

The Correlation Factors on Epilepsy Stigma amongst People in Indonesia

Saniya Ashilah Rabbani¹, Joseph Ekowahono R², Viskasari P. Kalanjati³

¹Clinical Students at Faculty of Medicine, ²Lecturer at Department of Neurology, ³Lecturer at Department of Anatomy and Histology, General Hospital of dr. Soetomo, Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia

Abstract

Background: Epilepsy is a recurrent attack or seizure disorder more than twice for no reason derived from cerebral cortical cerebral neurons, and sometimes accompanied by a decrease in consciousness, both motor and sensory and behavioral or emotional intermittent and stereotyped behavioral or emotional. Until now the etiology of epilepsy is still not known with certainty and multifactorial nature of this matter that raises many wrong assumptions and views of some Indonesian people about epilepsy disease. The study was conducted to find out the correlation between social factors background (domicile, age and occupation as well as education) and stigma towards people with epilepsy in the community.

Method: This study was an observational analytic study by observing domicile, age, occupation, last education, and knowledge of epilepsy in society and analyzing the relationship between age, domicile, occupation and education of respondents with stigma against epilepsy patients. The method used is cross sectional data collection through a modified questionnaire from Knowledge, Attitudes, and Practice towards Epilepsy Survey (KAPE) which has passed the validation stage of previous research. The data taken were analyzed descriptively and tested by *chi-square* test using SPSS.

Result: With a total of 127 respondents based on domicile got significant correlation, based on last education level also got significant relation with p value is $0,028 < 0,05$ whereas no correlation on age variable with stigma where p value is $0.834 > 0.05$ and there is no significant correlation between occupation with stigma where p value is $0.730 > 0.05$.

Conclusion: There is correlation between domicile and education level with stigma to epilepsy patient.

Keywords: Epilepsy; Stigma; Knowledge, Attitudes, and Practice.

Introduction

Epilepsy is a brain disease that define by conditions occurring at least two attacks without symptom (or

reflex) by a distance of more than 24 hours. Epilepsy consider treatable for individuals having epilepsy, but they are having no seizures for the past 10 years, and without seizure drugs for the past 5 years¹. Epilepsy is the second chronic neurological disease which is often faced by neurologists and affects nearly fifty million people worldwide² while the patient's seizure-free condition were taken from medical records. Then quality of life of seizure-free temporal lobe epilepsy patients were compared with not seizure-free patients after amygdalohippocampectomy. The statistical tests used were unpaired t-test if the data was distributed normally, and Mann-Whitney test if the data was not distributed

Corresponding Author:

Saniya Ashilah Rabbani

Clinical Students at Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia
Campus A, Jl. Mayjen Prof. Dr. Moestopo 47,
Surabaya, Indonesia-60131
e-mail: saniyashilah@gmail.com

normally. Results: 31 patients, 21 were seizure free (Engel 1. In developed countries, it is estimated that every year 30 to 50 new cases occur from 1,000 people in the general population, whereas in developing countries it can reach double³ hypopharynx cancers account for a small proportion of the head and neck cancer workload in the UK, and thus suffer from the lack of high level evidence. This paper discusses the evidence base pertaining to the management of hypopharyngeal cancer and provides recommendations on management for this group of patients receiving cancer care. Recommendations * Cross-sectional imaging with computed tomography of the head, neck and chest is necessary for all patients; magnetic resonance imaging of the primary site is useful particularly in advanced disease; and computed tomography and positron emission tomography to look for distant disease. (R. There are around 1.5 million sufferers of epilepsy in Indonesia the prevalence of 0.5-0.6%⁴.

Stigma is all forms of physical and social attributes that reduce a person's identity⁵. Stigma is usually associated with health problems or illness as a social process characterized by rejection, reproach, or exclusion of certain individuals or groups⁶. In Indonesia the stigma about epilepsy is rather high, many assumptions and wrong point of views to Indonesian regarding epilepsy. Most Indonesian consider that epilepsy is a contagious hereditary disease and curse. This assumption causes suffering to sufferers because in addition to having to bear the weight of suffering at the time of the coming attack the sufferer is sometimes cleansed by the community. This can affect the quality of life of epilepsy patients⁷.

Many factors influence the emergence of wrong views about the disease epilepsy, namely knowledge of health, education level, and culture. Many inconsistencies in the results of a treatment due to the influence of ethnic and socio-economic cultural factors. This is also due to differences in understanding and perception at the time of receiving information, daily lifestyle and adherence to treatment⁸. Data on public perceptions about epilepsy sufferers in Indonesia has not been widely reported.

