

Perception of stigma in people with epilepsy and their relatives in Butajira, Ethiopia

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Abstract

Background: The occurrence of psychosocial problems related to epilepsy is well recognized and in certain situations could even be more troublesome than the effect of the seizure disorders themselves.

Objective: This study was conducted to assess the magnitude of stigma experienced by patients and relatives of people with epilepsy in a rural Ethiopian community, and to identify socio-demographic and other factors that may be associated with stigma in this setting.

Method: Hospital based cross-sectional survey.

Result: The prevalence estimate of perceived stigma was found to be 81%. Students with epilepsy reported experiencing significantly greater levels of stigma at school ($X^2=39.065$, $p=0.000$) compared with people living and working in other settings. Those who had seizure at least once a month reported being stigmatized more often compared to those who had less frequent seizure attacks ($X^2=12.76$, $p=0.002$).

Conclusion: Stigma was found to be a common problem among patients suffering from epilepsy, and their relatives. The results reinforce the need for creating awareness among patients, relatives and the community at large about epilepsy and addressing misconceptions attached to it. [*Ethiop.J.Health Dev.* 2006;20(3):170-176]

Introduction

Epilepsy is the world's most common neurological disorder, affecting approximately 50 million people worldwide (1). 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 (2). In a large community-based epidemiological study, the prevalence of epilepsy in Ethiopia was reported to be 5.2/1000 population (3-4). The incidence was also reported to be 64/100,000 population as reported in a community-based study conducted in Meskan & Mareko districts of rural central Ethiopia (5). People with epilepsy report significant, negative psychosocial consequences of the disorder including decreased social and leisure opportunities, low self esteem (6) and feelings of shame and guilt compared with individuals without epilepsy (7-8). Misconceptions about etiological factors, curability, course and outcome have contributed to the social stigma and poor quality of life among sufferers and their family members (3, 8-10). There are reports of elevated psychological distress among people with epilepsy (7, 11), in addition to the increased morbidity resulting from seizure-related accidents, injuries and the side effects of antiepileptic medication (12). It is generally believed that the sequelae of a condition such as epilepsy are determined not only by the disease process itself, but also, and perhaps to an even greater extent, by the meaning ascribed to the condition within the patients' social environment (9, 13).

A community-based study investigating community attitudes towards epilepsy was conducted in Meskan and Mareko districts (Butajira), rural Ethiopia, between 1986

and 1988 (3-4). Following the completion of that study, Girarbet Ledekuman, a neurology and ophthalmology clinic that has an associated rehabilitation unit was established by the research project to treat patients suffering from epilepsy among other services. Since then the treatment and care of persons with epilepsy has improved considerably in the district. One other study project, the Butajira study on the course and outcome of schizophrenia and bipolar disorder project, has also initiated treatment for persons with epilepsy at Butajira health centre since 1998 (14). The service includes regular follow-up and free treatment for psychiatric patients and people with epilepsy based on the tradition that people with epilepsy are treated at psychiatric clinics.

Little is known about how stigma towards epilepsy is perceived in a traditional society in rural Ethiopia and such issues were also not addressed in the earlier population based study. We therefore conducted an outpatient clinic-based cross-sectional survey in a district where clinics and outreach services for treating people with epilepsy are well established in order to estimate the magnitude of stigma experienced by patients and relatives and to identify demographic and other factors which may contribute to stigma in this setting.

Methods

Setting: The study was conducted in Butajira (Meskan and Mareko districts); a predominantly rural district located 135 km south of the capital city of Addis Ababa. According to the the 1994 Office of Population and Housing Census Commission report the district had a population of 227,135 (15).

