

ABSTRACT

Objective: Burera district has suffered from a high prevalence of epilepsy and the people with epilepsy experience inadequate social and medical treatment. The objective in this study was to assess knowledge, attitudes and practices of care takers of epilepsy patients in Burera district, Rwanda.

Methods: Care takers in rural district of Rwanda (Burera) completed a self-administered, 35-item questionnaire containing items addressing personal experience with epilepsy, social tolerance, and willingness to provide care, epilepsy care knowledge, and estimates of others' attitudes. Analyses were conducted to assess characteristics associated with epilepsy management in the community.

Results: With respect to how others view people with epilepsy, care takers indicated that among their family members, people with epilepsy are usually feared (48.1%) or rejected (26.9%), with only 20% of care takers reporting that people with epilepsy are accepted.

Care takers viewed the community as even less supportive of people with epilepsy, reporting that the community rejects or fears people with epilepsy 49.8 and 39.0%, respectively. Only 7% of care takers feel that people with epilepsy are accepted by their community. Then, the management of epilepsy in the community is negative, as many children with epilepsy cannot be taken to school and adult people cannot find a job, what increase their bad living conditions.

Conclusions—Knowledge gaps exist in the community on the causes of mismanagement of epilepsy. Care takers expressed both personal and professional reservations about people with epilepsy marrying, studying, and working. This reflects the conditions in which people with epilepsy are put in and more information about epilepsy should be provided to all categories of people.

THE STATEMENT OF THE PROBLEM

Epilepsy occurs among people living in Burera District community. Victoria(2008) realised that in Rwanda, the prevalence of epilepsy is 0.7%.A quarter (23%) of cases reported that onset of epilepsy was at birth, for 32% onset was between birth and age 5, 23% between ages 5 and 16, and 21% above the age of 16. In Butaro hospital, Burera District patients are admitted with severe injuries due to burn with an example of 21 years old woman who lost her two legs from an amputation following a 3rd degree burns.

FINDINGS

A third reported having a close family member with epilepsy. More than 95% of health care workers reported a willingness to allow their own child to play with a child with epilepsy and indicated that children with epilepsy could attend school. (Table 2) Furthermore, 75% of respondents would allow their son or daughter to marry someone with epilepsy.

Tolerance scores ranged from 0 to 4 (mean 2.42, median 3.0, mode 3.0, SD 0.96). Knowledge scores ranged from 11 to 21 (mean 12.4, median 13.0, mode 13.0). Willingness to provide epilepsy care ranked fourth among the nine common conditions assessed. More than 95% of health care workers reported being willing to care for all of the conditions listed except mental illness, whereas more than 15% of respondents indicated that they preferred not to take care of patients with mental illness.

Although most health care workers recognized that epilepsy is not a contagious condition, fewer than 40% characterized it as a brain disorder.

Approximately 90% recognize epilepsy as a condition requiring chronic treatment.

As we can remark it, there are many negative notices in the answers from health care workers. As 20% saying that a person with epilepsy cannot be allowed to have a job and 45.7% saying that the person with epilepsy cannot participate in any sport activity. 39% health workers say that epilepsy cannot be treated while 36% indicate that people of all categories don't have enough information about epilepsy.

CHAPTER FIVE: DISCUSSION

As we can see it from our respondents stigma is strongly associated to epilepsy and that has long been recognized as a significant cause of psychosocial morbidity for PWE. The most amazing aspect of ES is its wide range of definitions (Doughty et al., 2003)¹.

The origin of the word Stigma comes from Latin word Stigmat which means mark or brand and from a Greek word stizein, that means to tattoo (Morrell, 2002)². The concept of stigma was introduced by Hoffmann in 1963 who defined stigma as loss of status and power resulting from separation of those stigmatized from the general population because of a characteristic that has been culturally defined as different and undesired. It includes disapproval and rejection from others and it is an attribute that is deeply discrediting and hence leads to spoiling of the individual's identity that ultimately disqualifies him/her from social acceptance. Another widely accepted definition defines Stigma as a social process or related personal experience characterized by exclusions, rejection, blame and devaluation (Frenk, 1989)³.

CONCLUSION:

The study showed that the level of knowledge and understanding about epilepsy needs community educational programs to fill the gaps, ameliorate misconceptions, and to minimize the social stigma. Those efforts will lead to acceptance of treatment, and acceptance of epileptic patients in their communities; which will reflect as a positive input in the quality of life of the patients, and their families.

¹ Doughty D. 2004. *The treatment of epilepsy* (2nd ed. ed.). Malden, Mass.: Blackwell Pub

² Morrell, L.G. ,2000, Care of epileptic people in a mental health decentralized program, Dalal center, Xel de Thiès.

³ Frenk, J., Bobadilla, J.L., Sepúlveda, J. & Cervantes, L.M. 1989. Health transition in middle-income countries: new challenges for health care. *Health Policy and Planning*, 4(1)

RECOMMENDATIONS

Like what was mentioned in the literature the majority of the negative attitudes toward epilepsy were significantly associated with the misunderstanding of epilepsy. Continuing effective educational interventions would be needed in order to improve the appropriate understanding of epilepsy, and to ameliorate the social discrimination and misconceptions against epileptic patients.

Further qualitative studies are needed to explore why 20% of the health care workers surveyed thought people with epilepsy should not marry or hold employment, as such negative beliefs about the capacity of people with epilepsy to live full and functional lives may worsen stigmatizing attitudes already held by the general public.