FACTORS AFFECTING THE BURDEN AMONG CAREGIVERS OF EPILEPSY PATIENTS IN HOSPITAL UNIVERSITI SAINS MALAYSIA

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List of Abbreviations

MZBI	Malay-Zarit Burden Interview
BDI-Malay	Beck’s Depression Inventory- Malay
BAI-Malay	Beck’s Anxiety Inventory- Malay
HUSM	Hospital Universiti Sains Malaysia

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Abstrak

Pengenalan: Penyakit epilepsi merupakan penyakit kronik dan memerlukan penjagaan yang khusus. Walaubagaimanapun, hal ini melibatkan banyak cabaran yang disebabkan oleh beberapa faktor. Cabaran ini juga kadangkala dianggap sebagai beban oleh penjaga pesakit epilepsi. Kemudiannya, hal ini akan memberikan kesan negatif dalam kehidupan pesakit mahupun penjaganya.

Objektif: Tujuan kajian adalah untuk mengetahui tahap beban di kalangan penjaga pesakit epilepsi serta faktor-faktornya.

Kaedah: Kajian ini merupakan kajian keratan rentas yang melibatkan penjaga pesakit epilepsi yang dijalankan di Klinik Neurologi, HUSM. Semua perserta dikehendaki menjawab soalan kajian berkenaan tahap beban (MZBI), tahap kemurungan (BDI-Malay) dan tahap kegelisahan (BAI-Malay).

Hasil: Terdapat 116 peserta kajian. Peserta berumur di antara 21 hingga 78 tahun, dengan purata umur 44.48 (SD:11.80 tahun). sebanyak 68.1% (n=79) ialah peserta wanita dan majoritinya adalah orang Melayu (98.3%, n=114). Dalam kajian ini, purata jumlah skor MZBI adalah 20.29 (SD: 11.46). Sebanyak 44.0% (n=51) mengalami beban jenis sedikit ke sederhana. Selain itu, analisis *multiple linear* *regression* menunjukkan faktor-faktor kepada beban penjaga. Faktor tersebut adalah, penjaga yang murung, penjaga yang kegelisahan, pendapatan penjaga, kekerapan sawan serta pesakit epilepsi yang mempunyai penyakit-penyakit lain. Didapati, korelasi positif di antara penjaga yang kemurungan (r=0.299, p-value 0.001), penjaga yang kegelisahan (r= 0.333, <0.005) and kekerapan sawan (r= 0.263, 0.004) dengan jumlah skor MZBI.

Kesimpulan: Kajian ini menunjukkan hampir separuh daripada penjaga pesakit epilepsi mengalami beban penjagaan tahap sedikit sehingga sederhana. Tahap beban penjaga adalah berkait dengan tahap emosi mereka (kemurungan dan kegelisahan), kekerapan sawan serta pesakit epilepsi yang mempunyai penyakit-penyakit lain. Kajian akan datang hendaklah berbentuk kajian intervensi untuk menangani masalah kemurungan serta kegelisahan bagi mengurangkan tahap beban kepada penjaga pesakit epilepsi.

Abstract

Background: Epilepsy is a chronic medical problem that needs a proper caregiving process. However, it imposed a great challenge to their caregivers because of many factors. These challenges can be perceived as burden to the caregivers. Later, it may negatively affect in many aspects of life in both patients and their caregivers.

Objectives: The aim of this study is to determine the severity of burden among caregivers of epilepsy patients and its associated factors.

Method: This cross-sectional study involved caregivers of epilepsy patients in Neurology Clinic, HUSM. All participants were asked to answer questionnaire regarding perceived burden (MZBI), severity of depression (BDI-Malay) and severity of anxiety (BAI-Malay).

Result: A total of 116 participants were recruited in this study. Their age ranged from 21 to 78 years old, with the mean age of 44.48 (SD:11.80 years). About two-thirds (68.1%, n=79) of the participants were female and almost all of caregivers were Malay (98.3%, n=114). The mean total score of MZBI was 20.29 (SD: 11.46). About 44.0% (n=51) of caregivers experienced mild to moderate burden. The predictors of caregiver burden were measured using multiple linear regression. The predictors were caregiver depression, caregiver anxiety, caregiver personal income, seizure frequency epilepsy patients with comorbidities. Positive correlations noted between caregiver depression (r=0.299, p-value 0.001), caregiver anxiety (r= 0.333, <0.005) and seizure frequencies (r= 0.263, 0.004) with total score of MZBI.

