KNOWLEDGE, AWARENESS AND PRACTICE OF EPILEPSY AMONG CAREGIVERS IN PEDIATRIC WARDS AT HOSPITAL USM

by

NURUL ASYIKIN BINTI MUHAMAD

Dissertation submitted in partial fulfillment of the requirement for the Degree of Bachelor of Nursing (Honours)

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CERTIFICATION

This is to certify that the dissertation entitled “Knowledge, Awareness And Practice of Epilepsy Among Caregivers In Pediatric Ward At Hospital USM” is the bonafide record of research work done by Ms. Nurul Asyikin Binti Muhamad during the period from January 2020 to June 2020 under my supervision. I have read this dissertation and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation to be submitted in partial fulfillment for the degree of Bachelor of Nursing (Honours)

Supervisor,

....

Madam Intan Baiduri Badri

Lecturer,

School of Health Sciences,

Universiti Sains Malaysia,

16150 Kubang Kerian,

Kelantan, Malaysia.

Date: ....

DECLARATION

I hereby declare that this dissertation title “Knowledge, Awareness And Practice Of Epilepsy Among Caregivers At Pediatric Ward At Hospital USM” is the result of my own investigations, excepts where otherwise stated and duly acknowledged. I also declared that it has not been previously or concurrently submitted as a whole for any degree at Universiti sains malaysia or other institutions. I grant Universiti Sains Malaysia is the right to use the dissertation for teaching, research, and promotional purposes.

....

Nurul Asyikin Binti Muhamad

Student Of Degree Of Bachelor Of Nursing (honours),

School of Health Sciences,

Health Campus,

Universiti Sains Malaysia,

16150 Kubang Kerian,

Kelantan, Malaysia.

Date: ....

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TABLE OF CONTENTS

LIST OF TABLES **PAGE NO**

LIST OF FIGURES PAGE NO

LIST OF ABBREVIATIONS

Hospital USM - Hospital Universiti Sains Malaysia

SPSS - Statistical package for social sciences

HBM - Health belief model

HREC - Human research ethics committe

WHO - World health organization

AESs - Antiepileptic drugs

Pengetahuan, Kesedaran Dan Amalan Tentang Epilepsi Dalam Kalangan Penjaga Di Wad Kanak-Kanak Di Hospital USM.

Abstrak

Epilepsi adalah penyakit neurologi yang paling biasa di kalangan kanak-kanak. Epilepsi masih merupakan penyakit yang sangat disalah pahami yang boleh menyebabkan salah faham dan salah faham sosial. Tujuan kajian ini adalah untuk menilai pengetahuan, kesedaran dan amalan penyakit epilepsi. Reka bentuk deskriptif keratan rentas digunakan untuk kajian ini. Sampel 62 penjaga di wad pediatrik diambil dengan menggunakan kaedah persampelan rawak mudah. Instrumen yang digunakan untuk kajian ini adalah sekumpulan penyusun data demografi, pengetahuan, kesedaran dan amalan penyakit epilepsi. Pemarkahan berdasarkan soalan dikotom. Untuk setiap jawapan yang betul satu titik akan diberikan. Data dianalisis pada SPSS (versi 24) dan hasilnya dibentangkan dalam jadual. Hasil kajian menunjukkan bahawa lebih daripada separuh (62.9%) mempunyai pengetahuan yang memuaskan, 33.9% mempunyai pengetahuan yang baik dan 3.2% mempunyai pengetahuan yang buruk mengenai epilepsi. Selain daripada majoriti itu, 45.2% responden mempunyai kesedaran yang sederhana, 29% mempunyai kesedaran yang baik dan 25,8% mempunyai kesedaran yang buruk. Lebih-lebih lagi, 80.6% mempunyai amalan yang baik, 17.8% mempunyai amalan sederhana dan 1.6% mempunyai amalan yang buruk. Terdapat hubungan linear yang signifikan antara tahap pengetahuan epilepsi dengan tahap amalan epilepsi di kalangan pengasuh di wad pediatrik. di Hospital USM.p nilai = 0,031 (<0,05), sehingga menolak nol hipotesis. r = 0.274, hubungannya lemah dan positif. Kesimpulannya, kajian penemuan menunjukkan keperluan untuk maklumat yang mencukupi,program epilepsi yang teratur dan amalan epilepsi yang betul di kalangan penjaga untuk mengurangkan penyakit epilepsi di Malaysia.

Knowledge, Awareness And Practice Of Epilepsy Among Caregivers At Pediatric Wards At Hospital USM.

