

Prevalence and Factors Associated with Perceived Stigma among Patients with Epilepsy in Ethiopia

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Abstract

Background: Epilepsy stigma is considered to be one of the most important factors that have a negative influence on people with epilepsy. Among all types of stigma perceived stigma further exerts stress and restricts normal participation in society. There are limited researches conducted on perceived stigma and associated factors among patients with epilepsy in developing countries including Ethiopia.

Methods: Hospital based cross-sectional quantitative study was conducted from May 1, 2013 to May 30, 2013 G.C. All patients with epilepsy in Ethiopia were source population. Patients with epilepsy treated from neuropsychiatric department at Amanuel Mental Specialized Hospital during study period were the study population. The sample size was determined using single population proportion formula and 347 subjects were selected by using systematic random sampling method. Data was analyzed by using SPSS version 20.

Results: A total of 346 participants with mean age of 29.3 ± 8.5 SD participated with a response rate of 99.7%. The prevalence of perceived stigma was 31.2%. Age range between 18-24 [AOR=2.84, 95% CI: 1.02, 7.92], difficulty to attend follow up because of fear of stigma [AOR=3.15, 95%CI: 1.19, 8.34], seizure related injury [AOR=1.88, 95% CI:1.12, 3.15] and contagion belief [AOR=1.88, 95%CI: 1.10, 5.08] were significantly associated with perceived stigma.

Conclusions: Perceived stigma was found to be a common problem among patients suffering from epilepsy. The results reinforce the need for creating awareness among patients with epilepsy and addressing misconceptions attached to epilepsy, and educating how to cope to the stigma.

Keywords: Perceived stigma; Epilepsy; Amanuel hospital

Introduction

Epilepsy is basically a chronic brain disorder characterized by recurrent derangement of the nervous system due to sudden excessive disorderly discharge of the cerebral neurons [1]. It is a neurological condition that knows no geographic, social, or racial boundaries, occurring in men and women and affecting people of all ages [2]. It affects approximately 50 million people worldwide [3]. The population prevalence of epilepsy varies across countries from 0.5 to 5%. The higher levels tend to be seen in developing countries where fewer than 50% of cases receive medication [4]. In a large community-based epidemiological study, the prevalence of epilepsy in Ethiopia was reported to be 5.2/1000 population [5,6]. The incidence was also reported to be 64/100,000 population as reported in a community-based study conducted in Mescal and Marko districts of rural central Ethiopia [7]. Stigma is social process or related personal experience characterized by exclusion, rejection, blame and devaluation and is a phenomenon associated with many chronic health conditions, including leprosy, HIV/AIDS, mental illness, epilepsy, disability and tuberculosis. Stigma and its psychosocial consequences cause indescribable suffering to those who are stigmatized. In addition, stigma has indirect but strongly negative implications for public health efforts to combat the diseases concerned [8]. Epilepsy has a considerable psychological and emotional impact on PWE. Uncontrolled seizures can be very unsettling. People may fear even going outside their homes unaccompanied. They may fear what people might think of them if they were to have a seizure in public. Across the world and throughout history, epilepsy has been a culturally devalued condition and awareness about epilepsy is usually very low. Such devaluing and lack of awareness often leads people with epilepsy being stigmatized, discriminated, excluded from society, problems at work, economic difficulties, bearing a psychosocial burden as well as inappropriate treatment [9-26]. From the patient's view,

the diagnosis of epilepsy triggers a change in perception, bringing on fears of being different and anxiety about the future in the community, with apprehension about getting a job or starting a family [10,27-33]. Understanding and reducing epilepsy-associated stigma is one of the stated aims of the World Health Organization's Global Campaign Against Epilepsy (GCAE) "Out of the Shadows" initiative [11]. The identification of the people with epilepsy's needs and the promotion of public and professional education about this condition would offer to the patient a greater quality of life in terms of feeling better. It is apparent that medical management of epilepsy alone is not always enough to control its psychological consequences. Services that enable people to deal with negative reactions and which facilitate a realistic perception of the limitations imposed by the condition may contribute substantially to the reduction of stigma [14,20]. Little is known about perceived stigma among people with epilepsy in Ethiopia and limited published research which focuses exclusively on people with epilepsy in Ethiopia regarding prevalence of perceived stigma. We therefore conducted hospital-based cross-sectional survey at AMSH where outpatient service is provided for people with epilepsy in order to estimate the magnitude of stigma perceived by patients and to identify socio-demographic and other factors which might contribute to perceived stigma in this setting.

