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Chapter

Determinants of Health-Care Seeking Behaviors and Quality of Life in Children with Epilepsy in Nigeria

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Abstract

Epilepsy is the commonest neurological condition affecting every sphere of a child's life ranging from physical and cognitive performances, and mixed feelings for the affected family. These feelings are worsened by the cultural beliefs, myths, and stigmatization that surround epilepsy with a consequent reduction in the healthcare-seeking behaviors and quality of life of these children. The goal of management is to control seizures with minimal use of antiepileptic medications and to improve the child's quality of life. This work is aimed to understand the health-seeking behavior of families and children diagnosed with epilepsy in Nigeria, the factors that influence their decisions, and the need to plan a "need-based" comprehensive healthcare program for all stakeholders, particularly the disprivileged groups. Despite some improvement in access to healthcare in Nigeria, there are existing inequalities relative to culture, socioeconomic class, accessibility to universal health insurance, and gender. Knowledge of barriers to optimal healthcare-seeking behavior could help reduce the impact of epilepsy on children's development and consequently improved quality of life. Efforts should be made to educate children with epilepsy, their caregivers, and other affected stakeholders and periodic trainings organized for the health workers. Subsidizing the cost of care by support groups and government is vital.

Keywords: epilepsy, pediatrics, determinants, health-seeking, quality

1. Introduction

Epilepsy is a chronic non-communicable disorder of the brain characterized by recurrent unprovoked seizures with neurological, cognitive, psychological, and social consequences [1]. The International League against epilepsy requires at least

two unprovoked seizures occurring greater than 24 hours apart or one unprovoked seizure and the probability of further seizures occurring over the next 10 years, or the presence of an epilepsy syndrome to make a definitive diagnosis of epilepsy [2]. It is the most common neurological disorder in children and sometimes has a negative impact on the quality of life of affected children [3, 4]. The mortality rate in people affected by epilepsy is 2–4 times higher than the rest of the population and 5–10 times higher in children [5]. Therefore, epilepsy affects the quality of life significantly because of its chronicity, frequent seizures, needs for regular medications, side effects of the medications, epilepsy-related injuries, and stigmatization surrounding it. The traditional medical goal in the management of epilepsy is aimed to control the seizure. However, current practices have moved further into improving the quality of life of these patients.

Appropriate healthcare-seeking behavior toward epilepsy can reduce its morbidity and mortality rate and ultimately improve the quality of life of those affected [6]. On the other hand, poor health-seeking behavior is a major bane in the outcome of seizure management and eventually the effect of seizures on the quality of life of children with epilepsy (CWE) in Nigeria and many low- and medium-income countries (LMIC).

2. Determinants of healthcare-seeking behavior

2.1 Caregiver perception

Children with epilepsy (CWE) just like other children are dependent on their caregivers and so the caregiver's perception and belief systems with regards to seizure etiology (hereditary, influence of spirits and witchcraft, excessive intake of palm oil) and their cultural background influence decisions regarding the choice of care for them [7–11]. In many parts of Nigeria, epilepsy is considered a spiritual disease and not amenable to medical treatment, consequently, treatment choices are often unorthodox involving consultation with traditional and spiritual healers [7, 11–13]. Sometimes herbal therapies are readily available at home and serve as the first treatment option before presentation to other facilities [7].

2.2 Myths and misconceptions about epilepsy

Misconceptions about the cause of epilepsy, mode of spread, and preferred mode of treatment play a significant role in the management of children with epilepsy in Nigeria [14]. In some parts of Nigeria particularly in rural settings, people perceive that epilepsy is a curse by the gods, a sign of witchcraft activity, or demon possession. In such communities, epilepsy is regarded as a spiritual problem that is not amenable to medical treatment, so a traditional or spiritual approach to treatment is often the first or preferred option [8, 12, 15]. These include scarifications, herbal preparations, spiritual exorcism, charms, fire/smoke therapy, and sometimes sacrificial offerings. Igwe et al. in South East Nigeria reported that the major reason for patronizing unorthodox medical practitioners was a belief in the cure, its affordability, and perception of the cause of the disease [7]. Sometimes, the patients eventually present to the hospital when the seizures persist/worsen or when they develop complications.

2.3 Finances: Cost of care

The availability and affordability of medical care cost influence the health-seeking behaviors of caregivers of children with epilepsy (CWE) [7]. A recent survey reveals that about 97% of the Nigerian population does not have any form of health insurance, inevitably, the additional financial burden of epilepsy care is usually borne by the caregiver [16]. Furthermore, an estimated population of 88.4 million people in Nigeria reportedly live in extreme poverty (on less than 1.90 US dollars a day) and accounted for 12.9% of extremely poor people globally in 2022 [17]. Consequently, cost of care and proximity to care are important factors that influence healthcare-seeking behaviors in Nigeria. These out-of-pocket costs and productivity losses can create substantial burdens on households. The consequence is a decline in the demand for healthcare services, poor compliance with therapy, seizure recurrence, and the increased patronage of quacks or outright abandonment of the children to a profoundly diminished quality of life. In addition, there can be deprivation of socioeconomic materiality and resources to other family members, deepening the family's financial crises.

