

# Assessment of the Prevalence and Factors Associated to Perceived Stigma among Epileptic Patient who are on Follow up at Hospitals in West Shewa Zone, Central Ethiopia, Institutional Based Cross-Sectional Study, 2017

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## Abstract

**Background:** Perceived stigma is considered to be one of the most important factors that have a negative influence on people with epilepsy. All types of perceived stigma further exert stress and restrict normal participation in society.

**Method:** Institutional based cross-sectional study was conducted from January 10, 2017 to February 10, 2017. All people with epilepsy in west Shewa zone were source population. The sample size was determined using single population proportion formula and 363 study subjects were selected. To select the study subjects the hospitals found in West Shewa Zone was stratified and the calculated sample size was proportional allocated. The study subject was selected using systematic random sampling. Data was analyzed using SPSS version 20.

**Result:** Prevalence of perceived stigma was 34.4% among People with epilepsy on follow up at west Shewa public hospitals. Age group 35 up to 44 years (AOR = 0.8, 95% 0.102, 0.52), no formal education (AOR = 8.8(2.29, 33.82)) and grade 1-8<sup>th</sup> (AOR = 6.07, 2.05, 17.97), less than one year on (AOR = 5.66, 2.09, 15.38), 2-5 years (AOR = 4.88, 2.09, 11.33) and 6-10 years duration of illness (AOR = 3.71(1.55, 8.87), depression symptoms(AOR = 29.66(12.55, 70.09), anxiety symptoms (AOR = 2.44(1.23, 4.84) were significantly associated with perceived stigma.

**Conclusion:** Prevalence of perceived stigma of PWE is high in the present. Age, educational status, duration of illness, depression and anxiety symptoms were significantly associated with perceived stigma among people with epilepsy.

**Keywords:** Perceived stigma; People with epilepsy; West Shewa; SS Central Ethiopia

**Abbreviations:** AEDs: Antiepileptic Drugs; KSSE: Kilifi Stigma Scale of Epilepsy; SPSS: Statistical Package Software; PWE: People with Epilepsy

## Background

Epilepsy is a chronic brain disorder characterized by recurrent derangement of the nervous system due to sudden excessive discharge of the cerebral neurons which has no geographical, racial, or social boundaries. Epilepsy is the world's most common neurological disorder that affects at least 69 million in the world today, 90% of whom live in developing countries the etiology of seizures is multi factorial in any given person [1-3]. The reported prevalence of active epilepsy in developing countries ranges from 5 to 10 per 1000 people [4]. The incidence of epilepsy in low-income countries may be as high as 190 per 100 000 people [5]. Consequently, in the context of the

large and rapidly increasing populations in these countries, epilepsy is a significant health and socioeconomic burden requiring urgent attention [6].

Epilepsy has a considerable psychological and emotional impact on People with epilepsy [7]. Perceived stigma in people with epilepsy was associated with experience of actual discrimination, introverted personality, degree of problem solving control, and emotional subscale of quality of life [8].

Patients with epilepsy have hidden their disease to their relatives and partners because of stigmatization [9]. Different literature

reported that perceived stigma affects many domains of epileptic patients such as marital status, unemployment and their children cannot even play with a person with epilepsy [10-12].

Enacted stigma is when PWE experience discrimination because of their condition and felt stigma is apparent when PWE fear being subjected to enacted stigma. Perceived stigma is subjective and will differ across individuals. Felt stigma has been shown to depend on whether the individual feels that they have been discriminated against in the work place or constrained in their day to day life as a consequence of having epilepsy.

The stigma of PWE can be seen as a negative self-evaluation, accompanied by a negative emotional experience [15]. The stigmatizing nature of epilepsy and its associated psychopathology in people with epilepsy has been well established. Frequency, duration, type seizure and knowledge of epilepsy are associated factors for perceived stigma [16] (Figure 1).

Therefore, Patients with epilepsy are sometimes more vulnerable to often more disabling psychosocial difficulties. The neurological deficit they may have come to bear on their families who may therefore be hesitant to disclose the illness to neighbors as such information may engender fear and social rejection. Consequently the patients suffer segregation and exclusion in the society with subsequent stigma.

