



Burden in caregivers of adults with epilepsy in Asian families

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ABSTRACT

Purpose: The literature on caregiver burden tends to focus on children and teenagers with epilepsy and less on adults. As caregiving is a dynamic, complex process across the trajectories, this study aims to examine the factors associated with caregiving burden in those caring for adults with epilepsy.

Method: This is a cross-sectional, survey-based study in which participants responded to questionnaires regarding perceived burden (ZBI), quality of life (IEQoL), psychological distress (DASS-21), family functioning (FAD) and perceived social support (MSPSS). Additional measures include socio-demographics and clinical characteristics of the care-recipient.

Results: A total of 111 caregivers participated, of whom 72.1% were females, 55% parents, 59.5% Chinese, 51.4% unemployed and 46.0% with tertiary education. Approximately half (42.3%) reported mild-to-moderate levels of burden (mean ZBI score 29.93, SD 16.09). Furthermore, multiple regression analysis identified 10 predictors of caregiver burden, namely family functioning, weekly caregiving hours, number of caregivers per family, attitude towards epilepsy, family support, caregivers' gender, personal income and as well as care-recipients' age of onset, seizure frequency and ADL dependency ($F(10, 85) = 11.37, p < 0.001$). Stepwise regression highlighted family functioning as the main predictor ($\beta = 0.299, p < 0.001$). The total ZBI score was positively correlated with caregivers' reported levels of depression ($r = 0.549, p < 0.001$), anxiety ($r = 0.599, p < 0.001$) and stress ($r = 0.576, p < 0.001$) subscales in DASS-21, and negatively correlated with IEQoL ($r = -0.637, p < 0.001$).

Conclusion: This study shows that caregivers' burden is highly associated with the family system (family functioning, support and number of caregivers), besides demographics, psychosocial and clinical characteristics. Future research is required to learn how to support this sub-group of caregivers within the family system.

1. Introduction

Epilepsy is an unpredictable, intrusive illness that impacts not only the patients but also those who care for them [1]. People with epilepsy (PWE) consistently report lower quality of life, higher levels of depression and anxiety [1]. Epilepsy could cause psychosocial distress, disrupt family routines and reorient the interests and activities of family members.

Support is particularly important in improving PWE's self-management, which varies depending on seizure type, severity and triggers [2]. Social support has a positive influence on health and well-being of PWE [3], particularly when it is encouraging; it enhances patient autonomy and fosters family cohesion [4,5]. As stated by Rosland (2010), "Self-management behaviors, which often take place in a shared environment and in the context of relationships, naturally involve individuals

beyond the patient". The supportive atmosphere contributes to increased self-efficacy to perform self-management behaviors.

Despite the crucial role of support providers, much of the literature on epilepsy burden and its impact on quality of life has focused on the patient as the "client" and failed to see the family as a "co-client", particularly in the case of caregivers of adult PWE [6]. In a survey of 44 families with adult PWE, the caregivers reported limited support from friends and services outside the home [7]. Furthermore, studies on the role of caregiving in epilepsy report that caregivers have poor quality of life and are at risk of developing psychiatric illnesses [2,3]. Quality of life, however, is subjective; it is influenced by people's perceptions of their caregiving burden.

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1.1. The burden of caregiving to adults with epilepsy

Literature on the burden of giving care to adults with epilepsy is scarce. Caregiver burden refers to the perceived distress and impact on caregivers as a result of providing care [8]. A caregiver's role in epilepsy includes monitoring medication adherence, offering support strategies for seizure management, processing and relaying information about seizure symptoms to healthcare providers [2]. Caregiving is said to feature chronic stress experience. The intense demand placed on caregivers include coping with patient's psychological distress, dealing with frequent recurrence of seizures, and addressing concerns about potential injury and even death of PWE [9]. Despite the challenges faced, it is important to note the positive benefits of caregiving, which include feelings of altruism and fulfillment of family obligation [9].

1.2. Factors influencing burden in caregivers of adults with epilepsy

Caregiver burden is mainly influenced by characteristics of the patient and the caregivers, as well as the care context.

1.2.1. Characteristics of the patient

Age of the patients with epilepsy has an effect on the caregiver's burden [10]. Compared to the pediatric population, caregivers of adult PWE experienced higher levels of burden and afflicted stigma [11]. Apart from the onset of the disease, seizure frequencies were found to moderate the level of caregiving burden [12,13]. A study focusing on the impact of seizure clusters on caregiver's quality of life revealed that 58% of caregivers reported significant psychological distress (e.g. being stressed out, helpless, scared and overwhelmed) with reduced vitality and work-related performances [12]. Furthermore, the study based on qualitative findings, showed that families caring for PWE with uncontrolled seizures projected worries and uncertainty about future care provision [13]. This is consistent with families caring for children and those with different types of epilepsies (e.g. TLE and JME) [14]. Caregiving burden was also found to be associated with PWE who had intellectual disabilities, had prolonged use of antiepileptic drugs, and who were unemployed and dependent on their caregivers for their daily living activities [10,13,15].

