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.

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 α=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

Table 1
Distribution of socio-demographic variables among children and adolescents with epilepsy at MRRH and RHC February–June 2017 (n = 191).

Variable	Children with high perceived stigma (n = 65)	Children with low perceived stigma (n = 126)	p values
Average age (years)	15.6 (S.D = 2.9)	14.5 (S.D = 3.7)	**0.025**
Sex			0.377
Male	37 (31.6%)	80	
Female	28 (37.8%)	46	
Residence			0.274
Semi urban	18 (40.9%)	26	
Rural	47 (32.0%)	100	
Main care giver			0.699
Mother	31 (32.6%)	64	
Father	16 (27.1%)	43	
Grand mother	5 (50%)	5	
Sibling	4 (36.4%)	7	
Others	9 (56.3%)	7	
Tribe			0.418
Munyankore	53 (35.8%)	95	
Muganda	8 (34.8%)	15	
Mukiga	2 (14.3%)	14	
Others	2 (50%)	2	
Education level			0.403
Never	8 (61.5%)	5	
Primary	39 (30.5%)	89	
Secondary	17 (37.8%)	28	
Tertiary	1 (20.0%)	4	

< 0.05 and 95% confidence interval. These included sex, age, epilepsy related injuries and deformities, other chronic medical illnesses, anti-epileptic drug use and its related factors, patients' belief about contagion, and location of the participant's school.

2.7. Ethical approval

Approval to conduct the study was obtained from Mbarara University of Science and Technology Research Ethical Committee; approval number 14/10–16.

3. Results

The study involved 191 children with epilepsy and the prevalence of high-perceived stigma of epilepsy as measured by the KSSE was 34.0% and was higher among older children (Table 1). Participants' ages ranged from 6 to 18 years with an average of 14.9 years and standard deviation of 3.5 (Table 1). Many of the participants were males (61.3%), from a rural setting (78%), living with their biological parents (80.6%) and of Banyankore tribe (45%). Most children and adolescents' response to the KSSE was "sometimes" (1273 responses) as indicated in Table 2 and the mean perceived stigma score was 15.9, standard deviation (S.D) = 8.8.

Perceived stigma of epilepsy was strongly associated with having epilepsy related physical injuries and deformities, having other chronic illnesses and long duration of anti-epileptic drug use. The commonest epilepsy related physical injuries and deformities (secondary to untreated or suboptimally controlled illness), included wounds and scars resulting from burns and other epilepsy related accidents contractures and fractures. Burns are often secondary to falling into open fireplaces, cooking stoves and other hot objects. Other chronic illnesses included HIV/AIDS, cerebral palsy and psychiatric disorders such as Attention Deficit Hyperactivity Disorder, psychosis, emotional and mood disorders. The odds of having high-perceived stigma was 3.8 times higher among children and adolescents having epilepsy related physical deformities or injuries and 5.5 times higher for those having other chronic illnesses than other children with epilepsy (Table 3). In addition, the odds of having perceived stigma were 1.2 times higher among those children and adolescents with long duration of antiepileptic drug use compared to those with a short duration (Table 3). Sex, age, seizure frequency and belief about contagion of epilepsy by the patient were not significantly associated with having stigma.

Multiple logistic regression was done taking all factors that could influence stigma simultaneously (Table 4). After controlling

Table 2
Number of responses by children and adolescents with epilepsy as per each KSSE item at MRRH and RHC February-June 2017.

No.	Question	Not at all	Sometimes	Always
1	Do you feel different from other people?	48	83	60
2	Do you feel lonely?	47	88	56
3	Do you feel embarrassed?	37	90	64
4	Do you feel disappointed in yourself?	47	82	62
5	Do you feel you cannot have a rewarding life?	53	85	53
6	Do you feel you cannot contribute anything in society?	62	80	49
7	Do you feel you cannot join others in public places?	47	85	59
8	Do you feel other people are uncomfortable with you?	44	83	64
9	Do you feel other people don't want to go to occasions with you?	46	87	58
10	Do you feel other people treat you like an inferior person?	49	76	66
11	Do you feel other people would prefer to avoid you?	35	91	65
12	Do you feel other people avoid exchanging greetings with you?	49	89	53
13	Do you feel you are mistreated by other people?	39	87	65
14	Do you feel other people discriminate against you?	36	89	66
15	Do you feel other people treat you like an outcast?	75	78	38
	Total	**714**	**1273**	**878**

Table 3
Factors associated with perceived stigma among children and adolescents with epilepsy (n = 191); univariate logistic regression.

