

Determinants of Public Knowledge about Epilepsy in Indonesia: A Cross-sectional Study in Banda Aceh

Nova Dian Lestari^{a,b*}, Fatimah Nuzhatuddin^c, Khusnul Amra^{a,b}, Dina Alia^{d,e},
Nur Astini^{a,b}, Teuku Romi Imansyah Putra^f, Rachmad Suhandar^g

*Email: novadianlestari@unsyiah.ac.id

^a Department of Neurology, Faculty of Medicine, Universitas Syiah Kuala, Banda Aceh, Indonesia

^b Department of Neurology, Dr. Zainoel Abidin Public Hospital, Banda Aceh, Indonesia

^c Medical Doctor Program, Faculty of Medicine, Universitas Syiah Kuala, Banda Aceh, Indonesia

^d Department of Otorhinolaryngology, Faculty of Medicine, Universitas Syiah Kuala Banda Aceh, Indonesia

^e Department of Otorhinolaryngology, Dr. Zainoel Abidin Public Hospital, Banda Aceh, Indonesia

^f Department of Parasitology, Medical Faculty, Universitas Syiah Kuala, Banda Aceh, Indonesia

^g Department of Public Health, Medical Faculty, Universitas Syiah Kuala, Banda Aceh, Indonesia

Abstract

Epilepsy is a neurological disease which is able to affect people of all ages, races, social classes, as well as regions. It is caused by abnormal release of neurons in the brain characterized with seizures. In addition, epilepsy is often surrounded by prejudices and myths caused with a lack of society knowledge. It is associated with negative attitude and belief as a stigma toward epilepsy patient and therefore it could influence psychological leading to decreasing the quality of life of the patients. The study aimed to assess the associations or correlations between demographic characteristics and knowledge of epilepsy in community members in Banda Aceh, Indonesia. A cross sectional with observational analytic design was conducted in nine districts from June 9 to July 14, 2021. The samples were those who fit with inclusion and exclusion criteria. Data collection was conducted using online questionnaire employed a Google form platform. Spearman correlation, Mann-Whitney, and Kruskal-Wallis were used to analysis the data. A total of 312 respondents were included in final analysis. There were 43.9%, 48.7%, and 7.4% of the respondents had the level of knowledge what was classified as high, average and low, respectively. The results of this study indicated that the level of knowledge was influenced by gender, ethnicity, and occupation. In addition, there was a relationship between the level of education and the level of knowledge about epilepsy ($p < 0.01$). There was no significant relationship between age and family history with knowledge about epilepsy in the community.

Keywords: Epilepsy, knowledge, society, determinant, Indonesia

1. Introduction

Knowledges about epilepsy are poorly understood, even among those who regularly interact with people with epilepsy. Limited knowledge and understanding have been associated with negative attitudes and beliefs towards people with epilepsy both at work and school. Epilepsy is a serious neurological disorder that can often be surrounded by prejudice and myth and is closely related to various misconceptions [1,2]. Epilepsy cases in Indonesia are reported around 8.2 per 1000 population with incidence rate of 50 per 100,000 population, and approximately 1.8 million epilepsy patients require treatment [3]. Visitation of patients with epilepsy at the Regional General Hospital dr. Zainoel Abidin Banda Aceh reached the number of 150-200 people.

Some study in Africa showed people believe that epilepsy is widely transmitted through direct contact with bodily fluids such as urine, saliva, and assume that people with epilepsy have been possessed, depending on their beliefs and culture. Many studies in Africa, have revealed that people with epilepsy are shunned and discriminated in education, institutions, work sector, even marriage because epilepsy is seen as a highly contagious and shameful disease. As a result, people with epilepsy experience problems in privacy and countless discrimination [1,4].

In Indonesia, epilepsy is better known as "paan" or "convulsion", due to the wrong views and assumptions about epilepsy. People believe that epilepsy is not a disease but a condition caused by evil spirits, possessions, or curses. People are generally afraid to give help if there are patients with epilepsy who recur because they think it might be contagious. Knowledge and perceptions that exist in this community are passed down from generation to generation and become a socio-cultural problem in people's thinking [5]. People with epilepsy often have difficulty doing social activities which affect their psychological or social welfare. Concern about epilepsy causes sufferers to isolate themselves from social activities and get negative stigmatization [6].

