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People with epilepsy aren't protected in Africa: What needs to be done

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Publication Details

Mugumbate, J. (2018). People with epilepsy aren't protected in Africa: What needs to be done. *The Conversation*, 15 April 1-3.

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People with epilepsy aren't protected in Africa: What needs to be done

Abstract

In October 2017 Abdul Matola was stoned and burnt to death in Malawi after being accused of being a "bloodsucking vampire". Matola had lived with uncontrolled epilepsy -- a highly treatable and non-infectious condition characterised by recurring seizures.

Keywords

done, epilepsy, be, people, needs, africa:, protected, aren't

Disciplines

Education | Social and Behavioral Sciences

Publication Details

Mugumbate, J. (2018). People with epilepsy aren't protected in Africa: What needs to be done. *The Conversation*, 15 April 1-3.

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April 15, 2018 6.45pm AEST

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In October 2017 Abdul Matola was stoned and burnt to death in Malawi after being accused of being a “bloodsucking vampire”. Matola had lived with uncontrolled epilepsy -- a highly treatable and non-infectious condition characterised by recurring seizures.

When he was caught by the mob, he was still recovering from a seizure in his garden. He was weak and not fully conscious.

Some Malawians, as well as people from other African countries, believe that epileptics could be witches or possessed by an evil spirit. People with epilepsy have been accused of eating human flesh, sucking human blood and committing various crimes.

Epilepsy is the most common serious chronic brain disorder in the world. More than 50 million people are affected by the condition. A fifth live in Africa. About 3% of Malawi's of 18 million people has epilepsy.

Matola's death elicited an outcry from the public. Local epilepsy awareness organisations issued a petition calling on the government to intervene. Over the following weeks and months several people were arrested.

But beyond the arrests, the government in Malawi – like many others across the continent – have done little to institute policies that improve awareness and protect people who have epilepsy.

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Matola's death exposed levels of ignorance about epilepsy that are commonplace in many communities across the continent. It highlighted the vulnerabilities that people with the condition face on a daily basis.

More importantly, it showed that there are gaps in the treatment offered to epileptics. These include a lack of awareness and a shortage of medicines, care services and facilities.

Unless governments on the continent increase awareness about epilepsy and create policies that protect people who suffer from this disease, little will change.

Not enough action

In the last 20 years there has been two attempts to get governments across the world to improve awareness around epilepsy.

In 2000 the World Health Organisation spearheaded the Global Campaign against Epilepsy which developed treatment guidelines in resource poor countries and trained health workers on how to handle people with epilepsy.

Projects were implemented in Zimbabwe, Senegal, Brazil and China. Studies evaluating them proved that it was possible to treat and manage epilepsy successfully in poor resource settings using very few resources. But the studies also showed that the projects had very little impact and that a significant number of people with epilepsy were not getting services.

Then in 2015 the WHO adopted a resolution to address the health, social and public knowledge of epilepsy. Governments agreed to put epilepsy high on their agendas. And most African governments were signed up too.

But three years have passed since the resolution was adopted, and very little action has been taken by governments on the continent. Aside from a workshop attended by 21 countries in Ghana in 2015 not much has been done.

Government could, in fact, have taken the simple step of setting up teams to implement the resolution and to translate the policy into a programme of action. But this hasn't been done.

Most of the advocacy efforts have been led by non-governmental organisations. But these have only taken place in only a few countries and there are no concrete results.

The challenge is that in most countries there is no office that coordinates epilepsy affairs. Other challenges include the fact that:

- Support for the condition is inadequately funded,

- Epilepsy falls under mental health and lacks proper short term or long term plans.

Where there is political will, these challenges are surmountable through an approach that involves major stakeholders and opinion leaders.

Building awareness

There are four steps that African governments should take to improve awareness around epilepsy. These would also address the risk of discrimination, disability or death associated with epilepsy.


Each country should form a national committee or task force to spearhead the implementation of the WHO's resolution. This could mean reactivating teams that were established 20 years ago as part of the global campaign against epilepsy.

Countries could also develop a national epilepsy plan to implement the resolution. This should include measures to ensure sustained epilepsy awareness, training of health workers, research, funding, treatment guidelines, human resourcing, medicines supply, operation of the national task force and other issues. And it should include a national epilepsy fund to resource the plan.

In addition to acknowledging the needs of people with epilepsy and resourcing them, governments also need to help strengthen organisations that support people with epilepsy.

If these steps are taken epilepsy could be better understood in Africa and people with epilepsy could be protected and afforded an opportunity to lead productive lives.

** Action Amos, Executive Director, Federation of Disability Organisations in Malawi (FEDOMA) for contributed to the writing of this article.*

 [Epilepsy](#) [World Health Organisation](#) [Malawi](#) [Africa Day](#) 

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