In china, people with epilepsy social isolation, employed over protected or neglected. Another study conducted in china showed in a particular socio-cultural context, these factors cause a perceived stigma are perceived stigma with people with epilepsy. According to study done in china on factors affecting internalized stigma showed that educational status type, frequency and severity of seizures, fear and anxiety in the surrounding people, family members and friends, long term duration of treatment, traditional beliefs and financial [15-16]. In study conducted in Europe showed that 18% perceived stigma because of their epilepsy and factors predictive of stigma, seizure frequency, duration of epilepsy, seizure type [17]. A study was conducted in Karachi, Pakistan showed that marital status was significant associated factors of perceived stigma [18]. A cross sectional study conducted in Birjand showed that the prevalence of perceived stigma was 53.7% and female gender and early age were significantly associated perceived

stigma [11]. A study conducted in Ecuador showed that 65.8% develop perceived stigmatized and rural residence and lower educational status were significantly associated perceived stigma among people with epilepsy [19]. A study conducted in Terhan showed that 34.6% of perceived stigma for discrimination experience and persons with lower educational status and unemployed significantly associated factors of stigma among PWE [20-21]. A study conducted in University of Florida showed that early age onset duration, frequency seizure and type of antiepileptic drugs being currently taken were significantly associated with perceived stigma [22]. A case control study conducted in Zambia showed among 176 potential study subjects community disclosure, being greatest for those who had forced disclosure either through a public seizure or someone else revealing their condition to the community, long duration of illness and People who believed their condition to be contagious or who reported contagion beliefs from within their community also had higher perceived stigma [23] (Figure 2). Comparative study conducted at kenya suba and Meru district showed that the prevalence of perceived stigma is 51.3% and 46.2% respectively among PWE [24]. Institutional based study conducted in university of Gondar hospital northern Ethiopia showed that prevalence of perceived stigma was found to be 71.6%. Single and widowed marital status, short duration of illness, seizure frequency was factors statistically significant with perceived stigma [25]. Community based cross sectional study conducted at Butajira southern Ethiopia showed that the prevalence perceived stigma was 81% and duration of illness, inability to find partner, serious physical injuries, complication of seizure are significantly associated among people with epilepsy [26,27]. In Ethiopia out of the 346 study subjects 31.2% fulfilled the criteria for perceived stigma as measured by the Kilifi stigma scale and early age, no difficulty in attending follow-up, seizure related injury and contagious were significantly associated of perceived stigma among people with epilepsy [28].

## Methods

Institutional based quantitative cross-sectional study was conducted from January 10, 2017 to February 10, 2017, at Ambo, Gindeberet and Gedo hospital which were west shewa zone which have psychiatry and neurology department. The required sample size for this study was determined using single population proportion formula and found