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Literature Review

Overview of stigma

A stigma is a sociologic concept, which includes occurred realities in all societies. Everywhere in the world, having a chronic disease is a handicap for individuals who are characterized as deviant. What can differ from one society to another is the answer given to this deviance and the nature of stigma. Why such behavior is accepted in a society and is strongly opposed in another? Cultural beliefs and practices affect the management of epilepsy, especially in countries where epilepsy is still misunderstood [34-36]. Epilepsy associated stigma 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. 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'. 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 disqualifying him/her from social acceptance. Another widely accepted definition of stigma is a social process or related personal experience characterized by exclusion, rejection, blame and devaluation [29].

Based on these definitions ES has been divided in to three kinds.

1. Courtesy ES: Is kind of ES that affects the whole family members and also those who have association with the patient [29].
2. Enacted ES: Refers to actual episode of discrimination against PWE only on the pretext that they suffer from Epilepsy [29].
3. Perceived ES: It refers to feeling of shame of being epileptic with its associated oppressive fear of encountering enacted stigma [29]; and is the concern of this study. Data from developed countries indicates that today felt stigma may be more limiting for PWE than enacted stigma. Felt stigma may result in the stigmatized person volitionally limiting their life experiences and opportunities in an effort to avoid enacted stigma [30].

Causes of stigma

There are many different causes of stigma which may vary according to the health condition. The most common ones are discussed here.

Fear: Fear is a common cause. This may be fear of catching a disease that is infectious (or perceived to be so), fear of death and fear of people that are thought to be dangerous. Unpredictable situations may also cause fear, such as with people with epilepsy. Fear can lead to stigma among members of the public or among health workers, but also among people who are affected with the condition themselves. The latter may fear the social consequences of disclosure of their condition. This is in fact fear of stigma [32].

Unattractiveness: Some conditions can cause people to be perceived as unattractive, particularly in cultures where outward beauty is highly valued. In that case, people with visible impairments on their face, People with facial skin lesions or burns may be rejected just because of the way they look [32].

Unease: Very visible conditions may make people feel uneasy or uncomfortable. They may not know how to behave in the presence of a person with such a condition and therefore choose to avoid the person.

These can be small things, such as not knowing how much to look at a person. Looking too much may be perceived as staring; not looking enough may be perceived as avoidance [32].

Association: Stigma by association is also known as 'symbolic stigma'. This may occur when a health condition is associated with a condition that is perceived to be undesirable. Examples are conditions that are associated with commercial sex work, illicit drug use, a particular sexual orientation, poverty or loss of employment. One condition may also become more stigmatized, because of association with another condition [32].

Values and beliefs: Values and beliefs can play a powerful role in creating or sustaining stigma [32].

Policies or legislation: Policies about how and where conditions are treated may cause stigma. This is typically seen when conditions are treated in separate locations. Special clinic days or hours in an outpatient department can have the same consequences. Other examples are immigration or employment policies requiring people with certain conditions to declare their status. Laws may be discriminatory, allowing divorce on grounds of the spouse having or developing a particular health condition or banning people from public office, elections or land ownership [32].

Lack of confidentiality: Unwanted disclosure of one's condition can be due to the way test results are handled or due to deliberate disclosure by health staff or careless handling of confidential data. This may be completely unintended, such as the sending of a reminder letter or a visit by a health worker in a vehicle marked with the programmed logo [32].

