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Working Together to Improve the Lives of People Affected by Epilepsy in Zambia

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Abstract

Epilepsy is a neurologic disorder that results in recurrent, unprovoked seizures. The biomedical burden of epilepsy can be substantial, but for many the social consequences may be just as extreme, with epilepsy victims suffering from social abandonment as well as economic and physical vulnerabilities. Since its founding in 2000, the Chikankata Epilepsy Care Team, a collaborative project between Michigan State University and the rural Zambian community of Chikankata, has worked to improve the lives of people with epilepsy. What began as a local nurse–medical student partnership in one small rural Zambian hospital has grown into a program that supports and enriches clinical services and advocacy programs throughout Zambia. Recognizing the imperative for knowledge to influence policy, this university-community partnership works tirelessly to inform key stakeholders and policy makers of its findings. The program received the 2011 Outreach Scholarship/W. K. Kellogg Foundation Engagement Award for the North Central region.

Setting the Context

As a medical student, the author, Gretchen Birbeck, undertook an elective rotation at Chikankata Hospital in rural Zambia, (which is located in the rural province of Chikankata in the Republic of Zambia located in Southern Africa) curious to see how medicine was practiced without the advanced technologies and extensive resources available in the United States. Among the many devastating conditions to be found there, the realities of epilepsy were the most disturbing. Epilepsy, a condition characterized by recurrent, unprovoked, and usually unpredictable seizures, is a treatable condition. Most people with epilepsy in the United States are able to live full and active lives, but people with epilepsy in the Chikankata community faced soul-crushing social and medical realities.

Living with Epilepsy in Zambia, Africa

No one with epilepsy in Zambia received treatment for this seizure disorder. Health care providers found themselves caring for children and adults with fatal or seriously disabling burns that occurred during a seizure, often while the family stood by too paralyzed by contagion fears to pull them from the fire. Children with epilepsy were routinely ejected from schools and often prevented from playing with other children, dooming them to social isolation and long-term economic vulnerability. In confidential disclosures, women with epilepsy offered details of spousal and familial abandonment with subsequent social vulnerability, physical violence, and sexual assault. Epilepsy was not formally recognized as a common chronic condition in the community, yet the consequences of untreated seizures filled the hospital. Birbeck decided that this paradox deserved formal investigation. After completing her training in neurology, she returned to Zambia, and, with other concerned health care workers at the hospital, undertook a formal hospital-based study of epilepsy at Chikankata.

Needs Assessment

The study confirmed several disturbing facts *(Birbeck, 2000a, 2000b, 2001)*. People with epilepsy were presenting to the hospital with their seizure-related injuries, but not with their seizures. Most of the inpatients who were identified with epilepsy had been admitted with severe burns or fractures experienced during a seizure, but they had failed to mention the seizure or their epileptic condition to the admitting health care provider. Less than 10% of the people with epilepsy who were seen as inpatients had ever been treated for the disorder, and even among those who had been identified and treated, the prescribing health care worker, usually a clinical officer or nurse, had provided doses of antiepileptic drugs for seizure prevention in doses so low as to be essentially useless. This mode of treatment indicated that the health care workers required additional training in epilepsy care. It was also noted that although the hospital routinely registered patients with chronic conditions to ensure that sufficient medications were kept in stock, the registry listed only 32 people with epilepsy. This was a low number, given the catchment area of 65,000, and it led to the conclusion that many unrecognized and untreated cases of epilepsy existed in the community *(Birbeck & Kalichi, 2004)*. Indeed, a subsequent population-based prevalence study identified almost 2,000 people with epilepsy in the catchment area *(Birbeck, 2009)*.

These findings were congruent with what has subsequently become evident globally. Approximately 80% of the 50 million people with epilepsy worldwide live in resource-poor regions *(de Boer, Engel, & Prilipko, 2005)*. Epilepsy represents 0.49% of the global burden of disease, and among neurologic disorders it ranks third after dementia and cerebrovascular disease in terms of its contribution to global disease and disability *(Leonardi & Ustun, 2002)*. Epilepsy is the most common chronic neurologic disorder in Sub-Saharan Africa *(Eisenberg, 1997; Leonardi & Ustun, 2002)*. The World Health Organization (WHO) estimates that a year's supply of phenobarbitone could cost as little as $5 per person *(WHO, 2004)*, yet the proportion of people with active epilepsy who warrant treatment, but who are not receiving it, remains more than 90% in most Sub-Saharan Africa countries *(Meyer & Birbeck, 2006)*. The avertable burden of death and disability due to epilepsy in Sub-Saharan Africa is particularly disturbing. The WHO estimates indicate that 41% of all lives lost and disabilities due to epilepsy could be avoided if drug availability could be scaled up.

