Coping with Epilepsy: How Do They Influence Health-Related Quality of Life (HRQoL)?

Pei Lin Lua (Ph.D)

corresponding author

Widiasmoro Selamat Neni (Bach. Biomed)

Talib Nor Samira (BPharm)

Citation:

Lua PL, Neni WS & Samira TN (2012). Coping with Epilepsy: How Do They Influence Health-Related Quality of Life (HRQoL)? *International Journal of Psychosocial Rehabilitation. Vol 17(1) 17-32*

Correspondence:

Centre for Clinical and Quality of Life Studies (CCQoLS) Faculty of Medicine and Health Sciences Universiti Sultan Zainal Abidin (UniSZA) Kampus Kota, 20400 Kuala Terengganu, Malaysia. Email for correspondence: peilinlua@unisza.edu.my

Abstract

Health-related quality of life (HRQoL) status of people with epilepsy (PWE) could likely be influenced by their coping mechanisms. Our study aimed to 1) determine the association between HRQoL profiles and coping categories, 2) correlate HROoL domains and coping mechanisms and 3) compare coping strategies of PWE with different HROoL levels. A crosssectional sample of epilepsy out-patients was recruited from the Neurology Clinic, Hospital Sultanah Nur Zahirah, Kuala Terengganu. SPSS 16 was employed for data analysis. Upon written consent, included patients completed the Malay Quality of Life In Epilepsy (MQOLIE-30) and the Malay Briefaaaaaa COPE instruments. Sixty out of 72 patients (response rate = 83.3%) consented participation (median age = 27.5 years; range 18-65 years; male = 53.3%; unmarried = 63.3%; Malay = 90.0%; SPM /Cambridge O' level equivalent education or lower = 81.4%; unemployed = 35.0%; rural residents = 70.0%). Problem-focused coping mechanisms were generally preferred by PWEs compared to emotion-focused strategies (p<0.05). Behavioural Disengagement and Self-Blame were significantly associated with almost all HROoL domains meanwhile Energy/Fatigue and Overall Quality of Life were significantly linked to the most coping strategies. Patients with good HROoL significantly preferred to cope via Positive Reframing, Planning and Religion compared to their counterparts (p<0.05). On the other hand, patients with poor HRQoL significantly favoured Substance Use, Denial, Behavioural Disengagement, Venting and Self-Blame to deal with epilepsy (p<0.05). Healthcare providers could incorporate advice on effective coping styles for PWE in an attempt to balance the treatment outcomes in terms of both physiological and psychosocial benefits.

Keywords: coping, health-related quality of life (HRQoL), epilepsy

Introduction

In Malaysia, epilepsy is referred to as "sawan" or "gila babi" and has affected approximately 1-2% of the population in 2004 (Statistics by country for epilepsy, 2004; Neni et al.,2010). Although for 70-80% of patients the disease is successfully controlled using medicine i.e. antiepileptic drugs (AEDs), the negative social stigma of epilepsy along with uncertainty of the disease effects on patients' health-related quality of life (HRQoL) status (Lua & Neni, 2011) could contribute to long-term stress and discomfort, impacting upon their coping patterns and outcomes. Previous studies have shown a high prevalence of psychological and social disorders which have been well documented and are often considered more handicapping than seizures themselves. The problems which have been documented included unemployment (Elwes et al., 1991), financial hardship, social isolation, fear of seizures (Mittan, 1986), anxiety and depression (Betts, 1993), low self-esteem (Collings, 1990), feelings of stigma (Jacoby, 1994) and externality of control (Gehlert, 1994). Consequently, the measurement of psychosocial functioning is becoming a crucial requirement for comprehensive healthcare particularly in a debilitating disease such as epilepsy.

Most literature findings have focused on how individuals cope with a variety of stresses, including those of chronic illnesses (Devins & Binik, 1996; Maes et al., 1996; Morse & Johnson, 1991). However, research on how coping mechanisms influence the HRQoL of people with epilepsy (PWE) is not as widespread. The process theory of coping describes a dynamic process whereby coping changes over time and in response to the situation in which it occurs (Lazarus & Folkman, 1984). Coping is concerned with the thoughts and actions a person makes in response to a taxing situation. The individual's response to the situation is governed by their cognitive appraisal of that situation. In order to ascertain the relative "adaptiveness" or "maladaptiveness" (Lazarus, 1993) of coping behaviour, coping needs to be studied independently from outcomes which are often measured in the form of psychological well-being.

