures and a blend of Arabic tribes that form the majority of the population and various African tribes and ethnicities, this enrichment may be contributing to its ever astounding cultural diversities and perhaps the fuel to political differences and the rather devastating civil wars that have crushed the country for ages, viciously affecting Sudan in every aspect possible. Sudanese people are still facing major challenges in everyday aspect of life due to this overwhelming political instability through its history.

1.2 Healthcare system in Sudan

As a low middle-income country, Sudan is confronted with many brutal challenges, especially in health sector. Some of the challenges encountered are the poor assessment and execution of policies, lack of firm health informatics system, inadequate financial spending, centralized medical services and facilities in Khartoum and urban cities, and insufficient training for postgraduate doctors. To add more to the burden on medical care is the deficiency of preventive medicine application, poor referral system, problematic diaspora of physicians, lack of communities' awareness leading to the fixed stigma and spiritual misconceptions of diseases that are causative of delayed medical seeking behaviors and use of folk medicine. These difficulties robustly affect the quality of health care and specifically the management of chronic diseases as epilepsy.

2. Neurology in Sudan

Neurology practice in Sudan is affected by the weakened health care system, Adult and child neurology is confronted by extreme challenges affecting people with neurological diseases. Up to the year 2005 there were only three practicing neurologists that were delivering medical care for an unconceivable ratio of one neurologist to 12 million people [4]. In addition to the enlarging population, this ratio could be attributed to lack of neurology training programs for postgraduate doctors which has begun in the past 10 years, in addition the shortage of neurology clinics in Sudan as today there are 3 tertiary neurology centers that provide adult neurology services, all of which are located in the capital which only aggravates the problem of the ability to seek neurology consultations and follow-ups especially for patients living outside Khartoum. Other major setbacks are the shortage of neuro-physiologists, neuro-imaging facilities and neuro-radiologists and the desperate need for neurology nursing and rehabilitation centers.

3. Epilepsy misconceptions in Sudan

There is a lot of stigma and misconceptions that befall (PWE) in Sudan, where epilepsy is perceived as demonic possession, Satanic rituals, spells and witchcraft [3],

some cultures have superstitions similar to that of Saudi tribes where they consider (PWE) as a presentiment of evil, a manifestation of envy and “Evil Eye” [5], while in some cultures (PWE) are considered a grace and bringers of god-bliss to their families [6]. However, others believe PWE are infectious, mentally ill, impotent and should neither get married nor have a job. Some people consider epilepsy an incurable disease, while others think the condition will pass on its’ own so they completely dismiss the therapeutic process as a futile endeavor. Some religious followers would resort to special forms of prayer involving rigorous movements to help alleviate the condition. Such beliefs direct people toward seeking traditional methods and healers, who antagonize demons, introduce herbs, ointments, cautery and prayers as stand-alone treatment for epilepsy.

A cross sectional study done in Sudan to evaluate the impact of spiritual and traditional believes of care givers on the management of children with epilepsy, it established that 80% of them were educated, one third of study population attributed epilepsy to supernatural causes. More than two thirds acknowledged use of both traditional and spiritual medicine, more than half used different religious methods to treat epilepsy. Almost half of participants believed that religious and or traditional treatment were truly effective in the management of epilepsy, and one third used herbs in the treatment of epilepsy [7].

4. Scarce personnel and trained physicians

In Sudan the number of centers where appropriate investigation tools has increased in the recent years, more cities are constructing new centers for neurology (like Madani neurology center, Aljazeera State), but it’s in no way comparable to the increase in patients and the services that need to be provided [8].

Despite the increase in number of medical faculties and doctors, the number of physicians with specialty training in neurology remains lacking. The overall condition of freedom and civil rights in the country along with the increased costs of living, which are all factors contributing to the mass immigration of doctors and other healthcare professionals to seek a respected income that enables them to live a decent life. It is worth mentioning that some doctors in Sudan live off salaries ranging anything from the equivalent of 15 to 300 dollars per month.