Abstract

Epilepsy is a most common neurological disease among children. Epilepsy is still a highly misunderstood disease that can cause misconception and social misunderstanding. The aim of this study was to assess the knowledge, awareness and practices ofepilepsy. A cross sectional descriptive design was used for this study. A sample of 62 cafegivers at pediatric wards was taken by using simple random sampling method. Instrument used for this study was set of questioner compose of demographic data, caregiver’s knowledge, awareness and practices ofepilepsy. Scoring was based on dichotomous questions. For each correct answer one point will be assigned. Data was analyzed on SPSS (version 24) and results were presented in tables. The findings revealed that more than half (62.9%) had a satisfactory knowledge, 33.9% had a good knowledge and 3.2% had a ppor knowledge of epilepsy. Other than that majority 45.2% of the respondents had a moderate awareness, 29% had a good awareness and 25.8% had a poor awareness. Moreover, 80.6% had a good practice, 17.8% had a moderate practice and 1.6% had a poor practice.There was significant linear relationship between level of knowledge of epilespsy with level of practice of epilepsy among caregivers in pediatric wards at Hospital USM.p value = 0.031 (<0.05), thus reject null hypothesis. r = 0.274, the relationship is weak and positive. In conclusion, the study findings showed a requirement for adequate information, well-organized epilepsy programs and proper practice of epilepsy among caregivers for reduction epilepsy disease in Malays

CHAPTER 1

INTRODUCTION

1.1 Introduction

This dissertation contains 6 chapters starting with an introductory chapter that provides concepts of the research, which includes a problem statement, research objectives, research questions and research hypothesis, the significance of the study and definitions of the operational term used in this study. It is then followed by Chapter two presents the literature review of concepts and issues about knowledge, awareness and practice regarding epilepsy. Chapter three follow the elements of research methodology and methods of the study, validity and reliability procedures, ethical considerations, data collection plan. Chapter four details the data analysis. Chapter five details the discussion. Following chapter includes the strengths and limitations, conclusion and recommendation of the study.

1.2 Background of the Study

Epilepsy is a chronic neurological condition characterized by spontaneous seizures, ranging in severity from a lapse in concentration to unconsciousness (Gilmour, Ramage-Morin & Wong, 2018). The World Health Organization (WHO) describes the epilepsy is a result of excessive electrical discharges in a group of brain cells. Different parts of the brain can be the site of such discharges. Epilepsy can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Other than that, it is also vary in frequency, from less than 1 per year to several per day (World Health Organization, 2019).

There are about 50 million people with epilepsy or seizures worldwide, with 80 percent of them in developing countries, including Malaysia. It is estimated that epileptic patients make up one per cent of the overall Malaysian population, with an estimated 230,000 diagnosed cases, affecting individuals of all races, ages and gender (New straits times, 2018). Elhassan, Alemairy, Amara, Hamadelneel, Mohamed and Elaimeri (2017) indicates that eight nine percent of the epilepsy burden is in developing countries, and 5–10 per 1000 people in developing countries are reported to have active epilepsy. Moreover, school children are one of the groups affected by epilepsy, thus the negative attitude toward them can lead in addition to physical injuries, social isolation and learning difficulties.

Parents' knowledge of epilepsy is associated with lowered parental anxiety. Knowledge of epilepsy can lead to less stigmatization, social isolation, and depressive symptoms. Furthermore, parents' attitudes toward children with epilepsy are significantly influenced by the depth of their knowledge of the disease (Zainy et al., 2013).

1.3 Problem Statement

Epilepsy is the most common childhood neurological disorder. Socio-cultural barriers are manifested in the form of negative attitudes and discrimination against persons with epilepsy. Moreover, causation beliefs play an important role in treatment choices made by persons with epilepsy and their families. Help-seeking behavior of parents of children with epilepsy is also influenced by their religious and cultural beliefs which can affect their epilepsy management skills. Traditional healing practices are considered the first line of treatment for childhood epilepsy because such services are provided in local communities by someone known to the family. Thus, that makes the family more comfortable in discussing their child's condition. Traditional healers also provide support and acceptance through flexible systems of payment that allow the family to pay through alternative means or in installments (Rani & Thomas, 2019). Most of the parents reported utilization of complementary and alternative medication for treatment of their child's epilepsy such as religious healers, using herbs, wearing a metallic bracelets, and rubbing the child with wool or sand (Masri et al., 2017).

Other than that, people with epilepsy suffer from discrimination, misunderstanding, social stigma, and the stress of living with a chronic unpredictable disease that can lead to loss of autonomy for activities of daily living (Moshé, Perucca, Ryvlin & Tomson, 2015)**.** Families try to hide the disorder to allow the person with epilepsy and other family members to marry and people with epilepsy find it difficult to obtain jobs. Besides, procuring a driver's license is often problematic and often fail to obtain health insurance in many countries (Ghanean, Nojomi & Jacobsson, 2013).