These negative stigmas in society are causing stress to person who suffer epilepsy. It prevents them from reaching their potential. Therefore, by educating the community, it is expected that the community will no longer give negative stigma and able to accept epilepsy sufferer in the community [7]. Education regarding epilepsy in Banda Aceh is still very limited which resulted on negative stigma that causes a decline on quality of life and

motivation in epilepsy patients. Therefore, the aim of this study was to assess the relationship between demographic characteristics and public knowledge on epilepsy in Banda Aceh, Indonesia.

2. Methods

This study was an analytical observational study with a cross sectional approach. This study was conducted in nine districts of Banda Aceh: Baiturrahman, Kuta Alam, Meuraxa, Syiah Kuala, Lueng Bata, Kuta Raja, Banda Raya, Jaya Baru, and Ulee Kareng. Data collection was carried out from June 9 to July 14, 2021.

The population in this study were all people of Banda Aceh who aged >17 years old with a total population of 270,321 people. The sample in this study was the people of Banda Aceh whose fulfill inclusion and exclusion criteria with a minimum sample size of 96 respondents.

This study uses data collection sheets derived from the Epilepsy: Knowledge, Attitude, and Behavior Study questionnaire which has been tested for validity and reliability with a Cronbach's Alpha value of 0.611. The data was collected using Google Forms and the link was distributed to community in Banda Aceh. The questionnaire consisted of demographic data including age, gender, ethnicity, education, occupation, and family history and knowledge about epilepsy.

The data was analyzed using univariate and bivariate analyses. The univariate analysis was used to describe the characteristics of the respondents and to describe the level of community knowledge about epilepsy, while the bivariate analysis was to assess the relationship between demographic characteristics and knowledge of epilepsy in the people of Banda Aceh using Spearman correlation test, Mann-Whitney and Kruskal-Wallis test.

3. Results

A total of 312 samples was included in the final analysis. The characteristics of the respondents in this study are presented in the Table 1. The results showed that the majority of respondents were 23–55 years old (57.4%), 67% were women and 90.7% were Acehnese. There were 41.7% of respondents graduated from bachelor, 39.4% were university students, and 94.4% did not have family history of epilepsy (Table 1).

Table 1. Correspondents' characteristics (n=312)

Characteristic	Frequency	Percentage (%)
Age		
17–22 years old	117	37.5
23–55 years old	179	57.4
>55 years old	16	5.1
Sex		
Male	103	33.0
Female	209	67.0
Ethnicity		
Aceh	283	90.7
Non-Aceh	29	9.3
Education		
Junior High School	1	0.3
Senior High School	97	31.1
Diploma	12	3.8
Bachelor	130	41.7
Postgraduate	72	23.1
Occupation		
Doctor	4	1.3
Lecturer/teacher	28	9.0
Entrepreneur	21	6.7
Civil servant/private sector employee	112	35.9
University student	123	39.4
Housewife/retired/not working	24	7.7
Family history		
No	296	94.9
Yes	16	5.1

Our data indicated that 14.74% of the respondents did not agree that epilepsy can be controlled or cured, 3.84% believed that epilepsy was an infectious disease, 1.28% believed that epilepsy was a disturbance of spirits, 7.05% believed that epilepsy is a mental disorder, and 31.08% believed that epilepsy always started in childhood (Table 2). From 312 respondents, the majority of people's knowledge regarding epilepsy was average (43.9%). This shows that most of the people of Banda Aceh have sufficient knowledge of epilepsy (Table 3).

