RESEARCH ARTICLE

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Caregivers' Knowledge on Epilepsy and Its Relationship with Quality of Life

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ABSTRACT

It is widely accepted that epilepsy is a disease that affects not only patients but also their families. The disease has a relevant impact on caregivers' quality of life. The study aimed to determine caregivers' knowledge of epilepsy and its relationship with their quality of life. Total of 308 participants were recruited. The Awareness Knowledge Attitude Questionnaire and the Adult Carer-Quality of Life (AC-QoL) questionnaire were used. The result demonstrates a significant association between caregivers' knowledge levels and the level of their quality of life. A significant association was identified between two socio-demographic characteristics-marital status and educational level-and level of knowledge. Furthermore, significant associations were found between other socio-demographic characteristics and the level of their quality of life: religion, marital status, educational level and monthly income. The findings of the study indicate that caregivers with high levels of epilepsy-related knowledge experience a moderate quality of life. Therefore, epilepsy support groups for caregivers are important as these would provide the appropriate emotional and practical support needed to improve the quality of live among caregivers.

Keywords: Caregiver, epilepsy, knowledge, quality of life.

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I. STUDY BACKGROUND

Epilepsy, the most well-known chronic neurological disorder, is characterised by repeated seizures. Over 50 million people worldwide suffer from epilepsy [1] and almost 80% of these are reported cases from developing countries, including Malaysia [2]. The average prevalence of active epilepsy was 4.9 over 1000 cases for developed countries and 12.7 over 1000 in rural and 5.9 over 1000 cases in urban area in developing countries [3]. It was supported by the incidence of epilepsy was higher in lower-income economies [4]. the percentage reported that, 25% of the global epilepsy populations are children under 15 years old that were diagnosed with active epilepsy. It is equivalent to 10.5 million of the total global population [5].

It is widely accepted that epilepsy is a disease that affects not only patients but also their families [6]. Being a caregiver to epilepsy patient will give a positive and negative impact on the caregiver's wellbeing. It required responsibility and commitment that the caregiver should spend to the patients and it can be psychologically and physically exhausted [7]. Moreover, it will give a huge effect on caregiver activities daily living and indirectly it will reduce their quality of life (QOL) especially on caregiver's life [8]. Caregiver's quality of life was being neglected field in the study of epilepsy. It is important to assess the quality of life who care the epilepsy patients.

A local study conducted in Kuala Terengganu found that, there are a lot of factors associated with epilepsy patients and the influence of the caregivers' QOL [9]. They aim to investigate the awareness, knowledge, attitude and health-related quality of life of family caregivers. The study's outcome signified that those with good awareness, knowledge and attitude experienced a better health-related quality of life. Limited studies have been undertaken in the central region of Malaysia to determine how caregivers' quality of life is associated with knowledge of epilepsy. Thus, the objective of this study was to determine caregivers' knowledge of epilepsy and the relationship with quality of life.

II. METHOD

A cross-sectional study design was chosen for this work. The sample size was calculated by using Cochran formula [10] and the sample size was 308 participants. The study population for this research was conducted in Selangor, Malaysia and involved the caregivers of family members with epilepsy.

The inclusion criteria for this study were: 1) 18 years old and above, 2) having epileptic family members, 3) Living in Selangor and 4) Being able to understand and speak English and/or Malay. The study excluded caregivers who had a medical illness.

The data were collected within three months by distributing an online questionnaire through Facebook messages. The name list of Selangor-based caregivers with epileptic family members was obtained from the Malaysian Epilepsy Association's official Facebook page. In total, 1160 names were listed as caregivers. Then, a systematic sampling method was used to decide that every third name on the list was chosen as a potential respondent and they were contacted by Facebook Messenger. If they agreed with the informed consent conditions and fulfilled the inclusion criteria, they received the online questionnaire and were recruited as a respondent.

The data were analyzed using the Statistical Package for Social Sciences (SPSS) version 22.