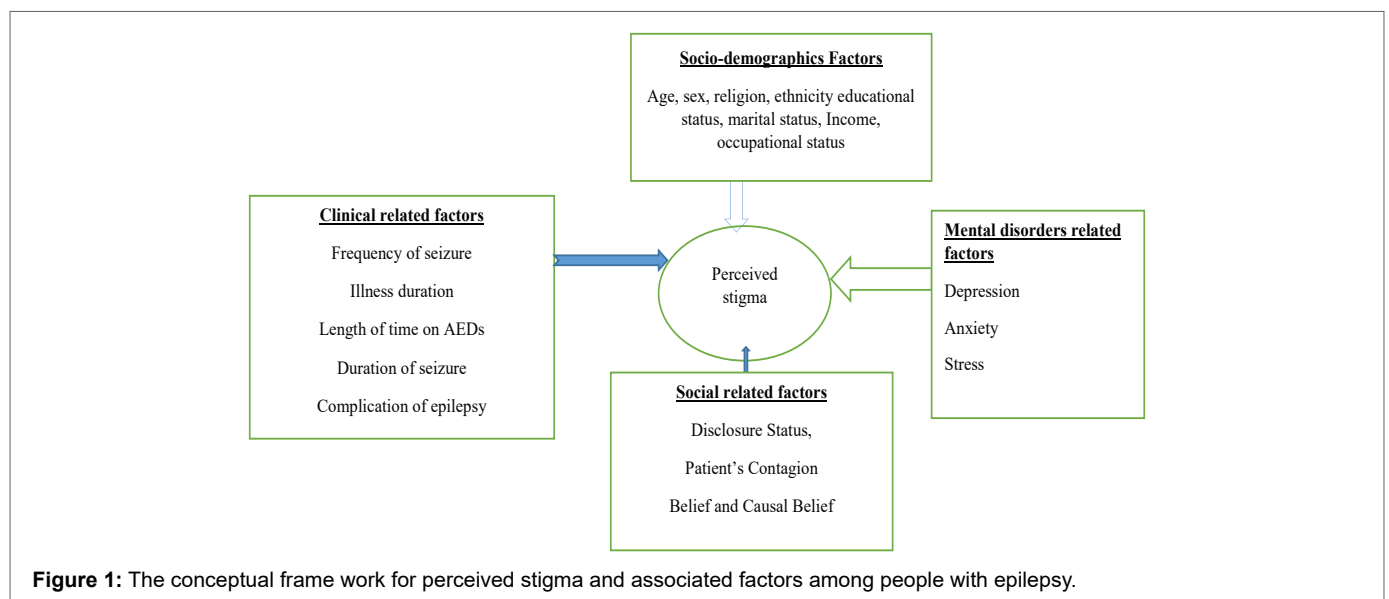
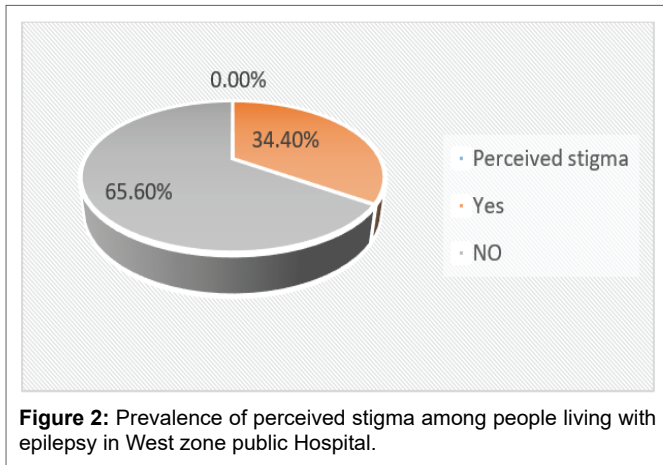


Figure 1: The conceptual frame work for perceived stigma and associated factors among people with epilepsy.



**Figure 2:** Prevalence of perceived stigma among people living with epilepsy in West zone public Hospital.

to be 363. Age equal or above 18 years were included in the study and subjects who had major cognitive impairments or intellectual and physical disability were excluded in the study. Stratification followed by a systematic random sampling technique was used to select participants. People with epilepsy who were already diagnosed and on regular follow-up at Ambo, Gindeberet and Gedo Hospitals Psychiatry and neurology unit were interviewed using the KSSE which was developed and validated in Kilifi, Kenya and adopted to Ethiopia.

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). It has fifteen items and a total score was calculated by addition of all item scores. The score above the value on 66<sup>th</sup> percentile of the data indicated presence of perceived/felt stigma [24,28]. Questions were used to assess socio demographic characteristics and clinical factors, patients’ belief about a nature of their illness, and disclosure status of the patient. Data was collected by three BSc Nurse and supervised by three BSc Psychiatry. The questionnaire was translated to Afan Oromo and translated back to English by language expert. Data was entered, and cleaned using EPI info version 3.5.1 and analyzed using SPSS version 20. Descriptive Statistical was done. Crude and adjusted OR was calculated using logistic regression and the level of significance of association was determined at *p* value <0.05. Ethical clearance was obtained from Ambo University research committee and from Ambo, Gindeberet and Gedo hospitals. Written informed consent for participation in the study was obtained from participants just after start of the interview.

## Result

97.8% response out of total participants.