Table 2. Community knowledge about epilepsy in Banda Aceh (n=312)

Question	Disagree n (%)	Doubtful n (%)	Agree n (%)
Epilepsy can be controlled	46 (14.74)	74 (23.71)	192 (61.53)
Epilepsy is an infectious disease	275 (88.15)	25 (8.01)	12 (3.84)
Epilepsy is caused by disturbance of spirits	293 (94)	15 (4.80)	4 (1.28)
Epilepsy is a mental disorder	244 (78.20)	46 (14.80)	22 (7.05)
Epilepsy always started in childhood	105 (33.66)	110 (35.26)	97 (31.08)

Table 3. Level of community knowledge about epilepsy in Banda Aceh (n=312)

Knowledge	Frequency	Percentage (%)
Low	23	7.4
Average	152	48.7
High	137	43.9

Our data indicated that knowledge increases within age, but decreases at the age of more than 55 years (Table 4). The high knowledge was dominant in 23–55 years old group (46.9%) and the low-average knowledge was dominant in age over 55 years group (68.8%) (Table 4). There was insignificant relationship between age and knowledge level, with $p=0.981$ and the correlation coefficient ($r=0.001$) which indicated that there was no relationship between age and public knowledge of epilepsy in Banda Aceh (Table 4).

It was found that the high level of knowledge was greater in women (49.8%) than men (32%). The Mann-Whitney test suggested there was a significant relationship between gender and the level of knowledge, $p=0.009$ indicating that there was a relationship between gender and knowledge of epilepsy (Table 4).

The non-Aceh ethnic group has a higher level of knowledge (62.1%) compared to the Aceh ethnic group (42.0%), and majority of average and low level of knowledge was from Acehnese ethnic group (58%). The Mann-Whitney test showed that there was a significant relationship between ethnicity and community knowledge, $p=0.038$. These results indicated that there were differences in knowledge based on ethnicity (Table 4).

Our data also indicated that the higher the level of education, the higher the level of one's knowledge, of which postgraduate and undergraduate were predominant in high knowledge, while students in Junior High School, Senior High School, and diploma had predominant on average level of knowledge. There was a significant relationship between education level and community knowledge ($p<0.01$), but the relationship between education and community knowledge is weak because the correlation coefficient value is ($r=0.230$) (Table 4).

Although the result of this study suggested that the respondents who had a family history of epilepsy had higher level of knowledge than respondents who did not have a family history of epilepsy (Table 3), the Mann-Whitney test showed that there was no difference in knowledge between respondents who had a family history of epilepsy and respondents who did not have a family history of epilepsy ($p=0.156$).

Occupations which had a high level of knowledge were dominant on doctors, lecturers/teachers, and entrepreneurs, while profession with an average level of knowledge were dominant on civil servant/private sector employees, university students, and house wife/not working/retired (Table 3). The Kruskal-Wallis test indicated that there was a significant relationship between occupation and knowledge of epilepsy with $p=0.015$ Aceh (Table 4). This suggested there was a difference in knowledge about epilepsy in each occupation (Table 4).

Further analysis about the difference in knowledge based on occupation using Mann-Whitney statistical are shown on Table 5. Our data suggested that the occupation of respondents as doctor, lecturer, and entrepreneur had relatively no different levels of knowledge. Doctors had different knowledge with civil servants, students, and housewives regarding epilepsy (Table 5). Lecturers also had different knowledge with civil servants or private sector employees, students, and housewives regarding epilepsy (Table 5).

Table 4 Analysis of demographic characteristics with public knowledge of epilepsy in Banda Aceh (n= 312)