In Malaysia, epilepsy is still a highly misunderstood illness and patients are often dodged by the public. Epileptic patients make up 1% of the overall Malaysian population Epilepsy is still considered as condition due to mythic causes, such as demonic possession. The more recurrent a person's epileptic seizures are, the more likely he or she will be exposed to derision and humiliation (Alina, Bey & Mohd Farooq, 2015).

1.4 Research Objective

1.4.1 General Objective:

The general objective for this study is to determine the knowledge, awareness and practice of epilepsy among caregiver in pediatric ward at Hospital Universiti Sains Malaysia (Hospital USM).

1.4.2 Specific objectives:

1) To determine the level of knowledge of epilepsy among caregiver in pediatric ward at Hospital USM

2) To determine the level of awareness of epilepsy among caregivers in pediatric ward at Hospital USM.

3) To determine the level of practice of epilepsy among caregivers in pediatric ward at Hospital USM.

4) To determine relationship between knowledge and practice of epilepsy among caregivers in pediatric ward at Hospital USM.

1.5 Research question

1. What is the level of knowledge of epilepsy among caregivers in pediatric ward at Hospital USM?
2. What is the level of awareness of epilepsy among caregivers in pediatric ward at Hospital USM?
3. What is the level of practice of epilepsy among caregivers in pediatric ward at Hospital USM?
4. Is there any relationship between knowledge and practice of epilepsy among caregivers in pediatric ward at Hospital USM?

1.6 Research Hypothesis

Hypothesis 1:

Null hypothesis, H_O: There is no significant relationship between knowledge and practice regarding epilepsy among caregiver in pediatric ward at Hospital USM.

Alternative hypothesis, H_A: There is significant relationship between knowledge and practice regarding epilepsy among caregiver in pediatric ward at Hospital USM.

1.7 Conceptual and Operational Definitions

The terms used in this research study is referring to the definitions as below:

Knowledge	:	Understanding of or information about a subject that you get by experience or study, either known by one person or by people generally (Cambridge Dictionary, 2019). In this study, the understanding of any related topic on epilepsy among caregivers
Awareness	:	Knowledge that something exists, or understanding of a situation or subject at the present time based on information or experience (Cambridge Dictionary, 2019). In this study, awareness are referred the feelings towards the epilepsy.
Practice	:	Is a repeated performance or systematic exercise for the purpose of acquiring skill or proficiency (Dictionary.com, 2019). In this study, practice is an act where person is doing thing or something with the use of knowledge,skill and expertise in preventing epilepsy.
Epilepsy	:	Epilepsy is a central nervous system (neurological) disorder in which brain activity becomes abnormal, causing seizures or periods of unusual behavior, sensations, and sometimes loss of awareness (Mayo Clinic, 2019). In this study, epilepsy is abnormal general body movement due to malformation brain tissue.

Caregivers : Someone who takes care of a person who is young, old, or sick(Cambridge Dictionary, 2019). In this study, caregivers are referred to fathers or mothers who are taking care their children in pediatric ward at Hospital USM.

1.8 Significance of the Study

The purpose of this study was to determine the knowledge, awareness and practice of epilepsy among caregiver in pediatric wards at Hospital USM and to examine the association between the variables. Knowledge, awareness and practice of epilepsy were important to determine the occurrence or outcome of epilepsy among the children. It is hope that the findings of the propose of the study can contribute to strengthen effective health information program on awareness and preventing of the epilepsy. Besides, the findings of this study may lead to recommendations for future health program and can help the caregiver to prevent or manage epilepsy among their children. From the health programs may include intervention strategies of control epilepsy episodes among children and to improve the knowledge of caregivers and improves their practice related to epilepsy.Then, health education is one of the core in nursing field,which the effective on will increasing individual’s capacity to acess and use heath information to make an appropriate health decision.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The purpose of this study is to determine the level of knowledge, awareness and practice of epilepsy among caregivers in pediatric ward at Hospital USM. This chapter provides informations about definition, classification, risk factor, complications, treatment and management; level of knowledge and practice regarding epilepsy; and conceptual framework

2.2 Epilepsy

According to Stanford children's health epilepsy is a brain condition that causes a child to have seizures and one of the most common disorders of the nervous system. A seizure occurs when one or more parts of the brain has a burst of abnormal electrical signals that interrupt normal brain signals. Anything that interrupts the normal connections between nerve cells in the brain can cause a seizure such as a high fever, high or low blood sugar, alcohol or drug withdrawal, or a brain concussion. Moreover, if a child has two or more seizures with no known cause, this is also diagnosed as epilepsy (Stanford Children's Health, 2019).

Besides, epilepsy is also defined as chronic brain disorder characterized by recurrent derangement of the nervous system due to sudden excessive disorderly discharge of the aggregate group of neurons from cerebrum. The excessive discharges result in disturbances of sensation, convulsive movement, or psychic function with or without loss of consciousness. It can affect all age groups but is more common in children (Thapa, Bhandari, Shrestha & Poudel, 2017).