HRQoL is generally defined as a multidimensional construct related to "individuals' perceptions of their position in life, in particular to their goals, expectations, standards and concerns" (Trimble & Dodson, 1994). For PWE, HRQoL has come to be seen as an important health outcome consideration (Baker et al.,1993; Baker, 2001). Although there have been numerous definitions of HRQoL, it is generally agreed that it is a largely subjective concept, comprising social, emotional, physical and material factors (Felce & Perry, 1995; Koot & Wallander, 2001) and that a "person-centered perspective" is central to its measurement. Over the past decade, there has been increased interest in how epilepsy and its treatment affect the HRQoL of epilepsy patients. In epilepsy, HRQoL measures have been used not only to characterise disease burden, but also to reflect the effects of AED treatment (Birbeck et al., 2002; Gilliam et al., 2004; Sackellares et al., 2002), seizure severity (Vickrey et al., 2000) and epilepsy surgery (Lowe et al., 2004; McLachlan et al., 2003; Spencer et al., 2003).

Neither seizure-related variables nor psychopathology fully explains the reduction in HRQoL status reported by PWE (Johnson et al., 2004). Several studies have further suggested that an individual's coping resources are an important determinant of their resilience to seizures (Kemp et al., 1999; Rosenbaum & Palmon, 1984; Snyder, 1990). Importantly, previous studies have demonstrated that PWE can be trained to adopt more problem-focused coping styles which are associated with improvements in functioning and overall HRQoL (Spector et al., 1999). Given that coping with epilepsy appears to impose clinical relevance, it is important that clinicians recognize their patients' coping behaviour and considers their coping resources when they make and communicate treatment decisions.

For these reasons, we are interested to study coping behaviours in dealing with epilepsy especially how they may influence HRQoL. Specifically, we intended to compare coping strategies and the frequency of practices between PWE of different HRQoL levels as well as the associations between coping mechanisms and HRQoL dimensions.

Methods

Study design and sample selection

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. The sample size was determined according to the descriptive observational cross-sectional design formula specific for pilot study which has been devised utilizing examples from Malaysian settings (Naing, 2009). This formula is usually used in prevalence study which is based on whether the parameter is a 'mean' or a 'proportion' (Dobson, 1984; Lemeshow et al., 1990; Lwanga & Lemeshow, 1991). To determine the sample size required to estimate the proportion with the desired level of precision, some idea is required beforehand about the possible proportion which can be obtained from literature or from a pilot study if there was similar study conducted before (Naing, 2009). According to the formula, at least 39 patients were needed at 90% power of study after considering a 20% drop-out.

Formula calculation:

 $n = [z]2 \ge 2(1-p)$ [Δ]

Where;

n = required sample size

p = anticipated population proportion (stated as %)

 Δ = absolute precision

z = value of the standard normal distribution cutting off probability α in one tail for a one-sided alternative

Commonly used values (with 90% power) were;

z = 1.28 for 90% power

 $\Delta = \pm 10\%$ as 90% power was selected

p = 2% (epilepsy prevalence in Malaysia estimated at approximately 1-2%) (Statistics by country for epilepsy, 2004).

Hence, $n = [1.28]2 \times 2(1-0.02)$ [0.1] = 32.11Considering a 20% drop-out, 120% x 32.11 = 38.54 Thus the minimum number of patients required for this study, n = 39 patients.

Ethical approval

Before the study began, ethical approval was first obtained from the Medical Research and Ethics Committee of the Ministry of Health, Malaysia via online application. Prior to that, discussions with hospital authorities were made to obtain full cooperation and permission to carry out the study. The study commenced once official clearance was provided by the Ministry of Health, Malaysia [reference: NMRR-10-359-5640/ (2) dlm. KKM/NIHSEC/08/0804/P10-158)].

Data collection procedure

Patients who attended the outpatient neurology clinic at Hospital Sultanah Nur Zahirah, Kuala Terengganu from April to June 2010 were invited to participate if they: have been diagnosed with epilepsy, were 18 years old and above, have been regularly visiting the hospital at least for the past 6 months, were able to either understand, read, speak or write in Malay language and were capable of answering the questions either in written

form or by interview. An information sheet was distributed to help them understand the nature of the study as well as to clarify the particulars needed, the instruments used and what was required from their cooperation. Once agreed, participants signed a written consent form before proceeding to complete the set of instruments in this order: Personal Information Form, Malay QOLIE-30 [36] and Malay Brief COPE-27 [36]. Once completed, they were thanked for their participation. Those who were not present on the study day were required to do the same when they visited the clinic. A hospital coordinator was identified and briefly-trained to help with patient identification and medical record examination prior to clinic day. Assistance in clarifying the questions, reading them aloud or circling the answers was offered whenever there was a need.