### Socio-demographic and clinical characteristics of the participants

The majority of the participants were men 206 (58%). The mean age of the participants was 33.60 ± 14.23 SD. One hundred and sixty eight (47.3%) of the participants completed primary education, 175 (49.3%) were protestant Christian and 166(46.8%) were married. Three hundred and ten (87.3%) of the participants were Oromo in Ethnicity (Table 1).

### Description of respondents by clinical factors

Out of the total 355 respondents, 47.9 % were with epilepsy for 2-5 years followed by 6-10 years (30.1 %). Sixty six percent of the study

**Table 1:** Distribution of study subjects by socio demographic factors patients with (n=355) epilepsy of follow up at west shewa zone public hospital, Oromia regional state, Central Ethiopia, 2017.

	Variables	Frequency	Percentage
Age	18-24	113	31.8
	25-34	95	26.8
	35-44	83	23.4
	>45	64	18
Sex	Male	206	58
	Female	149	42
Ethnicity	Oromo	310	87.3
	Amhara	28	7.9
	Others	17	4.8
Religion	Orthodox	139	39.2
	protestant	175	49.3
	Muslim	41	11.5
Marital Status	Unmarried	152	42.8
	Married	166	46.8
	Divorced	15	4.2
	Others	22	6.2
Educational Status	No formal education	52	14.6
	8-Jan	168	47.3
	12-Sep	105	29.6
	>12	30	8.5
Occupational Status	Farmer	102	28.7
	House wife	68	19.2
	Student	78	22
	Merchant	51	14.4
	Government employee	30	8.5
	Others	26	7.3
Monthly family income	<300	111	31.3
	301-600	87	24.5
	601-1000	75	21.1
	≥ 1001	82	23.1

participants reported that they had seizure in past three months of which majority of them (121 (34.1%)) reported that they experienced seizure 1-2 times (Table 2).

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

All of the respondents (355 (100%)) reported that their condition is disclosed to the society among these 255 (71.8%) reported that their condition is forced disclosed. Regarding the causes of epilepsy a (126 (35. %)) and (122(34.4%)) is evil spirit and do not know the cause respectively (Table 3).

**Table 2:** Clinical related factors of patients with (n=355) epilepsy on follow up at West shewa zone public hospital, Oromia regional state, central Ethiopia, 2017.

	Variables	Frequency	Percentage
Duration of illness	≤ 1 year	10	2.8
	2-5 years	170	47.9
	6-10 years	107	30.1
	≥ 11 years	68	19.2
Duration of on AEDs	≤ 1 years	10	2.8
	2-5 years	170	47.9
	6-10 years	107	30.1
	≥ 11 years	68	19.2
Frequency of Seizure in three months	0	120	33.8
	1- 2x	121	34.1
	>2x	114	32.1
Complication of seizure	Yes	93	26.2
	No	262	73.8

**Table 3:** Disclosure Status, Patient's Contagion Belief, and Causal Belief of (n=355) epilepsy on- follow up at West shewa zone public hospital, Oromia regional state, Ethiopia, 2017.

	Variables	Frequency	Percentage
Duration of illness	≤ 1 year	10	2.8
	2-5 years	170	47.9
	6-10 years	107	30.1
	≥ 11 years	68	19.2
Duration of on AEDs	≤ 1 years	10	2.8
	2-5 years	170	47.9
	6-10 years	107	30.1
	≥ 11 years	68	19.2
Frequency of Seizure in three months	0	120	33.8
	1- 2x	121	34.1
	>2x	114	32.1
Complication of seizure	Yes	93	26.2
	No	262	73.8

### Multivariate analysis of perceived stigma and explanatory variables

Bivariate analyses were done between perceived stigma and response variables such as socio-demographic variables (age, education status), Clinical factors (duration of illness, duration on AEDs, depression symptoms, anxiety symptoms and stress symptoms) were found to be significantly associated with perceived stigma at p value less than 0.2. Individual factors that were significant at this level were entered in to a subsequent multivariate analysis. Accordingly age group between 35 and 44 years were about 0.8 times less likely to have perceived stigma as compared to age group ≥ 45 years (AOR = 0.8, 95% 0.102, 0.52). No formal education 9 times more likely and primary school six times more likely to have perceived stigma when compares to beyond grade 12(AOR = 8.8(2.29, 33.82)) and (AOR = 6.07(2.05, 17.97)) respectively. Those who reported less than one year, 2-5 years and 6-10

years were 6,5 and 4 times more likely to experience perceived stigma than those who stay with illness for greater than 11 years (AOR = 5.66 (2.09, 15.38), (AOR = 4.88 (2.099, 11.333) and (AOR = 3.71(1.55, 8.87) respectively.