2.4 Parental level of education

Parental level of education and in particular, the maternal level of education is a major determinant of health-seeking behavior. In Ibadan, Lagunju et al. reported a statistically significant association between maternal educational level, economic agency, and the health-related quality of life (HRQOL), with children of mothers with less than 10 years of formal education having a poorer HRQOL [18]. With the higher educational level of parents, the potential for the affected child's parents to seek appropriate care early has been linked to high prognostic factors. Whereas less educated parents may not have a robust understanding of the chronic nature of the illness or the need to adhere to therapy and follow-up assessment throughout the course of treatment. Children from less educated backgrounds have a greater risk of lower drug compliance, relapses, refractory seizures, and drop-out of therapy. This is because as minors, they depend on their caregiver's perception and cooperation for decisions that affect them including medical treatment. Besides, educated caregivers are more likely to seek care early and from orthodox practitioners than uneducated caregivers who are less compliant with medications and counseling. The work done by Igwe et al. [7] also confirmed these findings.

2.5 Role of teachers

For children that attend school, there is the risk of having seizures in school and at such times, the knowledge and attitudes of their teachers come to play in determining the kind of care the CWE get before their parents are reached. In addition, in rural settings, some parents consider teachers quite knowledgeable and can easily be influenced by their suggestions [15]. In some surveys in different sub-regions in Nigeria, the knowledge of teachers was surprisingly low and many opted for alternative medicine as the preferred mode of care of epilepsy [11, 13, 19, 20].

2.6 Stigmatization

The stigmatization associated with epilepsy in many parts of Nigeria also affects healthcare-seeking behaviors as some parents, especially in pastoral settings are

reticent to seek treatment for seizures in hospitals for fear of getting the “epilepsy” label which impacts negatively the family name and may be an obstacle for marriage of ladies in their families. They choose rather to seek help with alternative healthcare personnel where other factors such as “spiritual attack” are attributed to the cause of the illness [6, 7]. This is further accentuated by efforts of family members in certain Nigerian cultural groups (like the Igbos in the South-east) to maintain the “chastity” of their family lines and avoid impurity with dreaded diseases like epilepsy [15]. For this reason, there is often resistance to marriage to any relation to a known person living with epilepsy which results in secretiveness and shrouding of disease notification.

2.7 Health workers’ knowledge and approach

Healthcare professionals are motivators of health and healthcare-seeking behaviors of patients. Often, patients relinquish the choice of care concerning their health to the doctors and other healthcare professionals believing that they are knowledgeable. However, concerning epilepsy and the myths and prejudices girding it, a study done in South East, Nigeria among healthcare professionals (doctors from different specialties and nurses) reported poor knowledge of epilepsy among health workers. In the study, only about 50% of doctors <10 yrs and 51.2% >10 yrs. had training in pediatric epilepsy [21]. Further, the study also showed their reluctance to undergo the training [21]. Physicians with poor knowledge of the pediatric epilepsy have little or nothing to step down to the public and accordingly, the patients and their caregiver gets little or no information concerning epilepsy from their physicians.

- All these factors determine not only the health-seeking behavior of parents of children with epilepsy but also affect the timing between the onset of seizures to the time of presentation to specialist care. Igwe et al. reported that only about 45% presented within 6 months while about 26% presented within 2 years [7]. Within the period when they have not presented to the specialists, several unorthodox practices are employed at home and other traditional facilities based on the religious and cultural beliefs and perceptions of the disease. Late presentation increases morbidity, decreases the quality of life, and consequently, the mortality rate in these children with epilepsy is increased.

3. Quality of life (QOL) of children with epilepsy in Nigeria

The World Health Organization (WHO) defines Quality of life (QOL) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their pretensions, prospects, norms, and concerns” [22]. Many chronic disorders such as epilepsy, cerebral palsy, or sickle cell anemia are known to have profound negative effects on the quality of life of the patients and their families. They may cause several changes in almost all spheres of the child’s life, from self-care, self-image, and daily duties to emotional and cognitive performance and relationships with their peers. The new trend in the management of most chronic conditions is not only to control the disease but to improve the quality of life of the patients and to ensure that patients live optimally to their satisfaction as this will help improve compliance with medications and follow-up. In Nigeria, in particular, studies across different geopolitical regions have shown that epilepsy reduces the quality of life of affected individuals significantly [18, 23–25]. The same applies

in some other low- and middle-income countries [26–28]. Conversely, Aldenkamp in a study in the Netherlands reported a high quality of life (QOL) for a majority of the patients studied. Nevertheless, those patients had uncomplicated well-controlled epilepsy [29]. This underscores the importance of bridging the treatment gap and optimizing seizure control among children living with epilepsy as this will markedly improve their health-related quality of life.