Ethical approval and permission to conduct this study was obtained from Jawantankuasa Etika Untuk Penyelidikan Manusia (JKEUPM), UPM/TNCPI/RMC/1.4.18.2 (JKEUPM).

A. Research Tool: Awareness Knowledge Attitude Questionnaire

This questionnaire was developed and validated by [11]. It consists of three domains: awareness, knowledge and attitude. The knowledge domain was used in this study to measure the caregivers' levels of knowledge about epilepsy. The knowledge domain contained eight items, which were scored on a range of 0 to 80. The scores were grouped as follows: 0-16 = 1, 17-32 = 2, 33-48 = 3, 49-65 = 4 and 66-80 = 5. Higher scores indicated that the caregiver had greater knowledge of epilepsy. The content validity index was used to validate the questionnaire. The questionnaire was bilingual (in English and Bahasa Melayu). A supervisory committee revised the content validity. To assess the validity of the questionnaire, a pre-test was carried out with 10% of the sample size (27 participants). The internal consistency reliability, assessed using Cronbach's α, for the knowledge domain was α= 0.90.

B. Research Tool: Adult Career- Quality of Life (QOL) Questionnaire

This questionnaire, developed by [12], was used to measure the quality of life among the caregivers. It consisted of eight main items, each of which consisted of five questions. The 40 items provided a total score ranging from 0 to 120. The AC-QoL scores were as follows: Never = 0, Some of the time = 1, A lot of the time =2, Always = 3. Higher scores indicated a higher quality of life. The questionnaire was bilingual (in English and Bahasa Melayu). A supervisory committee revised the content validity. To assess the validity of the questionnaire, a pre-test was carried out with 10% of the sample size (27 participants). The internal consistency reliability of the AC-QoL, assessed using Cronbach's α, was α = 0.86.

III. RESULTS

A. Participant Demographics

The mean age of the respondents was 38.24. Regarding to gender, the majority were female (67.9%), while 32.1% were male. The majority of the respondents were Muslim (65.3%). In terms of marital status, most respondents were married (79.9%). For of education, the largest proportion of respondents (39.6%) had been educated to degree level. In addition, the largest proportion of respondents (29.5%) had a monthly income of RM 3,001 to RM 4,000.

B. Total Level of Epilepsy-related Knowledge of Epilepsy among the Caregivers

The caregivers' levels of knowledge of epilepsy were analyzed using descriptive statistics. It was found that 0.3% of the respondents had a deficient level of knowledge, 13.3% had a low level of knowledge and 20.5% had a moderate level of knowledge. However, 50.0% of all the respondents had a high level of knowledge and 15.9% had a very high level of knowledge.

The finding related to the caregivers' knowledge scores showed that 59.4% of the respondents knew the causes of epilepsy and 92.2% knew that epilepsy is not an infectionus disease. Meanwhile, 41.6% of the respondents realised that epilepsy is an inherited disease. Moreover, 82.5% of them were aware that epilepsy is not a mental disease, while 89.3% knew that evil spirits do not cause epilepsy. Furthermore, 56.2% of the respondents recognised that epilepsy could cause death. Next, only 34.7% of the respondents knew that epilepsy is incurable. Lastly, only 47.4% of the respondents knew how to perform emergency help during epileptic attacks.

C. Socio-demographic Characteristics and Levels of Knowledge among Caregivers with an Epileptic Family Member

The socio-demographic characteristics and levels of knowledge among caregivers with an epileptic family member were analyzed using Chi-square. In terms of age, 23.1% of the respondents aged between 31 and 40 had a higher level of knowledge than those in the other age groups. Furthermore, female respondents with a high level of knowledge amounted to 36.4%. Muslim respondents with a high level of knowledge amounted to 33.1%. Meanwhile, 42.9% of married respondents had a high level of knowledge. A significant association was identified between marital status and knowledge level ($p<0.001$). Next, 19.8% of the respondents with degree-level education had a high level of knowledge about epilepsy. A significant association was found between educational and knowledge level ($p=0.05$). Lastly, most respondents with a monthly income of RM 3,001 to RM 4,000 15.2% had a high level of knowledge. Table I illustrates these statistics.