Characteristic	Knowledge						Total		p-value	Correlation coefficient
	Low		Average		High					
	n	%	n	%	n	%	n	%		
Age									0.981*	0.001
17–22 years old	6	5.1	63	53.8	48	41.0	117	100		
23–55 years old	15	8.4	80	44.7	84	46.9	179	100		
>55 years old	2	12.5	9	56.3	5	31.3	16	100		
Sex									0.009**	-
Male	9	8.7	61	59.2	33	32.0	103	100		
Female	14	6.7	91	43.5	104	49.8	209	100		
Ethnicity									0.038**	-
Acehnese	22	7.8	142	50.2	119	42.0	283	100		
Non-Acehnese	1	3.4	10	34.5	18	62.1	29	100		
Education									<0.01*	0.230
Junior High School	0	0.0	1	100.0	0	0.0	1	100		
Senior High School	8	8.2	61	62.9	28	28.9	97	100		
Diploma	1	8.3	7	58.3	4	33.3	12	100		
Bachelor	10	7.7	59	45.4	61	46.9	130	100		
Postgraduate	4	5.6	24	33.3	44	61.1	72	100		
Family history									0.156**	-
No	22	7.4	147	49.7	127	42.9	296	100		
Yes	1	6.3	5	31.3	10	62.5	16	100		
Occupation									0.015***	-
Doctor	0	0.0	0	0.0	4	100.0	4	100		
Lecturer/teacher	2	7.1	6	21.4	20	71.4	28	100		
Entrepreneur	3	14.3	8	38.1	10	47.6	21	100		
Civil servant/private sector employee	8	7.1	57	50.9	47	42.0	112	100		
University student	6	4.9	69	56.1	48	39.0	123	100		
Housewife/retired/not working	4	16.7	12	50.0	8	33.3	24	100		

* Analyzed using Spearman; ** Analyzed using Mann-Whitney test; *** Analyzed using Kruskal-Wallis test

Table 5 Analysis of knowledge levels about epilepsy by occupation in the community in Banda Aceh (n=312)

	Doc	Le/Te	Ent	CS/PE	Stu	HW/R/NW	p-value
Doc		0.392**	0.113**	0.027**	0.018**	0.035**	
Le/Te			0.097**	0.012**	0.006**	0.009**	
Ent				0.929**	0.840**	0.400**	
CS/PE					0.832**	0.246**	0.015*
Stu						0.269**	
HW/R/NW	0.035	0.009	0.400	0.246	0.269		

Doc: doctor; Le/Te: lecturer/teacher; Ent: entrepreneur; CS/PE: civil servant/private sector employee; Stu: university student; HW/R/NW: housewife/retired/not working

* Analyzed using Kruskal-Wallis test; ** Analyzed using Mann-Whitney test

4. Discussion

Based on the level of knowledge, our data suggested that most of the people had an average level of knowledge which was 48.7%. This suggested that most of the people of Banda Aceh had sufficient knowledge of epilepsy. The

results of this study are in line with study conducted previously in 2021 of which the level of knowledge of epilepsy was average in the community in Medan [8]. Good knowledge is a factor that influences a person's behavior and perception in dealing with epilepsy sufferers which will later affect the management and prognosis of patients [8]. Another study that supports this study was carried out by Gunawan et al (2013) in another place in Indonesia and the study found that the level of knowledge of epilepsy in the community in Sangehi Regency was sufficient [9].

Our present study found that there was no correlation between age and knowledge level (Table 4). However, the high level of knowledge was dominant in the age group of 23-55 years and the low-average knowledge was dominant in the age group of more than 55 years (Table 3). The results of this study are in line a previous study showing that older respondents had a low level of knowledge [10]. Another study that was conducted by Abate et al (2019) also showed lack of knowledge about epilepsy in those more than 45 years, and good knowledge was observed in 18-35 years group [11]. A study by Yuni Valentri (2021) showed that 75% respondents aged more than 60 years had low level of knowledge of epilepsy [8].

This study showed that there was no relationship between age and public knowledge of epilepsy in Banda Aceh. The result is supported by a previous study, where there was no significant relationship between age and knowledge of epilepsy [12]. Another study also found no significant relationship between age and knowledge of epilepsy with $p=0.087$ [13].

Our study suggested that women had a higher level of knowledge than men and there was a relationship between gender and public knowledge of epilepsy. The results of this study are supported by a previous study showing that men had poor knowledge of epilepsy, especially if they did not know someone with epilepsy [14]. Another supporting study is by Emine and Nuray (2017) which showed that there was a significant relationship between gender and knowledge [10]. Female respondents had a significantly higher mean score of epilepsy knowledge compared to males ($p=0.020$) [10]. The results of this study are also in line with a study conducted in 2019 that found a significant relationship between gender and knowledge epilepsy where the score was higher in women compared to men ($p=0.025$) [15].