1.2.2. Characteristics of caregivers

Caregivers were predominantly females, and the caregiving burden was dependent on the type of tasks performed [8]. Interpersonal relationships between caregivers and patients have a positive influence on perceived levels of caregiving burden. Among married PWE who reported higher levels of marital satisfaction, the caregiving role was assimilated by their spouses [9]. The caregiver burden, however, shifted to adult children as the patients aged [8]. Higher caregiver education level was associated with better psychological health [6], speculated to be due to better insights towards one's medical condition, resulting in better coping strategies [10]. Socioeconomic status (e.g. family income) is another significant predictor in perceived burden among caregivers in rural/developing countries [16]. This is more prominent if the patients were newly diagnosed, on polytherapy and expensive newer antiepileptic medications [17].

1.2.3. Family functioning

Care demands by PWE can be complex and family members are recognized as important allies to provide sustainable and effective epilepsy self-management. In this context, family functioning (FF) refers to the family's ability to work together in satisfying the basic needs of its members [18]. FF can impact patients and caregiver's health-related quality of life (HRQOL) and vice-versa [19]. A study showed that upon controlling for seizure onset and frequency, elements of FF like communication and affective involvement predicted HRQOL in PWE [19]. In addition, formal support system like temporary care facilities was found to provide respite to caregivers, thereby lowering their level

of burden [20]. Likewise, informal social support like caregiver support group had an ameliorative effect [9]. Nevertheless, psychological demands of caregiving, such as anxiety, depression and psychological distress are common in caregivers of epilepsy patients [9]. It is therefore important to consider the relation between the psychosocial impacts of epilepsy and the practical care demands assumed by caregivers.

Though studies have been conducted on caregivers of children and adolescents with epilepsy, there have been fewer on how caregivers prepare and assimilate the caregiving roles in adults with epilepsy. Being a caregiver is a dynamic process which requires an individual to make considerable transitions and restructuring of responsibilities. The psychological ability to cope may be expected to decrease as the caregivers grow older and their own physical health declines. Research needs to explore the impact of such extensive caregiving on one's physical and mental health. In addition, social support for adults with epilepsy, especially those with learning disability, is less compared to what is available for children. Filling this gap, i.e. studying caregivers of adult PWE, will provide a broader understanding of the acquisition needs of caregivers across a lifespan.

1.3. Aim of study

The aim of this study is to examine the factors associated with caregiver burden and the quality of life among caregivers of adult PWE. We hypothesize that the caregiver's burden depends on the individual's perceived social support and family functioning, which can be affected by the socio-cultural and psychological context as well as the patient's clinical characteristics. We also postulate that caregiver's QoL and emotional well-being is dependent on the perceived levels of care burden.

2. Method

2.1. Design of study

This study used a cross-sectional design. Participants were required to complete a paper-and-pen questionnaire on caregiver's burden, prior to which written informed consent was obtained. The study was approved by the University Malaya Medical Center (UMMC) Ethics Committee (MECID.NO: 201642358).

2.2. Participant selection and recruitment

A consecutive sampling method was adopted to recruit caregivers of PWE who were attending the outpatient UMMC neurology clinic over a 6-month period. Caregivers of PWE were defined as the main informal, unpaid individuals who provide care and assistance to manage the daily needs of persons diagnosed with epilepsy. Primary caregivers are the main caregivers and non-primary caregivers are those who assist the former. Examples of caregiving-related tasks include medication monitoring, participation in emergency and outpatient clinical consultations, and providing transport to any patient-related activities.

The diagnosis of epilepsy was verified by an epileptologist (KSL) according to the criteria of the International League against Epilepsy (ILAE). Further assessments on the physical and mental state of PWE were based on the patient's medical records and the opinions of the neurologists' (KSL and SBA).

Caregivers who were 18 years or older, who provided care to adult PWE and were able to comply with study procedures were selected. Caregivers who were: (1) employed from formal care institutions, and (2) were financially compensated for caregiving tasks were excluded. Caregivers of epilepsy patients who were below 18 years old and who had not experienced seizures in the previous 12 months were also excluded.

2.3. Procedure

All eligible participants were approached in the clinic by two research assistants (RAs, i.e. TWY and MWCM) who were trained in research methodology of the study. The background of the study was explained and an information sheet that contained details of the study was provided. Participants were only recruited upon written consent. Participants who consented were required to complete and return the questionnaire to the RA on the same day of recruitment. Approximately 20 min were required to complete the questionnaire which comprised of demographic information and five scales that assessed factors related to caregiver burden.

2.4. Measures

2.4.1. Clinical and sociodemographic information

The questionnaire required the participants to provide socio-demographic information regarding both the caregiver and the patient (age, gender, education, employment, marital and socioeconomic status) as well as and the familial care context (time allocated by caregiver for weekly caregiving duties, nature of relationship with PWE, and number of family members involved in caregiving duties).

Epilepsy-related information included age at onset, disease duration, seizure frequency, seizure control, number of antiepileptic drugs (AEDs) and profile on activities of daily living (ADL). Information collected was cross-validated with medical records.