2.2.1 Classification of Epilepsy

Epilepsy can be divided into focal onset, generalized onset and unknown onset. Some focal epilepsy can spread quickly to produce a tonic-clonic seizure, previously known as a ‘grand mal’ seizure or convulsion. The epilepsy types can be focal, generalized or both in some circumstances, this will be unclear(unknown).

Focal seizure is the abnormal electrical activity originates on one side of the brain. Focal seizures can present with a range of symptoms, depending on the site of origin of the abnormal electrical discharges and the extent and speed of their spread in the brain. There is a jerkin of one arm or leg. Generalized seizure is the abnormal electrical activity apparently originates simultaneously on both sides of the brain and spread via neuronal network. There is a range of other generalized epilepsy. These include absences, where the affected individual losses their awareness for several seconds resulting in a blank stare. Besides, sign and symptoms such as flickering of the eyelids and mouth movement will appear (Brodie, Sameer, Scheffer & Fisher, 2018). The children may not recall what just occurred. Children may go on with activities as though nothing happened. These seizures may occur several times a day. This type of seizure is sometimes mistaken for a learning or behavioral problem. Absence seizures almost always start between ages 4 to 12 (Stanford Children's Health, 2019).

Moreover, focal and generalized seizures is a group consists of people who have both focal and generalized seizures. Unknown is a classification of seizure which is the doctor cannot decide whether the epilepsy is focal or generalized (Brodie et al., 2018).

2.2.2 Risk factors of epilepsy

People with no known cause of epilepsy may have a genetic form of epilepsy. One or more genes may cause the epilepsy or epilepsy may be caused by the way some genes work in the brain. The relationship between genes and seizures can be very complex and genetic testing is not available yet for many forms of epilepsy. About 3 out of 10 people have a change in the structure of their brains that causes the electrical storms of seizures. Moreover, some young children may be born with a structural change in an area of the brain that gives rise to seizures. However, the exact cause and relationship still not clear (Epilepsy Foundation, 2014).

Furthermore, any infection in the brain or its lining, whether acute or chronic, can produce seizures. The commonest infective cause of epilepsy is neurocysticercosis, a tapeworm that is found commonly in Latin America, Africa and Asia. This is caused by ingestion of tapeworm eggs. These hatch in the stomach or intestines and the worms migrate to the brain, producing characteristic cyst. Other potential infective causes include HIV, tuberculosis, malaria, bacterial meningitis, and viral encephalitis. Treatment of the infection is an essential component of the therapeutic strategy. The more widespread the brain damage, the more likely the seizures will be difficult to control. Sometimes, is there are history of a previous infection in infancy or childhood, can cause of epilepsy later in life (Brodie et al., 2018).

2.2.3 Complications of epilepsy

Comparison was made between children with epilepsy and their siblings in order to conclude the elements which are associated with greater sleep disturbances. The severity of the epileptic disorder is associated with the sleep disturbances. The findings show that, the epileptic children were having a higher prevalence of co-sleeping and more sleep disturbances than their healthy siblings. It was observed that children with epilepsy have difficulty in the initiation and maintenance of the sleep and experiences sleep-wake transition disorders. Besides, impairment in life quality of adult epilepsy patients is also influenced by sleep disturbance. A cross-sectional study was done to measure quality of life for Malaysian epileptic patients with obstructive sleep apnea and the effect of obstructive sleep apnea treatment at the Neurology Clinic of the Hospital University Sains Malaysia. The study also showed that the medication does affect the quality of life of the Malaysian patients, specifically, it helps emolliating the seizure worry and improving their cognitive functioning (Alina et al., 2015).

2.2.4 Treatment and management of epilepsy

Current treatment options for epilepsy treatment include antiepileptic drugs (AEDs) and brain surgery. AEDs help to gradually decrease the frequency and severity of epileptic seizures and have been proven to have an efficiency rate of 60-70% in all treated epilepsy cases. AEDs are used to enhance the inhibitory action on neurons (hyperpolarization) and inhibit the excitatory action on neurons (depolarization) and controlling the abnormal electrical impulses in the brain. However, despite its efficiency, AEDs are having many adverse effects such as skin rash, drowsiness, ataxia, bleeding gums, hyperplasia and even osteoporosis (long-term usage). Some patients do not react to AEDs effectively and therefore are subjected to brain surgery instead, which is more costly and has a high risk of resulting in further complications (Alina et al., 2015).

Other than that, epilepsy surgery has proven to be an important treatment for medically resistant epilepsy. Epilepsy surgery has been performed by a few centers in Malaysia, including Hospital Universiti Sains Malaysia (HUSM). The durations of the illnesses before their surgeries ranged from 12 to 47 years. (Yee et al., 2017).

