ORIGINAL ARTICLE

RELATIONSHIPS BETWEEN AWARENESS, KNOWLEDGE, ATTITUDES AND COPING MECHANISMS IN EPILEPSY

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Abstract

Objective: **The relationships between awareness, knowledge and attitudes (AKA) and coping mechanisms among people with epilepsy (PWE) have not been well-explored particularly in Asia. This study aimed to: identify preferred coping strategies, correlate between AKA and coping mechanisms and compare coping strategies of PWE with different AKA levels.** ***Methods:*** **A cross-sectional sample of epilepsy out-patients was recruited from the Neurology Clinic, Hospital Sultanah Nur Zahirah, Kuala Terengganu. The participants completed the** ***Malay AKA Epilepsy*** **and the** ***Malay Brief COPE*** **instruments. The data was analysed using non-parametric statistics.** ***Results:*** **Sixty out of 72 patients (response rate = 83.3%) consented participation (median age = 27.5 years; male = 53.3%; unmarried = 63.3%; Malay = 90.0%; SPM education = 54.2%; unemployed = 35.0%; rural residents = 70.0%).** ***Religion*** **was the most preferred coping strategy (93.3%), followed by** ***Emotional Support*** **(86.7%) and** ***Instrumental Support*** **(81.7%).** ***Awareness*** **was negatively correlated with** ***Instrumental Support*** **(r_s = -0.268; $p<0.05$) while** ***Knowledge*** **was positively linked to** ***Humour*** **(r_s = +0.267; $p<0.05$). Positive associations between** ***Attitudes*** **versus** ***Active Coping*** **and** ***Positive Reframing*** **were also detected (r_s = +0.284 to +0.331; $p<0.05$). Patients with good AKA levels coped significantly better through** ***Self Distraction*****,** ***Positive Reframing*** **and** ***Humour*** **($p<0.01$).** ***Conclusion:*** **AKA levels seemed to influence the type of coping strategies adopted by PWE in dealing with their illness suggesting that, efforts in improving AKA level should be combined with appropriate coping strategies to provide better health outcomes in epilepsy management.** ***ASEAN Journal of Psychiatry, Vol.12(2), July – Dec 2011: XX XX.***

Keywords: Epilepsy, Awareness, Knowledge, Attitudes, Coping

Introduction

Epilepsy is a common neurological disorder, affecting at least 0.5 to 1.0% of any population [1-3]. It is relatively unique among chronic neurological diseases as it has potentially significant influence on health-related quality of life (HRQoL). This medical morbidity often begins at a young age and may hinder social and cognitive development. Despite seizures only lasting for a few seconds or a few minutes, they give rise to significant psychosocial repercussions to the patients and their family members [4,5]. Nevertheless, an epileptic seizure is still considered a mystical event, mostly in developing countries such as Malaysia [6]. Hence, it has often been regarded as one of the most stigmatizing medical impairments [7].

Awareness, knowledge and attitudes (AKA) regarding epilepsy have been shown to be important in reducing the impact of seizures, potentially harmful self-management practices and the emotional impact of both seizures and treatment. Increased AKA may also lead to an improvement in health-related quality of life (HRQoL) not only for patients but also for their families [7-13].

On the other hand, AKA alone is not adequate to deal with epilepsy and its consequences as patients still need to learn to cope with its misfortunes. In the literature on coping, various styles have been reported to be related to psychological, physical and social well-being [14,15]. In adjusting to this chronic condition the method of coping with epilepsy seems to be a significant determinant in the self-perceived severity of seizures [16-18]. Interestingly, coping strategies do not only play an important role in the psychosocial adjustment of individuals with disabilities but also influence the HRQoL of people with disorders [19]. Together with AKA, it becomes a vital factor in improving the ability to deal successfully with epilepsy by minimizing its impact on social and psychological functioning [9]. Coping is purported to have a direct effect on people with epilepsy (PWE)'s psychological adjustment which in this case could be linked to their AKA [20]. Furthermore, recent stress and coping research has also supported these proposed relations [21].

