Vassar College, Julianna Shinnick

Creating Peace for People with Epilepsy

9 weeks (June 10-August 17)

Tanzania

Background

In Tanzania, you may recognize people with epilepsy by large burns across their bodies or by the way they are segregated within their community, unable to find work due to their disability. In many areas of Sub-Saharan Africa such as Western Tanzania, rates of epilepsy are more than 10 times that of the United States due to viral infection and parasites (WHO). These people with *kifafa* (epilepsy) are victims of discrimination due to the belief that seizures are the result of evil or ancestral spirits, witchcraft, or poisoning (Jilek-Aal, 382). In many cases, discrimination is so strong and fear so intense that members of the community are afraid to help friends or family members as they fall into the flames of an open fire or into a river as they are doing daily work (Jilek-Aal, 383). Due to this structural violence and its personal implications, many epilepsy patients deal with psychological issues such as trauma as well as feelings of shame and guilt (Jilek-Aal, 384).

The Project

With the funds from the Davis Projects for Peace Fellowship, I will create an art program for the patients of the Mahenge clinic. The project will be three-pronged. First, the program will be therapeutic for the patients, many of whom are trauma survivors and are ostracized from their communities. Therefore, I have designed an art therapy curriculum under the guidance of Robin Snow[1], PhD and Leigh Horne-Mebel[2], LICSW that will encourage conversation about challenges while building community.

Second, the content of several art projects will raise awareness about the realities of epilepsy within the community. Many of the problems that patients face are due to lack of awareness. For example, members of the community are often afraid to share food with people with epilepsy because

they fear contagion, which leaves people with epilepsy out of an important time of connection. Therefore, one art project will encourage participants to include messages that they would like to deliver to the community (such as the message that epilepsy cannot be spread), which we will then display at the clinic.

Third, I will work with patients to sell their crafts in a micro-finance project. One of the central problems for the patients of the Mahenge is that others believe they are unfit to work. People with epilepsy are subsequently much poorer than others in the community and often suffer from lack of plumbing and other basic necessities. The clinic has recently completed the first stage of a pilot program that taught patients to farm and successfully led them to jobs in the village. Working with the leaders of that program and collaborating with local artisans, I will help organize the selling of patients' crafts.

Given the significant success of the Mahenge Epilepsy Clinic's recent farming micro-finance project in improving quality of life of community members with seizures, a craft program promises to expand the benefits of microfinance to patients with different sets of skills. The Mahenge Clinic has reported increased self-esteem, increased integration into the community, and improved living conditions in patients who completed the farming project. I hope that this program will bring similar benefits associated with employment, especially to women in the community who face further discrimination.

Following the model of Shanga, a crafts organization for people with disabilities in Arusha, Tanzania, I will measure the success of the project through quantitative measures of profit gained for each individual. However, recent medical sociology has also supported the collection of personal stories to document the success of programming within social and cultural context (Polletta, 2011). Therefore, I will also document personal stories to measure the success of the project.