D. Level of quality of Life Among caregivers with an Epileptic Family Member

The levels of the caregivers' quality of life were analyzed using descriptive statistics. A minimal percentage of the respondents (2.9%) had a poor quality of life. The majority of the respondents had a moderate quality of life, 61.7%, while 35.4% had a high quality of life.

E. Socio-demographic Characteristic and the Level of Quality of Life among Caregivers with an Epileptic Family Member

Most respondents aged between 31 and 40 had a moderate quality of life, amounting to 25.3%. In terms of gender, 41.2% of the female respondents had a moderate quality of life. Moreover, regarding the religion factor, 49.9% of Muslim respondents had a moderate quality of life. A significant association was identified between religion and the quality of life level (p=0.003). In addition, a high percentage of married respondents (46.4%) had a moderate quality of life. A significant association was found between marital status and the quality of life level (p=0.006). Furthermore, 27.6% of degree-holding respondents had a moderate quality of life, a higher percentage than those with other levels of education. There was a significant association between educational level and quality of life level (p=0.004). Lastly, 21.4% of the respondents with a monthly income from RM 3,001 to RM 4000 had a moderate quality of life. There was a significant association between monthly income and quality of life level (P<0.001). Table II illustrates these statistics.

F. The Association Between Caregivers' Level of Knowledge about Epilepsy and Their Quality of Life

The normality test for both continuous variables was based on Shapiro-Wilk, producing a p-value < 0.05 (p<0.001). According to Shapiro-Wilk, the data were not normally distributed. Hence, Spearman's correlation test was used to determine the association between the caregivers' levels of knowledge about epilepsy and their quality of life. Based on the data analysis, the Spearman's correlation test indicated that there was a significant association between the caregivers' levels of knowledge and the level of their quality of life (p<0.001).

TABLE I: Socio-Demographic associated Factors with Level of Knowledge

Variables	Level of knowledge					p-value
	0-16 Very low n (%)	17-32 Low n (%)	33-48 Moderate n (%)	49-65 High n (%)	66-80 Very high n (%)	
Age						
21-30	-	11 (3.6)	12 (3.9)	31 (10.1)	8 (2.6)	0.109
31-40	-	11 (3.6)	29 (9.4)	71 (23.1)	27 (8.8)	
41-50	1 (0.3)	17 (5.5)	16 (5.2)	32 (10.4)	12 (3.9)	
Above 50	-	2 (0.6)	6 (1.9)	20 (6.5)	2 (0.6)	
Gender						
Male	1 (0.3)	16 (5.2)	25 (8.1)	42 (13.6)	15 (4.9)	0.173
Female	-	25 (8.1)	38 (12.3)	112 (36.4)	34 (11.0)	
Religion						
Islam	-	25 (8.1)	40 (13.0)	102 (33.1)	34 (11.0)	0.087
Christian	-	6 (1.9)	6 (1.9)	22 (7.1)	4 (1.3)	
Buddha	1 (0.3)	3 (1.0)	10 (3.2)	14 (4.5)	4 (1.3)	
Hindu	1 (0.3)	3 (1.0)	3 (1.0)	15 (4.9)	4 (1.3)	
Others	-	4 (1.3)	4 (1.3)	1 (0.3)	3 (1.0)	
Marital status						
Single	-	12 (3.9)	8 (2.6)	12 (3.9)	1 (0.3)	0.001*
Married	-	26 (8.4)	46 (14.9)	132 (42.9)	42 (13.6)	
Divorced	1 (0.3)	3 (1.0)	9 (2.9)	10 (3.2)	6 (1.9)	
Educational level						
Secondary school	1 (0.3)	10 (3.2)	11 (3.6)	18 (5.8)	3 (1.0)	0.05*
Diploma/ STPM	-	19 (6.2)	26 (8.4)	58 (18.8)	19 (6.2)	
Degree	-	12 (3.9)	21 (6.8)	61 (19.8)	18 (5.8)	
Master	-	-	4 (1.3)	15 (4.9)	9 (2.9)	
Ph.D.	-	-	1 (0.3)	2 (0.6)	-	
Monthly income						
< RM1000	-	5 (1.6)	4 (1.3)	5(1.6)	3 (1.0)	0.130
RM1001-RM2000	-	4 (1.3)	7 (2.3)	11 (3.6)	6 (1.9)	
RM2001-RM3000	-	18 (5.8)	13 (4.2)	36 (11.7)	11 (3.6)	
RM3001-RM4000	1 (0.3)	7 (2.3)	24 (7.8)	50 (16.2)	9 (2.9)	
RM4001-RM5000	-	4 (1.3)	8 (1.0)	27 (8.8)	11 (3.6)	
> RM5000	-	3 (1.0)	7 (2.3)	25 (8.1)	9 (2.9)	