Prevalence of Perceived Stigma

According to study conducted among more than 5,000 patients living in 15 Countries in Europe 51% reported feeling stigmatized, with 18% reporting feeling highly stigmatized [33]. Another study conducted in Via Christi Comprehensive Epilepsy Center in Wichita, KS, USA on PWE indicates that Approximately 34% of the respondents who are on AEDs indicated they had belief that the general public had negative feelings and reactions toward individuals with epilepsy [34]. The case-control study conducted in Cambodia, reveals that the mean perceived stigma in the population was 1.9-1.1 on a range of 0-3 and about 46% cases reported highest stigma score [35]. Another institutional based Cross sectional study conducted at Brooklyn Hospital Academic medical center on patients with epilepsy came from different countries reveals that 69% of respondents fulfill the criteria of perceived stigma [36]. According to community based cross sectional study conducted in Campinas Brazil on 1850 PWE; the overall score for epilepsy stigma perception was 42 (range, 3-98; SD, 14) [37]. According to the institutional based cross sectional study conducted in Iran, the Gulf, and Near East on 3,889 people with epilepsy attending epilepsy clinic, about one third (~33%) of the patients felt stigmatized by their epilepsy(38). A community based cross sectional study conducted in Benin reveals that the mean score of perceived stigma with the Jacoby's stigma scale was 6.9 - 3.6, with values ranging from 3-12. The lower quartile, median, and upper quartile values were, respectively, 3.0, 6.0, and 11.7. The proportion of PWE who felt stigmatized by their condition was 68.7%, and 38.8% of them reported high feelings of stigma [38,39]. According to case-control study conducted in Zambia Lusaka on 169 adults who were on follow up at epilepsy clinic the median stigma score was 2.5 [40]. A Descriptive cross-sectional survey conducted in Kilifi Kenya on 673 respondents reported that 33% felt stigmatized as measured by the KSSE [41]. According to the institutional based cross

sectional study which was conducted in Butajira, Ethiopia on 831 respondents with mean age of 26.5+12.7 years, the prevalence estimate of perceived stigma was 81% [42].

Factors Associated with Perceived Stigma

A study conducted in European countries reported that people with epilepsy who experienced injury reported high feeling of stigma [33]. Another case-control study conducted in Zambia reveals that; higher stigma scores were associated with community disclosure, being greatest for those who had forced disclosure either through a public seizure or someone else revealing their condition to the community. People who believed their condition to be contagious or who reported contagion beliefs from within their community also had higher felt stigma. Stigma scores were not associated with age, gender, stigmata, wealth, and seizure-type or seizure frequency [40]. The cross sectional study conducted in Kilifi Kenya reported that younger age is associated with Perceived stigma [41].

Significance of the Study

There is high prevalence and different factors which contribute for the development of perceived stigma that leads to negative consequence on many domains of the lives of people living with epilepsy in the developed world; like impacts on daily activity, recovery from the illness, inability to take their drug daily, unwillingness to seek help and so on. Despite these evidences; the issue of perceived stigma was less explored and there were few published studies regarding the prevalence and factors associated with perceived stigma among patients with epilepsy in developed world and there is limited published research in Ethiopia regarding prevalence of perceived stigma among patients with epilepsy. Therefore this study was intended to bridge this gap by assessing the prevalence and factors associated with perceived stigma among patients with epilepsy; and contributes additional information regarding issue of felt stigma. This research is also important to provide some input for AMSH and MOH.

Hypothesis

1. Prevalence of perceived stigma is high among people with epilepsy in Ethiopia
2. Socio demographic factors have association with perceived stigma
3. Factors such as difficulty to attend follow up because of fear of stigma, seizure related injury and contagion belief have association with perceived stigma.

Objective

The aim of the study is to assess the prevalence of perceived stigma and factors associated with it among patients with epilepsy in Ethiopia.

Methods

Study design and period

Institutional based quantitative cross-sectional study was conducted from May 1, 2013 to May 30, 2013 G.C.

Study setting: The study was conducted in Amanuel Mental Specialized Hospital in Addis Ababa. It is one of the oldest hospitals established in 1930.E.C during the Ethio-Italian war and it is the only mental hospital in Ethiopia. In the hospital the health service had been given in 1940 by low level psychiatric professionals. Starting from 1946-1970 the treatment had been given by doctors who came

from Russia, Bulgaria, and Cuba. It is located in western part of Addis Ababa in Addis Ketema sub-city, kebele 08. The hospital is working on increasing the efficiency and effectiveness of the serves to make itself the center of mental health care excellences by giving core mental clinical services, conducting research and trainings and other administrative services. On average 14,340 people with epilepsy are seen as outpatients treated each year. The hospital has 18 OPDs from which 2 OPDs serve as NEP clinic.

Source and study population

Source population: The source population for this study were; all patients with epilepsy in Ethiopia.

Study population: The study population for this study were; clients who were diagnosed as patients with epilepsy and were attending the outpatient department at Amanuel Mental Specialized Hospital during the study period.

Inclusion and Exclusion Criteria

Inclusion criteria: Patients who were clinically diagnosed as a case of epilepsy and in the age group 18 years and above in the outpatient units of Amanuel Mental Specialized Hospital were included in the study.