Conclusion: This study shows about half of the caregivers of epilepsy patients has mild to moderate burden. The predictors of caregiver burden were caregiver emotional status (depression and anxiety), caregiver personal income, seizure frequency and epilepsy patients with comorbidities. In future, intervention study, focussing on ways to reduce depression and anxiety among caregivers of epilepsy patients is required to overcome the caregiver burden.

CHAPTER 1- INTRODUCTION

1.1 Background

Epilepsy is a chronic medical condition which can be unpredictable and debilitating to the individuals. The International League Against Epilepsy (ILAE, 2014) defines epilepsy as a disease where at least two unprovoked (or reflex) seizures occurring more than 24 hours apart. Besides, in a condition where one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years is still considered as epilepsy. The risk of recurrence in individuals are higher in condition occurred with remote structural lesions, such as stroke, central nervous system infection, certain types of traumatic brain injury, diagnosis of a specific epilepsy syndrome, or in some circumstances with the presence of other risk factors.

The World Health Organization (WHO) reported that approximately 50 million people worldwide are suffering from epilepsy (WHO, 2012). They believe that almost 80% of these cases originate from developing countries including Malaysia. The prevalence of epilepsy varies substantially between developed and developing countries. In a systematic review and meta-analysis of published reports, the median lifetime prevalence for developed countries was 5.8 per 1000 compared to 15.4 per 1000 for rural and 10.3 per 1000 for urban studies in developing countries (Ngugi et al., 2010). These findings are almost similar with the data available in Asia. The lifetime prevalence of epilepsy varies among countries from 1.5 to 14.0 per 1000 in Asia. In Malaysia, we have multi-ethnicity population and the prevalence is varied according to the ethnics. Lim and colleagues (2017) reported about ethnic variations of epilepsy cases in their study. They had found that epilepsy cases were lower among in Chinese compared to the Malays and Indian because of genetic variations.

The impacts of epilepsy are not only to those who suffer from the illness, but it involves those who care for them as well (Karakis et al., 2014). From the bigger perspective, more than 85% of the global burden of epilepsy occurs among the caretaker (Ngugi et al., 2010, Newton and Garcia, 2012). From the viewpoint of the individuals who suffer from epilepsy, this disease is associated with stigma and psychological, social, cognitive and economics consequences. These factors have caused the individuals to depend regularly on their caregivers. There were about 70% of the epilepsy patients respond to anti-epileptic treatment and were seizure-free. However, up to 25% cases suffer from refractory forms of epilepsy which prevents them from living an independent life (Rathor et al., 2017). Hence, it may directly increase the caregiver burden and lead to the emergence of the negative consequences to both patients and their caregivers.

1.2 Problem statement

Living with epilepsy imposes great challenges to both patients and their family caregivers but most researchers only explored the impact on patients, with less attention given to family caregivers. Karakis and colleagues (2013) highlighted that these areas are considered as understudied. Acknowledging this problem, this study is crucial to find the magnitude of the caregiver burden and its associated factors among caregivers of epilepsy patients in Neurology Clinic, HUSM. Based on the local search at the Neurology Clinic, HUSM, there are numbers of patients attended the clinic for various neurological disorders. However, there were no information about numbers of epilepsy cases that available in their clinic data.

CHAPTER 2- LITERATURE REVIEW

2.1 Epilepsy in global perspective

Epilepsy is one of the most common neurological disorders affecting approximately 1% of people in the world, globally. The World Health Organization (WHO) reported that approximately 50 million people worldwide are suffering from epilepsy (WHO, 2012). In a 2015 morbidity report done in United States of America, approximately 3 million adults and 470,000 children had active epilepsy (Zack and Kobau, 2017). They noticed increased number of persons with active epilepsy compared with earlier years as their population growth.