Overview of the Chikankata Epilepsy Care Team Program

The early hospital-based studies of seizures and epilepsy at Chikankata involved collaboration with several clinical officers and nurses who shared the perception that something was missing when it came to epilepsy in the community. Once the formal hospital-based study of epilepsy at Chikankata began to provide insights into the local burden of disease, hospital administrators gained an interest. The busy (and expensive to run) burn unit was filled mostly with people with epilepsy, and seizures accounted for a substantial proportion of the ICU (intensive care unit) admissions. In 2000, with support from hospital administration and seed money from Michigan State University (Michigan State), the Chikankata Epilepsy Care Team (Epilepsy Care Team) was founded. The initial Epilepsy Care Team coordinator was Ellie Kalichi. Prior to accepting the position with the Epilepsy Care Team, Kalichi was head of nursing at Chikankata Hospital. Having completed additional training in leprosy diagnosis and control in Tanzania, she also served as the hospital's leprosy control officer. Her work with leprosy had given her great insights into the burden of stigmatized conditions in the community. These insights proved critical for guiding the Epilepsy Care Team's work, and the development of additional partnerships within the broader community.

Program Activities

Members of the Chikankata Epilepsy Care Team provide clinical services, conduct research, and support local capacity building and medical education in Zambia. Birbeck, a Michigan State faculty member and the Epilepsy Care Team director, spends 4 to 6 months a year at the site, and maintains weekly contact when off site by email and Skype. Since 2000, the number of community partners involved in Epilepsy Care Team activities has expanded to include collaborative partners from other Zambian health care institutions, faculty members from the University of Zambia and Chainama Hills College, and officials from the Zambian Ministry of Health. Epilepsy Care Team work depends on its grassroots partners from the community, including teachers, clerics, and traditional healers. As director, Birbeck works with the Epilepsy Care Team's Zambian academic colleagues on grant preparation and research dissemination. As a health care worker at Chikankata, she provides inpatient, outpatient, and community-based care. Specific program activities include improving health care services, advocacy, teaching/capacity building, and research.

Improving Health Care Services.

In addition to epilepsy care at the hospital, the Epilepsy Care Team mobile clinic makes weekly visits to rural health centers serving the district to ensure that drugs are available, and to provide more advanced services to people with epilepsy closer to their own homes.

Workers who underwent neurologic training through a grant to Birbeck from the Lancet International Fellowship lobbied for incorporating neurologic training into the basic curriculum for all clinical officers in Zambia. (Clinical officers, who provide most of the health care services in Zambia, have completed a 3-year course in basic health care provision following secondary school [analogous to high school].) With funding from the World Federation of Neurology, formal training materials were developed, and an ongoing visiting professorship was funded to ensure that experts return annually to train and re-train trainers.

With faculty from the University of Zambia, the Epilepsy Care Team co-founded the Neurologic and Psychiatric Society of Zambia, a professional organization of health care workers who focus on neurologic and psychiatric disorders. The Society has been an important organization for providing expert advice to Zambia's Ministry of Health, and for offering continuing medical education opportunities for Zambian physicians. Recently, the Society has been awarded funds from the World Federation of Neurology to develop a Center of Excellence that will focus on epilepsy care.

Advocacy.

With leadership from a past graduate of the clinical officer training program, the Epilepsy Care Team was among the co-founders of the Epilepsy Society of Zambia. This grassroots organization is affiliated with the World Health Organization's International League Against Epilepsy and is focused on an Out of the Shadows campaign, which is aimed at improving acceptance and treatment of epilepsy.

Ongoing peer-support group activities are supported by the Chikankata Epilepsy Care Team. The Epilepsy Care Team was first to notify the WHO and then publish reports describing

- antiepileptic drug toxicity related to extreme weight loss in famine *(Birbeck & Kalichi, 2003)*;
- the lack of appropriate medications for treatment of co-morbid HIV and epilepsy *(Birbeck, Chomba, Ddumba, Kauye, & Mielke, 2007)*; and
- unintended consequences of the WHO programs to improve pharmaceutical regulations, which have resulted in a global decrease in epilepsy treatment availability *(Chomba et al., 2010)*.

Teaching and capacity building.

Neurologic rotations under Birbeck's supervision are available to Zambian medical students. No other neurology rotations are available in-country. Michigan State medical students have also taken advantage of this opportunity. Several master's level students in Zambia have worked with the Epilepsy Care Team as part of their training. Director Birbeck served as the primary advisor for two of these students. She also serves as the primary advisor and mentor for Zambian Ph.D. and master's degree students studying issues related to epilepsy, stigma, and co-morbid social and medical problems in Zambia. In addition, training for grant administrators in Zambia has been provided by Michigan State grant administration specialists, funded through an National Institutes of Health Research Grant Program (R01) award.

Research.

Over $3 million in research funds, mostly through NIH, have been awarded to support research related to this work. More than 40 peer-reviewed publications have resulted from the research findings.

Evaluating Outcomes

The agenda for the Epilepsy Care Team is guided by the priorities set by the Zambian community. All activities (teaching, community education, health care service delivery) are undertaken in a way that allows an academic evaluation of the circumstances in the community and impact of the activity. The academic productivity associated with the various activities has been substantial. Findings from these scholarly activities are also relayed back to the community for their interpretation and feedback. The process of developing by consensus the agenda for the Epilepsy Care Team activities includes ongoing, regular, informal communications as well as formal meetings with community representatives, and retreats with academic and professional partners.