5. Anti-epileptic drugs (AEDs) in Sudan

Currently, there are more than 25 licensed AEDs in clinical practice in the developed world, compared to few registered AEDS in Sudan, most of which are old generation AEDs, although older generation medications are still effective even in comparison to newer generation AEDs, the newer generation have less side effects and are more tolerable [9]. Tolerability and adverse effects are a major influence on compliance, and discontinuation of therapy, therefore increasing morbidity and mortality in people with epilepsy.

The use of AEDs is influenced by the pre-existing belief system that pushes people towards traditional herbals and local healers [3], with some believing the medication is useless while others consider s it to be undermining of the more trusted traditional methods. However, among those who would have access to proper medical help, and those who appreciate the need for medication, other factors further affect the treatment gap and challenge adherence to medication. Patients who are seizure free for a long duration or those taking more than one medication may fail to adhere to therapy or omit doses.

Descriptive analysis of cost-benefit for some patients indicates that their concern about the high price of the medication greatly outweighs the need for the drug, and would as a result seek free samples provided by charity organizations, while some patients fail to obtain the drug [10]. Antiepileptic drugs represent a tremendous economic burden on families of patients with epilepsy. The yearly cost of AEDs alone falls not less than 276 US dollars per patient per year, while visitations and consultations along with investigation could reach 51 dollars. Other indirect costs can include travel, for those who live far from the capital, reaching up to 90 dollars. Insurance rarely helps and patients find themselves forced to sell valuable assets like one's cow or shop to cover the expenses, and many find themselves in debt. All of these factors need to be accounted for by the patient and caregivers and affect adherence negatively [11].

6. The collapse of the health care system

Access to AEDs like other medications in Sudan was subject to variations related to inflation and other complex geopolitical factors, resulting in fluctuating prices in the period from 2009 to 2013 (6 times change in pricing). And while the general market dynamics in the country were somewhat fluctuant, the general indicators of regional macroeconomics have been declining steadily (e.g. GDP in dollars) following factors like change in market policies, conflicts in the south leading to loss of big fractions of the country's resources, up to the more recent financial crisis in the country in the period 2018-2020, where cash was virtually inaccessible to the public, making all medications into a luxury, and culminating in an event of pharmaceutical scarcity of drugs, despite the government's best efforts to mitigate the impact of the economic situation [12]. Some policies had a relatively positive effect, like price liberalization privatization of the sector. And while reports and studies are yet to fully estimate the on-going catastrophe, the global status of lock-down and quarantine due to the COVID-19 pandemic certainly made it more challenging to get access to medical care or self-management for (PWE) in such a collapsing healthcare system [13].

7. Stigma

Stigma is the social outspoken or perceived labeling of an individual or a group of people according to true or presumed different characteristics attributed to specific health related and non-health related conditions, rendering these individuals incapable of leading equal lives to their peers in society [14, 15].

Components of stigma include behavioral, emotional and cognitive elements that are portrayed in patients responses or attitudes and their interaction with society [16]. The burden of stigma unfolds in both active and passive manners, those who discriminate and those facing discrimination can inflict stigma after being subjected to it. This gives rise to the different entities of stigma and its effects on different life attributes of stigmatized individuals in society [15].

The manifestations and impact of stigma in the attitude form further branches it into perceived, anticipated, and internalized stigmas, while the social form of stigma includes the enacted or experienced stigma. Perceived stigma describes one's thoughts or self-image perceived through the eyes of those surrounding one's life regarding an acknowledged distinguishing characteristic [16]. Anticipated stigma refers to a presumed inappropriate response in the form of an act of discrimination or labeling in a social setting to one's condition by others. Internalized stigma

denotes self-inflicted discrediting and undermining due to awareness and acknowledgment of one's difference. Experienced or felt stigma refers to consequences of an act of labeling or discrimination that was made intentionally to point out a stigmatizing characteristic [14, 16, 17].

7.1 Health related stigma

Stigma is a major social determinant of health, attributing to disease morbidity, mortality and to the successfulness of healthcare services [18].

