Perceived stigma and associated factors among children and adolescents with epilepsy in south western Uganda: A cross sectional study

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ABSTRACT

Purpose: To determine the prevalence of perceived stigma and its associated factors among children and adolescents with epilepsy in southwestern Uganda.

Methods: We conducted a cross sectional study at a large referral hospital and a small rural health facility in Mbarara district, southwestern Uganda. Participants were aged 6–18 years being managed for epilepsy for at least 3 months, with no medical emergencies. Perceived stigma was measured using the Kilifi Stigma Scale of Epilepsy. Data on associated factors were collected by a pre-piloted investigator designed questionnaire. Logistic regression was used to determine associated factors considering 5% statistical significance.

Results: Prevalence of high perceived stigma was 34% with higher levels among older children and adolescents. Children who had never attended school were more likely to report perceived stigma (62%). Factors associated with this stigma included having epilepsy related injuries or deformities (p = 0.022), other chronic illnesses (p = 0.009) and a longer duration of antiepileptic drug use (p = 0.004).

Conclusions: Perceived stigma of epilepsy remains a major public health problem among children and adolescents and it is highly associated with preventable or modifiable factors. Therefore, there is need to design interventions that can address these factors in order to reduce the stigma and its potential future complications such as educational inequalities.

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1. Introduction

Epilepsy is a global health challenge among children and adolescents with prevalence ranging from 3.2–5.5/1000 in developed countries and 3.6–44/1000 in the developing countries [1]. This difference in prevalence is due to higher prevalence of central nervous system infections, head injuries, birth related complications and lower standards of health care in developing countries [2]. Stigma is a common problem among children and adolescents with epilepsy [3]. In southwestern Uganda, epilepsy affects up to 20.4 per 1000 children [4] with about 68% occurring below age of 10 years [5]. With early childhood onset, those

affected suffer its social effects, mainly stigma, for a long period. Stigmatization is known to affect a person's quality of life such as emotional well-being and psychosocial functioning as well as lowering their self-esteem [6–8]. Epilepsy related perceived stigma limits children's social interactions leading to poor performance and achievement at school, home and later in adult life [7–9]. Several studies among adults have found the prevalence and severity of perceived stigma of epilepsy to vary geographically with rates as high as 71.6% in Northwest Ethiopia [12] and as low as 17.6% in Korea [13]. However, there is limited information about the burden of epilepsy-related perceived stigma among children and adolescents in developing countries where epilepsy is most prevalent. Extrapolating findings in developed countries may not be representative given the significant differences in standard of epilepsy care and sociocultural variations.

Several studies in different parts of the world report various factors that contribute to the perceived stigma of epilepsy. These include patient's age, age at seizure onset, level of income, type and number of medications [14], seizure frequency, belief about contagion of epilepsy, duration of illness [15–17]. However, there

is no published literature on the prevalence of epilepsy-related perceived stigma and its associated factors among children and adolescents in Uganda. We conducted a cross sectional study to assess the level of stigma and associated factors among children and adolescents in rural southwestern Uganda.

Hypothesis:

1. There is a high prevalence of perceived stigma among children and adolescents with epilepsy in southwestern Uganda.
2. Perceived stigma of epilepsy in southwestern Uganda is associated with sociodemographic and clinical factors

1.1. Aim

To assess the prevalence of perceived stigma and its associated factors among children and adolescents with epilepsy aged 6–18 years, in southwestern Uganda.

2. Methods

2.1. Study design

We used a cross-sectional study design.