Exclusion criteria: Patients who couldn't communicate.

Sample size determination and sampling techniques

Sample size determination: The minimum number of sample required for this study was determined by using single population proportion formula considering the following assumptions:

$$n_i = \frac{(Z\alpha/2)^2 p (1-p)}{d^2}$$

Where

n_i = minimum sample size required for the study.

Z= standard normal distribution (Z=1.96) with confidence interval of 95% and $\alpha=0.05$

P= Prevalence of perceived stigma among a person with epilepsy in Benin which is 68.7% (0.687) was used.

d= Absolute precision or tolerable margin of error (d) =5%=0.05

$$n_i = \frac{(Z\alpha/2)^2 p (1-p)}{d^2 (0.05)^2} = \frac{(1.96)^2 \times 0.687(1-0.687)}{0.05^2} = 330$$

Then by adding 5% (330 x 0.05=17) of non-respondent rate the total sample size for this study was 330+17=347.

Sampling techniques: A systematic random sampling technique was used to select from 1195 patients with epilepsy. The sample size was decided to be 347. The sampling fraction was: 1195/347= ~3. Hence, the sample interval was 3. Individuals were chosen at regular intervals (every 3rd) and the selected patients were directed by the facilitator to the office where the data collectors were working.

Study Variables

Dependent variable

Perceived stigma (Present/Absent) independent variables:

- Socio demographic factors
- Age

- o Sex
- o Residence
- o Ethnicity
- o Religion
- o Marital status
- o Educational status
- o Occupational status
- Clinical factors:
 - o duration of the illness,
 - o frequency of seizure,
 - o length of time on AEDs,
 - o Difficulty to attend follow up because of stigma,
 - o Difficulty to take AEDs daily because of stigma,
 - o Injury during epilepsy attack.
- Patient's belief:
 - o Cause of epilepsy
 - o Contagion belief
- Disclosure status of the patient

Data Collection Procedures

People with epilepsy presenting to the NEP clinic were interviewed using the Kilifi Stigma Scale of Epilepsy which was developed and validated in Kilifi Kenya. It is a simple three-point Likert scoring system scored as “not at all” (score of 0), “sometimes” (score of 1) and “always” (score of 2). A total score was calculated by addition of all item scores. The score above 66th percentile of the data indicated presence of Perceived/felt stigma (41, 43). Questions used to assess socio-demographic data and other relevant information was designed by the investigator. There were also some questions to assess clinical factors, patient's belief about the causes and contagion of epilepsy; and disclosure status of the patient. Data was collected by two trained psychiatry nurses and data collectors were supervised by one BSC nurse.

Data quality control

The questionnaire was translated to local language (Amharic) to be understood by all participants and translated back to English. Training was given for data collectors and supervisor at AMSH. Pre-test was done 2 days before the start of actual data collection at AMSH NEP case team and the results were not included in the main study. Based on the finding from the pretest, the questionnaire revised and adopted and time needed for interview was estimated. The data collectors were supervised daily and the filled questionnaires were checked daily by the supervisors and principal investigator.

Data processing and analysis

Data was entered, cleaned and stored by using EPI info version 3.5.1; then exported into Statistical Package for the Social Sciences (SPSS) version 20 for analysis. Frequency and percentage was used to describe the data. Crude and adjusted OR was analyzed using logistic regression and the level of significance of association was determined at P- value <0.05.

Ethical consideration

Ethical clearance was obtained from the Institutional Review Board (IRB) of college of medicine and health sciences, University of Gondar and from Amanuel Mental Specialized Hospital. The data collectors were clearly explained the aims of the study for study participants. Information was collected after obtaining verbal consent from each participant. The right was given to the study participants to refuse or discontinue participation at any time they wanted and the chance to ask any thing about the study. For the purpose of anonymity participant's names were not used at the time of data collection and all other personnel information kept entirely anonymously and confidentiality was assured throughout the study period. Data collectors were put their signature for they could obtain verbal consent for the interview from the respondents. The investigator has commitment that findings will be used later to minimize perceived stigma among people with epilepsy.

Results

A total of 347 patients with epilepsy were recruited in the study. Out of 347 patients with epilepsy 346 responded to the questionnaire with overall response rate of 99.7%.