Factors that contribute to the low quality of life in children with epilepsy in Nigeria include poor health-seeking behaviors, seizure frequency, stigma, availability and accessibility to health facilities, availability of drugs, adverse drug reactions, quality of medical care, parental level of education, rural residence, the attitude of health workers, affordability of medical care cost, seizure frequency, polytherapy, adverse drug reactions (ADRs) to antiepileptic medications (AEDs), and duration of epilepsy [23, 30].

Many children living with epilepsy face the scourge of stigmatization regularly particularly female children due to the erroneous belief that epilepsy is contagious and can be transmitted through contact with affected individuals or their body products such as saliva, urine, and feces of the affected individuals. [8, 11] They are sometimes restrained from interacting with others and those with refractory seizures are sometimes withdrawn from school. Unfortunately, in certain situations, they are outrightly rejected by the school authorities. For example, Nuhu et al. reported an 18% school rejection rate among a group of adolescents with epilepsy in Kaduna, a megacity in North Central Nigeria [25]. This is mostly due to the perceived or even experienced stigma associated with circumstances of seizures in public places and the risk of physical injuries as well as the attitude of teachers to them [15].

The Nigerian child has a right to education as enshrined in Chapter 2 of the 1999 Constitution of the Federal Republic of Nigeria and the Child's Rights Act of 2003 [31]. This is important because quality education can impact appreciatively on the quality of life of a child with short- and long-term benefits. In Ibadan, Lagunju [18] reported a statistically significant association between maternal level of education and impaired health-related quality of life (HRQOL) such that children of mothers with lower than secondary education have a poorer HRQOL. But uncontrolled epilepsy robs a child of their fundamental right to education and this can be attributed to several factors such as uncontrolled seizures resulting in absenteeism, stigmatization in school, and the adverse effects of some anti-seizure medications on cognition [25, 32]. In a 5-year study in the University teaching hospital, Ibadan, Lagunju et al. reported that 10.6% had severe to profound limitations in school work, 6.1% dropped out of school on account of severe epilepsy, 36.4% missed school occasionally as a result of seizures, 18.3% had deterioration in academic performance while 53.0% of the children did not experience any form of limitation in school work [18].

The impact of epilepsy extends beyond those affected by seizures to other members of the family particularly parents who are likely to witness anxiety, passions of helplessness, or guilt in response to the child's seizures and seizure-threat. Sometimes, these factors can lead to a shattered cohesion in the family union and eventually a divorce. In view of this, parental emotional stability has been found a major predictor of the quality of life in children with epilepsy, and psychopathology in parents is significantly associated with poorer quality of life of these adolescents [33].

Epilepsy is an illness that has a major impact on the HRQOL of Nigerian children, with significant impairments in at least one-quarter of the cases in all the disciplines tested among patients presenting in a tertiary health institution in South West

Nigeria [18]. The duration of epilepsy, seizure frequency, and severity, number of antiepileptic drugs (polytherapy), and adverse drug reactions (ADRs) to antiepileptic drugs (AED) are significantly associated with poor QOL in adolescents with epilepsy [33]. On the other hand, epilepsy can be controlled in a large number of cases so it is advocated that children with epilepsy get the right treatment early. Usually, the goal of treatment is to achieve complete resolution of seizure or a significant reduction in seizure frequency with a minimal number of drugs as well as to ensure the best quality of life for the child [18]. Therefore appropriate treatment should be instituted early and heavy polytherapy as well as specific medications with severe cognitive adverse effects should be avoided.

Seizures are often associated with comorbidities that affect the quality of life of sufferers, particularly for patients with early-onset seizures, status seizures, and long stays before presentation in the hospital for care. These include cerebral palsy, visual impairment, hemiplegia, attention deficit hyperactivity disorder, irrational behavior, auditory disability, visual disability, expressive aphasia, intellectual disability (mental retardation), deafness, etc. [34–36]. Akinsulore et al. also reported psychiatric comorbidities such as depressive disorders, anxiety disorders, disruptive behaviors, and personality disorders in adolescents with epilepsy [33].

Due to the myriads of health and social problems that children with epilepsy present with, a multi-disciplinary management approach involving pediatric neurologists, ophthalmologists, ear, nose, and throat surgeons, speech therapists, psychologists, physiotherapists, and social workers, becomes imperative and pivotal. They are often depressed and unhappy with their lives being dependent on drugs and frequent hospital visitations and also not being free to mingle with other children. Efforts should be geared toward reducing the number of anti-epileptic medications as poly-pharmacy significantly reduces compliance and consequently contributes to poor quality of life seen in children with epilepsy.

Education plays a key role in the management of children with epilepsy and should involve the child, the parents, and society at large. Accurate information should be given concerning the cause, consequences, self management, epilepsy's risks including injuries, other morbidities and mortalities, skill development, and available support groups and resources within and around their environ. They should also be supported to go to school because education improves compliance with medications and quality of care. Enlightenment campaigns against the myth surrounding epilepsy and societal stigma should be paramount.

4. Conclusion

Epilepsy is a neurologic condition surrounded by myths and consequently, stigmatization. It present not only with seizures but also with other comorbidities with a resultant reduction in the quality of life of these patients. Efforts should be made to educate the general public including personnel on the cause and management of children with epilepsy.

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