Elements that articulate the complex process of health conditions related stigma include illness nature, its course, and characteristics that represent origins of stigma; population related elements; treatment modalities and healthcare providers sought for consultation; reactions as well as coping mechanisms of stigmatized individuals to social acts of discrimination that may take a toll on their identity, social life, and economic thriving [17, 19, 20].

What is not so clearly defined however, is the relationship between stigma and healthcare outcomes, attributing to stigma being an entity that while having similar grounds in most health related conditions, its effects can be as illness specific as exclusive features of that illness, often referred to as the hidden burden of an illness, and this is an area that is deficient in research data [21, 22].

7.2 Manifestation of stigma in high income vs. low-income countries

Health related stigma, can be visualized more clearly in communities where compensation of one's health condition related disability is lacking. These compensations aim towards minimizing the gap between individuals with disabling health conditions and their peers in community. Communities where efforts to minimize this gap are lacking are mostly those of low-income economical index [20].

Stigma adversely affects individual health outcomes as well as related life chances, including educational opportunities, employment, housing, and social relationships. It has also been shown to negatively affect help- and treatment-seeking behaviors, compromising the ability to treat and prevent stigmatized health conditions. Masking of research on illness specific stigma under the generalization of its nature has limited the ability to understand the overall impact of stigma on individual wellbeing and the overall disease burden, restricting the ability to develop interventions addressing stigma, and this masking is amplified especially in low-income countries, because of the lacking resources available to healthcare research and services in general [20, 23].

Stigma affects caregivers of individuals being stigmatized, be it their families, relatives or close companions. Caregivers of patients in low-income countries suffer a heavier burden due to lacking national health agencies support, which widens the gap between illness-limited individuals and their peers in society, further enforcing stigma as well as worsening the financial burden. All these elements associated with stigma in low income countries develop a synergistic effect, in which each element contributes to the vicious cycle of further reducing the quality of life of stigmatized individuals [23].

7.3 Stigma of epilepsy in low-income countries

The weight and burden associated with epilepsy in terms of stigma manifests with variable intensities and forms across different age groups and communities [6, 24].

Developmental aspects of one's life including physical, mental and social development, and their bases of parenting by one's family, education and an uninterrupted

social learning experience, are affected differently with various onset age groups of epilepsy. For example, having a child with epilepsy puts tremendous pressure on the family and caregivers, especially in a low-income country where taking care of an illness free child can be troublesome. This leads to stressful parenting, creating many obstacles for a child who has epilepsy to develop at a normal rate. A child with epilepsy has a higher chance of academic underachievement, which would setback building of self-esteem and eventually in conjunction with other epilepsy related elements leads to enforcement of stigma and further disability and unsuccessful treatment, in contrast to adolescence onset of epilepsy which would have a different impact on their quality of life and would manifest in different aspects like social withdrawal despite being in a functional social and economic status. Adulthood onset of epilepsy and the manifestation of stigma associated with it could be less severe than childhood and adolescence onset and would affect one's ability to be involved in certain elements of society, but could also be devastating in certain low-income regions with plummeting education and awareness levels, for example not being able to have a spouse in a low-income community where having epilepsy is thought to be of demonic possession [1, 6, 24].

7.4 Stigma and mismanagement of epilepsy in Sudan

Epilepsy in Sudan accounts for 1.6 annual mortality rates and 238.7 disability adjusted life years per 100,000. It is associated with notable stigma and social burdens. Patients with epilepsy suffer a tremendous burden of social discrimination adversely affecting their quality of life [6]. These patients are subject to being denied equal chances to a dignified life following neglect, isolation and lack of national healthcare support.

As studies in Sudan regarding epilepsy are primarily focused on clinical presentation of epilepsy, no in depth illustration or correlation between stigma of epilepsy and the outcome of epilepsy healthcare have been conducted.

However, some of the magnitude of epilepsy stigma in the Sudanese population has been captured across the different age groups of patients with epilepsy in urban and rural areas.