Instruments

Two instruments were employed for this study;

1) The Malay QOLIE-30 (Lua et al., 2007) was developed from the original English QOLIE-31 (Vickrey et al., 1993). This is the recommended HRQoL tool choice in epilepsy (Leone et al., 2005). Besides being widely used in patients with epilepsy, it has also been established to be reliable (Vickrey et al., 1993). This tool contains 30 items tapping on 7 domains: Emotional Well-Being (5 items), Social Functioning (4 items), Energy/Fatigue (3 items), Cognitive Functioning (6 items), Seizure Worry (5 items), Medication Effects (4 items) and Overall QoL (2 items) and a single item assessing Overall Health. Responses are scored on a mixture of numerical scale (0-10) and Likert choices (1-3, 1-4, 1-5, 1-6). All scale scores are transformed linearly into scales of 0-100 with higher values indicating better functioning and well-being. The Total HRQoL Score can be derived by weighting and summing the scale scores according to guidelines in the manual (Vickrey et al., 1993).

2) The Malay Brief COPE-27 (Lua et al., 2007) contains 27 items assessing 14 domains as those in the original Brief COPE (Carver, 1997). Similarly, fourteen dimensions of coping are focused in the scales such as Self-Distraction, Active-Coping, Denial, Substance Use, Emotional Support, Instrumental Support, Behavioural Disengagement, Venting, Positive Reframing, Planning, Humour, Acceptance, Religion and Self-Blame. It was constructed from the complete version of 60-item COPE Inventory (Carver et al., 1989) in an attempt to reduce respondent burden during questionnaire completion. Responses are scored on Likert-type scale (1-4) and the instrument can be either self- or interviewer-administered. Individual scale total is computed as an unweighted sum of responses to the four items that make up that scale.

Statistical analysis

This study employed the Statistical Package for Social Sciences version 16 (SPSS 16) for data analysis. All socio-demographic data were analysed descriptively and presented as frequencies and percentages. As data did not conform to normality (Shapiro-Wilks statistics <0.05), non-parametric tests such as Spearman's Rho (rs) was utilized to measure the correlation between HRQoL and coping mechanisms. Coping strategies were grouped into emotion-focused or problem-focused categories by comparing the relative tendencies and preference of each patient in adopting the styles. The association between HRQoL profiles and coping strategies was tested using Chi-Square ($\chi 2$) test for relatedness where p-value of less than 0.05 was considered significant. The Mann-Whitney U test was carried out to determine between-group score comparisons (the frequency of various coping practices between PWE with different HRQoL levels). For the purpose of between-group comparisons, patients were regrouped into Good HRQoL and Poor HRQoL. Patients who generated the Total HR-QoL Score of higher than the sample median was considered to possess good HRQoL while those with Total HRQoL score of equal to or lower than the sample median was regarded as experiencing poor HRQoL.

Results

Informed consent was obtained from 72 PWE. Of these, 60 completed all instruments giving a response rate of 83.3%.

Characteristics of the patients

The median age was 27.5 years, ranging from 18 to 65 years. The number of male and female respondents were quite balanced. Most of the respondents were Malay (90.0%), Muslim (90.0%), single (63.3%), possessed education level at SPM/ Cambridge O' level equivalent or lower (81.4%), unemployed (35.0%), were earning not more than RM 500/USD 166.5 equivalent (68.4%), and were living with their spouse or family (96.7%) in rural areas (70%). Details in Table 1.

Variables	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 **				
No formal education	2	3.4		
Primary school	8	13.6		
SRP/PMR or equivalent to lower secondary	6	10.2	<0.001	
SPM or equivalent to Cambridge O' level				
STPM or equivalent to Cambridge A' level	32	54.2		
Diploma or equivalent	1	1.7		

Degree or equivalent	8	13.6	
	2	3.4	
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	
RM 501-RM 1,000	8	14.0	
RM 1,001-RM 1,500	2	3.5	<0.001
RM 1,501-RM 2,000	2	3.5	
RM 2,001-RM 2,500	1	1.8	
RM 2, 501 and above	5	8.8	
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	
Types of epilepsy			
Complex partial seizure	27	45.0	
Generalised tonic clonic seizure	10	16.7	-

Temporal lobe epilepsy	8	13.3				
Idiopathic generalised epilepsy	6	10.0				
Others	9	15.0				
Duration of being diagnosed with epilepsy						
> 5 years	44	73.3	-			
6 months to 5 years	10	16.7				
< 6 months	6	10.0				
Type of AED						
Sodium valproate	37	61.7				
Carbamazepine	21	35.0	-			
Levetiracetam	11	18.3				
Topiramate	10	16.7				
Phenytoin	6	10.3				
Phenobarbitone	2	3.3				
Lamotrigine	2	3.3				
Lorazepam	1	2.0				

PWE with all subtypes of epilepsy were recruited whereby majority were represented by complex partial seizure (45.0%). Forty-four patients have been diagnosed with epilepsy for 5 years or longer. The most frequently-prescribed antiepileptic drugs (AEDs) was sodium valproate (61.7%) – Table 1.

