Eastern African Journal of Humanities and Social Sciences
Vol. 4 No. 2 (2025): ISSN (Online): 2958-4558
DOI: https://doi.org/10.58721/eajhss.v4i2.1419
Global and Local Discourse Encounters: The case study of Epilepsy among the Wapogoro People of Mahenge, Tanzania

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Article History
Received: 2025-06-02
Revised: 2025-11-09
Accepted: 2025-11-09
Published: 2025-11-11

Keywords
Epilepsy
Local knowledge
Mahenge
Tanzania

How to cite:
Halii, B. E. (2025). Global and Local Discourse Encounters: The case study of Epilepsy among the Wapogoro People of Mahenge, Tanzania. *Eastern African Journal of Humanities and Social Sciences, 4*(2), 260-268.

Abstract
Despite being a global health priority, epilepsy has remained a public health crisis among the Wapogoro people in Mahenge, Tanzania. The World Health Organisation (WHO) has pointed out Mahenge as a hotspot area of epilepsy in the World. Decades of biomedical intervention have failed to curb the disease, presenting a critical challenge to global health. Employing a qualitative research method, life histories, oral traditions, and in-depth interviews, this paper examines the complex encounter between global biomedical discourses and local knowledge systems using epilepsy as a case study. It specifically examines the manner in which globally constructed ideas about epilepsy were received by the Wapogoro people of Tanzania, who had their own perceptions of epilepsy for many generations that engage dynamically with global ideas. This study concludes that the failure of past interventions stems from the failure to acknowledge this complexity and the systematic exclusion of local voices and epistemologies about epilepsy. It argues that defeating ancient diseases like epilepsy in Mahenge and similar contexts requires a community-integrated approach that treats local knowledge and wisdom not as a barrier, but as a crucial resource in crafting effective and sustainable public health strategies against ancient diseases in the 21st century.

Introduction
Epilepsy is an ancient disease. It received international recognition recently in the 20th century through the establishment of the International League Against Epilepsy (ILAE) in Budapest, Hungary, in 1909 (Gallo, 2003). The organisation ceased operations between 1914 and 1935 following the outbreak of World War I and the subsequent Great Depression of 1929 (Gallo, 2003). Systematic concern for the people suffering from epilepsy restarted in 1935 but ceased again following the outbreak of WWII. It was restarted in 1946 and extended its mission to Africa, including Tanganyika (Gallo, 2003). The organisation developed scientific explanations of the disease and operated within the biomedical theory of health, disease, and healing. The International League Against Epilepsy (ILAE) defines epilepsy as a disease of the brain whereby a person can experience abnormal bursts of electrical activity in the brain (Shorvon, 2019). Generally, the biomedical conception of epilepsy did not bear much fruit in the 20th century. There was slow progress in these global efforts against epilepsy following political and economic instability associated with the outbreak of the First World War (WWI), the Great Depression, and the Second World War (WWII) (Gallo, 2003).

The recognition that epilepsy was a complicated health condition resulted in the introduction of the International Bureau for Epilepsy (IBE) in 1961. The main agenda was to investigate the social dimensions of epilepsy as an attempt to diversify interventions and battles against epilepsy. The

International Bureau for Epilepsy directed special attention to issues such as social deprivation, social exclusion and marginalisation of people suffering from epilepsy in employment, education, marriage, and other sectors. It focused on raising public awareness of the disease to reduce stigma and improve treatment, particularly in developing countries and rural areas (Shorvon, 2019). However, a study conducted in 15 European countries and involving 5000 patients reported that 51% of patients experienced exclusion and marginalisation in 2001 (Bakery, 2001). In Africa, stigma and social exclusion were complicated by poverty, gender issues, taboos, myths and prejudices about epilepsy. (Mireille, 2019)

Towards the end of the second Millennium AD, the World Health Organisation (WHO), International League Against Epilepsy and the International Bureau of Epilepsy declared epilepsy as one of the significant public health concerns (Reynolds, 2023). The Global Campaign Against Epilepsy was launched in Geneva and Dublin in 1997 to raise awareness of the disease (Reynolds, 2023). Its implementation involved organising national campaigns to promote the diagnosis, prevention and treatment of people with epilepsy (Reynolds, 2023).

