

# The forgotten

Gretchen L. Birbeck, MD, MPH, DTMH

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## Correspondence

Dr. Birbeck  
gretchen\_birbeck@  
urmc.rochester.edu

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As a medical student, prompted purely by curiosity, I undertook an international elective at a hospital in rural Zambia. This was in the era before major US investments in African AIDS care and before global health gained popularity among trainees from high-income countries. Twenty-five years later, over half my lifetime, I find myself still here. As an academic neurologist, I've had the privilege of being able to work in Africa 6 months a year for over 2 decades. This puzzles people. A Russian physician friend once asked, "What did you do to make them send you there?" But for me, Zambia is my Land of Oz. Everything is in Technicolor—more intense, more real, more relevant than the dull gray of Kansas. But Oz has a dark side as well—flying monkeys wreak havoc, taking pleasure in death and destruction. None are more targeted than people with epilepsy.

The Chikankata Epilepsy Care Team was founded in 2000. Initially, minimal resources for outreach yielded big gains in bringing people out of the shadows.<sup>1</sup> The burn unit of the hospital was able to close. Modest training of health care workers<sup>2</sup> and local stigma reduction programs<sup>3</sup> were successful. Scale-up was planned. Sure, we had some concerns that phenobarbital, our mainstay of treatment, wasn't the drug of choice for our HIV+ patients,<sup>4,5</sup> but overall there was progress. Progress, until well-intended capacity building endeavors aimed at improving drug regulatory capacities led to irrational enforcement of The UN Convention on Psychotropic Substances.<sup>6</sup>

Though hardly a recreational drug, phenobarbital has become increasingly unavailable around the globe, with disastrous consequences for the world's poorest people with epilepsy.<sup>7</sup> These are the voiceless. The forgotten. Can you hear them in the excerpts taken from reports filed by the Chikankata Epilepsy Care Team?

September 13, 2010.

The Namaila nurse mentioned that because of the shortage of antiepileptic drugs...most patients had lost hope of finding the medicine.

March 28, 2011.

All the clinics that we visited had run out of both drugs. The roads were very bad because of the rains. On our way back...the vehicle slid and went into a ditch where it got stuck. The driver slept in the vehicle.

June 8, 2011.

His right hand was amputated because he fell in an open fire during a seizure and got badly burnt. The community health worker mentioned that there are many people with epilepsy around the area. Most of them go to traditional healers for care.

September 28, 2011.

One...has been asked to stop going to school by the parents due to the many seizures. The parent said that the child may get hurt since there is no one to take good care of her at school.

January 25, 2012.

...a 36-year-old breastfeeding mother [who] was twitching for close to an hour. She had been fundraising for transport to come to Chikankata for her epilepsy.

March 7, 2012.

...a lady of 20 years old who didn't want to disclose that she suffers from epilepsy. The mother is the one who came forth to say that her daughter has epilepsy.

March 28, 2012.

...a 15-year-old known epilepsy patient. She sustained a wound on her neck after being beaten last week by a female neighbor. She says it was for no apparent reason. She has difficulties in her speech. She is not in school because of her condition.

September 26, 2012.

A father came to collect medicine for his 12-year-old son who is unable to walk long distances because one leg is shorter than the other and so is the hand. The boy is doing well on phenobarbitone.

February 13, 2013.

...a 44-year-old man who had a fit last Wednesday. Still complaining of pain on the arm where he had an amputation due to seizure-related burns. He doesn't adhere to medicine because it is difficult to break a pill in half. The relative who escorted him to the clinic was advised to help him break the tablets.

May 15, 2013.

There were no epilepsy patients seen on this day. Phenobarbitone is out of stock and the clinic has been forced to put all their patients on carbamazepine. Most of the patients are not responding well.

October 20, 2013.

...a 35-year-old HIV-positive male. Since his wife died, he has had problems remembering to take his medication. He lives with his sister, who is usually out selling merchandise to earn a living. Counseling was done.

January 22, 2014.

...a 6-year-old female with epilepsy and cerebral palsy. She is not adhering to medication because sometimes no one comes to collect medicine for her. The mother says she is very busy most of the time because she has to look for food for the family since her husband doesn't care to do so.

March 5, 2014.

...a 14-year-old female with known epilepsy, seizure-free on phenobarbitone. Her father has stopped her from going to school. At first, he told her that it was no longer safe given that she used to experience a lot of seizures and since the school is at a distance. Now the father tells her that he has no money to pay for her. Her siblings are all going to school with not much problems. Counseling was done with the mother, who has no source of income but will try and see if she can convince the husband to take their daughter back to school.

March 7, 2014.

...a 22-year-old female with known epilepsy came to collect AEDs. Recently had a baby. She delivered at home and had multiple seizures during the labor. She can't remember the date or month the baby was born. She was told by her mother. The baby is looking well.

March 19, 2014.

...a 15-year-old female with known epilepsy in status. Before this episode, she had been seizure-free since the time she was commenced on phenobarbitone. She was switched to carbamazepine due to the lack of phenobarbitone.