Those patients who had depression symptoms were 29 times more likely to have perceived stigma when compared to those who have no depression symptoms (AOR = 29.66(12.55, 70.09). The participants who had anxiety symptoms were 2 times more likely to have perceived stigma as compared to those who had no anxiety symptoms (AOR = 2.44(1.23, 4.84) (Table 4).

**Table 4:** Factors associated with perceived stigma in people with epilepsy (bivariate and multivariate analysis).

Variables	Perceived stigma		Bivariate and multivariate analysis	
	Yes	No	COR (95%,CI)	AOR (95%,CI)
<b>Age</b>				
18-24	41	72	0.61(0.33,1.13)	3.91(1.54,9.91)*
25-34	36	59	0.65(0.34,1.23)	0.89(0.40, 1.98)
35-44	14	69	0.22(0.10,0.46)*	0.231(0.10, 1.52)*
>45	31	33	1	1
<b>Educational Status</b>				
No formal education	34	18	2.12 (0.73, 6.12)	8.78(2.29, 33.82)*
8-Jan	102	66	2.59 (1.00, 6.67)	6.07(2.05, 17.97)*
12-Sep	73	32	1.75 (0.65, 4.70)	2.72(0.95, 7.76)
>12	24	6	1	1
<b>Monthly family income</b>				
<300	74	37	1.019(0.56, 1.87)	0.75(0.35, 1.61)
301-600	69	18	0.531(0.27, 1.06)	0.33(0.15, 0.74)
601-1000	35	40	2.33(1.06, 4.44)	1.45(0.68, 3.06)
≥ 1001	55	27	1	1
<b>Duration of illness</b>				
≤ 1 year	22	20	4.09(1.71, 9.77)	5.66(2.09, 15.34)*
2-5 years	91	57	2.82(1.39, 5.72)	4.88(2.09, 11.33)*
6-10 years	66	33	2.25(1.06, 4.77)	3.71(1.55, 8.87)*
≥ 11 years	54	12	1	1
<b>Duration of on AEDs</b>				
≤ 1 years	20	20	4.09(1.71, 9.77)	2.40(0.10,57.51)
2-5 years	57	57	2.82(1.39,5.72)	1.52(0.07, 31.58)
6-10 years	33	33	2.25(1.06, 4.77)	13.15(0.49, 53.25)
≥ 11 years	12	12	1	1
<b>Depression symptoms</b>				
Yes	182	51	18.20 (10.28 , 32.22 )	29.66(12.55 ,70.09)*
No	20	102	1	1
<b>Anxiety symptoms</b>				
Yes	193	40	6.95(4.23, 11.41)	2.44(1.23, 4.84)
No	50	72	1	1



## Discussion

The aim of this study was to assess the prevalence of perceived stigma and associated factors among people with epilepsy who are on regular follow up at Ambo, Gindeberet and Gedo hospitals. Overall, the prevalence of perceived stigma was found to be 34.4%.

### Prevalence and factors associated with perceived stigma among patients with epilepsy

The result of the present study is almost line with the study done Iran (34.6%) and Amanuel mental specialized hospital (31.2%) [20,28]. The result of this study supported by the study carried out elsewhere as perceived stigma is a common problem among epileptic patients. The result of the present study is lower as compared to the study carried out in South Korea (62.2%), Kenya Suba and Meru district (51.3%, 46.2%), Gondar University hospital North Ethiopia (71.6%) and the study conducted in Butajira southern Ethiopia (81%) [15,24,26,27].