Association between HRQoL profiles and coping categories.

Coping strategies were categorised into emotion-focused and problem-focused groups whereby their associations with HRQoL profiles were observed. Generally, our respondents preferred problem-focused coping over emotion-focused types in dealing with their diseases irrespective of their HRQoL status (p<0.05). Refer to Table 2.

Table 2. The general distribution of the health-related quality of life (HRQoL) scores,

 $(\min = 1.0; \max = 20.0).$

WHOQoL-BREF	Median (Mean ± SD)	Minimum	Maximum
Items / Domains			
Overall HRQoL*	$4.0(3.8\pm0.7)$	1.0	5.0
General Health*	$4.0(3.8\pm0.8)$	1.0	5.0
Physical Health	$15.4(15.5\pm2.2)$	9.7	20.0
Psychological	14.7 (15.0 ± 2.0)	9.3	19.3
Social Relationship	14.7 (14.4 ± 2.7)	5.3	20.0
Environment	$14.5(14.6 \pm 1.9)$	10.5	19.5
Total HRQoL	$14.8(14.9\pm1.7)$	10.7	18.7

* Untransformed scores (1.0 - 5.0).

Correlation between HRQoL domains and coping mechanisms

Among the HRQoL domains, Energy/Fatigue and Overall QoL were associated with many types of coping mechanisms. For both domains, results were significant for Behavioural Disengagement, Positive Reframing, Planning, Acceptance, Religion and Self-Blame (-0.343 \leq rs \leq 0.519). On the other hand, compared to the other 12 coping skills, Behavioural Disengagement and Self-Blame generated the most significant although negative and weak correlations with HRQoL domains specifically Seizure Worry, Emotional Well-Being, Energy/Fatigue, Medication Effects and Overall QoL (-0.260 \leq rs \leq -0.454). Additionally, Planning showed significant positive associations with Emotional Well-Being, Energy/Fatigue, Cognitive Functioning and Overall QoL. Lastly, Religion was significantly linked to Social Functioning, Emotional Well-Being, Energy/Fatigue, Cognitive Functioning and Overall QoL in a favourable way. Refer to Table 3.

Table 3. Correlation between HRQoL and coping mechanisms.

	HRQoL ITEMS / DOMAINS						
COPING	(r_s)						
MECHANISMS	Overall	General	Physical	Psychological	Environment	Social	Total
	HRQoL	Health	Health			Relationship	HRQoL
Acceptance	-0.05	+0.12	+0.03	-0.10	-0.04	+0.16	-0.03
Active-Coping	-0.01	+0.07	-0.09	-0.19	-0.04	+0.05	-0.13
Behavioural Disen	0.14	+0.03	-0.06	+0.06	-0.06	-0.15	-0.04
gagement							
Denial	-0.24	-0.01	-0.26*	-0.18	+0.07	-0.40 †	-0.18
Emotional Support	+0.02	-0.10	-0.09	+0.01	+0.22	+0.08	+0.04
Instrumental Support	+0.18	+0.16	+0.05	+0.20	+0.38 †	+0.25	+0.25
Humour	-0.04	-0.09	+0.09	+0.17	+0.08	+0.07	+0.12
Self-Distraction	-0.04	-0.18	-0.23	-0.17	-0.10	-0.08	-0.22
Substance Use	+0.25	+0.26*	-0.15	-0.02	-0.04	+0.08	-0.06
Planning	+0.30*	+0.05	-0.06	+0.01	+0.14	+0.18	+0.05
Positive Reframing	+0.15	+0.01	+0.14	+0.17	+0.31*	+0.22	+0.24
Religion	+0.34 †	+0.11	-0.19	-0.08	+0.06	+0.17	-0.02
Self-Blame	-0.03	-0.08	-0.10	-0.01	-0.05	-0.14	-0.10
Venting	-0.17	-0.07	-0.07	+0.11	+0.13	+0.05	+0.08

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

Comparison of coping mechanisms between PWE with different HRQoL profiles.

The proportion of patients with both good and poor HRQoL were almost balanced (good HRQoL=29, poor HRQoL=31). However, in terms of the types of coping skills and frequency of practices between the two HR-QoL groups, PWE with poor HRQoL were discovered to significantly prefer Denial, Substance Use, Behaviour Disengagement, Venting and Self-Blame to deal with epilepsy and its consequences (p<0.05). On the contrary, Positive Reframing, Planning and Religion were significantly favoured by their counterparts (p<0.05). Generally but not significantly, compared to those with poor HRQoL, PWE with good HRQoL demonstrated a trend of coping more frequently via employment of Self-Distraction, Active Coping, Emotional Support, Instrumental Support, Humour and Acceptance (p>0.05) – Figure 1.