*Correlation is significant at p-value < 0.05

IV. DISCUSSION

The findings from the current study showed that 50.0% of the respondents had a high level of knowledge. Knowing how to provide emergency help for epileptic attacks is important because it enables caregivers to manage emergencies situations effectively and create a safe, supportive environment for the epileptic family member. A study reported that people with epilepsy and first aid knowledge might benefit from self-management interventions because this could improve their and their caregivers' confidence in managing seizures and their ability to do so [13]. Overall, this study revealed that most Selangor-based caregivers with an epileptic family member had a high level of knowledge regarding epilepsy.

TABLE II: SOCIO-DEMOGRAPHIC ASSOCIATED FACTORS WITH LEVEL OF KNOWLEDGE

Variables	Level of knowledge					P-value
	0-16 Very low n (%)	17-32 Low n (%)	33-48 Moderate n (%)	49-65 High n (%)	66-80 Very high n (%)	
Age						
21-30	-	11 (3.6)	12 (3.9)	31 (10.1)	8 (2.6)	0.109
31-40	-	11 (3.6)	29 (9.4)	71 (23.1)	27 (8.8)	
41-50	1 (0.3)	17 (5.5)	16 (5.2)	32 (10.4)	12 (3.9)	
Above 50	-	2 (0.6)	6 (1.9)	20 (6.5)	2 (0.6)	
Gender						
Male	1 (0.3)	16 (5.2)	25 (8.1)	42 (13.6)	15 (4.9)	0.173
Female	-	25 (8.1)	38 (12.3)	112 (36.4)	34 (11.0)	
Religious						
Islam	-	25 (8.1)	40 (13.0)	102 (33.1)	34 (11.0)	0.087
Christian	-	6 (1.9)	6 (1.9)	22 (7.1)	4 (1.3)	
Buddha	1 (0.3)	3 (1.0)	10 (3.2)	14 (4.5)	4 (1.3)	
Hindu	1 (0.3)	3 (1.0)	3 (1.0)	15 (4.9)	4 (1.3)	
Others	-	4 (1.3)	4 (1.3)	1 (0.3)	3 (1.0)	
Marital Status						
Single	-	12 (3.9)	8 (2.6)	12 (3.9)	1 (0.3)	0.001*
Married	-	26 (8.4)	46 (14.9)	132 (42.9)	42 (13.6)	
Divorced	1 (0.3)	3 (1.0)	9 (2.9)	10 (3.2)	6 (1.9)	
Educational Level						
Secondary school	1 (0.3)	10 (3.2)	11 (3.6)	18 (5.8)	3 (1.0)	0.05*
Diploma/ STPM	-	19 (6.2)	26 (8.4)	58 (18.8)	19 (6.2)	
Degree	-	12 (3.9)	21 (6.8)	61 (19.8)	18 (5.8)	
Master	-	-	4 (1.3)	15 (4.9)	9 (2.9)	
Ph.D.	-	-	1 (0.3)	2 (0.6)	-	
Monthly Income						
<RM 1000	-	5 (1.6)	4 (1.3)	5(1.6)	3 (1.0)	0.130
RM 1001- RM2000	-	4 (1.3)	7 (2.3)	11 (3.6)	6 (1.9)	
RM 2001- RM3000	-	18 (5.8)	13 (4.2)	36 (11.7)	11 (3.6)	
RM 3001- RM4000	1 (0.3)	7 (2.3)	24 (7.8)	50 (16.2)	9 (2.9)	
RM 4001 – RM 5000	-	4 (1.3)	8 (1.0)	27 (8.8)	11 (3.6)	
>RM 5001	-	3 (1.0)	7 (2.3)	25 (8.1)	9 (2.9)	