2.4.2. Zarit Burden Interview (ZBI)

The Zarit Burden Interview (ZBI), a scale used among those caring for PWE [14] was administered to caregivers to assess the levels of burden [21] they faced. This scale consisted of 22 items that evaluated the caregiver's perceptions towards changes in physical and emotional health, as well as social and financial difficulties brought about by caregiving. All items were scored on a 5-point Likert scale, with total scores ranging from 0 to 88. Levels of burden were indicated by cutoff points: mild (scores of 21–40); moderate (scores of 41–60) and severe (scores of 61 and above).

2.4.3. Impact of epilepsy on the quality of life (IEQoL)

The IEQoL has been used to measure the quality of life (QoL) of the caregivers looking after younger PWE [22]. It consists of six domains which explore caregiver's satisfaction of knowledge obtained from treating physician (A1–A2), attitude towards epilepsy (B1–B3), family's QoL after onset of disease (C1–C7), family wellness (D1–D5), concerns on the status of the child's/adolescent's QoL (E1–E4) and the perception towards effects of treatment administration (F1–F4). Each domain has its own response format; hence scores obtained are merely reflective of the examined QoL aspect that has been examined.

For the purposes of this study, only items in domains B to D were selected to determine the levels of wellbeing of caregivers looking after adult PWE. The selected domains resonate with a previous study [23] which explored various aspects of HRQoL of patients and families according to the illness trajectories (e.g. those newly diagnosed vs. those with long term experience of epilepsy).

2.4.4. Family assessment device general functioning (FAD-GF) subscale

The McMaster Family Assessment Device (FAD) is a theory-informed self-report scale designed to assess family member's perception of family functioning [24]. General Functioning (GF) represents one of the subscales of the multi-faceted FAD. It has been applied in various medical and psychiatric conditions [25], including epilepsy [26]. The FAD-GF comprises 12-items, half of which are framed as positive statements and the other half as negative statements to capture levels of family functioning. Answers are coded on a 4-point Likert scale (1 = strongly agree to 4 = strongly disagree). The global family functioning score ranges from 1 to 4, with lower scores denoting better family

functioning. Previous validation studies on the GF subscale have demonstrated good internal consistency, temporal stability, as well as convergent and discriminant validity [27].

2.4.5. Multidimensional scale of perceived social support (MSPSS)

The MSPSS is aimed at assessing an individual's perceived social support [28]. The total of 12-items reflects three perceived sources of social support: family (items 3, 4, 8, 11), friends (items 6, 7, 9, 12), and significant others (items 1, 2, 5, 10). All items are positively worded, and studies have found the scale to be relatively free of social desirability bias. Respondents rate on a 7-point Likert scale (1 = very strongly disagree to 7 = very strongly agree) to indicate strength of agreement within each subscale (scores range from 4 to 28). Scores derived from subscales are then added to obtain the global perceived social support (scores range from 12 to 84). Higher scores indicate higher level of perceived social support. This scale has strong internal reliability as well as factorial and constructs validity [28]. The MSPSS is often applied on PWE to assess perceived social support but it has not been commonly reported on epilepsy caregivers [29]. However, the scale has been found to be suitable for caregivers of neurological conditions like stroke [30], an important consideration for its inclusion in this study.

2.4.6. Depression, anxiety and stress scale (DASS-21)

The DASS-21 is a self-reported measure of depression, anxiety and stress, used as a screening tool for susceptible clinical conditions [31]. Each subscale has seven items based on a 4-point Likert scale (0 = never to 3 = almost always). Cutoff points for the following subscales are indicated as:

- Depression (DASS-D): mild (10–13), moderate (14–20), severe (21–27) and extremely severe (28 and above).
- Anxiety (DASS-A): mild (8–9), moderate (10–14), severe (15–19) and extremely severe (20 and above).
- Stress (DASS-S): mild (15–18), moderate (19–25), severe (26–33) and extremely severe (34 and above).

The sum of each subscale provides the indicator for general psychological distress (GPD). Scoring 25 and above denotes the presence of distress, with higher scores indicating higher levels. The DASS-21 tested on caregivers of PWE [32] has reported good psychometric properties [33].

2.5. Analysis

Data was analyzed using the Statistical Package for Social Sciences version 19 (SPSS 19.0). Demographic information of participants and care recipients (adult PWE) was explored using descriptive statistics. Correlations between participant's characteristics and caregiver's burden for continuous variables were performed using Pearson correlation analysis. Stepwise linear regression analysis was carried out to ascertain which variables significantly predicted caregiver burden (ZBI score). Between-subject group factors were analyzed using independent-sample T-test and one-way analysis of variance (ANOVA). For further comparisons of groups, post-hoc analysis was carried out for significant variables. Partial η^2 was used to determine effect sizes, with values of 0.01–0.06 indicating small, 0.07–0.14 medium, and > 0.14 large.