Figure 1. Comparison of coping skills and the corresponding frequency of practices between PWE with different HR-QoL profiles.

%



Figure 1. Types of coping mechanism stratified by different addiction duration of study respondents.

Error bar: 5% error, SD=1. (*p<0.05 **p<0.01)



Figure 2. Comparison of coping practices among patients with different HRQoL profiles.

Figure 2. Comparison of coping practices among patients with different HRQoL profiles. Error bar:

5% error, \$D=1.

Error bar: 5% error, SD=1.

Discussion

Studies concerning HRQoL and how patients cope with epilepsy have been identified and widely carried out but most have investigated these issues separately. Due to the possible relationships and interactions between the two aspects, our study intended to compare coping strategies by different HRQoL groups and correlate between these two parameters pertinent to the lives of such patients.

The general preference of our respondents towards problem-focused coping over emotion-focused methods showed their tendencies of perceiving the former strategies to be more effective in dealing with epilepsy. Supported by a previous study, problem-focused or approach coping mode has been shown to be more functional whereas the emotion-focused or avoidant coping method was rather dysfunctional and could lead to withdrawal, fatalistic attitudes and avoidance of problems (Herman-Stahl et al., 1995). These coping methods were directed at efforts to solve or manage problems in more practical ways, including strategies for gathering information, making decisions, planning and resolving conflict (Folkman & Moskowitz, 2004). It has also been suggested that long-term, enduring stressors such as epilepsy require problem-focused strategies because continuous use of avoidant tactics would only prevent change and consume substantial effort, which over time, could deplete the individual's psychological and physical resources (Chronister & Chan, 2007). Nevertheless, emotion and problem-focused coping approaches could sometimes either facilitate or impede each other i.e. patients may need to learn to control their emotion before adopting problem-focused strategies (Folkman & Moskowitz, 2000; Moskowitz et al., 1996). Consequently, problem-focused coping strategies could probably serve as the best options for PWEs in dealing with epilepsy while maintaining emotional-focused approaches as alternative options depending on situation, timing and social resources (Folkman & Moskowitz, 2000).

Interestingly, significant but negative correlations were found between HRQoL domains and coping mechanisms specifically Denial, Behavioural Disengagement and Venting. This could be interpreted to imply that emotion-driven ways were less-likely to be practiced once patients were in better states of well-being. However, those with poorer HRQoL on the other hand have favourably resorted to these negative emotions expressing strategies. PWE especially those with poor HRQoL frequently reported diminished socialization, negative self-image, feeling of stigmatisation, reduced earning potential and diminished hope and ambition (Gilham et al., 2000; Jacoby et al., 2005). Due to all such negative attributes, many failed to accept the situation and encountered adjustment problems. Denial may not eliminate negative mood states but may help patients distance themselves from negative thoughts and feelings (Saniah & Zainal, 2010). PWE could have expressed the negative emotions by venting out the anger and dissatisfaction to the people surrounding them. Consequently, probably due to feeling of lost and hopeless, some PWE decided to disengage behaviourally in order to reduce the amount of effort in dealing with epilepsy, even by giving up efforts to accomplish objectives with which the disease is interfering with (Carver et al., 1989).

Lastly, HRQoL domains were significantly and positively associated with Emotional Support, Instrumental Support, Positive Reframing, Planning, Acceptance and Religion. The more favourable the HRQoL profile, the more frequent patient seek for help, advices and emotional support. It could be that religious approaches have effectively "persuaded" them to gradually accept their condition, hence encouraging them to plan and reframe the problem to become more positive-minded. Like many other studies of such nature, religious belief was the major coping strategy used to confront this particular chronic disease (Ebadi et al., 2009; Hassankhani et al., 2009; Ismail et al., 2005; Taleghani et al., 2006). These strategies seemed to help patients reform their views on the illness and consequently, facilitate them to overcome its related problems. Some PWE also considered the disease as their "destiny" and "God's test", therefore surrendering themselves to their fate (Hosseini et al., 2010). Similar to a previous study, the participants were seeking emotional and instrumental supports which emphasize the role of families' emotional and instrumental backings in helping PWE to adapt to the situation (Ismail et al., 2005).