A systematic review (Ngugi et al.,2010) stated the median lifetime prevalence were difference among developed and developing countries. on the incidence of epilepsy among Asian countries. The median lifetime prevalence for developed countries was 5.8 per 1000 compared to 15.4 per 1000 for rural and 10.3 per 1000 for urban studies in developing countries

WHO had reported that almost 80% of the epilepsy cases originate from developing countries including Malaysia. In a local study by Lim and colleagues (2017), they reported 15% lifetime prevalence of epilepsy occurs among family members of epilepsy mainly their first-degree relatives. Despite the high prevalence, epilepsy in Malaysia is considered as an area of less studied.

2.2 Caregivers burden of epilepsy patients

Burden is defined as the extent to which a caregiver perceives emotional, physical health, social life and financial consequences that can impairs his ability to provide care to the loved one. Most of the studies available at present shows the level of burden among caregivers of epilepsy patients range from mild to moderate burden. Karakis and colleagues (2014) conduct a research among 126 epilepsy patients admitted to Massachusetts General Hospital and their caregiver who accompany them. They found that average score of Zarit Burden Interview (ZBI) was 20, reflect mild-to-moderate burden.

In other study run among 231 caregivers of epilepsy patients attended the outpatient clinic in government psychiatric hospital in Kaduna, Northern Nigeria. Nuhu and colleagues (2010) reported more than half of the caregivers who had been taking care of the patients at least for 1 year experienced high burden. Almost 41.3% of caregivers among Asian families had been reported of mild to moderate burden with ZBI total score of 29.93 in a study done by Lai and colleagues (2019). This study shows the caregiver burden is highly associated with the family functioning, support and number of caregivers, besides demographics, psychosocial and clinical characteristics.

2.3 Factors affecting the burden among caregivers of epilepsy patients

There are multiple factors that affect the level of burden among caregivers. The studies reported different factors based on their population. On regression analysis (Karakis et al., 2014), there were a few predictors reported having association with caregiver burden. The predictors included, higher number of antiepileptic drugs used, poorer patient neuropsychological performance, lower patient quality of life score, and lower caregiver education level were associated with higher caregiver burden.

These finding also supported by the other study. Caregiver burden were associated with decreased quality of life of epilepsy patient. It was due to their caretakers taking more responsibility and care of patient and the economic burden (Sirari et al., 2014).

In a research done by Nuhu and colleagues (2010) they reported different predictors associated with the caregiver burden. The predictors such as younger patient's age, patient's unemployment, longer disease duration, shorter periods of seizure freedom, family history of epilepsy and rural residence possibly for poorer access to health care.

From a recent study, they reported ten predictors of caregiver burden (Lai et at., 2019). The predictors were 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.

2.4 Anxiety and depression among caregiver of epilepsy patient

From the studies that available in global as well as the local settings, there are a systematic review that showed depression in caregiver of epilepsy patient (Ferro et al., 2009). The study only investigates female caregivers (mother) and the burden must be more as they need to take care people in child-age group. It was reported about 50% of mothers of children with epilepsy are at risk for clinical depression. In addition, studies suggest that depressive symptoms in mothers have a negative impact on child outcomes in epilepsy including behavior problems and health-related quality of life.

Apart from that, the emotional distress was found significant in other study by Yusuf and colleagues (2013). There were about 65.7% of the caregivers reported having distress, measured using Hospital Anxiety-Depression Scale (HADS). In a survey of 44 families with epilepsy patients, the caregivers reported limited support from friends and services outside the home (Saada et al., 2015). These factors had predisposed the caregivers to have psychological distress.

A similar situation happened in a study conducted among the caregivers of epilepsy patient in Iran. There were significant level of depression and anxiety before they received a family-centred intervention program (Etemadifar et al., 2018). These had improvement after the caregivers underwent the program. Meanwhile the recent study done by Lai and colleagues (2019) reported the total ZBI score was positively correlated with caregivers' reported levels of depression ($r = 0.549$, $p < 0.001$) and anxiety ($r = 0.599$, $p < 0.001$).