Unfortunately, PWEs' AKA in relation to their coping styles is a less studied topic. This study was carried out with the main intention of investigating the relationship between these two parameters.

Methods

Study design, sample selection and sampling method

This cross-sectional pilot study was carried out in the Neurology Clinic, Hospital Sultanah Nur Zahirah (HSNZ), Kuala Terengganu, Malaysia for a two-month period which employed convenience sampling method. Under this sampling method, available epilepsy out-patients who satisfied inclusion criteria were recruited. The sample size was determined according to the descriptive observational cross-sectional design formula specific for pilot study [22]. According to the formula, at least 39 patients were needed at 90% power of study after considering a 20% drop-out.

Ethical approval

Ethical approval was obtained from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia via online application [reference: NMRR-10-359-5640/ (2) dlm. KKM/NIHSEC/08/0804/P10-158)].

Data collection procedure

Data was collected during epilepsy clinic day whereby the research assistants approached, explained and invited potential patients to participate in the study. Potential patients were defined as those who met and satisfied all the study inclusion criteria i.e. 1) epilepsy patients aged 18 years old and above, 2) had been regularly visiting the hospital at least for the past 6 months, 3) able to either understand, read, speak or write in Malay language and 4) capable of answering the questions either in written form or by interview. An information sheet was given to enhance their understanding on the nature of the study as well as to clarify the particulars needed, the instruments used and what was required from them. Once agreed, participants signed a written consent form before proceeding to complete the set instruments in this order: Personal Information Form, *Malay AKA Epilepsy* [23] and *Malay Brief COPE-27* [24]. Once completed, they were thanked for their participation.

Instruments

There were two instruments employed for this study:

1) *Malay AKA Epilepsy* [23]
This instrument contained three domains; *Awareness*, *Knowledge* and *Attitudes*. Each response score ranged from 0 to 10. The first domain was to detect *Awareness* level which contained 5 items with a total score range from 0-50. The total scores were grouped as follows: 0-10 = very low, 11-20 = low, 21-30 = moderate, 31-40 = high and 41-50 = very high. The second domain was to determine *Knowledge* level containing 8 items with a total score of 0 to 80. The scores were grouped as follows: 0-16 = very low, 17-32 = low, 33-48 = moderate, 49-65 = high and 66-80 = very high. The last domain measured *Attitude* level which was sampled by 4 items with a minimum total score of 0 and maximum of 40. The scores were again grouped as follows: 0-9 = very negative, 10-19 = negative, 20-29 = indifferent, 30-39 = positive and 40-49 = very positive. Finally the *Total AKA* score was generated via the summation of all three domain scores to give the general AKA level of all respondents. The score ranged from 0 to 170 with the interpretation of total AKA level set as: 0-33 = very poor, 34-67 = poor, 68-101 = moderate, 102-135 = good and 136-170 = excellent. Finally there were also individual items inquiring about the patients' perception of the best epilepsy treatment, their preference of epilepsy information delivery and the mode of transportation to seek medical treatment. The responses were recorded in the form of multiple-choice answer scales. Overall there were three domains with a total number of 20 items.

2) *Malay Brief COPE-27* [24] consisted of 27 items assessing 14 domains as those in the original *Brief COPE* [25]. Similarly, fourteen dimensions of coping were focused in the scales examining *Self-Distraction, Active-Coping, Denial, Substance Use, Emotional Support, Instrumental Support, Behavioural Disengagement, Venting, Positive Reframing, Planning, Humour, Acceptance, Religion* and *Self-Blame*. Responses were scored on Likert-type scale (1-4, whereby higher scores indicated higher frequency) and the instrument could either be self- or interviewer-administered. Each scale's total was computed as an unweighted sum of responses to the four items which made up that scale.