By 2020, the number of people living with epilepsy was estimated at 70 million, and five million new cases were identified each year (Bhui, 2007). Substantial as they were, cases of epilepsy were not evenly distributed. New cases of epilepsy were high in Africa and Latin America (Owolabi et al., 2020). The United States of America, Asia and Europe have been celebrating the general declining rate of epilepsy cases. The declining trend of the cases of epilepsy in developed countries such as the USA and Canada has been associated with early detection, effective use of ant-epileptic drugs, as well as prevention of infectious diseases (Baker et al., 2000). New cases of epilepsy have been devastating people in Latin America and in Africa, which is home to one-third of the world's population (Owolabi et al., 2020). It is out of this part of the world's population that 90% of the global cases of epilepsy have been found (Owolabi et al., 2020).

The burden was higher in Africa, where the share is 11.26 cases per 1000 population, while in the USA, the prevalence rate is 1.2 cases per 1000 population (Baker et al., 2000). Countries with very high rates of epilepsy in sub-Saharan Africa include Tanzania, Ghana, South Africa and Nigeria (Owolabi et al., 2020). In Africa, oral traditions and historical linguistics have been rich in names, songs, and narratives about epilepsy. For instance, epilepsy was called *chinzilisa, okugwaensimbo* and *kisilika* by the Gogo, Haya and Pogoro, respectively. All these people referred to epilepsy as a falling sickness, because it clinically manifests with a seizure. The Pogoro people's description of Epilepsy is similar to the global elaboration of the disease. The root causes of seizures were not clear and often debatable among the Wapogoro. Still, immediate causes reported included light, water, fire, lack of enough sleep, alcoholism and strong emotions of anger, fear and even happiness (H. Choma, interview, November 20, 2023). The prevalence rate of epilepsy is 10% per 1000 people in Tanzania (Owolabi et al., 2020). Morogoro, Ruvuma, Mwanza and Kilimanjaro have been cited as regions with very many epilepsy cases in Tanzania (Goodall et al., 2018).

Mahenge has been a hotspot area of epilepsy in Tanzania and was verified by a WHO survey on neurological and seizure disorders (Chilipweli et al., 2021). The cases of epilepsy have been higher in the villages located at medium altitudes than in those located at low and high altitudes. The prevalence rate of epilepsy was 21.1 cases per 1000 people in the medium altitude in the year 2021. At low altitude, the prevalence of epilepsy was reported to be as low as 3.2% per population unit in the same year (Chilipweli et al., 2021).

Epilepsy was one of the neglected diseases throughout the colonial period in Mahenge. Africans had to rely on traditional healing practices that combined myths and realities. As a personal initiative, Dr

Louise Jilek-Aall opened the Mahenge Epilepsy Centre in 1950 and handed it over to the Catholic Church (C. B. Katyawa, interview, November 12, 2023). Government intervention against the disease was stimulated by the Global Epilepsy Campaigns of the 1990s (Rwiza et al., 1992). However, new cases of epilepsy were alarming in Mahenge.

A comprehensive study carried out in 1989 revealed a persistently high prevalence rate of epilepsy in Mahenge, Ulanga, compared to other areas in Tanzania. By 2002, cases of people who were living with epilepsy in Mahenge had reached 1381 (Rwiza et al., 1992).

The high prevalence of epilepsy in Ulanga District, particularly in Mahenge, has attracted several scientific, quantitative explorations. However, little attention has been paid to the local voices of the people of Mahenge itself. This study therefore incorporates the voices of people with epilepsy from the local community into the discussion. The study examines how the Wapogoro interpreted and incorporated global ideas about epilepsy into their local knowledge, as global ideas did not erase their local ontology of epilepsy.

Literature Review

There are two dominant theoretical frameworks regarding health, disease, and healing practices. The social construction theory interprets diseases as social phenomena (Feierman & Janzen, 1992), whereas biomedical or Germ theory views diseases as biological phenomena (Gaynes, 2011). However, scholars such as Frederick Kaijage insist on considering both the biological and social dimensions of health, disease, and healing practices (Kaijage, 1993).

Ancient physicians and philosophers such as Alcmaeon, Democritus, Hippocrates, Herodotus, and Aristotle suggested that brain disorders might cause epilepsy. They insisted on the use of herbs, diet and even surgical procedures of the skull in treating epilepsy. These ideas about epilepsy revolutionised ancient people's understanding of ailments and spurred the development of antiepileptic drugs (Kaculini et al., 2021). Nevertheless, the new perception of epilepsy had little influence on the local perspective that viewed epilepsy as contagious and associated epilepsy with superstition, gods, nature and ancestral spirits (Kaculini et al., 2021).