Variable	Odds ratio	Confidence interval	p value
Sex	1.32	0.71–2.42	0.378
Age	1.10	0.99–1.21	0.053
Participant's belief that epilepsy is contagious	0.67	0.34–1.33	0.254
Having epilepsy related physical deformities and/or injuries	3.80	2.02–7.18	<**0.001**
Number of times of forgetting to take AEDs	1.02	0.99–1.06	0.194
Having other chronic illnesses	5.49	1.99–15.09	**0.001**
Getting undesirable effects of AEDs	1.12	0.61–2.05	0.723
Duration of AEDs use	1.22	1.12–1.33	<**0.001**
Duration of epilepsy	1.08	0.98–1.20	0.126
Estimated number of seizures in the last three months	1.03	0.97–1.09	0.262

Table 4
Factors associated with perceived stigma among children and adolescents with epilepsy (n = 191); after multiple logistic regression.

Variable	Univariable regression			Multiple regression		
	Odds ratio	*Confidence interval*	*p value*	*Adjusted Odds ratio*	*Confidence Interval*	*p value*
Sex	1.32	0.71–2.42	0.378	*1.04*	*0.93–1.18*	*0.481*
Age	1.10	0.99–1.21	0.053	*1.43*	*0.71–2.89*	*0.314*
Having epilepsy related physical deformities and/or injuries	3.80	2.02–7.18	0.000	2.48	1.14–5.38	**0.022**
Number of times of forgetting to take AEDs	1.02	0.99–1.06	0.194	1.02	0.98–1.06	0.432
Having other chronic illnesses	5.49	1.99–15.09	0.001	4.29	1.43–12.85	**0.009**
Participant's belief that epilepsy is contagious	0.67	0.34–1.33	0.254	0.47	0.21–1.08	0.074
Duration of AEDs use	1.22	1.12–1.33	0.000	1.16	1.05–1.28	**0.004**

for age; sex; missing anti-epileptic drugs and belief that epilepsy is contagious, some factors remained significant. These are; having epilepsy related physical deformities or injuries (adjusted OR (aOR) = 2.48, p value = 0.022), having other chronic illnesses (aOR = 4.29, p value = 0.009) and longer duration of antiepileptic drug use (aOR = 1.16, p value = 0.004).

4. Discussion

This study was conducted to assess the level of stigma and its associated factors among children with epilepsy aged 6–18 years, in southwestern Uganda. In this study population of youth with epilepsy, the prevalence of high-perceived stigma was 34%. It was highly associated with having epilepsy related physical deformities or injuries, having other chronic illnesses (including medical and psychiatric comorbidities) and longer duration of anti-epileptic drug use.

The prevalence of perceived stigma of 34% found in this study is closely similar to what has been found among adults with epilepsy in other places such as 34% in Turkey [15], 31.2% in Ethiopia [20] and 33% in Kenya [19] assessed using the same scale (KSSE) and 39.1% in Ecuador [21]. However, the prevalence in this study was lower than what was found in northwest Ethiopia (71.6%) [12], Croatia (53%) [16] and Benin 68.7% [22]. These differences may be due to stigma scales used (such as modified Family Interview Schedule (FIS), Explanatory Model Interview Catalogue (EMIC) and Jacoby's stigma scale, among others), different study settings, socio-cultural understandings of epilepsy and general participant characteristics.

On the other hand, our prevalence is higher than what was found in Iran (23.7%) [23], and 17.6% in Korea after one year of follow up [13]. Again, the difference may be due to the differences in, health care systems and study settings. It may also be due to the difference in stigma scales used since they have different psychometric properties, different number of items and different target/study populations (adults).

Having epilepsy related injuries or physical deformities was highly associated with stigma in this study, similar findings have

been reported in Ethiopia and Zambia though patient's belief about contagion of epilepsy was not [20,24]. Epilepsy-related injuries (and subsequent physical deformities) may also be due to the treatment gaps that are more common with chronic illnesses and chronic medication use in Sub Saharan Africa [25]. There are many barriers to consistent access to treatment for epilepsy in Uganda, which include system-wide intermittent availability of medications and limited health human resources (including few providers with expertise in the diagnosis and treatment of epilepsy). Additionally, limited ability for individuals to pay out-of-pocket for medications, geographical discrepancies (difficulty to access clinics from rural areas), difficulty for caretakers to leave household or occupational duties to travel to clinics, and limited access to transportation for many families halt access to treatment. Delayed access to treatment or inconsistent or suboptimal treatment leaves individuals vulnerable to physical injuries and impaired function secondary to their epilepsy. Improving consistent access to AEDs for youth with epilepsy would help decrease risk of physical injuries from seizures. If youth have fewer physical markings from their illness, this may help reduce perceived stigma.