Statistical analysis

This study employed the Statistical Package for Social Sciences version 16 (SPSS 16) for the purpose of data analysis. All socio-demographic data were analysed descriptively and presented as frequencies and percentages. Prior to subsequent group comparisons, normality test was carried out employing the Shapiro-Wilk statistic to determine the distribution pattern of the variables. The scores of all domains were not normally distributed as indicated by its significant value (<0.05) and the absence of a normal curve as required for parametric testing. Due to the relatively small sample size (n<100) and failure to conform to normality requirement, tests for subsequent univariate analysis were carried out using non-parametric techniques. The chi-square (χ^2) for goodness of fit was utilized to test for homogeneity of the proportion of categorical variables while Spearman's Rho (r_s) was used to measure the strength and direction of correlation between AKA and coping strategies. For the purpose of the between-group comparisons, the patients were regrouped into; Good AKA and Poor AKA. Patients who generated the Total AKA Score of higher than the group median was considered to possess good AKA level while those with Total AKA score equal to or lower than the group median was considered as having poor AKA level. The Mann-Whitney U test was the analysis of choice for between-group score comparisons (Coping mechanisms of Good vs Poor AKA groups). The value of $p<0.05$ was considered statistically significant.

Results

Socio-demographic characteristics

Sixty out of 72 out-patients diagnosed with all subtypes of epilepsy participated in this study (response rate = 83.3%). These subtypes comprised mostly of complex partial seizure, symptomatic epilepsy, generalised seizure and generalised tonic clonic seizure. The median age was 27.5 years, ranging from 18 to 65 years. The male to female ratio was almost equal. Most of the respondents were Malay (90.0%), Muslim (90.0%), single (63.3%), possessed education level at SPM (equivalent to Cambridge O' level) and lower (81.4%), unemployed (58.4%), were earning not more than RM 500 (equivalent to USD 163.3) monthly (68.4%), living with spouse or family (96.7%) and were rural dwellers (70.0%). Further details are shown in Table 1.

Table 1. Socio-demographic characteristics of sample respondents (n=60).

Variables	Mean	Standard deviation	Median	Minimum-maximum
Age	31.07	11.07	27.5	18-65
	Frequency (n)	Percentage (%)	p value*	
Gender				
Male	32	53.3	0.606	
Female	28	46.7		
Marital status				
Married	20	33.3	**<0.001**	
Single	38	63.3		
Widowed	2	3.3		
Race				
Malay	54	90.0	**<0.001**	
Chinese	6	10.0		
Religion				
Islam	54	90.0	**<0.001**	
Buddhism	6	10.0		
*Education level ***				
SPM (equivalent to Cambridge O' level) and lower	48	81.4	**<0.001**	
Higher than SPM	11	18.6		
Occupation				
Professional	2	3.3		
Supportive	5	8.3		
House-wife	18	30.0	**<0.001**	
Retiree	7	11.7		
Student	7	11.7		
Unemployed	21	35.0		
*Monthly income ***				
RM 500 and below	39	68.4	**<0.001**	
Above RM 500	18	31.6		
Living arrangement				
Alone	1	1.7		
With spouse/family	58	96.7	**<0.001**	
Rent a room	1	1.7		

Living area			
Urban	18	30.0	**<0.01**
Rural	42	70.0	

* Chi-square test for goodness of fit; ** contains missing data, thus n≠60.

Coping strategies

Among all the coping mechanisms reported by our respondents, *Religion* was the most popular (93.3%). *Emotional Support*, *Instrumental Support* and *Acceptance* were also highly preferred (80.0 – 87.0%). However *Active Coping*, *Planning*, *Positive Reframing*, *Self-Distraction*, *Humour*, *Venting*, *Denial*, and *Behavioural Disengagement* were all fairly favored (12.0 – 73.0%) while *Self-Blame* was the least-practiced coping skill (<2.0%) – Figure 1.