Socio-demographic characteristics

All of the respondents were between the age group of 18-57 years with the mean age of 29.3 ± 8.5SD. Among all participants, 216 (62.4%) were male. The participants from urban area were (268) (77.5%) and the rest were from rural area. Among the total study subjects 232 (67.1%) were Orthodox religion followers and 177 (51.2%) were single (Table 1).

Description of respondents by clinical factors

Majority of the study subjects 150 (43.4%) were living with epilepsy for more than 11Years and 114 (33%) were on AEDs for more than 11years. Among the study subjects who had seizure in past three months (81 (23.4%)) majority of them (58 (71.6%)) reported that they experienced seizure less than six times in past three months (Table 2).

Description of respondents by disclosure status, patient's contagion belief and causal belief of epilepsy

Majority of the respondents 241 (69.7%) reported that their condition is disclosed to the society, and among these 196 (81.3%) reported that their condition is disclosed involuntarily (Attack occurred at public place and, or other person disclosed their condition). Forty two percent of the participants belief that the cause of their epilepsy is evil spirit (Table 3).

Perceived stigma scores of participants

Most of the participants reported that they feel disappointed in their self which is followed by feeling embarrassed (Table 4). The lowest score of the data was 0 and the highest score was 30. The lower quartile, median and upper quartile values were 1, 4, and 9 respectively. The 66th percentile of the data was 7, so that scores above 7 were considered to show the PWE who felt stigmatized (Figure 1). Accordingly; out of the 346 study subjects recruited in the study, 31.2% fulfilled the criteria for perceived stigma as measured by the KSSE.

Multivariate analysis of perceived stigma and explanatory variables

The multivariate logistic regression which controls the effect of confounding variables was used by taking all covariates in to account

Variables		(n/346)	(%)
Age	18-24	112	32.4
	25-34	136	32.4
	35-44	57	16.5
	≥45	41	11.8
Sex	Male	216	62.4
	Female	130	37.6
Residence	Rural	78	22.5
	Urban	268	77.5
Ethnicity	Amhara	122	35.5
	Oromo	110	31.8
	Tigre	26	7.5
	Gurage	78	22.5
Marital Status	Others	10	2.9
	Married	125	36.1
	Single	177	51.2
Religion	Divorced	23	6.6
	Widowed	21	6.1
	Orthodox	232	67.1
Educational status	Protestant	52	15
	Muslim	57	16.5
Occupational status	No formal education	45	13
	1-8	145	41.9
	9-12	123	35.5
	12+	33	9.5
Occupational status	Employed		
	Farmer		
	Employed	134	38.7
	Farmer	50	14.5
	Student	49	14.2
Occupational status	Daily laborer	97	28
	Others	16	4.6

Table 1: Distribution of study subjects by socio-demographic factors.

Variables		(n/346)	(%)
Duration of the illness	≤1yr	21	6.1
	2-5yr	90	26
	6-10yr	85	24.6
	≥11yr	150	43.4
Duration on AEDs	≤1yr	56	16.2
	2-5yr	106	30.6
	6-10yr	70	20.2
	≥11yr	114	32.9
Seizure in last 3m	No	265	76.6
	Yes	81	23.4
Frequency of seizure in three months	≤ 6x/3m	58	17.1
	>6x/3m	23	6.7
Difficulty to attend follow up because of fear of stigma	No	312	90.2
	Yes	34	9.8
Difficulty to take AEDs daily because of fear of stigma	Yes	28	8.1
	No	318	91.9
Injury during seizure	No	212	61.3
	Yes	134	38.7

Table 2: Distribution of study subjects by clinical factors.

simultaneously for perceived stigma. Analysis was done after adjusting for age, residence, educational status, difficulty to attend follow up, difficulty to take medication daily, seizure related injury and Contagion belief of epilepsy. Accordingly age group between 18-24 years were

about 2.8 times more likely to have perceived stigma as compared to age group ≥ 45years [AOR=2.84, 95%CI: 1.02,7.92]. Those who reported difficulty to attend follow up because of stigma were 3 times more likely to perceive stigmatized compared to those who have no difficulty to attend follow up because of stigma [AOR=3.15, 95%CI: 1.19,8.34]. The patients with epilepsy who had seizure related injury were about 1.8 times more likely to have perceived stigma when compared to those who have no seizure related injury [AOR= 1.88, 95%CI: 1.12,3.15]. The participants those who believe that epilepsy is contagious were 2.4

Variables		(n/346)	(%)
Cause of epilepsy	Supernatural force	90	26
	Evil spirit	147	42.5
	Other	15	4.3
	I don't know	94	27.2
Contagion belief	No	306	88.4
	Yes	40	11.6
Disclosure status	Not disclosed	105	30.3
	Disclosed	241	69.7
Way of disclosure	Voluntarily disclosed	45	13.0
	Forced Disclosure	196	56.7

Table 3: Distribution of study subjects by disclosure status, patient's contagion belief and causal belief of epilepsy.