Scholars, such as Samuel Tissot, William Cullen, Maisonneuve, Robert Bentley, and John Jackson, associated epilepsy with abnormal electrical activity in the brain, resulting in a seizure (Reynolds, 2005). In this sense, the fundamental cause of epilepsy was sought in brain nerves, thus supporting Hippocrates' assumption that its cause was in the brain anomalies (Andermann, 2008). In this scholarship, the significant factors identified for the high prevalence of epilepsy in different places included increasing cases of infectious diseases, injuries, stroke, vascular diseases and a genetic influence (Murthy, 2003).

Social construction theory places issues of health, disease, and healing practices within the broader social, economic, and political contexts. The theory maintains that social, economic, and cultural factors are arguably more essential causes of the disease than germs (Feierman & Janzen, 1992).

Sjoerd Rijpma noted the presence of a few cases of epilepsy in pre-colonial Africa (Rijpma, 2015). Epilepsy was prevalent in pre-colonial Africa, though it was not very frightening and rampant (Eastman, 2005). Epilepsy was confined to specific clans, which were widely known in respective villages (L. Mfanyakazi, interview, November 20, 2023). In pre-colonial Africa, epilepsy was placed low on the list of highly debilitating and death-causing morbidities in the 19th century. According to Koponen, the highly dreadful morbidities in pre-colonial Tanzania included malaria, smallpox, cholera and syphilis (Koponen, 1988).

Sjoerd Rijpma associated the increase in the cases of epilepsy in the colonial period with increased social and economic interactions (Rijpma, 2015). Due to colonial activities and operations, infectious diseases and epilepsy became widespread phenomena in Africa, including Tanzania. Mfanyakazi associated an increase in cases of epilepsy with detribalisation, a process in which an individual separates from family, clan, tribal authority, social codes, and beliefs that initially guided their thoughts and actions (L. Mfanyakazi, interview, November 20, 2023). Cases of epilepsy were noticed even in the clans that had no prior history of the disease. In post-colonial Tanzania, many cases of epilepsy were observed in Morogoro, Lindi, Mtwara, Kilimanjaro, Arusha and Manyara (Mushi et al., 2011). Scholars have associated the high prevalence of epilepsy in post-colonial Tanzania with increased interactions that transformed social interactions, economic activities, political set-up, moral values and health status of the people (Mushi et al., 2011).

There has been a public debate on the causes of the widespread phenomenon of epilepsy in Mahenge. However, the voices of the Wapogoro, who are at the centre of this issue, are missing from this debate. This paper discusses the influence of global ideas about epilepsy on Wapogoro's beliefs and knowledge about the disease. However, unless the Wapogoro perspective is contextualised, it is, in and of itself, inadequate. To have a comprehensive understanding of the widespread phenomenon of epilepsy among the Wapogoro, one must take into consideration the social, economic, political and historical contexts of the disease.

Method and Contexts

Study design
This study employs a qualitative research approach in data collection, presentation and analysis.

Study Area
The study was carried out in Mahenge, the HQ of Ulanga district, Morogoro, Tanzania. Although epilepsy is prevalent in many regions of Tanzania, this study focused on Mahenge-Ulanga because several studies have reported persistently higher prevalence rates of epilepsy in Mahenge since the 1960s to the present. Active sites included Mdindo, Msogezi, Mzelezi and Sali villages, representing an understanding of epilepsy in wider rural Tanzania.

Study Population
The study population consists of adults who have experienced epilepsy in their families. Participants were recruited through the snowball sampling technique to reach people who might be reluctant to discuss their health issues. The sample size was determined by data saturation. The final sample included 23 participants.

In-depth Interviews
In-depth interviews were conducted with health personnel working at Mahenge epilepsy Clinic, Ten-cell leaders, religious leaders, people suffering from epilepsy and their relatives.

Life Histories
A Life history approach was employed to capture the history of epilepsy across generations. People suffering from epilepsy were encouraged to trace the history of epilepsy in their families and to provide social and cultural meanings of epilepsy.

Oral Traditions
The study also gathered oral traditions because epilepsy is an ancient disease. There were a number of beliefs, customs and values that have existed in the Pogoro community for a long time concerning epilepsy. Narratives, sayings, beliefs and cultural practices with regard to epilepsy were collected from knowledgeable elders and cultural practitioners.