3. Results

3.1. Socio-demographic and clinical characteristics

Although a total of 114 participants who met the inclusion criteria were approached, only 111 qualified, yielding a recruitment rate of 97.4% ($n = 111$) (Fig. 1). Participants' age ranged from 20 to 80 years (mean: 52.46, SD: 14.32 years). Their predominant characteristics were

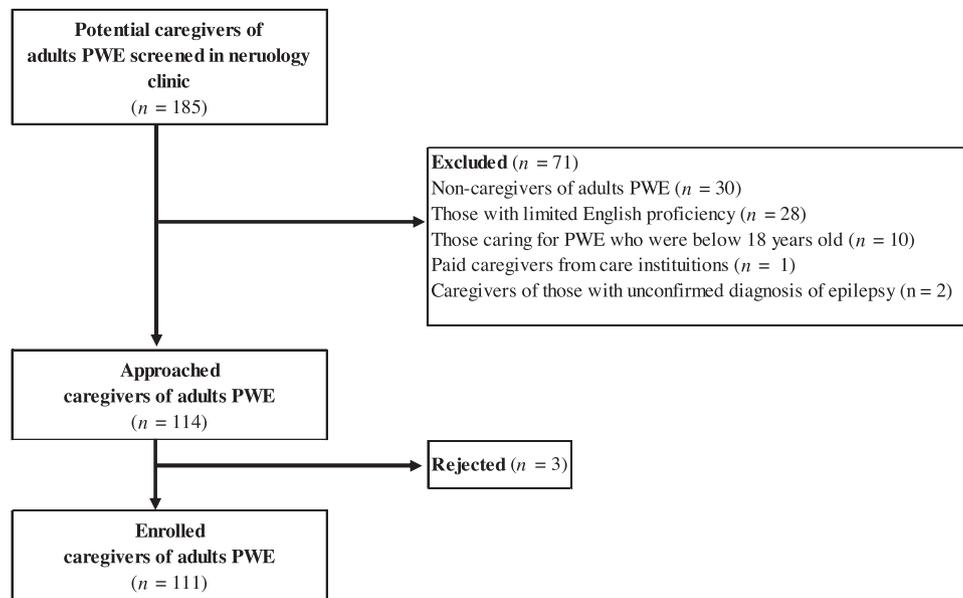


Fig. 1. Recruitment flow chart.

that 72.1% was female, 59.5% Chinese, 83.8% married, 51.4% unemployed and 46.0% had completed tertiary education. Furthermore, they were predominantly parents (55%), had assumed primary caregiver's role (88.3%), and spent an average of 77.67 h per week (range, 1–168 h), or approximately 11 h per day for caregiving (Table 1). The mean ZBI total score was 29.93 (SD, 16.09; range 0–71), with 42.3% of the participants expressing mild to moderate burden (ZBI score of 21–40).

The care recipients (adult PWE) comprising 54.1% male, 69.4% unemployed, 70.3% single, 62.2% independent in activities of daily living (ADL), and had a mean age of 37.51 years (SD, 14.78 years). The average age of seizure onset was 17.73 years old (SD, 17.32 years) and most were on polytherapy (57.6%) (Table 1). 61.1% of the PWE had comorbidities. Of this, most (38.0%) had mental comorbid symptoms which included neurodevelopmental or psychiatric diagnoses like autism, intellectual disabilities, and schizophrenia. The remaining 23.1% had other medical comorbidities like stroke, dystonia and diabetes.

3.2. Factors affecting caregiver's burden

3.2.1. Caregiver burden in relation to caregiver characteristics

Higher levels of caregiver burden were noted among females (32.35 ± 16.79 vs. 23.68 ± 12.29 in males, $p < 0.05$), the unemployed (33.00 ± 17.64 vs. 26.69 ± 13.71 in the employed, $p < 0.05$), primary caregivers (31.41 ± 16.13 vs. 18.77 ± 10.89 in non-primary caregivers, $p < 0.01$), and parents (34.41 ± 16.37 vs. 24.45 ± 16.41 in spouse and 28.07 ± 13.09 in siblings, $p < 0.05$) (Table 2). Caregiver burden was positively correlated with weekly caregiving hours ($r = 0.332$, $p < 0.01$) and age of caregivers ($r = 0.193$, $p < 0.05$), and negatively correlated with number of family members involved in caregiving ($r = -0.231$, $p < 0.05$) (Table 3)

3.2.2. Caregiver burden in relation to care-recipient characteristics

Caregivers reported higher levels of burden if the care-recipients were single (32.37 ± 15.98 vs. 22.94 ± 14.72 in those married, $p < 0.01$), had mental comorbidities (35.80 ± 16.50 vs. 23.90 ± 13.30 in those without comorbidities, $p < 0.01$), and dependent where activities of daily living were concerned (35.62 ± 18.32 vs. 26.20 ± 13.87 in those independent, $p < 0.01$) (Table 2). The burden of caregivers was positively correlated with patient's seizure frequency ($r = 0.270$, $p < 0.01$), but negatively correlated with age of

onset ($r = -0.191$, $p < 0.05$). (Table 3).

3.2.3. Caregiver burden in relation to psychosocial factors

The total ZBI score was positively correlated with the score in FAD's general functioning (GF) subscale ($r = 0.490$, $p < 0.001$), with lower scores denoting better family functioning. Conversely, the ZBI score was negatively correlated to the score for family support ($r = -0.347$, $p < 0.001$) and perceived current well-being of family ($r = -0.375$, $p < 0.001$).