2.3 Level of knowledge of epilepsy among caregivers in pediatric wards at Hospital USM

A descriptive study conducted among 950 adult Saudi parents in Jeddah City shows that more than half of the respondents 78.2% had inadequate level of knowledge which can resulted in poor attitude and practice pattern. Inadequate knowledge can cause many complications, negative effects and depression among children (Al Zubaidi, Alsudairy, Alzubaidi,Alsadi,Abulela &Alqurashi 2017). Another study found that the majority of the subjects in caregivers groups had inadequate knowledge about epilepsy and its first-aid management. The mean knowledge score of caregivers regarding epilepsy were 7.19±2.69 and for the first-aid management was 6.53±2.21. Futhermore, many of subjects in caregivers were following wrong first-aid measures during seizures. The common wrong first-aid measures are 56 % will keeping an object between the teeth, 67% of subjects pulling the tongue out, 52% smelling the shoes and 45% performing prayers to remove the evil spirits (Dinta Suresh, Meena Aggarwal, Achal Srivastava, & Mamta Bhushan Singh, 2017).

2.4 Level of practice of epilepsy among caregivers in pediatric wards at Hospital USM

A study conducted by Hassan, Yahya, Tariq, and Hussamaldin Tariq (2018) conducted among parents Abha City, Saudi Arabia showed the result among 440 parents, more than half of the parents had an adequate practice regarding epilepsy. Moreover, the practice pattern was adequate among most of the subjects regarding helping epileptic subject. Another study found out that out of 930 participants 68.9% had inadequate level of practice among most of parents. Most of the parents 68.9% did not know what to do when seeing an epileptic child, 22.8% gave him the first aid and 8.3% would call an ambulance. About 57.1% of parents would not deal with epileptic person. Besides, 58.1%

of parents would advise to follow up the epilepsy with a doctor, 22.7% would advise other parents to seek herbal medicine and 19.2% thought that there was no need for treatment (Al.Zubaidi et al., 2017)

2.5 Conceptual Framework

The proposed study will use the Health Belief Model (HBM) as conceptual framework. Health Belief Model (HBM) which is a type of psychological health behaviour change model that developed to be able to understand health behaviour and possible reasons for non-compliance with recommended health action (Brezzo, Hunt, Jones & Tuner, 2004). This model was developed in the year of 1950s by the psychologists Houchbaum, Rosenstock, and Kegels. The HBM addresses four major components for compliance with recommended health action which are perceived barriers of recommended health action, perceived benefits of recommended health action, perceived susceptibility of the disease, and perceived severity of the disease (Brezzo, Hunt, Jones & Tuner, 2004). But there is also a modifying factor that can affect someone behavior compliance. These modifying factors would include media, health professionals, personal relationships, incentives, and self-efficacy of recommended health action (Brezzo, Hunt, Jones & Tuner, 2004).

This model implicit conception that follow Lewin was of an individual existing in a life space that composed some of which were positively valued, negatively valued and neutral. If disease is represented in the life space at all, there would be regions of negative valence which could be expected to exert a force moving the person away from that region. One’s daily activities were conceived a process of being pulled by positive forces and repelled by negative forces (Rosenstock, 1974).

The earliest characteristics of the model, as they were translated from the foregoing abstraction , were that in order for an individual to take action to avoid a disease he would need to believe that (1) he was personally susceptible to it, (2) the occurrence of the disease would have at least moderate severity on some component of his life, (3) that taking a particular action would in fact be beneficial by reducing his susceptibility to the condition or, if the disease occurred, by reducing its severity, and that it will not require in overcoming the important psychological barriers such as cost, convenience, pain, embarrassment. Even though the individual taking a test for the early detection of a disease, the same factors were deemed necessary, but in addition there was also the requirement that the individual to believe that he could get the disease even in the absence of symptoms (Rosenstock, 1974). Figure 2.1 shows the illustrates of Health Belief Model (HBM).