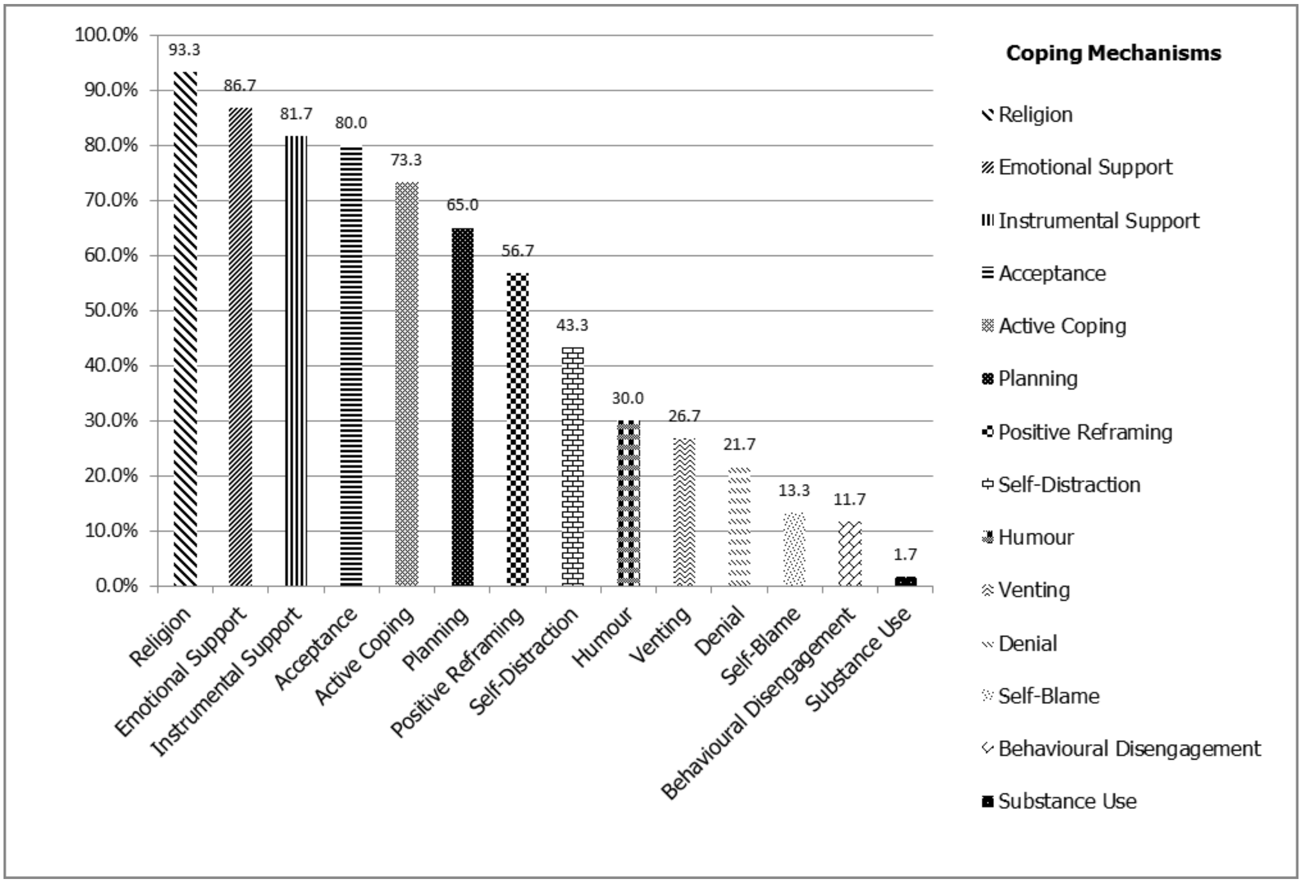

Figure 1. Coping mechanisms of PWE (n=60).

Correlation between AKA and coping mechanism

Awareness was negatively correlated with the use of *Instrumental Support* (r_s = -0.268, p<0.05). *Knowledge* was significantly but weakly linked to *Humour* (r_s = +0.267, p<0.05) while *Attitudes* was significantly associated with *Active Coping* and *Positive Reframing* (r_s = +0.284 to +0.331, p<0.05). Details are shown in Table 2.