3.3. Impact of burden on caregiver's psychological health and quality of life

The total ZBI score was positively correlated with the subscales scores in the DASS-21 (depression subscale, $r = 0.549$, $p < 0.001$; anxiety subscale, $r = 0.599$, $p < 0.001$; stress subscale, $r = 0.576$, $p < 0.001$), and negatively correlated with the mean score in IEQoL ($r = -0.637$, $p < 0.001$) (Table 3).

3.4. Regression analysis

Multiple linear regression analysis was conducted to determine the predictors of caregiver burden. Of the 17 variables that correlated significantly with caregiver burden, 7 (participant's age, employment status, relationship with care-recipient, caregiving role, perceived support from friends, as well as care-recipient's marital status and comorbidities) were excluded due to low correlation coefficient value and strong correlation with another independent variable.

Stepwise linear regression was used to assess the remaining 10 variables in predicting caregiving burden. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The first 5 variables which comprised clinical characteristics (i.e. patient's seizure onset, seizure frequency and status of ADL) and demographics (i.e. caregiver's gender and personal income) were entered at Step 1, explaining 16% of the variance in caregiving burden, $F(5, 90) = 4.603$, $p < .001$.

Subsequent psychosocial factors (i.e. family functioning, family members involved in caregiving, caregiving hours, family support and attitude towards epilepsy) were entered at Step 2, which further explained an additional 36% of the variance in predicting caregiving burden after controlling for the influence of clinical and demographic characteristics. The final model demonstrated that apart from caregiver's gender ($p > .05$), all measures were statistically significant in

Table 1
Socio-demographic characteristics of caregivers and clinical characteristics of care recipients (adult PWE) (n = 111).

Demographics	N	Mean ± SD	(Range)/ Percentage
Caregivers' socio-demographics			
Age (years)		52.46 ± 14.32	(20 – 80)
Number of family members involved in care giving		2.73 ± 1.59	(1 – 10)
Time spent in care giving/ week (hours)	104	77.67 (62.05)	(1 – 168)
Gender			
Female	80		72.1
Male	31		27.9
Race			
Chinese	66		59.5
Malay	23		20.7
Indian	20		18.0
Others	2		1.8
Education level			
None	1		0.9
Primary	14		12.6
Secondary	45		40.5
Tertiary	51		46.0
Marital status			
Married	93		83.8
Single	18		16.2
Employment status			
Unemployed	57		51.4
Employed	54		48.6
Relationship with care recipient			
Parents	61		55.0
Spouse	22		19.8
Siblings	15		13.5
Children	7		6.3
Others	6		5.4
Caregiver			
Primary	98		88.3
Non-primary	13		11.7
Household monthly income			
None	7		6.3
Below RM1000 (USD257)	5		4.5
RM1000-RM2000 (USD257-514)	15		13.5
Above RM2000 (USD514)	83		74.8
Personal monthly income/ allowance			
None	25		22.5
Below RM1000	12		10.8
RM1000-RM2000	22		19.8
Above RM2000	51		45.9
Adults with Epilepsy (PWE) characteristics			
Socio-demographics			
Age (years)	108	37.51 ± 14.78	(18 – 71)
Gender			
Female	51		45.9
Male	60		54.1
Employment status			
Unemployed	77		69.4
Employed	31		27.9
Marital status			
Single	78		70.3
Married	31		27.9
Clinical characteristics			
Age of seizure onset (years)	108	17.73 ± 17.32	(1 – 66)
Seizure frequency / year	107	30.98 ± 91.89	(1 – 730)
Number of seizure medication			
One	44		39.6
Two	33		29.7
Three	29		26.1
Four	2		1.8
Activities of daily living (ADL)			
Independent	69		62.2
Dependent	39		35.1
Comorbidities			
No comorbidities	42		38.9
Mental (i.e. Neurodevelopmental and/or psychiatric)	41		38.0

Table 1 (continued)

Demographics	N	Mean ± SD	(Range)/ Percentage
Medical	25		23.1

Note. No comorbidities refer to those with only epileptic seizures; Mental comorbidities include neurodevelopmental and psychiatric disorders; Medical comorbidities involve other concurrent physical illnesses.

Table 2
Sub-group analyses of characteristics of caregivers and adult PWE in influencing caregivers' burden (n = 111).