Data Analysis
Data analysis was done through the content and thematic frameworks for analysing qualitative data. It therefore involved an examination of data from primary and secondary sources, as well as the identification and integration of emerging major themes in relation to the research questions. Then, the researcher collated themes from various sources and complemented them with evidence from different sources. Finally, the findings were interpreted, and several conclusions were drawn about the research questions, findings and research methods.

Ethical Consideration
Research has been approved by the Mwalimu Nyerere Memorial Academy (MNMA) and relevant authorities in Mahenge and Morogoro Region. Informed consent was obtained from all participants. The study respected the oral and cultural issues of informants.

Epilepsy as Hereditary Disease
The findings reveal that the Wapogoro do not have a single unified theory of epilepsy but rather a flexible set of coexisting explanations. A significant number of oral traditions of Wapogoro highlighted the belief that epilepsy was a hereditary disease. This belief is supported by the theory of hereditary disease that highlights the importance of genetic factors in the vulnerability to certain diseases. The theory holds that certain diseases or health conditions can be passed from parents to offspring. This theory is supported by the genetic theory of inheritance, which explains the transmission of genetic traits from parents to offspring (Galton, 1876). A good number of oral interviews pointed to cases of epilepsy in specific clans, which were well known to other members of communities. Some of the clans mentioned in Sali village were Kamchimba, Bangimoto, Tengeneza, Mkondoa and Bangimoto to mention just a few (C. B. Katyawa, interview, November 12, 2023). In this, Benignus Katyawa said: "Epilepsy is a family disease, passed from generation to generation up to the 12th generation" (C. B. Katyawa, interview, November 2023).

According to Lazaro Mfanyakazi, the likelihood of developing epilepsy varies even among individuals belonging to the same clan (L. Mfanyakazi, interview, November 21, 2023). He further argues that epilepsy is transmitted from the mother's side. So, if the woman was suffering from epilepsy, the chances of transferring it to children were viewed to be higher. Epilepsy from the father's side was considered as dormant and inactive to bring about infections (L. Mfanyakazi, interview, November 21, 2023). In the pre-colonial period, people were taught to observe certain traditions to minimise interactions with vulnerable clans (L. Mfanyakazi, interview, November 21, 2023). The people suffering from epilepsy and leprosy lived together in Mkolongo village; they could hardly interact with people from other villages (L. Mfanyakazi, interview, November 21, 2023).

The Wapogoro calls hereditary epilepsy traditional epilepsy. Bernard Fabian distinguished traditional and modern epilepsy using the following differences:

Traditional epilepsy was not a disease for everybody; it was confined to specific clans. Seizures often occurred around the full moon and were accompanied by a strong smell during an active seizure. But modern epilepsy has no specific formula; it can attack anybody during any phase of the moon, and there is no smell from the body during an active seizure. In addition, modern epilepsy is characterised by mental problems and delayed growth (B. Fabian, interview, November 23, 2023).

Epilepsy as Spiritual Condition
Developments associated with colonialism, and particularly the introduction of Christianity, developed beliefs that associated epilepsy with spiritual issues. A good number of scholars examined the role of religions, such as Judaism, African traditional religion, Hinduism, Christianity and Islam in relation to their conception of epilepsy. In Ancient Greece, epilepsy was viewed as a sacred disease,

as it was associated with some divine activities. The people who were suffering from epilepsy often turned to priests for healing procedures. The view that epilepsy is caused by demonic possessions continued throughout the Middle Ages. Some Christian scholars linked diseases, including epilepsy, with sins (Gloria et al., 2017). With the introduction of a new religion, the belief that associated epilepsy with being possessed by ancestral spirits, *mbui* or demons grew among the Wapogoro.

Christianity consolidated the idea that linking epilepsy with natural spirits, that epilepsy could be cured through prayer and intercessions, including the intercession of St. Valentine, the patron of epilepsy. With the influence of Christianity, which took shape after the work of missionaries had been done, beginning with the Benedictine, Capuchin, and Pentecostal churches, mental convulsions and epileptic seizures were attributed to the work of the devil. Exorcisms, prayers and psychological treatments were often considered against the disease (Wenceslaus, 2019).

