

**Marie Schuler**

**'Out of the Shadows'? – On the Pragmatics of Dealing with Epilepsy and the Impact of Sensitization in Kabale, Uganda**

The aim of this presentation is to critically review the introduction of a specific concept of epilepsy to a community in Uganda in the form of sensitization as a way of educating people in order to change their behaviour. Since the Global Campaign Against Epilepsy was introduced to several African countries under the aegis of the World Health Organization (WHO), the International League Against Epilepsy (ILAE), and the International Bureau for Epilepsy (IBE) in 2000, epilepsy is treated as a major health concern in Uganda. It is the aim of the campaign to bring epilepsy 'out of the shadows' by means of overcoming the treatment gap. Sensitization about epilepsy is anchored in a biomedical understanding of the condition: epilepsy is seen as a universal neurological condition for which medical intervention in the form of drugs is the solution. The phenomenon of disability or illness is therefore reduced to the function of the body and does not take socio-economic, cultural or political factors into account. Furthermore, within a culturalist approach, 'traditional beliefs' are seen as major obstacles to the desired compliance of patients, their social network and the community. The core idea of sensitization lies in the assumption that people behave in a certain way because of a lack of specific information and that the provision of that knowledge leads directly to a change in practices.

On the basis of ethnographic data and case studies collected in South-Western Uganda within the fieldwork for my MA thesis, the influence of sensitization is critically assessed. By examining the ways sensitization is locally understood and applied and by looking at individual cases of people with epilepsy and their caretakers trying to find a way to deal with their condition, several points become clear. On the basis of ethnographic data and case studies collected in South-Western Uganda within the fieldwork for my MA thesis, the influence of sensitization is critically assessed. By examining the ways sensitization is locally understood and applied and by looking at individual cases of people with epilepsy and their caretakers trying to find a way to deal with their condition, several points become clear.

The universalistic, reductionist biomedical approach is incommensurable to the manifold local understandings of epilepsy, wherein two different concepts, *ensimbu* and *ebiyaga*, are of importance. The first one is usually treated by medical personnel, whereas the occurrence of the latter often leads to the consultancy of a traditional healer or herbalist. Although the local construction of epilepsy certainly plays a crucial role, people are not trapped in their culture but reflect on their lives and rationally adjust their behaviour. Furthermore, changes in knowledge do not necessarily lead to changes in practice and the so-called problem is not merely a lack of information. Thus, it is a very complex process of how individuals and their caretakers make sense of epilepsy and take specific actions to deal with it – a process that is shaped by negotiation, experiences and strategies. An anthropological approach within disability studies opens the chance to perceive the way of dealing with epilepsy as an on-going negotiation process in a context of various perspectives on it. Without denying the benefits and desirability of medicalization and awareness raising about epilepsy or the increased possibilities of support groups, it needs to be recognized that the influence of sensitization with this biomedical and culturalist approach is limited and involves the danger of distracting attention from the role of poverty and other inequalities concerning questions of disability and illness.