Measures	Sub-groups	N	Mean ± SD	p
Caregivers' socio-demographics				
Gender	a Female	80	32.35 ± 16.79	0.010*
	a Male	31	23.68 ± 12.29	
Race	a Chinese	66	30.85 ± 15.92	0.121
	a Malay	23	23.22 ± 14.07	
	a Indian	20	33.95 ± 17.53	
	a Others	2	36.50 ± 17.68	
	a None	1	48.00	
Education level	a Primary	14	34.21 ± 20.50	0.288
	a Secondary	45	31.09 ± 17.05	
	a Tertiary	51	27.37 ± 13.61	
	a None	1	48.00	
Marital status ^a	a Married	93	31.09 ± 16.69	0.085
	a Single	18	23.94 ± 11.06	
Employment status	a Unemployed	57	33.00 ± 17.64	0.038*
	a Employed	54	26.69 ± 13.71	
Relationship with care recipient ^b	a Parents	61	34.41 ± 16.37	0.014*
	a Spouse	22	24.45 ± 16.41	
	a Siblings	15	28.07 ± 13.09	
	a Children	7	19.57 ± 6.71	
	a Others	6	21.17 ± 13.75	
Caregiving role	a Primary caregiver	98	31.41 ± 16.13	0.007**
	a Non-primary caregiver	13	18.77 ± 10.89	
Household monthly income	a None	7	32.00 ± 11.43	0.098
	a Below RM1000 (USD257)	5	47.00 ± 19.62	
	a RM1000-RM2000 (USD257-514)	15	27.27 ± 19.84	
	a Above RM2000 (USD514)	83	29.48 ± 15.03	
Personal monthly income/ allowance ^c	a None	25	38.04 ± 18.13	0.022*
	a Below RM1000	12	31.75 ± 17.62	
	a RM1000-RM2000	22	24.77 ± 15.11	
	a Above RM2000	51	28.20 ± 13.74	
Adults with Epilepsy (PWE) characteristics				
Socio-demographics				
Gender	a Female	51	28.78 ± 15.55	0.419
	a Male	60	31.27 ± 16.76	
Employment status	a Unemployed	77	30.32 ± 16.84	0.467
	a Employed	31	27.81 ± 14.55	
Marital status	a Single	78	32.37 ± 15.98	0.005**
	a Married	31	22.94 ± 14.72	
Clinical characteristics				
Comorbidities ^{d,e}	a No comorbidity	42	23.90 ± 13.30	0.003**
	a Mental	41	35.80 ± 16.50	
	a Medical	25	29.00 ± 17.02	
Activities of daily living (ADL)	a Independent	69	26.20 ± 13.87	0.003**
	a Dependent	39	35.62 ± 18.32	

Note. ** p < .01; *p < .05.

^a Those whose marital status was denoted as single, divorced or widowed were categorized under the single group.

^b Tukey HSD tests showed none of the pairs to be significantly different (p > .05).

^c Tukey HSD tests showed that the only pairs to be significantly different (p < .05) were No income and RM1000-RM2000 (p = 0.022).

^d Comorbidities were grouped as follows: No comorbidity (i.e. only epileptic seizures); Mental (includes those with neurodevelopmental or psychiatric diagnoses); Medical (physical diseases only).

^e Tukey HSD tests showed that the only pairs to be significantly different (p < .05) were no comorbidity and mental comorbidities (p = 0.002).

Table 3
Correlation analysis between caregivers' burden and other variables.

Measures	Caregiver burden
Participant's (caregiver) characteristics	
Age	0.193*
Weekly care giving hours	0.332**
Number of family members involved in care giving	−0.231*
Care recipient's (adult PWE) characteristics	
Age	−0.129
Age of onset	−0.191*
Number of seizure medication	0.140
Seizure frequency/ year	0.270**
Psychosocial factors in caregiving	
IEQoL	
B: Attitude towards epilepsy	−0.475***
C: Changes in family QoL	−0.637***
D3: Current level of family wellness	−0.375***
D3-D1: Wellness deterioration (current - before diagnosis)	−0.187
D2-D1: Wellness deterioration (after - before diagnosis)	−0.070
FAD-GF subscale	
	.490***
MSPSS	
Total score	−0.314**
Family	−0.347***
Friend	−0.265**
Significant others	−0.160
Caregiver's psychological health	
DASS-21	
Depression	0.549***
Anxiety	0.599***
Stress	0.576***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$.

predicting caregiver's burden, $F(10, 85) = 11.37$, $p < .001$), with family functioning recording the highest beta value ($\beta = 0.299$, $p < .001$) (Table 4).

4. Discussion

This study examined the degree of caregiving burden among caregivers of adult PWE and the factors that predict it. On average, caregivers scored 29.93 (SD, 16.09) on the Zarit Burden Interview (ZBI). Almost half the caregivers (42.3%) experienced mild-to-moderate levels of burden (ZBI scores ranged from 21 to 40). Our study found that caregivers who were females, were not employed, had adopted the

Table 4
Stepwise regression analyses in predicting caregivers' burden ($N = 111$).

Variable	B	SE B	β	(95% CI)	p
Model A: Clinical and demographics variables only (adjusted $R^2 = .159$)					
Caregiver's gender (Female) ^a	5.468	3.332	.159	(-1.15 to 12.09)	.104
Caregiver's personal monthly income/ allowance ^a	−1.046	1.311	−.082	(-3.65 to 1.56)	.427
Age of seizure onset ^b	−.151	.088	−.167	(-.325 to .025)	.089
Seizure frequency ^b	.038	.016	.237	(-.007 to .070)	.017*
ADL dependency ^b	5.653	3.088	.177	(-.482 to 11.79)	.070
Model B: All including psychosocial variables (adjusted $R^2 = .522$)					
Family functioning (FAD-GF) ^c	10.086	2.758	.299	(4.60 to 15.57)	.000***
Number of family members involved in caregiving ^c	−2.338	.773	−.241	(-3.87 to -.802)	.003**
Caregiving hours/ week ^c	.066	.020	.261	(.027 to .105)	.001**
Family support (MSPSS) ^c	−.527	.211	−.209	(-.992 to -.152)	.008**
Attitude towards epilepsy ^c	−1.118	.543	−.172	(-2.20 to -.038)	.043*
Caregiver's gender (Female)	4.969	2.558	.144	(.116 to 10.06)	.055
Caregiver's personal monthly income/ allowance	2.357	1.095	.184	(.179 to 4.534)	.034*
Age of seizure onset	−.174	.067	−.192	(-.306 to -.041)	.011*
Seizure frequency	.034	.012	.214	(.010 to .059)	.006**
ADL dependency	6.695	2.472	.209	(1.78 to 11.61)	.008**