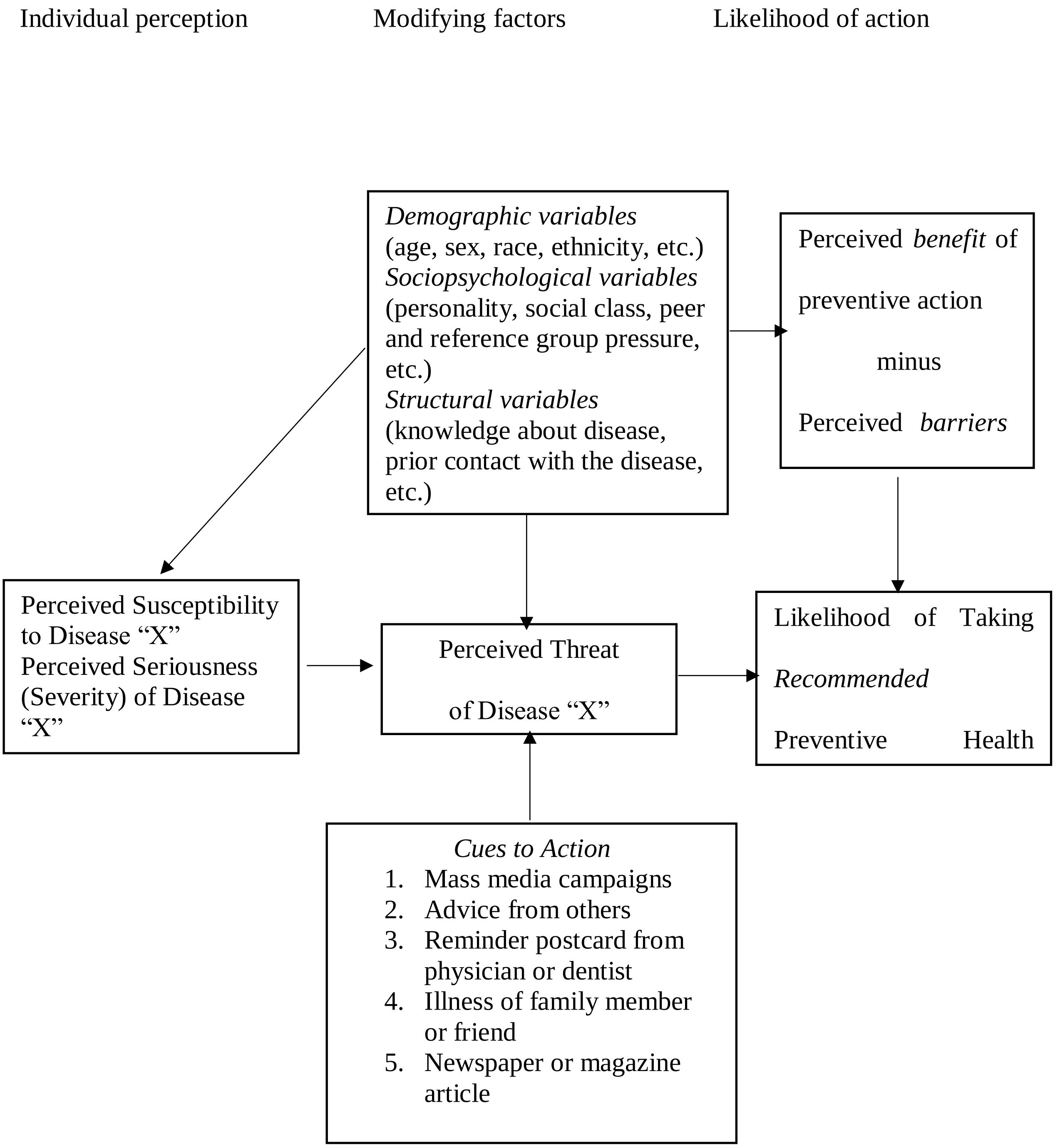


Figure 2.1: Conceptual framework Health Belief Model (HBM)