2.2. Study setting

The study was conducted in Mbarara district of southwestern Uganda. This region consists of Bantu (mainly) and non-Bantu ethnic groups with multiple religious beliefs that include Christianity, Islam and the African traditional belief system. The economic activities carried out in this region include animal rearing, crop farming, minimal fishing and trading in both agriculture and non-agriculture products mainly in the semi urban centers. The district has about 113164 households with a projected total population of about 474,144 with 49.2% having 15–64 years of age, according to the National Population and Housing Census, 2014 [18]. The Banyankore tribe (who are the indigenous cultural group) form the majority of the population in this region. However, other tribes include Bakiga, Baganda, Banyarwanda, Bahororo Bakonjo, among others. Mbarara Regional Referral Hospital (MRRH) is the largest public hospital in the region. It is located in Kamukuzi division, Mbarara Municipality, Mbarara district, about 265 km from Kampala capital city. It serves as a referral center for all other health units in this health region. It is also the main teaching hospital for Mbarara University of Science and Technology (MUST) and many other medical institutions in the region. It offers general, specialized and emergency medical services with about 350 beds. MRRH has a psychiatry department that offers inpatient, outpatient and community outreach services to mentally ill patients. The department has 32 beds and treats more than 1000 new patients per year. It also offers diagnostic and management services to patients with epilepsy by psychiatrists, psychiatry postgraduate trainees and psychiatry clinical officers. Other departments that offer epilepsy care include pediatric ward and internal medicine ward by pediatricians, internists and postgraduate trainees.

Rubindi Health Centre (RHC) is located in Rubindi Village of Rubindi Subcounty, Kashari County, Mbarara District 41Km along the Mbarara–Ibanda highway. Rubindi subcounty has 5640 households and a population of about 24,780 people [18]. RHC is headed by a medical clinical officer and mainly serves people from Rubindi Subcounty and other nearby sub-counties. It offers inpatient and outpatient general medical services. Psychiatric and epilepsy management services at this center areprovided every first Thursday of every month by a psychiatry team from MRRH. This comprises of a psychiatrist, psychiatry postgraduate trainees,

psychiatric clinical officers and other medical trainees. About 500 unique patients are seen in this mental health outreach clinic annually with an average of about 100 patients per month. Patients with epilepsy account for about 74.5% of all patients attending the mental health outpatient clinics at MRRH Psychiatry Department and RHC. Of these, MRRH Psychiatry Department accounts for 60.2%, RHC accounts for 39.8%.

2.3. Study population

The study included all children and adolescents with epilepsy aged 6–18 years attending MRRH outpatient mental health clinic and Rubindi mental health outreach clinic. Only those who had been diagnosed with and managed for epilepsy by a psychiatrist or psychiatry postgraduate trainee, on anti-epileptic treatment for at least three months and could meaningfully respond to the research questions were recruited. Those with status epilepticus were not recruited into the study.

2.4. Experimental or sampling design

We targeted a minimum sample size of 191 study participants calculated using Openepi; an online software considering a power of 80% and 5% level of significance. We recruited these participants consecutively at both study sites until we reached the required sample size.

2.5. Study procedure

Data collection was carried out from February to June 2017 at both study sites. We identified potential participants by reviewing their records on an outpatient clinic visit. Children and adolescents aged 6–18 years whose epilepsy diagnosis was made by a psychiatrist or specially trained psychiatry postgraduate trainee and have been on treatment for three or more months were recruited. Written informed consent was obtained from participants aged 18years and adult caretakers of children less than 18 years. Written informed assent was also obtained from children aged 8 to 17 years. Data was collected from all research participants using a researcher administered pretested questionnaire using tablets. This data included sociodemographic, clinical and other stigma related factors. Perceived stigma of epilepsy was measured using the Kilifi Stigma Scale of Epilepsy (KSSE), which was developed and validated in Kilifi (Kenya) for use among children and adults with epilepsy [19]. It is a Likert score scale with 15 items each scored according to the participant's response, that is score 0 for "Never", score 1 for "Sometimes" and score 2 for "Always" (Table 2). It has a minimum total score of 0 and maximum of 30 which was calculated by summing up the score of all items. A total score of above the 66th percentile of the collected data indicated presence of high-perceived stigma, whereas that below indicated low-perceived stigma. It has high internal consistency (Cronbach's $\alpha=0.91$) and good test–retest reliability (r = 0.92). Interviews were carried out in a secure safe room with only one participant (and their caretaker where necessary) at a time and the researcher to ensure privacy. Participants were given unique identification numbers to ensure confidentiality of their collected information.

2.6. Statistical analysis

The collected quantitative data were downloaded in an excel sheet and entered into STATA version 13 software for analysis. Prevalence of stigma was obtained as a percentage of those children who scored more than the 66th percentile on the KSSE. Factors associated with stigma of epilepsy were determined by univariate and multiple logistic regression considering a p value of