Items	n/346	%
1 Do you feel different from other people?	119	34.4
2 Do you feel lonely?	125	36.1
3 Do you feel embarrassed?	166	48
4 Do you feel disappointed in yourself?	181	52.3
5 Do you feel you cannot have a rewarding life?	135	39
6 Do you feel you cannot contribute anything in society?	86	24.8
7 Do you feel you cannot join others in public places?	106	30.6
8 Do you feel other people are uncomfortable with you?	105	30.4
9 Do you feel other people don't want to go to occasions with you?	80	23.1
10 Do you feel other people treat you like an inferior person?	110	31.8
11 Do you feel other people would prefer to avoid you?	106	30.6
12 Do you feel other people avoid exchanging greetings with you?	62	17.9
13 Do you feel you are mistreated by other people?	60	17.3
14 Do you feel other people discriminate against you?	83	24
15 Do you feel other people treat you like an outcast?	51	14.7

Table 4: Proportion of responses to KSSE by study participants.

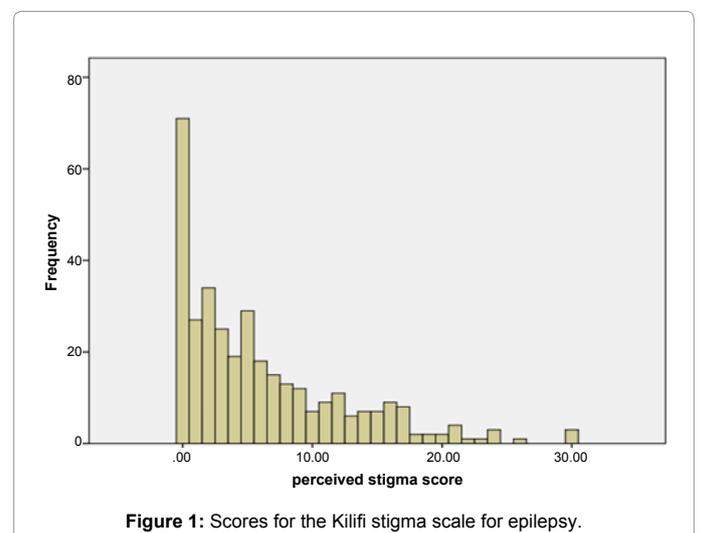


Figure 1: Scores for the Kilifi stigma scale for epilepsy.

times more likely to perceive stigmatized as compared to those who believe that epilepsy is not contagious [AOR=2.37, 95%CI: 1.10, 5.08] (Table 5).

Discussion

The study found that the prevalence of perceived stigma among patients with epilepsy in Ethiopia in year 2013 was 31.2%. The prevalence of PS in current study is lower when compared with other study conducted in Butajira Ethiopia which was 81% [41]. The discrepancy might be due to difference in study setting and difference in instrument used. The prevalence of PS in our study in lines with that of Kenya which was 33% [42]. The prevalence of perceived stigma in our study is lower when compared to that of Benin which was 68.7% [38]. The variation might be due to difference in instrument they used which was Jacoby stigma scale and difference in study setting. The study conducted in Brazil and Zambia reported that the median stigma score of patients with epilepsy was 42 and 2.5 respectively [36]. The median score of current study which is 4 is lower when compared with median stigma score in Brazil and is higher when compared to that of Zambia. This could be due to instrument difference which was Stigma Scale of Epilepsy in case of Brazil; and Jacoby Stigma Scale in case of Zambia. The other reason might be population difference. The prevalence of perceived stigma reported by our study is lower when compared with the studies conducted in European countries, Cambodia, Kansas and Brooklyn which was 51%, 46%, 34% and 69% respectively [31,34,33,35]. This is explained by population difference, instrument difference which was Jacoby Stigma Scale in all, large sample size they used and difference in study setting. In other ways the prevalence of perceived stigma found in our study in lines with that of Iran the Gulf, and Near East, which was 33% [37].