2.5 Rationale of Study

This study will provide a local data of burden experienced by the caregivers of epilepsy patients. Besides, it also will provide the information about the associated factors of the caregiver burden. Finding from this study will help the clinicians to initiate interventions in order to improve quality of life of both epilepsy patients and their caregivers.

2.6 Research gap

There are limited studies about the burden among caregivers of epilepsy patients. In addition to the studies available, there are unclear association between the level of burden in caregivers of epilepsy patients to sociodemographic of the patients and the caregivers, patient’s clinical status and the caregiver's depression and anxiety. Lack of the information in this area may increase the hurdle in managing epilepsy patient. Acknowledging the predictors of caregiver burden may give benefit in improving patients’ health and caregivers’ quality of life.

CHAPTER 3- OBJECTIVES

3.1 General Objectives

To study the level of the burden and the psychological distress among caregivers of epilepsy patients and its associated factors.

3.2 Specific Objectives

1. To determine level of burden among caregivers of epilepsy patients.
2. To determine the prevalence of anxiety and depression among caregivers of epilepsy patients.
3. To identify the associated factors of caregiver burden.

3.3 Research Questions

1. What is the level of burden among caregivers of epilepsy patients?
2. How many caregivers of epilepsy patients have anxiety and depression?
3. What are the associated factors of the caregiver burden?

3.4 Research Hypotheses

3.4.1 Null Hypothesis

There is no association between the caregiver burden and sociodemographic characteristics of patients, clinical status of epilepsy and caregivers’ anxiety and depression.

3.4.2 Alternative Hypothesis

There is association between the caregiver burden and sociodemographic of patients, clinical status of epilepsy and caregivers’ anxiety and depression.

CHAPTER 4- METHODOLOGY

4.1 Study Design

This is a cross sectional study, assessing the burden among caregivers of epilepsy patients. The study was approved by Human Research Ethics Committee (HREC), Universiti Sains Malaysia. The study protocol code was USM/JEPeM/ 18100588. Consent was gathered from the participants prior to data collection.

4.2 Study Location

This study was conducted in Neurology Clinic, HUSM. The clinic operates twice a week, which are every Sunday and Tuesday. There is no specific epilepsy clinic. Therefore, the researcher has to cross-checked with the patients' medical record for the correct diagnosis.

4.3 Study Period

The data collection was conducted from 1st May 2019 till 14th October 2019.

4.4 Study Population

4.4.1 Reference population

The reference population was caregivers of epilepsy patients in Kelantan.

4.4.2 Source population

Caregivers of epilepsy patients who were attending Neurology Clinic, HUSM during the study period had been selected as participants of this study.

4.4.3 Sampling frame

The sampling frame consisted of caregivers of epilepsy patients who attended Neurology Clinic, HUSM and they had fulfilled the inclusion and exclusion criteria. A total of 116 participants were recruited for the study. Sociodemographic profiling questionnaire, Malay version-ZBI, BDI-Malay and BAI-Malay were handed out to the participants by the researcher. All participants were medically stable and cooperative to answer the questionnaires. Apart from this, the researcher also gathered the clinical data of epilepsy patients from their medical record.

4.5 Subject Criteria

4.5.1 Inclusion Criteria

1. Caregivers of epilepsy patients between the age of 18 to 60.
2. Caregivers who accompanying epilepsy patients, attending Neurology Clinic, HUSM for follow up.

4.5.2 Exclusion Criteria

1. Caregivers with severe communication problems e.g. deaf, mute, and unable to communicate in English or Bahasa Malaysia.
2. Caregivers who are illiterate.

4.6 Operational definition

Caregivers:

In this study, caregiver is defined as either spouse, parents, children or any family member who is primarily responsible for providing everyday care for the patient.

4.7 Sampling Method

In this study, convenience sampling method was applied. The researcher took all the caregivers of epilepsy patients who attended the clinic within the study period.

4.8 Sample Size Determination

The calculation of sample size for objective 1 is using single mean formula, while for objective 2 is done by using single proportion formula. It is performed following the requirement for (α) = 0.05 level of significance and power (1-β) = 0.80.