This study aimed to determine the correlation between social factors background (domicile, age and occupation as well as education) and stigma towards people with epilepsy in the community.

Method

This study is an observational analysis of data

from a questionnaire sheet modified from Knowledge, Attitudes, and Practice towards epilepsy survey (KAPE) 9 with a cross sectional case study.

Sample: The research sample was taken using the simple random sampling method where a minimum quota was determined in each sampling area consisting of, 50 people from Surabaya and 50 people from Mataram and the surrounding area. With the following details, 25 who live in urban areas of Surabaya, 25 people who live in rural areas of Surabaya, 25 people who live in urban areas of Mataram and surrounding areas and 25 people who live in rural areas of Mataram and surrounding areas. With a minimum total of 100 samples.

Time and Place: This research was conducted in 2 cities, Surabaya City (the working area of Pacar Keling Health Center and East Silver Health Center) and Mataram City (working area of Pagesangan Health Center and Tanjungkarang Health Center). The period was conducted on 1 September 2016 - 1 October 2017 based on questionnaire sheet data.

Data Analysis: Data from the questionnaire sheets analyzed with frequency and chi-square with SPSS 19.0 (SPSS.Inc., Chicago, IL). Significant level was reached when $p < 0.05$. Odd ratio calculation was used to calculate the ratio of differences between groups of stigma against patients with epilepsy.

Result

Behaviors and Actions (Stigma) of Respondents Against Patients with Epilepsy: Based on stigma of respondents towards people with epilepsy, it said that stigma are severe when answering $> 75\%$ (> 2 of the stigma questions, Score = 0-6) and to be mild stigma if answering $\leq 25\%$ (≤ 2 of the questions) stigma, Score = 7-9). (Table 1)

Analysis of Factors of Domicile, Age, Occupation, Education with Stigma Against People with Epilepsy: There was a difference shown by the statistics of the domicile of respondents in the city and in the village. The value of $p = 0.001$ with an odd ratio of 6,300 (95% CI 2,100 - 18,903) which shows that respondents who live in Surabaya City or in the City Matrix have severe stigma against those who live in Surabaya Desa or Mataram Desa. (Table 2)

While for the age factor, it can be seen that from 127 respondents found stigma against patients with epilepsy, were at least in the age group 65-74 years

with a total of 2 respondents (50%). Likewise, stigma to the most severe patients with epilepsy were found in the 18-24 age group with 22 respondents (44.9%). Mild and severe stigma towards patients with epilepsy are dominated by the 18-24 age group because the most respondents obtained from the 18-24 age group with a total of 49 respondents. This difference was not statistically significant with a value of $p = 0.834$. (Table 2).

The type of respondent's occupation with severe stigma towards epilepsy sufferers was at least in the type of occupation as a farmer with 2 respondents (33.3%), besides the most severe stigma towards epilepsy sufferers were found in the type of occupation as a housewife with 20 respondents (37%). Each of the severe and mild stigma was dominated by the type of housewife's work because the largest number of respondents comes from the type of work as a housewife. P Chi-square value of $p = 0.730$ obtained where the value was not statistically significant. (Table 2).

The results showed that there were more people who had behaviors and actions towards patients with mild epilepsy (stigma) against sufferers of epilepsy in the amount of 58.3%. While people who have behaviors and actions towards patients with severe epilepsy (stigma) against epilepsy in the community category based on recent education were only 41.7%, and the difference was statistically significant with a p value = 0.028. (Table 2).

Respondents who have good knowledge about epilepsy with severe stigma categories were 13 people (32.5%) and the difference was not statistically significant with $p = 0.153$. an odd ratio value of 1.768 (CI 95% 0.807 -3,874) shown that respondents with less knowledge have a tendency to be 1,768 times more likely to have severe stigma towards sufferers of epilepsy compared to respondents who have good knowledge. (Table 2).

The correlation between the respondent's education level category and stigma of epilepsy sufferers: Out of the 127 respondents obtained stigma

towards patients with severe epilepsy in the last education under primary school as many as 9 respondents (29%), while the stigma in the last education higher than elementary school were 44 respondents (45.8 %) and the difference was not statistically significant with $p = 0.099$ and an odd ratio of 2.068 (95% CI 0.864-4953). Respondents with more than elementary school education have a tendency to have 2 times more severe behavior and actions (stigma) compared to respondents with education below elementary school.

Comparison of the latest education under junior high school and more than junior high school shown that from 127 respondents found the stigma in the last education less than junior high school were 12 respondents (26.1%), while the behavior and stigma in the last education higher than junior high school as many as 41 respondents (50.6%). The difference was statistically significant with $p = 0.007$ and an odd ratio of 2.904 (95% CI 2.904-6.394). It is obtained where respondents with education more than junior high has a tendency to have stigmatized compared to respondents with education below junior high. (Table 3).