Table 2. Correlation between AKA and coping mechanisms.

	AKA		
COPING MECHANISMS	***Awareness* (r_s)**	***Knowledge* (r_s)**	***Attitudes* (r_s)**
Self-Distraction	+0.212	+0.084	+0.203
Active Coping	-0.007	+0.070	+0.284*
Denial	-0.224	-0.124	-0.124
Substance Use	-0.022	+0.015	-0.004
Emotional Support	-0.076	+0.030	+0.157
Instrumental Support	-0.268*	-0.016	+0.230
Behavioural Disengagement	+0.067	+0.063	-0.216
Venting	+0.023	+0.048	+0.001
Positive Reframing	+0.044	+0.183	+0.331**
Planning	-0.022	+0.073	+0.195
Humour	+0.053	+0.267*	+0.226
Acceptance	-0.117	-0.113	+0.193
Religion	+0.237	+0.078	+0.234
Self-Blame	-0.128	+0.097	-0.101

r_s = Spearman's correlation coefficient * $p<0.05$ **$p<0.01$

Comparison of coping mechanism between PWE with different AKA levels

Results showed that PWE with good AKA level coped significantly better in *Self-Distraction, Positive Reframing* and *Humour* compared to those with poor AKA. Moreover, they were also generally coping better in *Active Coping*, *Substance Use*, *Emotional Support*, *Instrumental Support*, *Venting*, *Planning* and *Religion* than their counterparts. However, in comparison to those with good AKA, respondents with poor AKA dealt with their disease more effectively via *Denial*, *Behavioural Disengagement*, *Acceptance* and *Self-Blame* – Figure 2.