In this study, it found that there were differences in knowledge based on ethnicity, which led to a tendency of ethnic relations with community knowledge of epilepsy in Banda Aceh. The results of this study indicated that the high level of knowledge was dominant in the non-Acehnese ethnic group and the level of average to low of knowledge was dominant in Acehnese group. A previous study found that there were significant differences found in ethnicity towards knowledge, especially in those who did not know someone with epilepsy ($p<0.001$), someone who knew people with epilepsy had a significantly higher knowledge than someone who does not know people with epilepsy [16]. The results of this study are also supported another study that found ethnicity had a significant relationship on beliefs or beliefs about epilepsy treatment ($p<0.005$), and had a significant relationship of the cause on the occurrence of epilepsy such as brain injury, hereditary diseases, punishment from God, head injuries, and blood disorders [17]. This study was also supported by the study of Birrie and Debebe (2016) that showing a significant relationship between ethnicity and knowledge on epilepsy, especially in urban and rural tribes [18].

Our data also suggested that the higher the level of education, the higher the level of one's knowledge and there was a relationship between education and public knowledge of epilepsy. Several studies that support the results of this study [15,19,20]. A community-based study found that respondents with higher education status such as Senior High School and college had a positive association with the level of knowledge about epilepsy [19]. A study in 2019 found there was a significant relationship between education and knowledge of epilepsy, where respondents who graduated from Senior High School had significantly higher knowledge than those who graduated from Elementary School and Junior High School [15]. This is also supported by study another study that found a statistical significant relationship between low education and false beliefs about epilepsy as a form of insanity [20].

The results of this study indicated that doctors, lecturers/teachers, and entrepreneurs most of them had high level of knowledge while civil servant/private sector employees, students, and housewife/not working/retired relatively had average levels of knowledge (Table 3). It was found that there were differences in knowledge about epilepsy in each occupation which indicated a tendency for the relationship between type of works and knowledge of epilepsy in Banda Aceh. The results of this study are in line with the community-based study of Abate et al (2019) that found that there was a significant relationship between occupation and knowledge of epilepsy, where government employees had good knowledge scores compared to housewife/farmers [11]. This study is also supported by another study where there was a significant relationship between occupation and knowledge about epilepsy, where civil servants had good knowledge compared to students, housewife, and retirees [10]. Based on a study conducted by Yuni Valentri et al (2021), it was found that civil servants/private respondents had good knowledge of epilepsy (50%), and respondents who did not work/housewife had a lower level of knowledge [8]. A study by Rodrigo et al (2012) showed doctors had good knowledge of epilepsy. This is not surprisingly because doctors had more access to information than other professions. Doctors have the inherent characteristics of professional activity, mainly because of their place of work. Doctors have seen larger seizures than other professional categories [21].

Interestingly our study found that there was no difference in knowledge on the presence or absence of a family history of epilepsy which indicated that there was no correlation between history of epilepsy and public knowledge of epilepsy in Banda Aceh. Meanwhile, a study by Jalle and Zewdu (2015) showing that someone who knew people with epilepsy had more knowledge of epilepsy than those who had never heard of or knew about epilepsy [19]. This study is also supported by community-based study by Birinus et al (2014) that found most of the general information about epilepsy came from family members [22]. A study in 2020, found a significant relationship between family history and level of knowledge about epilepsy [23]. Family history is one of the factors associated with the level of knowledge of epilepsy. A study found that someone who had a family history of epilepsy was fifteen times more likely to have a good knowledge of epilepsy compared to someone who did not have a family history of epilepsy [23]. This difference may occur due to the different sample variations in this study. Family history is not a benchmark in assessing knowledge, but it can be seen also in work and education, that in this study someone who did not have a family history of epilepsy had a fairly good education and occupation, so that the knowledge was not much lower than someone who had a history of epilepsy in his family.

5. Conclusion

Almost half of the community members in Banda Aceh included in this study had average level of knowledge of epilepsy (48.7%). The results of this study indicated that the level of knowledge was influenced by age, gender, ethnicity, education and occupation. There was no significant relationship between age and family history with knowledge about epilepsy in the community in Banda Aceh.

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