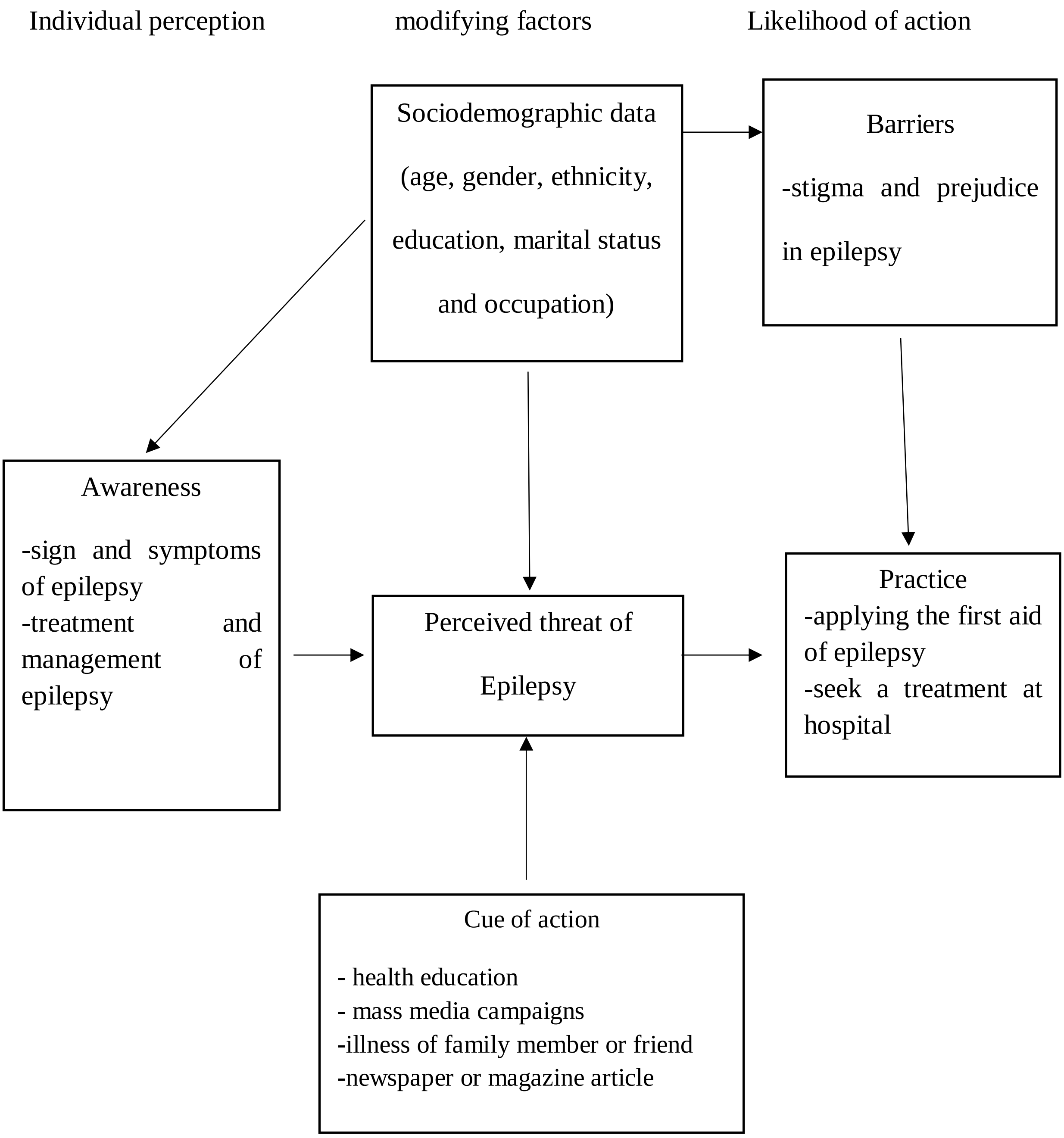


Figure 2.2: Conceptual framework of knowledge, awareness and practice of epilepsy among caregivers at pediatric wards (Adapted from HBM Rosenstock, 1974)

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter describe the research methodology used in the study. The approach and rationale about the method chosen will be explained.in this chapter is divided to several parts which are an explanation of the research design and within reason for choosing to apply the approach in this study. Next is an explanation of the study setting, samples selection criteria, sample size, variables and instruments. This is followed by an ethical consideration which is needed to do before conduct of this study and data collection. The last part is a descriptive of data analysis of the quantitative data and expected finding of the study.

3.2 Research design

This is a cross-sectional study and a quantitative study. The objectives of this study are to determine the level of knowledge, awareness and practice of epilepsy among caregivers in pediatric wards at Hospital USM.

3.3 Population and setting

The population of this study are among caregivers at pediatric ward which is 6 Utara (6U), 6 Selatan (6S) and 2 Selatan (2S) at Hospital USM. All respondents will be collects data from January 2020 until February 2020.

3.4 Sampling plan

3.4.1 Inclusion and exclusion criteria

Inclusion criteria

1. Caregivers which are father or mother who are caring their children in pediatric ward at 6 Utara, 6 Selatan and 2 Selatan
2. Understand, speak and write in Malay

Exclusion criteria

1. Caregivers that diagnosed with any mental problem
2. Caregivers that diagnosed with cognitive disorder such as alzheimer's disease