With the influence of new religions, the Wapogoro came to associate epilepsy with angered ancestors *(mizimu)*. Thus, when patients experienced seizures, the immediate reaction was to consult the healer, who helped appease the ancestors through sacrifices and other relevant rites rather than attending hospitals. With the rise of religious fundamentalism, the relationship between such diseases as epilepsy and such religions became even more consolidated.

A study conducted in America in 2012 revealed that a majority of Americans associate demon possession with mental illness, and the belief appears to be growing. Survey results show that 44% of Americans over the age of 65 believe in demon possession, and 57% of those between the ages of 47–65 also do (Hamel, 2015).

Onchocerciasis-Associated Epilepsy (OAE)

The Wapogoro identified this new type of epilepsy in the 1950s, and cases increased over time. According to Galán-Puchades (2017), the vulnerability of Onchocerciasis-Associated Epilepsy is determined by natural immunity, viral load, and malnutrition. According to Bernard Fabian, the Wapogoro called it modern epilepsy or head nodding epilepsy (B. Fabian, interview, November 2023). Bernard Fabian argued that, unlike traditional epilepsy, which was hereditary, the Wapogoro believed that modern epilepsy was contagious and severe. Any contact with an epileptic patient, excretion and saliva was feared (B. Fabian, interview, November 23, 2023). These beliefs dramatically informed and justified exclusionary practices, particularly during active epileptic seizure (B. Fabian, interview, November 23, 2023). This new type of epilepsy, later recognised by scientists as Onchocerciasis-Associated Epilepsy (OAE), is characterised by head nodding attacks, cognitive deterioration, stunted growth, delayed puberty, and mental impairment (Colebunders et al., 2017). The onset of OAE usually occurs in previously healthy children aged 3 to 18 years, without an apparent cause (Vinkeles Melchers et al., 2018). The OAE is transmitted by the bite of infected blackflies that breed in fast-flowing rivers (Vinkeles Melchers et al., 2018). Rivers can increase their speed over time due to factors such as bank and bed erosion, increased water volume from heavy rains, and human activities such as deforestation (J. Kuandika, interview, November 2023). Some scholars have associated increased cases of epilepsy with climate change (Sisodiya et al., 2019).

Onchocerciasis-associated epilepsy was first observed in Mexico in the 1930s (Colebunders et al., 2017). However, the knowledge was not widely shared. Many people remained ignorant of Onchocerciasis-Associated Epilepsy (OAE) (Vinkeles Melchers et al., 2018). It was documented in African countries such as Tanzania, Sudan, Cameroon, Uganda and Congo, particularly among societies living around hills and river valleys in the 1990s (Vinkeles Melchers et al., 2018). This form of epilepsy came to be known as the nodding syndrome (Colebunders et al., 2017).

95% of people with epilepsy in Mahenge were also tested positive for onchocerciasis (Bhwana et al., 2023). With these discoveries and evidence that supported the relationship between Onchocerca volvulus and Onchocerciasis-Associated Epilepsy (OAE), ILAE had to revise its definition of epilepsy (Vinkeles Melchers et al., 2018). The parasitic transmission of epilepsy in Mahenge was persistent due to the moist climatic conditions (J. Kuandika, interview, November 26, 2023). Onchocerciasis-Associated Epilepsy changed the nature of epilepsy in Mahenge from being an endemic disease to an epidemic disease (Bhwana et al., 2023).

The accommodation of Onchocerciasis-Associated Epilepsy in the Wapogoro understanding of epilepsy was not easy. Some villagers did not see the relationship between epilepsy and the infections caused by Onchocerca volvulus. In this regard, Hatia Choma explained: In my opinion, the primary cause of this new type of epilepsy is still unknown. This partly explains why there are many explanations of the disease with little impact. It has for a long time been alleged that the Wapogoro were marrying their close relatives; hence, they continue suffering from epilepsy. But the blame has been shifted to *Vifuna*. *Vifuna* (Onchocerca volvulus) are a widespread phenomenon in our villages. We have been living with these insects for generations. Why didn't our grandparents catch the disease from *vifuna*? (H. Choma, interview, November 20, 2023).

Following the emphasis of Onchocerciasis-Associated Epilepsy, community treatment with ivermectin (CDTi) was introduced to eliminate onchocerciasis in Mahenge. However, after 25 years of annual CDTi, the prevalence of OAE remained high Mahenge, Bhwana et al., 2023). Therefore, in 2019, bi-annual CDTi was introduced in the area (Bhwana et al., 2023). Reasons for the persistence of Onchocerciasis-Associated Epilepsy despite decades of interventions in Mahenge need to be investigated (Colebunders et al., 2018).