Further, having other chronic illnesses and longer duration of AED use was found to be associated with high levels of perceived stigma which are in line with previous findings in Zambia [26]. However, findings from other studies in other continents have found no association between duration of AED use and perceived stigma [21]. This raises the possibility that local beliefs about medication use contribute to the perceived burden of epilepsy. This may be due to individual beliefs and community concern about the meaning of long-term use of medication as well as incurability of such illnesses. Children with high-perceived stigma were more likely not to attend school which makes them vulnerable to future inequalities due to the lack of education, and risks greater levels of functional impairment from their epilepsy.

Understanding the factors that influence perceived stigma offers opportunities to design interventions to potentially reduce these negative beliefs about self. If reducing stigma leads to improved school attendance and community acceptance, this may help improve these children's trajectories and future

opportunities. On an individual level, possible interventions include educating individuals and families on how to prevent epilepsy related injuries such as avoiding risky activities like cooking, driving, reckless use of roads among others. Providing community-based education on the local level about the symptoms, causes, and treatment of epilepsy may also lead to earlier access of care and to help to gradually change the understanding and beliefs about this illness. This may also help reduce perceived stigma if there is a greater degree of health literacy in the general population. Further, to reduce the physical consequences of untreated epilepsy, improving consistent access to treatment is imperative. A consistent, reliable supply of affordable (or publically funded) AEDs for youth is critical. Training more community-based local health care providers to assess, prescribe for, and monitor youth with epilepsy would also improve access to care, potentially reducing delays in treatment or suboptimal treatment that can result in physical injuries from seizures. The community outreach model of care established by our local department, and the recent integration of a community-based specialist residency-training program are two systems-level interventions that may help improve access to care. Training local physicians to provide care in rural and semi-urban underserved settings will hopefully increase capacity, improve treatment access, reduce epilepsy-related complications, and subsequently help reduce perceived stigma over time.

Sex and age of the child had no significant association with perceived stigma contrary to findings in some other places [27], which may be because this study mainly involved children and adolescents unlike those that involved adults.

However, this was a health facility based study and this may have limited the level of participation since there are other children with epilepsy who do not access health facilities. Therefore, our findings may not be generalized to all children and adolescents with epilepsy in southwestern Uganda. Hence, there is need for bigger community surveys that may include many more participants from different settings. In addition, the cross-sectional study design depended on the individual's recall of their experiences. Some of the participants had recall difficulties. This could have affected the outcomes of the study. The opportunity to follow a cohort longitudinally could reduce the impact of recall bias in future studies.

5. Conclusions

Perceived stigma of epilepsy remains a major burden among children and adolescents in southwestern Uganda. It is highly correlated with school non-attendance among those who are most impacted by perceived stigma. Reduced school attendance, can result further inequalities for this vulnerable population and result in a trajectory with lower levels of function lifelong. Providing increased individual and community-based education may help change beliefs about epilepsy, and reduce perceived stigma. Additionally, improving access to consistent, quality epilepsy care may decrease physical injuries from untreated seizures and subsequent permanent markings that are associated with higher perceived stigma. Increasing the number of trained health care providers may help close the gap between local outcomes and those in more highly resourced countries. Working toward these system changes may help reduce the burden for youth with epilepsy and ultimately improve their long-term function and quality of life.

Ethical approval and consent to participate

Ethical approval to conduct the study was obtained from MUST REC (approval number: 14/10-16). In addition, permission to

collect data was sought from the administrators of both MRRH and RHC. Written informed consent to participate was obtained participants aged 18 years. Assent was obtained from children aged 8 to 17 years and consent was obtained from their parents or adult caretakers.

Availability of data and material

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

"The authors declare no competing interests"

Authors' contributions

KJ: developed the research question and was at the center of all activities involved in the study as well as coordinating the team.

NM contributed in proposal writing, data collection and manuscript writing

RF, contributed in proposal writing, literature review and manuscript writing

GZR was the main supervisor and mentor of the study. He offered technical advice and participated in all activities of the study and manuscript writing.

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