In general, findings showed that PWE with poor HRQoL significantly chose to cope via Denial, Substance use, Behavioural Disengagement, Venting and Self-Blame more frequently compared to PWE with good HRQoL. All these coping styles are emotion expressing strategies. Similar to a previous study, patients have been found to use an emotion expressing strategy that included anger, aggression and crying to pacify themselves (Livneh et al., 2001). This was supported by another study which claimed that PWE with more severe seizures, those with poor HRQoL, those who were more resistant to medications and those who felt hopeless tended to employ such mechanisms (Hosseini et al., 2010). Emotion is part of the coping process and reflects the weight that the person gives to experiences which can be considered as part of a person's long-term attempts to survive (Raty et al., 2007). All of these attributes could have possibly encouraged our patients to favour such coping strategies which suited their characters as well as the disease conditions.

On the contrary, respondents with good HRQoL significantly preferred to cope via Positive Reframing, Planning and Religion. This suggests that their more positive views on the illness were reflected through their preference. Positive Reframing and Planning are categorized in the problem-focused coping strategies (Piazzini et al., 2007). Among the more specific coping strategies, PWE who adopted problem-focused and cognitive restructuring modes were reported to experience relatively favourable psychosocial outcomes, including better mental health, increased psychological well-being, decreased psychological distress and lower levels of reported depression and anxiety which could all lead to improved HRQoL (Livneh et al., 2001).

It is acknowledged that the findings from this study should still be approached with caution due to the relatively small number of participants whom may not have adequately represented the larger PWE population, due to the recruitment process being conducted in only one general hospital. This sample may have therefore differed from community-based samples recruited by the general practitioners. Because of the limited number too, more powerful statistical analyses were not appropriate at this point to substantiate the outcomes. A comparison of hospital-based and community-based samples of PWE may be an important area for future research to determine if coping strategies may have been affected by the type of services they receive.

Conclusion

Several coping strategies were shown to demonstrate significant associations with HRQoL profiles whereby patients generally possessed the tendencies to cope via problem-focused styles rather than the emotion-focused ones. Groups of PWE with different HRQoL profiles largely differed in their preference and frequency toward coping mechanisms. Those with good HRQoL status chose positive (adaptive) coping styles while their counterparts preferred the opposite. Significant but weak association between HRQoL domains and coping strategies suggested that further research needs to be carried out with larger sample sizes to strengthen our findings. Enhanced awareness and a clearer perception of the ways to help PWE to cope more effectively with their problems will enormously benefit both patients and caregivers in the constant pursuit of improved health outcomes.

Acknowledgement

We wish to thank the Director General of Health, Malaysia for permission to publish this paper and the hospital director, Heads of Neurology Department and staff of Hospital Sultanah Nur Zahirah for their cooperation in ensuring the success of this study. Thank you also to the Dean of Faculty of Medicine and Health Sciences, UniSZA, all participants and their families for supporting our study. Our appreciation is also directed to the Pusat Pengurusan Penyelidikan dan Inovasi (PPPI) UniSZA for its financial support [grant no: UDM/10/BR (029)].

References

1. Baker, G.A., Smith, D.F., Dewey, M., Jacoby. A., & Chadwick, D.W. (1993). The development of a health-related quality of life measure for patients with intractable epilepsy. Epilepsy Research, 16, 65-81.

2. Baker, G.A. (2001). Assessment of quality of life in people with epilepsy: some practical implications. Epilepsia, 42, 66-69.

3. Betts, T.A. (1993). Neuropsychiatry. In J. Laidlaw, A. Richens, & D. Chadwick, (Ed.), A Textbook of Epilepsy. Churchill Livingstone.

4. Birbeck, G.L., Hays, R.D., Cui, X., & Vickrey, B.G. (2002). Seizure reduction and quality of life improvements in people with epilepsy. Epilepsia, 43, 535-538.

5. Carver, C. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. International Journal of Behavioural Medicine, 4, 92-100.

6. Carver, C.S., Scheier, M.F., & Weintraub, J.K. (1989). Assessing coping strategies: a theorically based approach. Journal of Personality & Social Psychology, 56, 267-283.

7. Chronister, J., & Chan, F. (2007). Hierarchical Coping: A Conceptual Framework for Understanding Coping Within the Context of Chronic Illness and Disability. In E. Martz, & H. Livneh, (Ed.), Coping with chronic illness and disability: Theoretical, empirical, and clinical aspects (pp. 49-71). Springer Science.

8. Collings, J.A. (1990). Psychosocial well-being and epilepsy: an empirical study. Epilepsia, 31, 418-426.

9. Devins, G.M., & Binik, Y.M. (1996). Facilitating coping with chronic physical illness. In M. Zeidner, & N.S. Endler, (Ed.), Handbook of Coping: Theory, Research, Applications (pp. 640-696). Toronto: John Wiley & Sons, Inc.