The possible explanations for the variation may be due to different in assessment tools, geographical areas, sample size and cultures of the study subject and for the Ethiopia study it may be due to the addition of family member as a study subject and the study setting. This may indicate that family members of the patient also suffer more perceived stigma. Study shows the moral weight attached to epilepsy not only applied to the affected person, but also threatened family members through a process of courtesy stigma because of fear of family disgrace, people with epilepsy were typically kept at home and their diagnosis was kept secret.

Regarding the associated factors, age group between 18 and 24 were more likely to have perceived stigma (AOR = 3.91, 95% CI: 1.54, 9.91) when compared to those who were 44 years and above. This result is in line with that the study conducted at Europe, Korea, Croatia, Iran, Zambia and Amanuel mental specialized hospital, Ethiopia [19-23,28].

This is explained by younger people who were more likely to report feeling stigmatized because discriminatory attitudes towards epilepsy may have more importance to them than older people. The younger people want to fit in with peers.

When we compare educational status; no formal education and educated up to grade 8 were nine and six times [(AOR = 8.78, 95% CI: 2.29, 33.82), (AOR = 6.07 (2.05, 17.97))] more likely to have perceived Stigma when compared to those who have diploma and above respectively. This is supported by the study conducted in china, Tehran Iran and Zambia University teaching hospital [16,20,23].

The possible explanations might be those individuals with no formal education might face difficulties, socioeconomic stressors like unemployment, poverty and economic dependency.

Those patients who had less than or equal 1, 2-5, and 6-10 years duration of illness were more than five, four and three times [(AOR = 5.66, 95% CI: 9.09, 15.34), 4.88, 95% CI 2.09, 11.33), 3.71, 95% CI 1.55, 8.87)] more likely to develop perceived stigma than those patients who had greater than or 11 years duration of illness respectively. These results were consistent with the previous studies in Korea, Croatia, Butajira southern Ethiopia and Gondar north Ethiopia [18,27,28]. This may be due to lack of coping strategies to different seizure effect such as perceived negative social attitude as a result of unaccepted sign of seizure, or the subjects may not develop stigma resistance ability through their life that help them to cope up with different cultural belief, social stigma and the impact of the illness that contributed to perceived stigma. This result indicates that those patients who had shorter duration of disease in their life had more perceived stigma compared to those who had longer duration of the disease.

Participants who experienced depression symptoms were more likely to feel stigmatized (AOR = 29.66, 95% CI: 12.55, 70.09) compared to those who did not experience depression symptoms. This finding is in line with that of Chinese [16]. This may be due to poor psychological adjustment when they face different stress, situations that lower self-esteem.

Those participants who had anxiety symptoms were more likely to have perceived stigma (AOR = 2.44, 95% CI: 1.23, 4.84) when compared to those who did not experience anxiety symptoms. This finding is in that line with that of Chinese study [16]. The possible explanation is first, anxiety may be caused by physiological reactions. Epileptic patients tend to have an increased fear and anxiety of seizure episodes. The inability to predict the occurrence of their seizure attacks frightens epileptic individuals and leaves them with a sense of vulnerability.

## Conclusion

The prevalence of perceived stigma was high among people with epilepsy in this study. Age, no formal education and grade 1-8<sup>th</sup>, less than 10 years duration of illness, depression symptoms and anxiety symptoms were significantly associated with people with epilepsy.

## Declarations

### Ethics approval and consent to participate

The study proposal was initially approved by the ethical review board of Ambo University. A formal letter of permission was obtained from the west Shewa hospitals and submitted to the respective outpatient department. The information about the study was given to the participants. Verbal and then written informed consent was sought from each participant who agreed to participate in the study and full filled the inclusions criteria. Only anonymous data collected in private rooms.

### Availability of data and materials

This study is a part of institutional based a cross sectional study among on people with epilepsy. The dataset pertaining to this study will be shared upon reasonable request.

## Conflict of Interests

The authors declare that they have no competing interests.

### Author's contributions

Takele T. has involved in the conception, design, analysis, data interpretation and report writing. Adamu B. has involved in the design, analysis and report writing. Kassa M. has involved supervising and follow up data. All of us read and approved the final manuscript.

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