A study conducted by Taha et al. to identify epilepsy related stigma in the Sudanese community and to find correlation between penetrance of the type of stigma on patients through stigma degree scoring, have detected that approximately 16% of both men and women with epilepsy suffer from highly precipitated felt stigma. 12.5% of remaining patients of epilepsy who did not suffer from felt stigma have noted the common belief in their communities of the contagious nature of epilepsy while 56.2% declared their communities believed epilepsy was of demonic possession, 13% mentioned people were afraid from them when they were having seizures in public and hence they do not help them. The Sudanese community surrounding patients with epilepsy also showed poor respect to patients' privacy evident with 77.4% of patients stating that despite not disclosing their condition, it was publicly known. Where expected least, Sudanese communities showed an alarming response to children with epilepsy from their teachers and mentors, as 22% of patients at primary school age mentioned that their teachers treated them badly. Two out of three patients with epilepsy were found to have either courtesy or coaching stigma, which represent enacted stigma of parents and guardians of patients with epilepsy, and this translates into a boosting effect for all forms of stigma being enforced in epileptic patients having their caregivers constantly reminding them of their condition. Patients who stated that their disease hindered their progress in life and those who expressed frustration and stress were found to be more than those who could cope with their condition, and this was significantly

associated with a high seizure frequency. This shows that poor control of seizures inevitably diminishes the ability of patients to conceal their condition, leading to more discrimination and exacerbation of stigma [1].

An important implication of living in a resource-limited country is deficiencies that could be noted across all social services especially healthcare services. Muwada Bashir et al. portrayed a brilliant scope in their study of detecting the quality of life of Sudanese patients with epilepsy under the burden of inequalities of healthcare services, which showed that stigmatization, social discrimination and inadequate health services are major problems that Sudanese patients with epilepsy and their families confront in their daily life. The study concluded that stigma among other factors associated with epilepsy is worsening the burden on both patients and caregivers by crippling their healthcare services accessibility and by increasing efforts of coping with the disease in a society with a culture that is shaped by a low economic status [6].

8. Children with epilepsy

Children constitute the main domain of people with epilepsy; this subpopulation faces many challenges. These challenges begin with the different etiologies of epilepsy in Sudan and Africa, of these etiologies central nervous system infectious agents (malaria, onchocerciasis), and perinatal insults constitute the main causes of epilepsy. Such causes could explain why the majority of people with epilepsy are in Africa. In addition, these causes along with other factors contribute to the poor outcome of epilepsy in the developing world.

Children with epilepsy have comorbidities including autism, intellectual disability that could be caused by perinatal insults and cerebral palsy; they are also more vulnerable to physical and sexual abuse. Studies from Sudan demonstrated that 10% of children with epilepsy have associated attention deficit hyperactivity disorder (ADHD) [25], one third had learning disabilities, and 10% had motor disabilities [26], these comorbidities represent the difficulty in the management of these children, as a multidisciplinary approach is required in management, which is usually unavailable in Sudan and the developing world.

Since the 1950s, children with neurological disorders were seen in adult neurology clinics, as pediatric neurology training program in Sudan has recently been initiated, with a few pediatric neurologists available.

Currently there is one pediatric neurology tertiary center and four specialized child neurology clinics in Sudan, 3 of them are located in the capital, these 4 clinics serve the whole of Sudan, as well as referred patients from neighboring countries including: Chad, Eritria, and South Sudan where facilities for neurological investigations are limited. The shortage of pediatric neurologists and pediatric neurology centers and their location mainly in the capital, along with the high cost of transportation to the center, long waiting lists till evaluation by a specialist, further complicate the management of children with epilepsy [8].