Table 1: Distribution of respondents based on domicile and stigma level

Stigma		Respondents (n)	Total
Mild	Surabaya City	10	74(58.3%)
	Surabaya Village	24	
	Mataram City	17	
	Mataram Village	23	
Severe	Surabaya City	21	53(41.7%)
	Surabaya Village	8	
	Mataram City	13	
	Mataram Village	11	
Total	Surabaya City	31	127(100%)
	Surabaya Village	32	
	Mataram City	30	
	Mataram Village	34	

Table 2: Analysis of variables correlation towards stigma in epilepsy sufferers

Stigma Against Sufferers of Epilepsy								
Variables	Severe Stigma		Mild Stigma		Total		P Value (chi Square test)	POR CI 95%
	N	%	N	%	N	%		
Domicile								
Surabaya City	21	67.7	10	32.3	31	100	0.001	6.300 (2.100-18.903)
Surabaya Village	8	25	24	75	32	100		
Mataram City	20	66.7	10	33.3	30	100	0.001	5.556 (1.895-16.286)
Mataram Village	9	26.5	25	73.5	34	100		
Age								
18-24	22	44.9	27	55.1	49	100	0.834	-
25-34	9	33.3	18	66.7	27	100		
35-44	9	50	9	50	18	100		
45-54	9	40.9	13	59.1	22	100		
55-64	2	28.6	5	71.4	7	100		
65-74	2	50	2	50	4	100		
Occupation								
Student	16	48.5	17	51.5	33	100	0.730	-
Housewife	34	62.9	20	37.1	54	100		
Farmer	4	66.7	2	33.3	6	100		
Entrepreneur	8	61.5	5	38.5	13	100		
Others	12	57.2	9	42.8	21	100		
Last Education								
Un-educated	1	10	0	90	10	100	0.028	-
Primary school	8	38.1	13	61.9	21	100		
Junior High School	3	20	12	80	15	100		
Senior High School	30	47.6	33	52.4	63	100		
Bachelors	11	61.1	7	38.9	18	100		
Knowledge								
Less	40	46	47	54	87	100	0.153	1.768 (0.807-3.874)
Good	13	32.5	27	67.5	40	100		

Table 3: Comparison of respondents' educational level and stigma against epilepsy sufferers

Stigma Against Sufferers of Epilepsy								
Variables	Severe Stigma		Mild Stigma		Total		P Value (chi square test)	POR CI 95%
	N	%	N	%	N	%		
Comparison of last education (Primary School)								
Under primary school	9	29	22	71	31	100	0.099	2.068 (0.864-4.953)
Above primary school	44	45.8	52	54.2	96	100		
Total	53	41.7	74	58.3	127	100		
Comparison of last education (Junior high school)								
Under junior high school	12	26.1	34	73.9	46	100	0.007	2.904 (2.904-6.394)
Above junior high school	41	50.6	40	49.4	81	100		
Total	53	41.7	74	58.3	127	100		

Discussion

Compared to respondents who live in rural areas, Respondents who live in urban areas experience stigma and get a p value smaller. As a result, it can be concluded that there is a significant correlation between domicile and stigma against patients with epilepsy. This trend is caused by people from rural areas tend to live in village-type communities and were closer to the tendency to offer support to one another. People in rural areas were more receptive to disease.¹⁰ Geographical regions with strong cultural perceptions of diseases that rely on non-scientific explanations, such as Asia and Africa have a worse attitude towards epilepsy as evidenced by the misunderstanding of epilepsy as an infectious disease caused by spiritual science¹¹

For the results of processing the correlation between age and stigma there is no significant correlation between it. Increased levels of stigma in the elderly age group shown differences in choosing social networks based on increasing age. With increasing age the perception of time constraints leads to psychological needs so as to produce smaller social networks with increased emotional ties. In general there is no correlation between age and community stigma against people with epilepsy.¹²

From the chi square results, it can be concluded that there is no significant correlation between work and stigma for patients with epilepsy. Based on previous research there was also no significant correlation between work status and the stigma, such as people who do not work, work part-time or work full day. Those all do not have a correlation with negative behavior or discrimination against epilepsy¹². Similarly, research conducted in the western world many people with epilepsy found working as employees and found no discrimination against epilepsy sufferers who work¹³cross- sectional epidemiologic study of 241 persons with epilepsy identified from an at-risk population of 24,130 individuals (64.7% from urban and 35.3% from rural areas.