Reluctance for Accepting Onchocerciasis-Associated Epilepsy

The experience of epilepsy in the clans and families having no history of epilepsy in Mahenge was a complicated phenomenon. Families of Soli, Mgaya Liheta and the sacred family of Kayohahela, to mention a few, have traces of epilepsy in their recent generations (C. Katyawa, interview, November 12, 2023). As a result of these changes, new explanations emerged and others were consolidated. It is said that a good number of people viewed epilepsy as a curse on the previously healthier clans with witchcraft accusations (S. Kagua, interview, November 12, 2023). In similar ways, Scholars such as Hill, Schnoebelen, and Asamoah-Gyadu have noted increased cases of witchcraft accusations in the period of health crises, such as HIV/AIDS, cholera, Ebola, meningitis, tetanus, and many other epidemics (Sanou, 2017). This point was supported by Ms Salivina Kagua, whose clan and family did not experience cases of epilepsy before the seizure of his son. She said:

I have four children: three daughters and one son. The son was doing well in his studies. One day, he answered all the mathematics questions correctly, and the teacher instructed his classmates to look at his paper and see his excellent work. He was given a prize. A few days later, he suffered from his first seizure while he was at school; his schooling ended because he started to experience frequent seizures at school (S. Kagua, interview, November 12, 2023).

According to Mlaganile, epilepsy associated with witchcraft could be healed by traditional healers or could disappear after the death of the person responsible for bewitching the patient. Furthermore, Mloganile noted that this type of epilepsy could be transmitted from one generation to another until appropriate remedies are found (A. Mloganile, interview, November 12, 2023).

Yustina Seusi had six children; one of her children developed epilepsy in 1987 because there was no traceable history of epilepsy in his clan. She was accused of having extra-marital affairs with men from vulnerable clans. In this, Yustina had this to say:

I do not know where the disease came from, but they all pointed fingers at me. I was very embarrassed. When I heard that other cases of epilepsy came from *vifuna* (Onchocerca volvulus), I thanked God. Still, I wondered why only one family member developed epilepsy while we were living in the same place, eating the same food, drinking the same water (Y. Seusi, interview, November 15, 2023).

Scientifically, epilepsy is not a contagious disease, and it cannot be transmitted through sex or other forms of physical contact.

This study has found several stories which associate epilepsy with 'activities' going on in the brain, in the mind and in the heart of an individual. These 'activities,' according to Benard Fabian, are the product of day-to-day life.

Persistent feelings of anger, stress and fear may trigger a seizure and, if not controlled, can lead to recurrent seizures and epilepsy. Nowadays, life has become complicated and too demanding; thus, people have to think over and over again. Many people lack peace of mind due to problems such as financial difficulties and love-related issues. They think until the brain becomes hot, which causes headache, seizures and eventually mental illnesses (B. Fabian, interview, November 23, 2023).

Addressed in a good number of studies is the relationship between epilepsy and the well-being of the mind, heart and soul. In the same line of reasoning, some studies have reported that chronic stress can trigger epilepsy, and it can worsen epilepsy (Galtrey et al., 2016). As a result, stress management has to be part and parcel of epilepsy management in the 21st century. The Wapogoro experience with epilepsy reveals a critical truth: local perceptions of health, illness, and healing practices are adaptive systems that correspond to social, economic, and technological changes.

Conclusion

Perceptions and perspectives of epilepsy have undergone considerable changes, warranting a special analysis. There has been an emergence of new ideas and a consolidation of old ones. Regions like Mahenge, where epilepsy is rampant, have experienced ongoing debate on the causes of the widespread phenomenon of epilepsy. The Wapogoro conceptions of epilepsy are broad and flexible, integrating ideas from the scientific, social, and spiritual worlds. The Wapogoro people, therefore, do not suffer from a lack of explanations for epilepsy but a deficit of intervention models that listen, respect and integrate medical and social perspectives of the disease.

Fighting epilepsy in the 21st century has to involve a multifaceted approach that integrates not only advanced science and technology but also lifestyle changes, collaborative care between health care professionals, patients, and the community. This study recognises that people suffering from epilepsy and their community have a lot to say about their experiences that may determine healing practices and the success of interventions against epilepsy in Mahenge, and rural Africa in general.

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