10. Dobson, A.J. (1984). Calculating sample size. Trans. Menzies Foundation, 7, 75-79.

11. Ebadi, A., Ahmadi, F., Ghanei, M., & Kazemnejad, A. (2009). Spirituality: a key factor in coping among Iranians chronically affected by mustard gas in the disaster of war. Journal of Nursing & Health Sciences, 11, 344-350.

12. Elwes, R.D.C., Marshall, D., Beattie, A., & Newman, P.K. (1991). Epilepsy and unemployment: A community based survey in an area of high unemployment. Journal of Neurology, Neurosurgery & Psychiatry, 54, 200-203.

13. Felce, D., & Perry, J. (1995). The extent of support for ordinary living provided in staffed housing: the relationship between staffing levels, resident characteristics, staff: resident interactions and resident activity patterns. Social Science & Medicine, 40, 799-810.

14. Folkman, S., & Moskowitz, J.T. (2004). Coping: Pitfalls and promise. Annual Review of Psychology, 55, 745-774.

15. Folkman, S., & Moskowitz, J.T. (2000). Positive effect and the other side of coping. American Psychology, 647-654.

16. Gehlert, S. (1994). Perceptions of control in adults with epilepsy. Epilepsia, 35, 81–88.

17. Gilham, R., Bryant-Comstock, L.K., & Kane, K. (2000). Validation of the side effect and life satisfaction (SEALS) inventory. Seizure, 9, 4584-63.

18. Gilliam, F.G., Fessler, A.J., Baker, G., et al. (2004). Systematic screening allows reduction of adverse antiepileptic drug effects: a randomized trial. Neurology, 62, 23-7.

19. Hassankhani, H., Taleghani, F., Mills, J., Birks, M., Francis, K., & Ahmadi, F. (2009). Being hopeful and continuing to move ahead: religious coping in Iranian chemical warfare poisoned veterans, a qualitative study. Journal of Religion & Health, 49, 311-21.

20. Herman-Stahl, M.A., Stemmier, M., & Petersen, A.C. (1995). Approach and avoidant coping: implications for adolescent mental health. Journal of Youth & Adolescence, 24, 649.

21. Hosseini, N., Sharif, F., Ahmadi, F., & Zare, M. (2010). Striving for balance: coping with epilepsy in Iranian patients. Epilepsy Behaviour, 18, 466-471.

22. Ismail, H., Wright, J., Rhodes, P., Small, N., & Jacoby, A. (2005). South Asians and epilepsy: exploring health experiences, needs and beliefs of communities in the North of England. Seizure, 14, 497-503.

23. Jacoby, A., Snape, D., & Baker, G.A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurology, 4, 171-178.

24. Jacoby, A. (1994). Felt versus enacted stigma: a concept revisited. Social Science & Medicine, 38, 269-274.

25. Johnson, E.K., Jones, J.E., Seidenberg, M., & Hermann, B.P. (2004). The relative impact of anxiety, depression and clinical seizure features on health-related quality of life in epilepsy. Epilepsia, 45, 544-50.

26. Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: do illness representations play a role?. British Journal of Clinical Psychology, 38, 43-58.

27. Koot, H.M., & Wallander, J.L. (2001). Challenges in child and adolescent quality of life research. In H.M. Koot, & J.L. Wallander J L, (Ed.). Quality of life in child and adolescent illness concepts, methods, and findings (pp. 403-424). East Sussex, England: Brunner-Routledge.

28. Lazarus, R. (1993). Coping theory and research: Past, present, and future. Psychosomatic Medicine, 55, 234-247.

29. Lazarus, R.S., & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer-Verlag.

30. Lemeshow, S., Hosmer, D.W., Klar, J., & Lwanga, S.K. (1990). Adequacy of sample size in health studies. World Health Organization, 1-4.

31. Leone, M.A., Beghib, E., Righini, C., Apolone, G., & Mosconi, P. (2005). Epilepsy and quality of life in adults: A review of instruments. Epilepsy Research, 66, 23-44.

32. Livneh, H., Wilson, L.M., Duchesneau, A., & Antorak, R.F. (2001). Psychosocial adaptation to epilepsy: the role of

coping strategies. Epilepsy Behaviour, 2, 533-544.

33. Lowe, A.J., David, E., Kilpatrick, C.J., Matkovic, Z., Cook, M.J., Kaye, A., et al. (2004). Epilepsy surgery for pathologically proven hippocampal sclerosis provides longterm seizure control and improved quality of life. Epilepsia, 45, 237–242.

34. Lua, P.L., Cosmas, G., & Md.Nawi, N.H. (2007). The burden of epilepsy: quality of life and coping strategies. University Publication Centre (UPENA), Universiti Teknologi MARA, Shah Alam. Selangor: Malaysia.