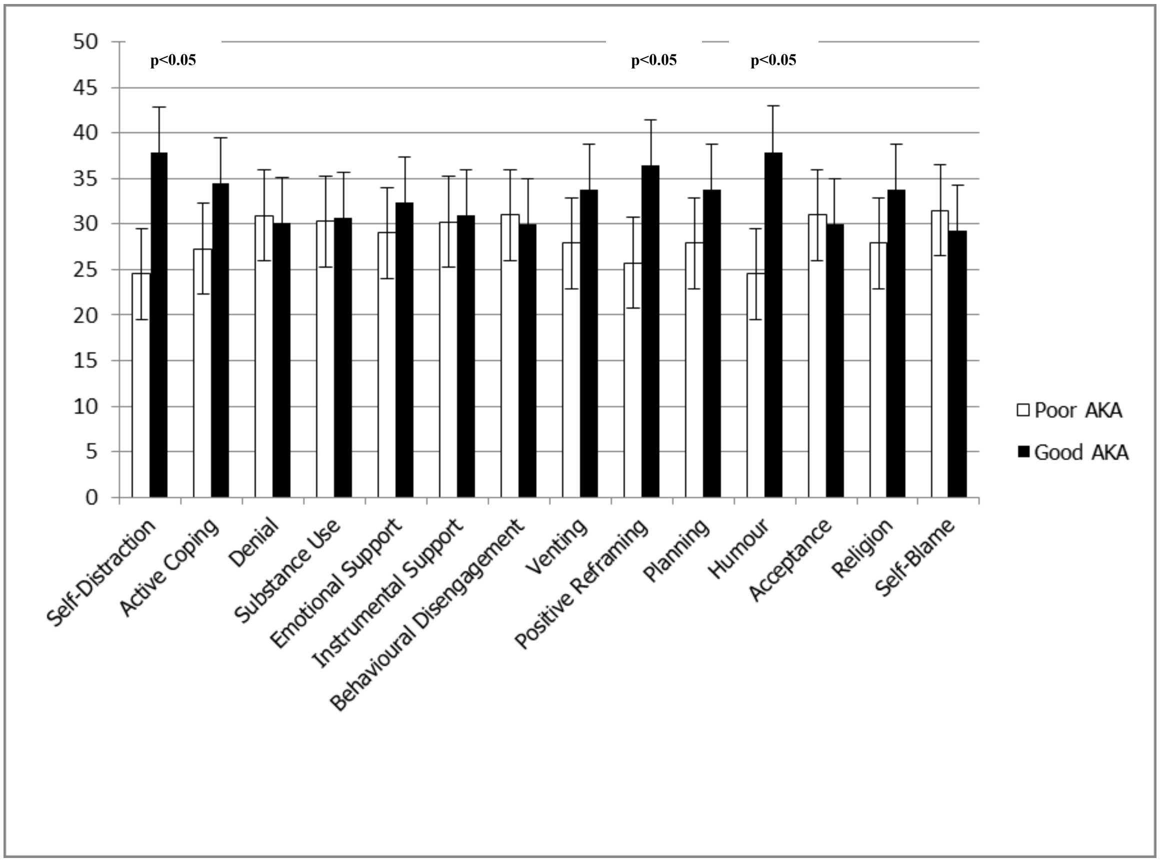

Figure 2. Comparison of coping skills and frequency of practices between PWE with different AKA level. Error bar: 5% error, SD=1.

Discussion

Through this study, the PWE's AKA towards epilepsy as well as their coping mechanisms were simultaneously studied. Considering the limited investigations which have been carried out to relate AKA and coping in epilepsy, our study was expected to benefit the psychosocial development of PWE in the process of managing their disease as well as facilitating their interactions with the society.

The most-frequently practiced coping strategy among PWE was *Religion*. This could be due to the socio-demographic background of our sample whereby 90% were Muslim. Islam teaches the concept of "redha" (acceptance) in facing the disease because it is considered a test from God. Marie [26] discovered that religion, faith or prayer could contribute to PWE's well-being and help them deal more effectively with epilepsy. However, it was also found that meditation and yoga had similar effects as prayer, so there is probability that religion may not be the absolute factor helping PWE to cope with their diseases but rather activities which relieve psychological stressors. Religion was nevertheless also seen as disengaging oneself from direct and active problem management by seeking comfort in and resorting to praying for reversal of condition course or minimization of condition impact on one's life [27].

The finding that showed *Substance Use* being the least-practiced coping skills was explained by the remarks by patients themselves who claimed that since they have already been consuming a number of drugs, taking additional substances would be unnecessary. A study by Raty and colleagues discovered that feelings of confidence and security were related to the use of antiepileptic drugs (AEDs) [28]. Besides that, the fear of adverse effects usually prevented patients from consuming drugs or alcohol to cope with their illnesses. Studies showed that between 10% and 25% of newly diagnosed cases of epilepsy in adults may show chronic alcohol abuse as a risk factor. Withdrawal from alcohol use is a factor in about 30% of persons experiencing alcohol-related seizures [29]. Alcohol would increase the sedative effect of AEDs and could affect the rate of absorption of AEDs [30]. AEDs on the other hand might weaken one's tolerance to alcohol, making it easier to become intoxicated. It was therefore not unexpected that considering all the side effects of drugs and alcohol, their combined consumption with AEDs had probably discouraged patients from adapting this coping style.

The negative association between *Awareness* and *Instrumental Support* indicated that the more aware PWE were of their own diseases, the less frequently they turned to advices and help from others. As we have long-acknowledged, the stigma attached to epilepsy is more debilitating not only to the patients but also to their family and caregivers. Stigma, prejudice and misunderstanding from their surrounding society have somehow exerted pressure on PWE, lowering their self-esteem, restricting their social lives and subsequently affecting their HRQoL. Because of this, PWE tend to depend on families and caregivers in managing their daily lives as well as for support, help and advices. But enhanced awareness towards this disorder has been identified as capable of helping to demystify the stigma surrounding epilepsy [31-35]. Moreover, increased vigilance of epilepsy helped facilitate better understanding of the clinical manifestation, psychological and psychosocial aspects of this medical morbidity. On top of that, these could lead to improved psychological judgement of PWE [5], plus enhanced awareness of their needs and the related services available [36]. Consequently, by being aware they depended on less advice and help from others.