4.8.1 Sample size calculation to determine level of burden among caregivers of epilepsy patients.

For objective 1, the calculation for sample size is based on single mean proportion formula, $n = \frac{Z_{1-\alpha/2}* (\sigma)}{\Delta}$. The $Z_{1-\alpha/2}$ value is 1.96, precision (Δ) is taken at 0.1 with standard deviation (σ) of 0.55 taken from the previous study (Karakis et al, 2014). The calculated sample size is 116 subjects. The sample would be 128 subjects after adding up the 10% dropout.

4.8.2 Sample size calculation to determine prevalence of anxiety and depression among caregivers.

For objective 2, the calculation is done using a single proportion formula, $\boldsymbol{n} = (\boldsymbol{Z}/\Delta)^2 * \boldsymbol{p}(\boldsymbol{1} - \boldsymbol{p})$**.** The Z value is 1.96, precision (Δ) is taken at 0.1 with prevalence from the previous study is 0.5 (Ferro et al, 2009). The calculated sample size are 96 subjects. The sample would be 107 subjects after adding up the 10% dropout.

4.8.3 Sample size calculation to identify the factors that associated with the level of burden among caregiver of epilepsy patient.

For this objective, comparing two means for categorical variable is used to calculate the sample size. The sample size is calculated using PS Power and Sample Size Calculations Software Version 3.0. By using power of study 0.8 and alpha value of 0.05, the sample would be 114 for each group. Thus, the total sample are 228.

Then, calculation of linear regression numerical variables also done using PS Power and Sample Size Calculations Software Version 3.0. With similar power of study and alpha value stated above, the sample size is 83. The parameters needed for calculation is considered based on the previous studies (Nuhu et al, 2010 and Karakis et al, 2014).

Based on all the above calculations, the sample was selected based on the sample size which was calculated using PS Power and

Sample Size Calculations Software Version 3.0. The required sample size in the calculation was 228 subjects. However, there was only 116 participants that had been recruited in this study. It was the total number of the caregivers of the epilepsy patients who had been attending the Neurology Clinic within the study period. The researcher noted a repeated group of the patients, where they are already included in the study, had attended the clinic after the study period.

4.9 Research Instruments

4.9.1 Sociodemographic Profiling Questionnaire

The self-rated questionnaire was related to the patient and caregiver profiles. The researcher reviewed the epilepsy patients' medical records and obtained information such as types of epilepsy, characteristics of the epilepsy, duration of illness and comorbidities.

4.9.2 Malay Version-Zarit Burden Interview (MZBI)

ZBI is the oldest and most widely used measure for assessment of caregiver burden. Since the publication of the original version in 1980, various translated and shorter revised versions of the ZBI in multiple languages have been produced. ZBI provides a comprehensive assessment of both objective and subjective burden. It has been validated in many culturally or ethnically different populations.

ZBI has 22 items that used to assess caregiver's perceived burden. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = 'never' to 4 = 'nearly always'. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. In various studies including the studies among caregivers burden of epilepsy patients (Lai et al, 2019; Karakis et al. 2014), the level of burden were indicated by cut-off points: little or no burden (score of less than 21); mild burden (score of 21 to 40); moderate burden (score of 41 to 60); severe burden (if the score were 61 to 88).The questions focus on major areas such as caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the patient.

Recently, ZBI had been translated into Malay version (MZBI) and it demonstrated a good reliability with high internal consistency (α = 0.898) and split-half correlation of 0.912 (Shim, Ng and Drahman, 2018). A written permission for using the questionnaire was obtained from the authors.

4.9.3 Beck's Depression Inventory for Malays (BDI-Malay)

Beck's Depression Inventory (BDI) is the most widely used psychometric tests for measuring the severity of depression. BDI is self-report questionnaire and it had been translated into many different languages. The translated questionnaire in Bahasa

Malaysia was validated by Firdaus and Tian (2008). It has 21 items that provide information about the level of depressed mood. It takes about 10 to 15 minutes to complete.