35. Lua, P.L., & Neni, W.S. (2011). Awareness, knowledge andattitudes with respect to epilepsy: an investigation in relation to health-related quality of life within a Malaysian setting. Epilepsy Behaviour, 21, 248-254.

36. Lwanga, S.K., & Lemeshow, S. (1991). Sample size determination in health studies: a practical manual. World Health Organization, 1-3.

37. Maes, S., Leventhal, H., & de Ridder, D.T. (1996). Coping with chronic diseases. In M. Zeidner, & N.S. Endler, (Ed.). Handbook of coping: theory, research, applications (pp. 221-251). New York: Wiley.

38. McLachlan, R.S., Sadler, M., Pillay, N., Guberman, A., Jones, M., Wiebe, S., & Schneiderman, J. (2003). Quality of life after vagus nerve stimulation for intractable epilepsy: is seizure control the only contributing factor? European Journal of Neurology, 50(1), 16-19.

39. Mittan, R.J. (1986). Fear of seizures. In S. Whitman, B.P. Hermann, (Ed.). Psychopathology in Epilepsy: Social Dimensions. Oxford: Oxford University Press.

40. Morse, J.M., & Johnson, J.L. (1991). Towards a theory of illness: the illness constellation model. In J.M. Morse, J.L. Johnson, (Ed.). The illness experience (pp. 315-342). London, England: Sage Press.

41. Moskowitz, J.T., Folkman, S., Collette, L., & Vittinghoff, E. (1996). Coping and mood during AIDS-related caregiving and bereavement. Annals of Behavioural Medicine, 18, 49-57.

42. Naing, N.N. (2009). A practical guide on determination of sample size in health sciences research: Sample size determination in descriptive studies. Kelantan, Malaysia: Pustaka Aman Press Sdn. Bhd.

43. Neni, W.S., Latif, A.Z.A., Wong, S.Y., Lua, P.L. (2010). Awareness, knowledge and attitudes towards epilepsy among rural populations in East Coast Peninsular Malaysia: a preliminary exploration. Seizure, 19, 280-290.

44. Piazzini, A., Ramaglia, G., Turner, K., Chifari, R., El Kiky, E., Canger, R., Canevini, M.P. (2007). Coping strategies in epilepsy: 50 drug-resistant and 50 seizure-free patients. Seizure, 16, 211-217.

45. Raty, L.K.A., Soderfeldt, B.A., Wilde Larsson, B.M. (2007). Daily life in epilepsy: patients' experiences described by emotions. Epilepsy Behaviour, 10, 389-396.

46. Rosenbaum, M., & Palmon, N. (1984). Helplessness and resourcefulness in coping with epilepsy. Journal of Consultancy & Clinical Psychology, 52, 244-53.

47. Sackellares, C.J., Kwong, J.W., Vuong, A., Hammer, A.E., Barrett, P.S. (2002). Lamotrigine monotherapy improves health-related quality of life in epilepsy: a double-blind comparison with valproate. Epilepsy Behaviour, 3, 376-382.

48. Saniah, A.R., & Zainal, N.Z. (2010). Anxiety, depression and coping strategies in breast cancer patients on chemotherapy. Malaysian Journal of Psychiatry, 19, 2.

49. Snyder, M. (1990). Stressor, coping mechanisms and perceived health in persons with epilepsy. International Disability Studies, 12, 100-103. 50. Spector, S., Tranah, A., Cull, C., & Goldstein, L.H. (1999). Reduction in seizure frequency following a short-term group intervention for adults with epilepsy. Seizure, 8, 297-303.

51. Spencer, S.S., Berg, A.T., Vickrey, B.G., et al. (2003). Initial outcomes in the multicenter study of epilepsy surgery. Neurology, 61:1680–1685.

52. Statistics by country for epilepsy in 2004. http://www.cureresearch.com/e/epilepsy/stats-country.htm. Accessed 5 Sept 2010.

53. Taleghani, F., Yekta, Z.P., & Nasrabadi, A.N. (2006). Coping with breast cancer in newly diagnosed Iranian women. Journal of Advanced Nursing, 54, 265-272.

54. Trimble, M.R., & Dodson, W.E. (1994). Epilepsy and quality of life. New York: Raven Press.

55. Vickrey, B.G., Berg, A.T., Sperling, M.R., Shinnar, S., Langfitt, J.T., Bazil, C.W. et al. (2000). Relationship between seizure severity and health-related quality of life in refractory localization-related epilepsy. Epilepsia, 41, 760-764.

56. Vickrey, B.G., Hays, R.D., Graber, J., et al. (1993). A health-related quality of life instrument for patients evaluated for epilepsy surgery. Medical Care, 30, 299-319.