Interestingly, *Knowledge* was found to be positively linked to *Humour*. PWE who were more knowledgeable in their disease were more likely to have a positive mind-frame, enabling them to joke about their condition. By adapting humour, our respondents seemed to be taking their conditions rather lightly and did not find it to be offensive to joke about. According to Couldridge and co-workers [37], accurate information could generate positive adaptation towards their diseases. Adequate knowledge regarding this brain disorder has also been shown to prevent misconception, unnecessary worry and discrimination towards PWE. The self-advocacy skills of the PWE might improve in parallel, which placed them in a better position to explain their condition to others even through humour and jokes, thereby promoting a positive view of epilepsy [38]. Despite limited scientific research, there was even theoretical and anecdotal support for the use of humour as a coping strategy [39]. A previous study suggested that there was a direct relationship between patients' knowledge and understanding of their disability and their evolving methods in coping [40].

Our findings have further divulged significant associations between *Attitudes* and coping styles which are "active" and those involving "positive reframing". Positive attitudes enabled PWE to adapt better with their disease by reframing the problems and situation favorably as well as to embark on actions actively [41]. Possessing a positive mindset had probably encouraged PWE to directly tackle their problem while simultaneously taking various actions to deal with it. The extent to which patients feel in control of their lives and their attitudes varied, and active coping strategies which promote a feeling of control, such as task-focused coping or positive reframing, were proven to be beneficial to PWE with positive attitudes [42]. On the other hand, negative self-concept and low self-esteem have been closely linked to unfavourable attitudes toward epilepsy in PWE [43]. Poorer adjustment and negative attitudes have been found to be associated with persistent denial, venting of emotions and behavioural disengagement that distanced PWE from dealing with change [42].

In terms of PWE with different AKA levels, those with good AKA significantly cope better in *Self-Distraction*, *Positive Reframing* and *Humour* compared to those with poor AKA. Good AKA has probably helped to boost patients' self-esteem, confidence and psychosocial adjustment leading to positive thinking and active dealings with the disease. Psychosocial factors in epilepsy, AKA for example have been found to be more significant than medical factors in predicting PWE's adjustment and coping mechanisms [5]. It is therefore crucial to enhance PWEs' AKA not only for achieving improved HRQoL but also to help patients cope effectively with their illness. Furthermore, providing PWE with detailed and proper information about the disease is clearly important in preventing their self-deprecation and in allaying their fears. Perceiving epilepsy appropriately and accurately could improve patients' adaptation to their treatment and most importantly increase treatment success rate [44-45]. For that purpose, intensive health education efforts in spreading the awareness, enriching their knowledge and cultivating positive attitudes toward epilepsy should be continuously carried out.

As with other studies of this nature, cautions should anyhow be taken in generalizing the results. Due to the limited sample (although it fulfilled the calculation formula), our findings could possibly have not been representative of the total PWE population within Malaysia. Other than that, the possible bias, as a consequent of interviewer- and self-administered questionnaire could not be ignored although we did not think this had imposed any major deviations in the outcomes.

Conclusion

The general AKA level of PWE in Terengganu was only moderate and could still be improved. Their most preferred coping strategy was *Religion* while *Substance Use* was the least popular coping mechanism. *Awareness* was negatively associated with *Instrumental Support*, *Knowledge* was positively linked to *Humour* while *Attitudes* was significantly correlated to *Active Coping* and *Positive Reframing*. PWE with good AKA significantly cope better via *Self-Distraction*, *Positive Reframing* and *Humour* compared to those with poor AKA. It could be concluded that AKA levels seemed to bear influence on the type of coping strategies adopted by PWE in dealing with their illness. Hence, coping styles should become a vital focus of their treatment management. Also, it might suggest that in the treatment of epilepsy, care should be taken to create opportunities for patients to actively participate in their own treatment plan. Patients' empowerment in AKA and coping strategies therefore should be incorporated into future epilepsy care.

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