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HEALTH

Epilepsy Patients in Africa Fight Stigma and Neglect

By Promise Eze



Angie Epilepsy Foundation advocates against epilepsy stigma in Benin City, Nigeria. Courtesy: Angie Epilepsy Foundation

BENIN, Nigeria, Mar 19 2025 (IPS) - When Angela Asemota's son began having seizures at six years old in 1996, people gossiped that he was possessed by evil spirits, leading her to seek healing from native healers and religious clerics. He underwent several traditional rituals and drank various concoctions, but the seizures persisted. It was not until his fourth year in secondary school in 2004 that she took him to a hospital, where he was diagnosed with epilepsy and began taking medication.

"For many years, I was going from pillar to post. I was ignorant about epilepsy and didn't know it was a medical condition. The native healers and religious houses said my son was cursed. I believed the seizures were caused by witches, wizards, or demonic forces because of false beliefs and misconceptions," Asemota, who lives in Benin City, Nigeria, told *Inter Press Service*.

Epilepsy is a brain disorder that affects about 50 million people worldwide, with nearly 80 percent living in low- and middle-income countries where treatment is difficult to access. In Nigeria, around 1.7 million people have the condition, based on a prevalence of 8 cases per 1,000 people.

The disorder causes repeated seizures due to abnormal brain activity. While there is no cure, medication can help control it. However, in many African communities, epilepsy is often linked to witchcraft or demonic possession, leading people to seek prayers or traditional healers instead of medical treatment. This stigma limits access to healthcare, leaving over 75% of epilepsy patients in Africa without proper medical care.



EAARF conducting an outreach to teach young students about epilepsy. Courtesy: EAARF

People with epilepsy in Africa often face discrimination and rejection. Many children with the condition are denied access to schools, while adults struggle to find jobs because employers fear they may have seizures at work. Even within families, some epilepsy patients are isolated or treated unfairly, which can lead to depression, anxiety, low self-esteem and in extreme cases, suicide.

The Curse of Stigma

"The stigma around epilepsy is worse than epilepsy itself. You are stigmatized by your family, relatives, in-laws, and friends because people don't even believe it's a medical condition. People call it a strange disease. Those who want to see you will look at you from afar, as if you are carrying epilepsy in your hands," said Asemota, who now runs a non-profit, Angie Epilepsy Foundation, to battle epilepsy stigma and provide support for people living with the condition.

After seeing that epilepsy can be managed with medication, she has been raising awareness and advocates for early diagnosis and treatment since 2010. Her organisation fights for patients' rights, empowers communities, trains healthcare workers, and runs awareness campaigns through schools, churches, radio, and social media. They also provide medical and material support for people living with epilepsy.

Nicholas Aderinto, a medical doctor, believes that campaigns against epilepsy stigma are very important as they encourage people to seek healthcare. Without treatment, he argued, epilepsy-related seizures could lead to death.

"I believe the prevalence of epilepsy in Africa is underreported because many people do not seek medical care due to social stigma. This underreporting affects the accuracy of prevalence data, which in turn leads to inadequate attention from policymakers and limited funding. As a result, epilepsy is not prioritized in policymaking, financing, and research," he said, adding, "This Lack of focus means fewer studies are conducted, medications remain scarce, and people living with epilepsy do not receive the proper care they need."

Gender-based Violence

For Elsie Chick, a teacher in Douala, Cameroon, epilepsy stigma cost her relationship. Her partner abandoned her eight years ago after discovering she had epilepsy. In the Central African country, the high prevalence of epilepsy has become a national health concern.

"I never told him I had epilepsy until I was pregnant. Most of the time, I was scared of what people would think, so I kept it from him. He has never called once to ask about the baby. His mother doesn't want him to take the child because, according to her, the baby might also develop epilepsy," she said.

She added, "Many times, I have cried. There were moments I wished I could wake up one day and be free from epilepsy. I wished I could sleep at night and hear God tell me, 'My daughter, you are healed.'"

Dr Mundih Noelar, the founder of Epilepsy Awareness, Aid and Research Foundation (EAARF), a non-profit organisation based in Bamenda, Cameroon, is worried that epilepsy stigma only helps to reinforce gender-based violence against women in Africa. She said myths surrounding epilepsy contribute to the victimisation of women.