This scale is divided into two subscales. They are a cognitive or affective subscale which are formed from the first 13 items, and a somatic or performance subscale that was formed from the last eight items. The score is ranging from 0 to 63, with the higher scores indicating more severe depression. There are 3 subcategories of depression, mild (score of 11 to 20), moderate (21 to 30 scores) and severe (score more than 31). The full scale is considered to have strong psychometric properties, with high internal consistency (Cronbach's α= 0.91) (Muhktar, F., & Oei, T. P. ,2008). This validation study of BDI-Malay also had shown good concurrent validity with correlations of 0.51 to 0.65 to the similar constructs. A written permission for using the questionnaire was obtained from the authors.

4.9.4Beck's Anxiety Inventory for Malays (BAI-Malay)

The Beck's Anxiety Inventory (BAI) is commonly used to measure the level of anxiety in adolescents and adults. The BAI was originally developed to differentiate the behavioural, emotional and physiological symptoms between individuals with anxiety and depression (Leyfer, Ruberg and Woodruff-Borden, 2006). BAI is self-report questionnaire and it had been translated into many different languages. BAI-Malay is a translated version of the original BAI with 21 items that provide lists symptoms of anxiety. Participants respond to questions in relation to how much each symptom has bothered them over the past week, with higher scores indicating more severe anxiety symptoms. The symptoms rated on a four-point scale, ranging from “not at all” (0) to severely (3). There are 3 subcategories of anxiety, which are mild (score of 8 to 15), moderate (16 to 25 scores) and severe (score more than 26). It takes about 10 to 15 minutes to complete.

The instrument has excellent internal consistency with Cronbach’s α of 0.91 (Mukhtar and Zulkefli, 2001). Besides, the concurrent validity in the similar study also shown a significantly positive correlations between the BAI-Malay with other similar constructs (correlations of 0.23 to 0.68). A written permission for using the questionnaire was from the authors.