The wrong view of epilepsy was also influenced by the level of education. Several studies have shown that a better level of education will provide an attitude towards epilepsy¹⁴. However, this opinion has not in line with the results of research conducted. Mild stigma was found at all levels of education except in the bachelor. There were more respondents who have severe stigma than mild stigma. The results of the chi square value indicated a

significant correlation. The level of education did not guarantee that a person does not have discrimination against sufferers with epilepsy. In a study from Thailand, 38% of elementary school teachers never heard or read about epilepsy and 15% preferred to find all children with epilepsy in a special class.¹⁵ Saudi Arabia included private/public schools designated for male and female students. A structured 37-item questionnaire was used to examine their demographics, knowledge, attitudes, and experience with epilepsy. Results Six hundred and twenty primary school teachers working in public (58%.

From the research conducted there were no significant correlation between the knowledge variables with stigma against patients with epilepsy. The data obtained respondents who have both of less knowledge and good knowledge have the amount of mild stigma more than severe stigma. Someone who has heard, obtained information and known about epilepsy tends to behave positively and does not discriminate against someone with epilepsy¹⁴.

Limitation: This research does not explain the factors that influence the presence of severe stigma in urban areas.

Conclusion

There is a significant correlation between the domicile (city or village) and the last education of the respondent and stigma towards sufferers of epilepsy.

Conflic of Interest: The authors declare that they have no competing interests.

Source of Funding: The authors declare that this study have self-funding

Ethical Clearance: This study received a certificate of ethical clearance no. 015/EC/KEPK/FKUA/2017from ethical commission of Faculty of Medicine, Universitas Airlangga Indonesia.

References

1. Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia*. 2014;
2. Ashari (Universitas Diponegoro). Perbandingan Kualitas Hidup Pasien Epilepsi Lobus Temporal Yang Bebas Kejang Dengan Yang Tidak Bebas Kejang Pasca Amigdalohippokampektomi. J

- Kedokt Diponegoro. 2012;1(1).
3. WHO. Epilepsy Fact sheet. Media Center. 2017.
4. Muttaqin Z. Epilepsy surgery in Indonesia: Achieving better result with limited resources. *Medica Hosp J Clin Med*. 2019;
5. Goffman E. Stigma. In: *Classic and Contemporary Readings in Sociology*. 2014.
6. Hidayati E. Pengetahuan Dan Stigma Masyarakat Terhadap TBC Setelah Diberikan Pendidikan Kesehatan Pencegahan Dan Penularan. *Soedirman J Nurs*. 2015;10(2):76–82.
7. Syam Yeni; Genisa, Maya EZ. Karakterisasi dan Digitalisasi Frekuensi Signal EEG Penderita Epilepsi. *Maj Kesehat Pharmamedika*. 2011;
8. Saing JH. Tingkat Pengetahuan, Perilaku, dan Kepatuhan Berobat Orangtua dari Pasien Epilepsi Anak di Medan. *Sari Pediatr*. 2016;
9. Chung K, Ivey SL, Guo W, Chung K, Nguyen C, Nguyen C, et al. Knowledge, attitudes, and practice toward epilepsy (KAPE): A survey of Chinese and Vietnamese adults in the United States. *Epilepsy Behav*. 2010;
10. Peters D, Ramsewak SS, Youssef FF. Knowledge of and attitudes toward medical professionalism among students and junior doctors in Trinidad and Tobago. *West Indian Med J*. 2015;
11. Kheng SL. Social Stigma in Epilepsy, a Population-Based Study in Malaysia Kheng-Seang Lim Thesis/Dissertation Submitted in Fulfilment of the Requirements for the Degree of Doctor of Philosophy Faculty of Medicine [Internet]. University of Malaya; 2013. Available from: <http://studentsrepo.um.edu.my/5642/>
12. Lim KS, Wu C, Choo WY, Tan CT. Development and validation of a public attitudes toward epilepsy (PATE) scale. *Epilepsy Behav*. 2012;
13. Aziz H, Akhtar SW, Hasan KZ. Epilepsy in Pakistan: Stigma and psychosocial problems. A population- based epidemiologic study. *Epilepsia*. 1997;
14. Teferi J, Shewangizaw Z. Assessment of knowledge, attitude, and practice related to epilepsy: A community-based study. *Neuropsychiatr Dis Treat*. 2015;
15. Abulhamail AS, Al-Sulami FE, Alnouri MA, Mahrous NM, Joharji DG, Albogami MM, et al. Primary school teacher's knowledge and attitudes toward children with epilepsy. *Seizure*. 2014;