March 26, 2014.

...a 14-year-old female with known epilepsy. There is history of epilepsy on the mother's side of the family. This girl's grandmother had a seizure and she fell on an open fire and later died due to the burns she sustained.

April 2, 2014.

...a 16-year-old female. In March 2014, she had seizures for 5 days continuous. She had run out of phenobarbitone.

June 25, 2014.

...a 10-year-old boy who started convulsing last year after suffering from cerebral malaria. There is no improvement on carbamazepine. Still experiencing generalized seizures daily.

September 17, 2014.

...a 20-year-old female with known epilepsy who had stopped taking phenobarbitone under the instruction of a prophet

who prayed for her and told her that she was healed and did not need to be taking medicine anymore. She had long generalized seizures for 2 days after stopping phenobarbitone.

October 22, 2014.

The mother wanted to know if there is anything that the Epilepsy Care Team can do for her 14-year-old boy. She has to tie him to her arm most of the time during the day because the boy throws stones at the other children or beats them. He is violent most of the time, and if not watched closely by the mother he gets confused and walks long distances and cannot find his way back. The mother is afraid because, now the boy is growing, she doesn't know how she will be taking care of him. She will not be able to tie him to her arm anymore when he is older.

July 13, 2016.

The District Office reported that pupils at Chikani are collapsing. We found 4 teachers there. They told us that a pupil had a fit the previous day after coming from the toilet. When the pupil regained consciousness and was told that she had a fit, she said it was because she saw blood in the toilet, flowing down the walls of the toilet. Everyone who went in the toilet immediately did not see any blood on the walls. When she went home and narrated what had happened to her, the parents and the neighbors became very upset, saying the teachers are practicing Satanism, hence the riot. The parents took the girl for prayers. Now the teachers are upset and do not want to teach because they are being accused of something they did not do. Nine pupils have been reported to have had fits at school, 3 of which are on our epilepsy registry.

September 7, 2016.

...a 62-year-old male with generalized seizures. He has been on traditional medicine on and off. Experiences these seizures only at night. Wife narrates that he starts by spitting, then, he stares in one specific direction for a while and at that time, even if you touch or call him, he doesn't respond. Thereafter, he starts fitting and passes urine. The following day he behaves like a mad person.

May 17, 2017.

...a 21-year-old female with known epilepsy also on anti-retroviral therapy. She had a seizure 3 days ago. She had run out of phenobarbitone. The father had no one to send to go and buy it in Lusaka [the capital city over 3 hours away by car]. She sustained burns on the left hand during the seizure. The wound is quite severe.

June 21, 2017.

...a 21-year-old female with epilepsy. Severe seizure attacks this month because the father was unable to buy

phenobarbitone like he has been doing. The patient only responds well on both carbamazepine and phenobarbitone. The clinic was only able to supply the last 15 tablets of carbamazepine they had in stock. She is also on TDF/3 TC/EFV [a common antiretroviral regimen].

June 28, 2017.

...a 30-year-old, 5-month pregnant female with epilepsy off AEDs for 2 months because they are out of stock. She sustained burns on her right hand during a seizure while preparing food for the family. Another seizure attack occurred while she was carrying her first child on her back. Her first child was hit by a bicycle and later died in Chikankata Hospital. He was only 4 years old. This is her second pregnancy. The person responsible for this pregnancy has denied responsibility, saying he does not even know the woman. His relatives have started spreading rumors that she was raped by the father and wants to implicate their relative. The father has been very upset about the news and always mistreats her. He has physically beaten her on 2 occasions. The first time was when her family found out that she is pregnant. Patient reports that she doesn't know why her father beat her the second time. Counseling was done. We asked if the patient would like the Epilepsy Care Team to speak with the parents. Patient said the father may only agree if the mother is present. Patient went home only on Panadol [acetaminophen] since there were no epilepsy drugs to supply.

July 5, 2017.

...a 23-year-old female with epilepsy, previously seizure-free. Two seizures since she has been off phenobarbitone because it is out of stock. She was advised to sell a chicken or two so that she can buy some phenobarbitone, if some can be found.

On the surface, it seems a simple issue. Recognize phenobarbital's limited abuse potential and modify regulations on its importation, handling, purchase, and prescribing. National and international appeals have been made.<sup>7</sup> But understaffed, overwhelmed pharmaceutical regulatory authorities cling to World Health Organization recommendations, and bureaucracies in Geneva defer to each other. Is this a pharmaceutical problem or an epilepsy problem? Deference and indifference breed inaction. All the while, international advocacy groups who might play a role in negotiating better global access to phenobarbital form task forces whose bold determination culminates in planning a systematic review of the literature. This leaves the tired Tin Man to anxiously check the skies and wonder who is truly heartless.

## Disclosure

G. Birbeck reports no disclosures relevant to the manuscript. Go to [Neurology.org/N](http://Neurology.org/N) for full disclosures.

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