Age group between 18-24 were more likely to perceive stigmatized

[AOR=2.84, 95%CI: 1.02, 7.92] when compared to those who were 44 years and above. This result in lines with that of Kenya [42]. This is explained by; older people were less likely to report feeling stigmatized because discriminatory attitudes toward epilepsy may have less importance to them than younger people. The younger people want to fit in with peers. Participants who reported that they had difficulty to attend follow up because of fear of stigma were more likely to have perceived stigma [AOR=3.15, 95%CI: 1.19, 8.34] when compared to those who had no difficulty to attend follow up because of fear of stigma. This could be due to fear of enacted stigma if the society knows that they were on follow up for epilepsy case. Participants who experienced injury during seizure attack were more likely to feel stigmatized [AOR=1.88, 95%CI: 1.12, 3.15] compared to those who didn't experience injury during seizure attack. This finding in lines with that of European countries [31]. This may be explained by the physical deformity and scars due to that injury may easily disclose their condition. The scar and the deformity may also cause another stigma or potentiate the existing stigma. The participants those who believe that epilepsy is contagious were more likely to perceive stigmatized compared to those who believe that epilepsy is not contagious [AOR= 2.37, 95%CI: 1.10, 5.08]. This result in lines with that of Zambia [39]. The possible explanation is; because they thought that the society also believe that epilepsy is contagious; so they felt they were stigmatized by society. Among the variables entered in to multivariate analysis; residence, educational status, difficulty to take AEDs daily because of fear of stigma and disclosure status were not associated to perceived stigma.

Conclusion

The prevalence of perceived stigma, even if it seems low it is not negligible and is showing a significant public health issue among patients with epilepsy that requires great emphasis. Age, difficulty to attend follow up, seizure related injury and contagion belief were significantly

Explanatory Variables	Perceived stigma		Bi-variate and multivariate analysis		
	Yes	No	COR (95%CI)	AOR (95%CI)	
Age	18-24	38	74	2.49 (1.01, 6.15)	2.84 (1.02, 7.92)**
	25-34	40	96	2.02 (0.83, 4.94)	2.23 (0.82, 6.06)
	35-44	23	34	3.29 (1.25, 8.67)	3.04 (0.34, 9.13)
	≥45	7	34	1.00	1.00
Educational status					
No formal Education	1-8	22	23	2.99 (1.11, 8.03)	2.52 (0.84, 7.58)
	9-12	49	96	1.59 (0.67, 3.79)	1.24 (0.47, 3.28)
	12+	29	94	0.96 (0.39, 2.37)	0.72 (0.27, 1.96)
		8	25	1.00	1.00
Residence					
Rural	33	45	1.89 (1.12, 3.18)	0.65 (0.34, 1.22)	
	75	193	1.00	1.00	
Difficulty to attend follow up					
Yes	23	11	5.58 (2.61, 11.95)	3.15 (1.19, 8.34)*	
	85	227	1.00	1.00	
Difficulty to take Medication daily					
Yes	18	10	4.56 (2.03, 10.26)	2.02 (0.70, 5.81)	
	90	228	1.00	1.00	
Injury during Seizure attack					
Yes	53	81	1.87 (1.18, 2.93)	1.88 (1.12, 3.15)*	
	55	157	1.00	1.00	
Contagion belief					
Yes	20	20	2.48 (1.27, 4.83)	2.37 (1.10, 5.08)*	
	88	218	1.00	1.00	

*Statistically significant at p-value <0.05. ** Statistically significant at p-value <0.001

Table 5: Factors associated with Perceived stigma of people with Epilepsy (bivariate and multivariate analysis).

associated with perceived stigma among patients with epilepsy.

Abbreviations

AEDs: Anti Epileptic Drugs; AMSH: Amanuel Mental Specialized Hospital; KSSE: Kilifi Stigma Scale of Epilepsy; PS: Perceived Stigma; PWE: People With Epilepsy

Competing Interests

The authors declare that they have no competing interests.

Authors' Contributions

TFis involved in the design of the study and TA, DA, MG were involved in the revising the manuscript critically for important intellectual content and analysis of data. All authors read and approved the final manuscript.

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