New Study Will Combat Stigma of Epilepsy in Zambia

BY DENISE NAPOLI

Elsevier Global Medical News

From left to right: Dr. Alan Haworth, Henry Kansembe, Dr. Elwyn Chomba, Edward Mbewe, Dr. Gretchen Birbeck, Dr. Masharip Atadzhanov, Dr. Phillimon Ndubani.

COURTESY DR. GRETCHEN BIRBECK

Dr. Gretchen Birbeck first became aware of the pervasive stigma experienced by Zambians with epilepsy in 1994, while working in a clinic in the small, southern African country. People with epilepsy would come in for treatment all the time—for a burn or another injury experienced during a seizure—but not for the disease itself. Having epilepsy was not something to be publicized, even to health care professionals.

Many epilepsy patients around the globe complain of stigma associated with the disease. In the western world, "Data ... strongly suggest that the stigma people with epilepsy have is often self-inflicted. They have life limitations that they've often self-imposed," said Dr. Birbeck. But in Zambia, the limitations experienced by epileptics are especially dramatic. And very real.

For example, "People with epilepsy are very disadvantaged in education and employment but also in terms of marriage," said Dr. Birbeck. It's difficult to find a partner, but perhaps even more troubling is that even after marriage, "the women, especially, were abandoned." Findings from an observational study conducted by Dr. Birbeck and her colleagues from 2003-2007 also revealed that single women with epilepsy felt vulnerable to sexual assault, which prevented them from seeking health care—and not unduly (Lancet Neurol. 2007;6:39-44). "When we did our quantitive assessment, the rate for rape for epilepsy was 20%, compared to less than 3% in our comparison group."

There is even evidence of discrimination against epileptic children by their own parents. In a comparison of epileptic childrens' food intake and nonaffected childrens' rations across households of similar means, "relative to the child in the other household, the child in the household with epilepsy has food deprivation," said Dr. Birbeck, associate professor and director of the International Neurologic and Psychiatric Epidemiology program at Michigan State University.

Now Dr. Birbeck and her colleagues from Michigan State, the University of Zambia, and several Zambian health care institutions will have an opportunity to affect some of that stigma faced by Zambians with epilepsy. The Epilepsy-Associated Stigma in Zambia study, to be led by Dr. Birbeck, will implement social, educational, and economic interventions that her team developed after analysis of the causes of stigma and discrimination in her last study.

The interventions will be specifically targeted to each of several "power groups"—those people with the most influence in society. "We know that health care workers, clerics, police officers, and teachers propagate [the stigma against epilepsy]. But those are also the individuals who could have the largest positive impact," said Dr. Birbeck.

In a targeted approach to overcoming discrimination by teachers, Dr. Birbeck will employ the observation made in her previous study that teachers who personally knew someone with epilepsy were less likely to stigmatize other epileptics. Dr. Birbeck plans to set up a "somewhat bogus" week-long intervention program, where the teachers will learn about the disease from an educator they have never met. At week's end, "the teachers will find out that this person they've been working with all week actually has epilepsy." She hopes that developing a bond with the educator, perhaps more than the lessons themselves, will break the teachers of discriminatory habits.

Another example involves Zambia's traditional healers. Dr. Birbeck's previous research showed that one of the factors in their discrimination against epilepsy patients is whether they believe the disease is medical or the result of witchcraft. She hopes to teach healers the scientific causes of epilepsy.

Intervention in households, however, will be more difficult, and will not be a focus of the present study. According to Dr. Birbeck, after her last study, "I don't think we understand that dynamic well enough to know."

For example, she said, sometimes it is not uncommon for parents of children with epilepsy to elect not to send their child to school. "Sometimes it's because they don't want to waste money" on a child who, they presume, won't amount to much.

But "sometimes it's because they're worried the child isn't safe at school." In both cases, the child loses, but they are "very different motivating factors. We need to understand that better, so we can intervene," said Dr. Birbeck.

Her upcoming study will be funded with a $1.38 million grant from the National Institute of Neurological Disorders and Stroke of the National Institutes of Health. ■