Impact of the Chikankata Epilepsy Care Team Partnership

This university-community partnership has had significant impact on Michigan State University students, on the Chikankata community, and on health care policy. For example, today Michigan State students participate in the Chikankata Epilepsy Care Team partnership. Graduate and medical students have participated in clinical and research rotations, including seven students whose dissertations have been based upon work in Zambia. Two Fulbright scholarships, two Fogarty Student Fellowships, and one American Medical Association grant have been awarded. U.S. neurology residents who have worked with the Chikankata Epilepsy Care Team have gone on to develop similar projects in other African countries.

For the Zambian community, more than $2 million in extramural research funding has been obtained for activities that include direct service delivery and outcome assessments related to services. The number of people with epilepsy in the Chikankata catchment area receiving regular care has improved substantially—so much so that the burn unit closed in 2005.

For health care policy, Chikankata Epilepsy Care Team partnership members now regularly serve as advisors to the World Health Organization, the U.S. National Institutes of Health (NIH), and the World Bank. The Chikankata Epilepsy Care Team's work has had a direct impact on health care policy at local, national, and international levels.

Sustaining the Partnership Over the Long Term

The Chikankata Epilepsy Care Team partnership is jointly supported by Chikankata Hospital and Michigan State University. The Epilepsy Care Team obtained its initial funding from Michigan State, and continues to be supported through Director Birbeck's leadership and the regular participation of Michigan State visiting scholars and students.

Community Contributions

Subsequent to the initial seed funding from Michigan State, funding has been acquired from the Lancet International Fellowship, the Rockefeller Brothers Fund, the Doris Duke Charitable Foundation, the U.S. National Institutes of Health, the World Federation of Neurology, and several private donors. In-kind contributions (e.g., staff, space) have been made by Chikankata Hospital, the Zambian Ministry of Health, and the University of Zambia. These resources indicate that the community continues to acknowledge and value the improvements in both health care policy and clinical care guidelines made possible through this work, as well as its substantial impact on the lives of people with epilepsy and those affected by epilepsy.

University Contributions

Michigan State has long valued global partnerships and recognized itself as a "world grant" university. In 2005, Michigan State's commitment to the Epilepsy Care Team's work was further demonstrated when it committed over $900,000 to the establishment of an academic unit, the International Neurologic and Psychiatric Epidemiology Program, for which Birbeck serves as director. Two additional full-time faculty members have been recruited, and a fellowship is sponsored. The mission of the International Neurologic and Psychiatric Epidemiology Program is to undertake research on neurologic or psychiatric conditions that affect public health in developing regions worldwide. Multidisciplinary training and collaborations involving Michigan State experts in neurology, psychiatry, epidemiology, and radiology are central to this effort. Experts in the social sciences, anthropology, political science, health services research, and the basic biomedical sciences also contribute. The research undertaken by the unit strives to place the diseases under study in the appropriate social and geopolitical context.

Next Steps

In 2012, the Chikankata Epilepsy Care Team activities continue in full force. The team is presently in the 4th year of a 5-year project funded by the U.S. National Institutes of Health to evaluate the impact of a series of multifaceted community-based interventions aimed at improving health care services and decreasing epilepsy-associated stigma. In 2011, the Epilepsy Care Team was awarded an NIH grant to conduct a cohort study of HIV-associated seizures and epilepsy. These community-based outreach activities continued with school-based interventions in 2011, and work with traditional healers in 2012.

Conclusion: Lessons Learned

Members of the Epilepsy Care Team have learned a number of valuable lessons through their work with the partnership. Initially, the inclusion of research endeavors within the structure of service delivery presented the most critical challenges in this university-community collaboration, chiefly due to issues of trust. Most of the Zambian partners had witnessed “research mercenaries” in action: academics from more developed regions who parachute into the community, collect their data, and fly away, never to be heard from again. Michigan State’s long-term commitment to the partnership has been an essential part of developing trust. As the Zambian grassroots partners came to appreciate their central role in determining research priorities, their concerns dissipated. Findings and best practices from Epilepsy Care Team work are being incorporated into programs in other regions of Zambia and in several other African countries.

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Gretchen L. Birbeck is professor of neurology & ophthalmology, epidemiology & biostatistics, and director of the International Neurologic and Psychiatric Epidemiology Program at Michigan State University. Her research focuses on the links between epilepsy and cerebral malaria. Much of her work has been conducted in Zambia and Sub-Saharan Africa. Birbeck earned her undergraduate degree at Indiana University before attending medical school at the University of Chicago, and completing a neurology residency and epilepsy fellowship at Johns Hopkins, a fellowship and graduate degree in epidemiology at the University of California–Los Angeles, and tropical medicine training at the University of Liverpool School of Tropical Medicine.