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Study design

The study design was a clinic-based cross-sectional survey. The original intention had been to conduct a community-based survey. As most people with epilepsy in the area receive free antiepileptic medication, it was anticipated that lay-interviewers interviewing people at home would reduce the bias in their responses that could occur when they are interviewed in the clinics. However, after collecting information from 127 individuals (15.3% of the total sample) it was found that house-to-house interviews were perceived to expose those persons with epilepsy who were living in the community but concealing their condition from others. One of four similar incidences during the community interviews is narrated as follows:

“Mr. A.B is a 28 year old farmer. He suffered from epilepsy since around age 5. A.B was diagnosed at a neurology clinic, “Girarbet,” and has been on a regular treatment with Phenobarbital and had regular follow up for more than 10 years and his seizure is controlled. Because of strong stigma and social ostracism he couldn't find a partner from his community and had to go a long distance to marry his current wife. He was married for six years without informing his spouse about his illness. When he was approached for the interview in this survey A.B and his siblings were resistant to being interviewed for the fear that his wife would know about his condition and that he is taking antiepileptic medication. He believed that the discovery of the illness by his wife would cause discord in the family and even lead to a divorce.”

Subsequent interview subjects were therefore recruited and interviewed in the outpatient clinics. There has been regular treatment service for persons with epilepsy at the Girarbet Ledekuman neurology clinic for about 15 years and at the psychiatry research and treatment clinic for the last seven years.

Sample Size: The prevalence of strongly negative attitudes and misconceptions regarding the aetiology of epilepsy and patient care were reported to be as high as 65.1% in the earlier study (3). We used EPI Info to calculate the required sample size for a cross-sectional population survey, taking an expected frequency of the experience of stigma to be 50% (17-18), worst acceptable prevalence of 46 or 54, (d=4), 95% Confidence Interval and to calculate the power of the sample. The required sample size was estimated as 600. Patient registration lists at the two clinics formed a sampling frame from which 600 patients and relatives were selected.

Data collection started in March 2004 according to the original community-based study design where 127 patients and their relatives were interviewed. After changing to recruitment through clinics, participants were interviewed over a period of six months between May

and October 2004. The assumption was that most people with epilepsy in the surrounding area or their relatives would present requesting antiepileptic medication refills at least once within a six-month period.

Instrument

People with epilepsy presenting to the clinic, or in their absence immediate family members who came for antiepileptic medication refills were interviewed using the 'stigma' section of the modified Family Interview Schedule (FIS), which was developed for use in the World Health Organization (WHO) study on the course and the outcome of schizophrenia (19). This questionnaire was used to examine the level of stigma and the extent to which it is perceived as a problem.

The stigma section of FIS was independently translated into Amharic by two medical doctors and a consensus was made between versions under the supervision of an experienced mental health researcher (TS). This questionnaire had been previously used in the same setting for people with schizophrenia or bipolar disorder and their relatives, and was found to be both acceptable and feasible. The details are published elsewhere (18). Ten high school graduates and two supervisors who were trained for two days in the administration of the questionnaire and interview techniques conducted interviews. The interview process was periodically supervised by one of the research team members (TS). Questions on the socio-demographic characteristics of the informants and the relationship of relatives to cases were included in the questionnaire. Although the original FIS stigma items numbered 14, only thirteen stigma questions were included to reduce redundancy after translation into Amharic. Each stigma item was rated on a 4-point scale from “not at all” (rated =0) to “a lot” (rated=3) with respect to perceived stigma. The presence of stigma experience was defined by the respondent's score of at least one when the FIS scores are summed.

Data processing: Data entry, cleaning and analysis was carried out using SPSS 11.0. Since the total FIS score was skewed we used non-parametric (Kruskal-Wallis and Mann-Whitney) tests to compare median stigma scores across levels of selected factors. Based on the results of the bivariate analysis a multiple linear regression model was used to assess factors significantly associated with stigma after a logarithmic transformation of the total FIS score. The results were interpreted as significant at a P-value of <0.05.

Ethical approval: Ethical clearance was obtained from the Department of Psychiatry, Faculty of Medicine, Addis Ababa University. Details of the objectives of the study and assurance of the confidentiality of all responses were explained to the participants before obtaining informed verbal consent. During the house to house

interview free treatment was made available to participants found to be suffering from acute illness at the time of interview.

Results

One hundred twenty seven patients and relatives were interviewed in the community in March 2004. Because of the difficulties encountered during house-to-house interviewing, an additional 415 persons were interviewed at the Girarbet Ledikuman neurology clinic, and the remaining 289 patients and relatives were interviewed at the Butajira out-patient clinic of the district general hospital. The demographic characteristics of the 831 respondents are shown in Table 1.