Note. * $p < .05$, ** $p < .01$, *** $p < .001$.

^a Caregivers' demographic characteristics.

^b Care-recipients' clinical characteristics.

^c Psychosocial characteristics.

primary role in caregiving and were parents of adult PWE indicated higher caregiving stress. It was also found that adult PWE who were unemployed, had early disease onset, suffered frequent seizures, who were dependent on ADL and with mental comorbid have significant impact on the caregivers' burden. Our study also demonstrated that a dysfunctional family unit, poor support from family members and negative attitude towards epilepsy had its impact on perceived burden. Consequently, caregivers of adult PWE experience extreme psychological distress and poor quality of life.

4.1. Psychosocial factors of caregiving environment

This study identified five main psychosocial factors determining caregiver burden, i.e. family functioning, family support and caregiver's attitudes towards epilepsy, caregiving hours, and number of caregivers in the family.

4.1.1. Family functioning and shared caregiving responsibilities

Higher burden has been found to correlate with poorer family functioning. A 20-year caregiving review study had found that families with one of the member experiencing chronic diseases like epilepsy and stroke, are not as close and are more likely to be dysfunctional than the control group [34]. Mahrer-Imhof and colleagues' findings illustrated poor family cohesion (i.e., bonding) as one of the main factors for a dysfunctional family unit [35]. Consequentially, family conflicts further contributed to caregiver's strain [8]. As such, strained caregivers received lesser instrumental and emotional support, which subsequently led to feelings of isolation and increased burden.

With reference to the number of caregivers in a family, increase in number of caretakers was associated with lesser perceived caregiver burden. This resonates with the findings of other studies. Caregiving of hospitalized patients diagnosed with stroke, cancer and other chronic diseases demonstrated that a large family network indicates greater availability of support [36], thereby, alleviating caregiver burden and promoting psychological well-being [2]. A study conducted on the caregivers of young adults with epilepsy in the Katsina state of North Western Nigeria also reported caregivers with smaller family size had higher mean anxiety and depression scores [37].

4.1.2. Caring for care-recipients with complex needs

Caregiving hours and ADL dependency correlated significantly with the perceived burden. Averaging 11 h a day, the caregivers spent most

of their waking hours on dedicated patient care. Weekly caregiving hours thus ranked as the second strongest predictor. Evidence has shown that hours of patient care per week (expressed in median) is consistently associated with burden [6]; in particular, those who assisted in basic ADL for more than 20 h per week reported greater psychological distress [38]. This also explains a higher burden in those caring for PWE with higher ADL dependency, comparable to a report on Taiwanese caregivers of hospitalized relatives [36].

4.1.3. Availability of support system

Caregivers' perception of their support system (family, friends, and significant others) was negatively correlated to burden. This echoes past studies that found strong family and social support was related to lower levels of caregiver burden for adults with epilepsy, and vice-versa [9,19]. Although the precise working mechanism of perceived social support on caregiver burden was not investigated in this study, a study on caregivers of adult PWE in Hong Kong found family support to be the most cited source of support [39] and attributed such findings to the close-knit relational patterns inherent in Chinese and other Asian families. The researchers also suggested that informal support from family members provided a temporary respite to the primary caregivers, thereby lowering their perceived burden, and reducing the load and psychological burden [39].

4.1.4. Attitude towards epilepsy

Attitude towards epilepsy, including perception of illness severity and anxiety about the future, was another psychological predictor in this study. Previous studies report that provision of care aside, caregiver's perception of patient's suffering is a robust distress factor [40]. Caregiver's perception of patient suffering generates varying degrees of compassion that has both emotional (e.g. feelings of love or concern) and motivation (e.g. behaviors to reduce suffering) component [40]. Even though Schulz (2007) pointed out that highly compassionate caregivers may provide better care quality than less compassionate individuals, the same cannot be said for scenarios in which suffering is chronic (i.e. multiple seizures) and intense (i.e. presence of comorbid). Under these circumstances, negative affect would become the dominant feature of compassion, and this in turn would lead to depression, hopelessness, and fatigue in the caregiver [40]. Hence, family members' perceptions of epilepsy may be more salient than severity of illness in family adjustment [9,12,41,42].