4.10 Conceptual Framework

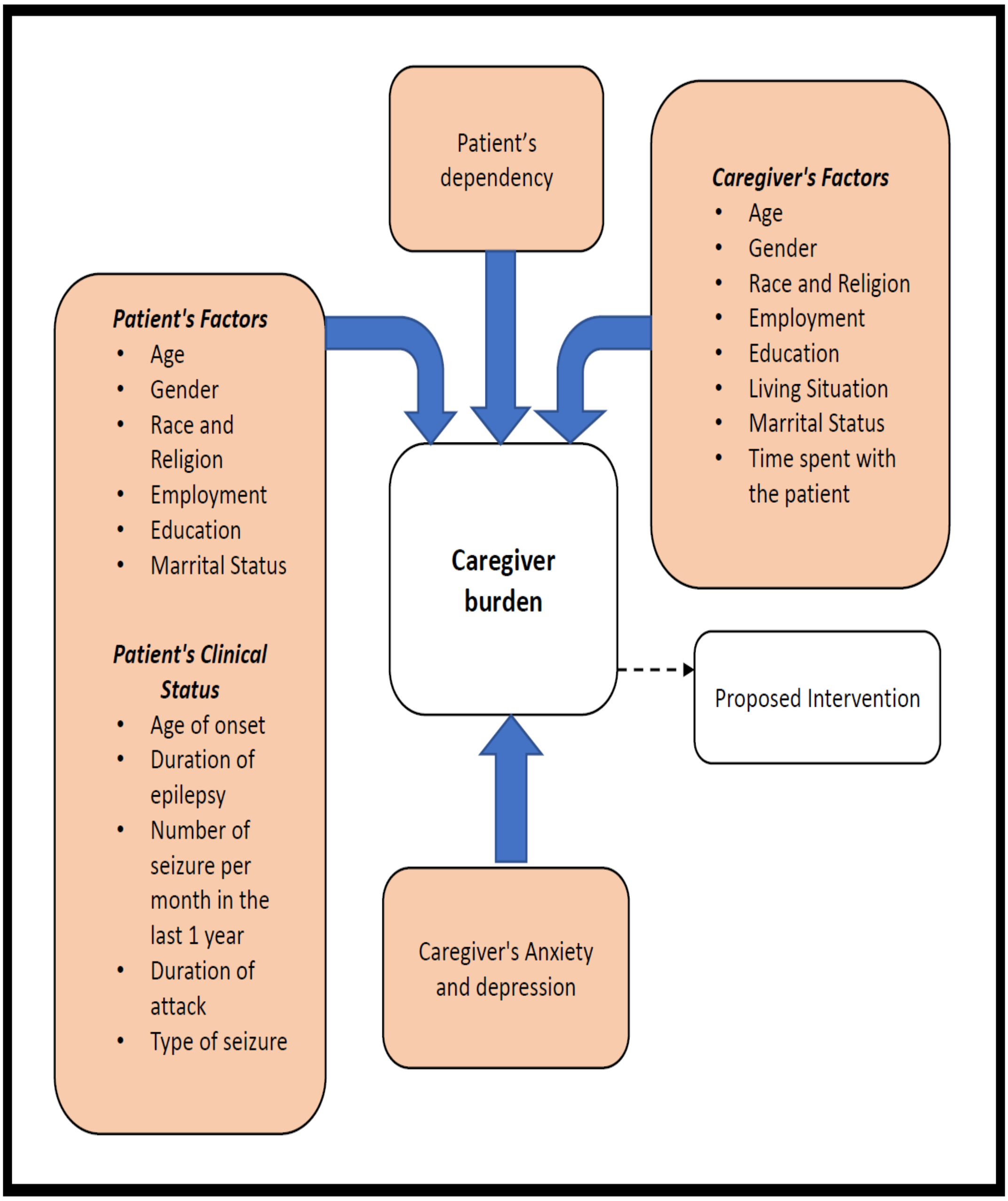

Figure 4.1 Conceptual framework of the study

4.11 Data Collection Method

All caregivers of epilepsy patients who attended Neurologi Clinic, HUSM from 1st May 2019 to 14th October 2019 and fulfilled the inclusion and exclusion criteria were enrolled in the study. After the participants signed the written consent, they were given a set of questionnaires containing Sociodemographic profiling of caregivers and the patients, together with MZBI, BDI-Malay and BAI-Malay. They were given adequate privacy to answer the questionnaires in an allocated room at their own time without assistance from another person. Clinical data of the patients were obtained from their medical records. Once the participants have completed the questionnaires, they returned them to the researcher for further evaluation. The researcher was available upon caregivers' request if they need any assistance. Verbal help was provided when necessary without influencing their answers.

4.12 Data Entry and Statistical Analysis

All data obtained from the study was entered and analysed using IBM SPSS 24.0. The power of study was 80% with 5% level of statistical significance was chosen.

For all the objectives, descriptive statistics were used to describe socio-demographics of the patients and their caregivers. Numerical variables were presented with mean and standard deviation, while categorical variables presented by frequency (n%).

Apart from this, multiple linear regression analysis was used to determine the associated factors of caregiver burden.

4.13 Selection of Variables

4.13.1 Independent Variables

The independent variables were sociodemographic variables of both caregivers and patients (age, gender, race, educational level, employment status, marital status, personal income and household income). Apart from this, patients' clinical status (duration of epilepsy, duration of each seizure attack, frequency of seizure in one month, over the last 1 year, type of the seizure and presence of comorbidities). Lastly, caregiver's emotional status (depression and anxiety) was also the independent variables.

4.13.2 Dependent Variables

The dependent variables for this study were total score of MZBI.

4.14 Ethical consideration

Ethical approval was obtained from the Human Research Ethics Committee, Universiti Sains Malaysia. Prior to the data collection, participants were informed that their participations would be entirely voluntary, and they have their rights to withdraw from the study, refused to answer any questions or leave whenever they wanted, all without any penalty. The study was conducted only if participants signed the written consent form. With respect to confidentiality, all data were kept in strictest confidence. The data will be coded, and the identifying characteristics of the participants will be kept anonymous both in the process of data analysis as well as in the report to protect the privacy of the participants.

Apart from this, the caregivers who have depression or anxiety would be referred to the health care facilities for psychiatric evaluation with their consent.