8.1 Epilepsy in schools

It is important to review epilepsy status in school settings where children spend most of their time. Schools in Sudan rarely have dedicated clinics to accommodate children's health needs, and while school teachers should act as caregivers, most of them are usually ill-informed or lacking appropriate knowledge about epilepsy, and none of them have had any sort of training to help in case of a seizure, so a considerable proportion does not know what to do when a child develops a seizure

[27, 28]. Many teachers fall as victims of the communities' misconceptions and could even play a passive role in the stigma, contributing to the child's anxiety. Many had no idea about possible causes of epilepsy and guessed that parents would not sign up their children with epilepsy to school due to suspected mental sub-normality, stigma, or fear of unattended falls or attacks. On the other hand, figures demonstrated a significant amount of children ditch school altogether because of the illness. Other students do not mind having a classmate with epilepsy at school but they share their teachers' beliefs and misconceptions, and would sometimes, as a result, engage in bullying and discriminatory behaviors against them. The condition is barely touched in school curriculums and students do not undergo any sort of training to help them act properly around their peers who have epilepsy.

9. Women with epilepsy

Globally, 50% of women and girls with epilepsy are in the reproductive age range [29]. Epilepsy in the developing countries has a slight male predominance; this is likely due to underreporting of epilepsy in women due to negative attitudes and stigma facing them, that include difficulties in getting married, increased divorce rates, having children or even being abandoned by their families because of their illness, and harder chances of being employed. This underreporting of epilepsy in women leads to deficits in health care seeking behavior, hence contributing to the epilepsy treatment gap in women.

Apart from the aforementioned social difficulties, women with epilepsy are challenged with many issues that include the effect of epilepsy and AEDs on their sexual function, contraception, pregnancy, fetal abnormalities, childbirth, and breastfeeding [30–33].

Due to the shortage of neurologists in Sudan, the majority of women with epilepsy are managed and counseled by non-specialized doctors. A study conducted in Sudan to assess doctors' knowledge of women issues and epilepsy using standardized knowledge of women issues and epilepsy (KOWIE II) questionnaire concluded that the majority of Sudanese doctors' knowledge was unsatisfactory. They were unaware of sexual dysfunction among women with epilepsy, that women with epilepsy should continue taking their AEDs when they are pregnant, and that women can safely breastfeed while taking AEDs [34].

10. Conclusion

Sudan has been a victim of war, poverty, substandard infrastructure, and a failing healthcare system. These factors along with epilepsy stigma, misconceptions and false beliefs represent major challenges in epilepsy management in Sudan.

11. Recommendations

All these challenges must be approached systematically to ensure the best management for patients with epilepsy. Such approaches include the need for a mass movement against epilepsy headed by individuals experienced in the field, and fundamental governmental partnership and aid to provide organizational efforts and funding for instituting and decentralizing neurology facilities outside Khartoum, and ensuring the availability and affordability of investigations and medications especially the new generation AEDs. Epidemiologic studies are needed

to outline the treatment gap of epilepsy and guide nationwide strategies and efforts to increase the awareness of communities about epilepsy are needed especially in the rural areas to fight disease stigma, Special groups need further attention such as making efforts for prevention of infections leading to epilepsy in children, the involvement of other healthcare providers such as social workers, speech and language therapists, nutritionists, and special teachers in the management of children with epilepsy can never be overemphasized. Lastly, telemedicine should be implemented in the management of epilepsy in Sudan.

Conflict of interest

The authors declare no conflict of interest.

Authors' contribution

Ismat Babiker wrote the following sections: children with epilepsy, women with epilepsy, co-wrote AEDs in Sudan, and contributed in chapter editing.

Awab Saad wrote Sudan: background and population, healthcare system in Sudan, Neurology in Sudan, co-wrote epilepsy misconceptions in Sudan, and contributed in chapter editing.

Basil Ibrahim wrote stigma, health related stigma, manifestation of stigma in high vs. low-income countries, stigma in low-income countries and in Sudan, and contributed in chapter editing.

Mohamed Abdelsadig wrote the collapse of the healthcare system in Sudan, epilepsy in schools, scarce personnel and trained physicians, co-wrote AEDs in Sudan, epilepsy misconceptions in Sudan, and contributed in chapter editing.

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