Table 1: Demographic characteristic of the respondents. Butajira, rural Ethiopia, 2004.

Characteristics	N	%
Center of visit		
Community	127	15.3
Girarbet Neurology clinic	415	40.9
Butajira hospital	289	34.8
Respondents		
Patients	342	41.1
Relatives	489	58.9
Sex		
Male	509	61.3
Female	322	38.7
Marital status		
Single	258	31.0
Married	510	61.4
All others	63	71.5
Occupation		
Farmers	386	46.5
Housewives	211	25.4
Merchants	56	6.7
Students	123	14.8
Others	55	6.6
Education		
Illiterates	463	55.7
Read & Write	55	6.6
School level	313	34.3
Religion		
Moslems	545	65.6
Christians	285	34.3
Others	1	0.1
Age group		
<25	276	33.2
25-34	190	22.9
35-44	-	-
>45	364	43.8
Illness duration		
≤1 year	165	19.9
2-5 years	225	27.1
6-10 years	238	28.6
> 11 years	203	24.4
Length of time on antiepileptic medication		
≤1 year	310	37.3
2-5 years	228	27.4
6-10 years	226	27.2
> 11 years	67	8.1
Seizure frequency per year		
≤6	708	85.2
7-12	63	7.6
>13	60	7.2

The mean age of the recruited people with epilepsy was 26.5 ± 12.7 years and that of the relatives (partners, parents, siblings and other members of the extended family), was 37.6 ± 14.1 . There was no significant difference in the median stigma score reported by these two groups of respondents ($Z = 1.85$, $p = 0.064$). Hence the stigma score was analyzed without differentiating the respondent category.

Taking one or more positive response to the FIS items to represent perceived or experienced stigma, the prevalence estimate of stigma was 81%. Positive scores ranged from 1-34 out of a possible total of 36. The distribution of positive responses to stigma items is shown in Fig. 1. About 60% of patients and relatives felt ashamed of suffering from epilepsy or having a family member with epilepsy. Feelings of guilt and depression together were the second highest score (41.5%) (Table 2).

Table 3 summarizes the mean FIS score in relation to respondents' demographic characteristics and other variables of interest. Using a non-parametric (Kruskal-Wallis) test, the mean stigma score was found to be significantly higher among people with epilepsy and their relatives when interviewed in the community compared to those interviewed at the clinics ($X^2=54.1$, $p < 0.001$). Male patients and their relatives experienced more stigma compared to females ($Z=2.07$, $p=0.038$). There was also a significant difference between the age groups with respondents who were 45 years and older reporting significantly higher stigma scores than the younger age group ($X^2=6.96$, $p=0.031$).

Students reported experiencing stigma at school more often than people who spent their day at other places ($X^2=39.065$, $p < 0.000$). Those who had more frequent seizures (at least once per month) also reported experiencing more stigma compared to those who had less frequent seizures ($X^2=12.76$, $p=0.002$) (Table 3).

Respondents who were interviewed in the neurology clinic and patients who had less seizure frequencies continued to show significantly lower levels of stigma after adjusting for sex, age group, and perceived areas of maximum stigma.

Discussion

The fact that our original study plan was changed from a community to clinical interview could be a major limitation of the study. When we first planned the community interview, we assumed that clinic recruitment would affect our results because the response of people who get free antiepileptic medication may be biased when interviewed at the clinics. But comparing the two has also given us a possibility of looking into the stigma experiences in different settings.

Table 2: Items presented to patients and family members and the corresponding responses. Butajira, rural Ethiopia, 2004.

Can you please tell me whether any of the following things have happened – since (you /your-----/name/) developed epilepsy: Not at all (0), Sometimes (1), Often (2), A lot (3)- since- (name)-. Were you:

Items	0	1	2	3	Any positive response
1. Worried to be treated differently.	624	19	75	113	207 (24.9%)
2. Worried people would know out about it.	532	12	88	199	299 (36.0%)
3. Felt the need to hide this fact.	607	7	104	113	224 (27.0%)
4. Helping other people to understand what it is like to have a family member with psychiatric problem.	666	37	81	47	165 (19.9%)
5. Worried to be avoided	645	11	72	103	186 (22.4%)
6. Explaining to others that -(name)- isn't like their Picture of "crazy" people.	671	36	78	46	160 (19.3%)
7. Worried that people would blame you for his or her problems.	662	11	55	103	169 (20.3%)
8. Worried that a person looking to marry would be reluctant to marry in to your family.	550	13	78	190	281 (33.8%)
9. Worried about taking him or her out.	778	2	18	33	53 (6.4%)
10. Felt ashamed or embarrassed about it.	333	35	151	312	498 (59.9%)
11. Sought out people who also have a family member who has had psychiatric problem.	630	34	78	89	201 (24.2%)
12. Felt guilt or depression because of it.	486	41	145	159	345 (41.5%)
13. Felt that somehow it might be your fault.	658	13	47	113	173 (19.8%)

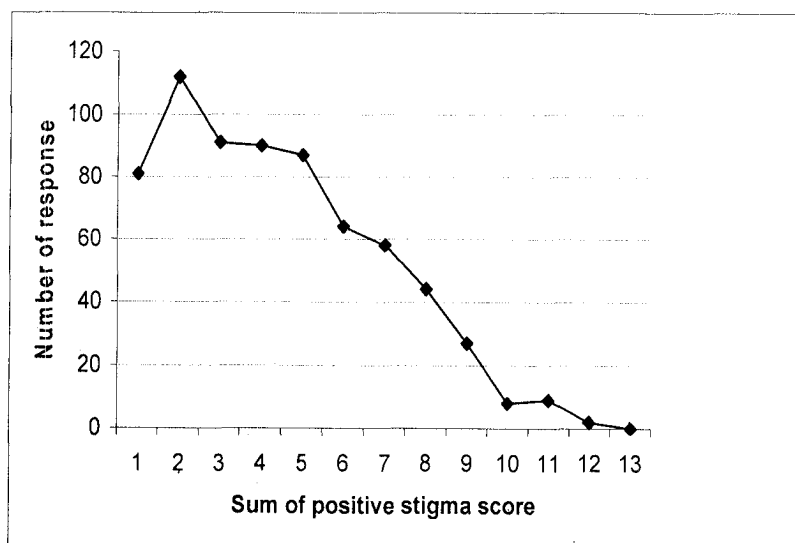


Figure 1: Distribution of stigma responses on the 13 stigma items. Butajira, Ethiopia. 2004

Table 3: Stigma mean score in relation to demographic characteristics of the respondents and other variables, Butajira, rural Ethiopia, 2004

Characteristics	n	Mean scores	X ²	P-value
Center of visit				
Community	127	10.86		
Girarbet Neurology clinic	415	6.93	54.1	0.000
Butajira hospital	289	10.43		
Sex				
Male	509	9.20		
Female	322	8.04	2.073*	0.039
Age group				
<25	276	8.84		
25-34	190	7.59	6.96	0.031
35-44	-	-		
>45	364	9.30		
Education				
Illiterates	463	8.76		
Read & Write	55	9.42	0.416	0.812
School level	313	8.61		
Religion				
Moslems	545	9.02		
Christians	285	8.24	0.831	0.406
Others	1			
Marital status				
Single	258	8.48		
Married	510	8.87	0.037	0.982
All others	63	8.83		
Occupation				
Farmers	386	9.43		
Housewives	211	7.47	8.840	0.77
Merchants	56	7.70		
Students	123	9.09		
Others	55	9.18		
Maximum experience of stigma at:				
Working place	495	7.86		
School	28	11.32	39.065	0.000
Marriage	52	9.35		
Peer	18	9.22		
Family	221	10.52		
Others	17	4.94		
Illness duration				
≤1 year	165	7.97		
2-5 years	225	8.76		
6-10 years	238	9.55	5.480	0.140
> 11 years	203	8.58		
Length of time on antiepileptic medication				
≤1 year	310	8.65		
2-5 years	228	9.42	5.21	0.157
6-10 years	226	8.74		
> 11 years	67	6.94		
Seizure frequency per year				
≤6	708	8.40		
7-12	63	11.84	12.76	0.002
>13	60	9.58		