4.2. Socio-demographic profile of caregivers

4.2.1. Gender

Caregivers were predominantly female (72%), a finding similar to previous studies on caregivers [8]. Female caregivers reported higher perceived burden than their counterparts. A meta-analysis on gender differences in caregiving found female caregivers to have higher perceived burden than males (58% vs. 42%) [43], albeit providing the same amount of caregiving hours [38]. In Malaysia, it has been reported that females are the ones who provide inter-generational support for their aged parents [44], aside from caring for those with epilepsy. Thus, it is postulated that females juggling multiple roles in the family contributed to the observed gender differences in caregiver burden.

4.2.2. Aging parents

Our study showed that most caregivers (55.0%) were aging parents with no occupation, and who had to spend more time and money on caregiving, thus experiencing a higher level of caregiving stress. In Kim's (2017) study, high expenditure of caregiving among those with lower income was found to have led to poor quality of life [45], especially when caring for adults with disabilities related to the brain or spinal cord damage. As medical advances continue to extend the life span of people with long-term chronic conditions, the greatest fear among the aged is that they themselves are getting older and that there

is no one to take up the caregiving tasks [46]. Further complexity in caregiving demands arises when family members disagree about the type of care needed and how it should be provided, or when family roles and responsibilities shift over time [34].

4.2.3. Ethnicity

Although there was no significant racial difference in caregiver burden, possibly due to small sample size, Indians had the highest mean burden score (33.95), followed by the Chinese (30.85), and lastly the Malays (23.22). Two studies on caregivers of patients with dementia [47] and Parkinson's disease [48] found lower burden among the Malay caregivers, a finding similar to the current study. This could perhaps be explained by the principles taught in Islam, the religion of the Malays, which encourage respect, patience, and tolerance towards the ill and elderly [47]. As culture shapes the perception and expression of burden [47], it is recommended that future studies examine caregiving burden within an inter-cultural context.

4.3. Clinical characteristics of adult PWE

Seizure frequency was found to be positively related to caregiver burden. This concurred with Thompson et al. (2014)'s finding that elevated level of psychological distress was noted in families where seizures were frequent. The number of antiepileptic drugs however was not a significant factor for caregiver burden, possibly because anti-epileptic drugs affect the patients more than their caregivers [49].

With reference to the general characteristics of the care recipient, caregiving stress was reported to be high when the care-recipient had additional neurodevelopmental or psychiatric comorbid and had to rely on caregivers' assistance for daily needs. This is probably due to the more complex nature of the illness and subsequent higher needs of these patients as compared to their counterparts who do not need extra care. This therefore explains the higher burden and lower QoL in their caregivers [50].

4.4. Impact of caregiver burden on QoL and psychological well-being

Caregiver burden has a significant impact on caregivers' psychological well-being, as shown in this study, where caregivers reported higher depression, anxiety and stress scores, and poorer quality of life as measured by IEQoL. The IEQoL examined three QoL aspects: caregivers' perception of epilepsy, perceived change in family life after the onset of epilepsy, and family's general wellness. This finding is in keeping with those of previous studies on caring, for both children and adults with epilepsy [10,23].

5. Limitations

This study has a number of limitations. It relied exclusively on self-report measures which may carry a risk of recall bias. The study sample was also limited to caregivers of adult PWE from Kuala Lumpur, a metropolitan urban city in Malaysia. Future work could extend to rural areas for a more representative sample. Although the current study does differentiate burden associated with presence of comorbidities (e.g. physical or neurodevelopmental), it has not considered the grades of complex care needs required, nor the contribution of different seizure types which could act as covariate in caregiver burden. We also acknowledge that we did not assess how care tasks are distributed within a family over time, how care responsibilities are negotiated, and how the physical and psychological effects of caregiving are shared among family members. A better understanding of these processes via qualitative design may help to identify new intervention opportunities for caregiving. It should be noted that not all the scales used were validated in epilepsy population (e.g. FAD-GF, MSPSS). Similarly, scales on cognitive and psychiatric comorbidities on the patients' end were not examined. This study has shown that if these limitations are taken into

account, a more rigorous research process would result in even more valid findings in establishing the factors that lead to increased caregiving burden.

6. Implication

In view of how the study has shown, for instance, that adult PWE and caregivers exert influence on each other – PWE QoL relies upon family members' QoL, and vice-versa [35], the findings could have several important implications. In line with family-centered care, the findings could inform intervention targeted at alleviating the burden of caregivers (often known as the hidden patients). Where clinical practices are concerned, family intervention and caregiver's support groups could be made available to the caregivers to buffer them against feelings of burden. In addition, psychoeducation could be offered to the caregivers of adult PWE to mitigate negative perceptions. Future caregiving research in this area should be sufficiently powered to enable meaningful subgroup analyses for individualized-tailored support programs.

7. Conclusion

Our key findings show that caregivers of adult PWE experience burden that is affected by the caregiver's family system (family functioning, support and number of caretakers), demographics (gender and employment status), and care-recipient's clinical characteristics (frequent seizures, comorbid symptoms and ADL-dependent). Among these, family functioning is the key predictor of caregiver burden which leads to psychological distress and poorer quality of life. Future caregiving research is required to learn how best to support this sub-group of caregivers within the family system.

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