*Correlation is significant at p-value < 0.05

Moreover, a similar previous study found that monthly income levels correlated significantly with knowledge levels, the opposite of the findings of the current study [14]. Monthly income is an important aspect today because people tend to have a complete set of communication and information tools, such as gadgets, as well as transportation, with which they can seek information regarding epilepsy. People in rural areas with higher incomes perceived modern medicine as the best treatment for epilepsy. In addition, people preferred to gain epilepsy-related information from their personal healthcare provider [11].

However, a significant association was identified between marital status, educational level and knowledge level, with $p<0.05$. The majority of the caregivers had degree-level education. This finding was similar to that of a previous study, which stated people with post-tertiary education tend to be able to make healthier choices and improve the quality of their health [12].

This study found a significant association between religion, marital status, educational level and monthly income on one hand and the level of quality of life ($p<0.05$). The findings of a previous local study were broadly similar to those of this study, identifying a significant association between age, religion, marital status and monthly income [9]. Monthly income was found to play an important role in contributing to a higher quality of life among individuals, especially caregivers. A previous study stated that earning a low income was an important factor that could lead to a poorer quality of life in terms of health. The study found significant differences in the health-related quality of life scores among certain subgroups of the low-income population. When income levels increased, the health-related quality of life scores improved [13].

The findings showed a significant relationship between the caregivers' levels of knowledge about epilepsy and their quality of life. This was similar to the findings of a previous local study, which found that, overall, carers with good knowledge appeared to have a better health-related quality of life [9]. Knowledge of epilepsy is essential for caregivers as it enables them to improve the care they provide for the epileptic family member. The status of epilepsy in Malaysia in terms of understanding the illness influences the quality of life of the individuals affected [14]. It was reported, caregiver required consistent epilepsy education to enhance their skill in order to understand and keep update with the disease and indirectly, it will help them to improve their QOL [9].

In conclusion, this study revealed important outcomes that reinforced the relationship between levels of knowledge about epilepsy and levels of quality of life among caregivers. Half of the respondents had a high level of knowledge about epilepsy, and more than half of the respondents had a moderate quality of life. These findings indicate the need to improve the standard of emergency help that caregivers can provide so they can effectively address and manage the emergency of an epilepsy attack. Thus, it is important that caregivers have knowledge and understanding of epilepsy because this may affect their quality of life as they provide care for their epileptic family member.

V. CONCLUSION

Nurses should provide education and training to caregivers so the latter can handle and manage the emergency that occurs during an epilepsy attack. Furthermore, health education can be delivered to the community through social media. This health education content should involve knowledge of epilepsy in general, the trigger factors of epilepsy and the step-by-step emergency help required during an epilepsy attack. In addition, nurses could refer caregivers to an epilepsy support group to obtain appropriate emotional and practical support. These measures could enhance caregivers' quality of life.

The researcher recommends further research with the interview method because it helps to generate qualitative data to complement the current cross-sectional study. Qualitative data such as feelings, perceptions and opinions allow more detailed questions to be asked if the study aims to understand deeper caregivers' quality of life.

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CONFLICT OF INTEREST

Authors declare that they do not have any conflict of interest.

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