Young EAARF activist with her epilepsy campaign message. Courtesy: EAARF

"Women with epilepsy are not valued and face a higher risk of gender-based violence. Many believe the women will pass the condition to their spouses and children. They are also vulnerable to sexual violence, yet even the police are often unwilling to seek justice for them. People rarely consider them for marriage, and those who do get married often endure abuse. I have received countless cases. One woman in a village was mocked by her husband whenever she had seizures. Another was thrown out of her home. One woman I know was regularly beaten by her husband. Many of these women remain in toxic marriages because they fear no one will love or accept them if they leave," she told *Inter Press Service*.

Through her initiative, Noelar leads a network of epilepsy survivors—mostly women—whom EAARF calls “epilepsy warriors.” These survivors visit communities and use mass media, including radio and social media, to share their stories, urging people to see epilepsy as a medical condition rather than a reason for stigma.

This community of women serves as a family for people like Chick, who says she is energized when she knows she can always talk to other women facing the same challenges.

“There are others around me who are struggling just like I am—people who are survivors yet still facing challenges. Knowing this gives me joy and a sense of peace, reminding me that I am not alone,” she said.

“We empower women with epilepsy, even in rural communities, on how to address gender-based violence,” Noelar said, emphasizing the importance of raising awareness at all levels of society.

“Even policymakers need to understand what epilepsy is. Many of them still hold onto myths and misconceptions, and because of this, they may never consider policies that support people with epilepsy.”

Addressing Epilepsy

A decade ago, at the 68th UN World Health Assembly, 194 countries, including African nations, committed to strengthening efforts to address epilepsy. The pledge raised hopes for support for those living with the condition. However, critics argue that government action of many African governments remains insufficient, forcing individuals and families affected by epilepsy to depend largely on charities and non-governmental organizations for help.

Action Amos, Regional Programs Coordinator for the International Bureau of Epilepsy, attributes this shortfall to the lack of a structured framework guiding the adoption of a comprehensive and sustainable approach to epilepsy care.

However, he stated, “Since May 2022, the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders has provided a blueprint to help governments develop plans, protocols, and strategies to place epilepsy on the health agenda. It addresses key issues such as the treatment gap, stigma, and policies, offering a comprehensive approach to tackling the condition.”

Amos emphasized the importance of engaging traditional and religious leaders, who are deeply embedded within local communities and often serve as the first point of contact for those seeking help. He stressed the need to help them understand that epilepsy is a health condition, not a spiritual problem.

“Bridging the gap between traditional healers and medical professionals is essential to ensuring that people with epilepsy receive the best possible care. Traditional and faith healers need to be educated and trained on epilepsy and its causes so they can recognize when to refer patients for medical care,” he said.

Asemota worries that with limited access to medication and inadequate healthcare facilities, epilepsy patients will continue to be isolated. She argues that, as is obtainable in many African countries, the Nigerian government is not providing enough support to people living with epilepsy, especially in terms of subsidizing the cost of medications.



Angie Epilepsy Foundation rallies against epilepsy stigma in Nigeria. Courtesy: Angie Epilepsy Foundation

“A lot of people are no longer buying medication because they cannot afford it anymore. This drives them back to native healers. When you are in dire need, you are vulnerable. You go back to the native healers for help, which is dangerous. Medication is now expensive. Epilepsy has become a condition only the rich can manage,” she said.

But it is not just hard to get medicine, there are also very few neurologists in Africa. This problem is worsened by the many health workers leaving the continent for better opportunities abroad. Without trained neurologists to diagnose patients, prescribe the right treatment, and provide ongoing care, many people with epilepsy face serious risks to their health and lives.

“Governments should invest in training healthcare workers and improving healthcare infrastructure, including increasing the number of neurologists. In most countries, epilepsy is treated by psychiatrists or specialists, so they also need proper support. It is also crucial to integrate epilepsy care into primary healthcare. When discussing primary healthcare, we should not forget community healthcare workers, who should also receive proper training,” argued Amos.

Chick does not believe epilepsy stigma will decrease anytime soon, as many African communities still hold myths in high regard.

“But I believe that if we work hard on advocacy, some people will come to understand that epilepsy is not a curse,” she told *Inter Press Service*.

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