*Z according to mann-whitney test

The occurrence of psychosocial problems related to epilepsy is well recognized and documented and in certain situations these problems are believed to be more troublesome than the seizure disorders themselves (16, 20-21). The results of our study show that social stigma is a common experience of people with epilepsy and their

relatives, as reported by 81% of the study subjects. This finding is consistent with reports from other studies which show clear evidence of stigma among persons suffering from epilepsy (16-17). In a recent European study only about 13.5% of the respondents did not feel stigmatized or scored 0 on the presented stigma scores

(10). Even if the ways in which the respondents experience stigma is likely to be different from our study because of differences in the culture, setting and other factors there are also a number of similarities. Compared to the previous study in Butajira among relatives of patients suffering from schizophrenia and bipolar disorder, the magnitude of perceived stigma was found to be significantly higher in the current study (18). A key informant study previously conducted in the Butajira area reported that epilepsy was perceived to be the commonest mental problem in its occurrence but less severe condition than schizophrenia and other major depressive disorders (22). Our finding of greater stigma which was associated with epilepsy despite being perceived as a less serious condition, might have resulted from the fact that epilepsy is also believed to be a form of insanity, which could result in a double stigma in patients suffering from epilepsy and their relatives.

Despite being a common neurological disorder, epilepsy seems to be the least understood and most feared disorder in most parts of the world (22-23), which is further complicated in developing countries by its traditional attribution to demonic possession, and the perception that it is transmissible by physical contact. All these misperceptions might explain why epilepsy carries more stigma than other disorders, including mental illnesses. Our finding of a higher experience of stigma in the community is in accordance with the reports from earlier studies that people with these disorders have been marginalized within their societies, and have had reduced opportunities for education, employment, marriage and social relationships as has been reported in earlier studies in developing countries including Ethiopia (22-24).

There are also recent reports of the perception of being stigmatized leading to difficulty in employment (10, 25), education (10) and some degree of male preponderance in experiencing stigma, which are in agreement with our findings. The narration described in the above method section, which is mainly related to matrimonial relations, could be a reflection of the finding of higher stigma means score among male respondents. This finding may need further exploration in a qualitative approach.

Those in the older age group (45+) who perceived stigma as a more major problem than other age groups is in accordance with other studies (26). These could be patients or parents who are taking care of their children and partners. However this difference disappeared after adjustment for other factors.

The finding that significant differences continued to exist in the community and the highest stigma mean score among students at school indicates important misconceptions about epilepsy in these environments. We believe that most parents who have a child with a heart condition or diabetes would inform teachers or

friends about these illnesses because they are less stigmatized or carry fewer misconceptions as to their nature. The concealment about the seizure in turn may contribute to the increased risk of a child's perception of stigma at school. The frequency of seizures, which is an indicator of the degree of severity of illness, was shown to associate with significantly higher perceptions of stigma after adjusting for other factors too. This finding is in line with other studies, which reported current seizure activity to be the most important predictor of perceived impact of epilepsy (8).

Experiences like feelings of shame and embarrassment about the illness, guilt and depression resulting from of the illness, and from worrying that people would discover about their illness were taken as important parameters to assess stigma in many studies (17-18). Compared to the report about perceived stigma towards schizophrenia and bipolar disorders from the same community more people felt that epilepsy was their own fault (4.5% Vs 19.8%) (18).

In spite of the extended family network, traditional social support systems and the continuous availability of antiepileptic medication in the area, it seems that there is substantial concern about stigma among people with epilepsy and their relatives. Studies show that there is a need for health professionals to work towards improving awareness among patients, relatives and the community at large to promote care (27).

Conclusion

The reported experience of stigma was found to be common among people with epilepsy and their relatives in this rural Ethiopian setting. This study has important social implications in that stigma could be a major obstacle in life, limiting opportunities for education, work and other social activities. Our results reinforce the need to improve awareness among patients, relatives and the community at large about the condition in order to counteract misconceptions attached to it. In the clinical setting, efforts should address psychosocial problems in addition to seizure control. Local beliefs and misconceptions in the community must be taken into consideration when planning interventions to improve the control of epilepsy in the community. In-depth interviews are indicated to better understand the nature of the stigma experienced in community settings.

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