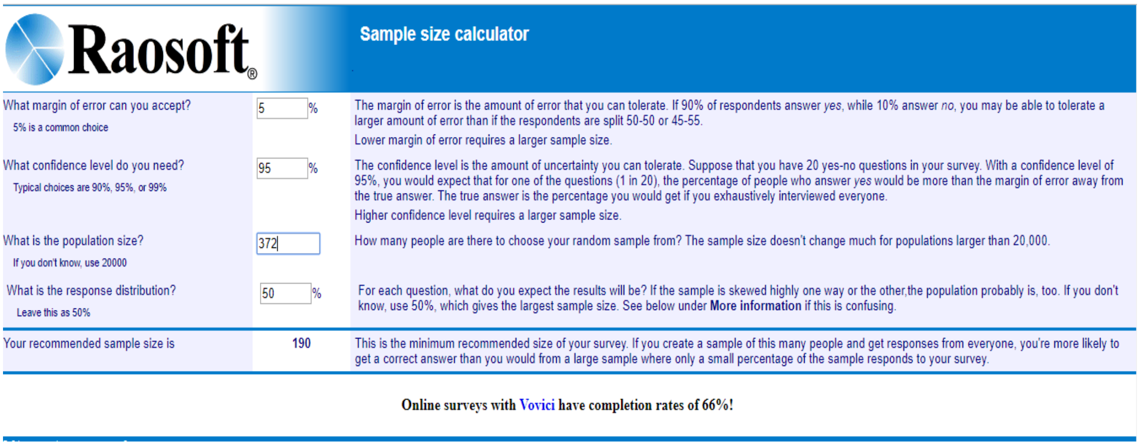
3.4.2 Sampling method

This study is using probability sampling that is simple random sampling method. Probability sampling is a sampling which permits every single item from the universe to have an equal chance of presence in the sample (Etikan & Bala ,2017). Each member of the population has an equal chance of being selected as subject. The entire process of sampling is done in a single step with each subject selected independently of the other members of the population (Gaganpreet Sharma, 2017). Firstly, the participants will be identified according to the name lists of admission. Respondent that meet the inclusion and exclusion criteria will be chosen according to the sequence of the name list**.** The caregivers will be selected based on inclusion criteria and exclusion criteria.

3.4.3 Sample size estimation

The total number of caregivers in pediatric ward such as 6 Utara, 6 Selatan and 2 Selatan are 372 caregivers. Raosoft sample size calculation software was used to calculate sample size for this study.

To determine the sample size for this study, the confidence level was set at 95% with margin error of 0.05 or 5%. By using these in the Raosoft sample size calculation software, the recommended sample size for this study are 190 caregivers. Figure 3.1 shows the Roasoft sample size calculation.



What margin of error can you accept? 5% is a common choice	5 %	The margin of error is the amount of error that you can tolerate. If 90% of respondents answer *yes*, while 10% answer *no*, you may be able to tolerate a larger amount of error than if the respondents are split 50-50 or 45-55. Lower margin of error requires a larger sample size.
What confidence level do you need? Typical choices are 90%, 95%, or 99%	95 %	The confidence level is the amount of uncertainty you can tolerate. Suppose that you have 20 yes-no questions in your survey. With a confidence level of 95%, you would expect that for one of the questions (1 in 20), the percentage of people who answer *yes* would be more than the margin of error away from the true answer. The true answer is the percentage you would get if you exhaustively interviewed everyone. Higher confidence level requires a larger sample size.
What is the population size? If you don't know, use 20000	372	How many people are there to choose your random sample from? The sample size doesn't change much for populations larger than 20,000.
What is the response distribution? Leave this as 50%	50 %	For each question, what do you expect the results will be? If the sample is skewed highly one way or the other,the population probably is, too. If you don't know, use 50%, which gives the largest sample size. See below under **More information** if this is confusing.
Your recommended sample size is	**190**	This is the minimum recommended size of your survey. If you create a sample of this many people and get responses from everyone, you're more likely to get a correct answer than you would from a large sample where only a small percentage of the sample responds to your survey.

Online surveys with Vovici have completion rates of 66%!

Figure 3.1: Roasoft sample size calculation

Taking into consideration the possibility of drop up participants or participant who do not return the questionnaire, 10% is added to the total 190 caregivers. Therefore, the total number of participants are:

=190 + drop out of 10%

=190 + 19

=209 caregivers

3.5 Research instrument

3.5.1 Instrument

A self-administered questionnaire adapted from author (Ghanean et al., 2013) is use in this study in order to gather information on knowledge, awareness and practice of epilepsy among caregiver in pediatric wards at Hospital USM. The questionnaire is categorized into four parts which are as follows:

Part A: Socio-demographic data

Demographic data consisted of five items that involving respondent's personal profile including age, ethnicity, education level, marital status and occupation.

Part B: Awareness towards Epilepsy

In this section, respondents need to answer five big questions related to awareness towards epilepsy that assess their awareness of epilepsy. There are two optional answers which are 'yes' or 'no'.

Part C: Knowledge towards Epilepsy

In this section, respondents need to answer nine big questions that will assess their knowledge of epilepsy. Respondents will be given two choices which are 'yes' or 'no', and they need to answer it based on their knowledge of the question.

Part D: Practice towards Epilepsy

In this section, respondents need to answer three big questions and divided questions that evaluate their practice of epilepsy. The answer to the question is a 'yes' or 'no' choice.

3.5.2 Validity and reliability

The validity and reliability of the research instrument is an essential aspect in a study and was validated by three panel experts in this field. Validity is the capability of a measurement or a research instrument to measure the true value of a concept in the hypothesis. High validity can be achieved if the instrument can truly measure the concept stated in the hypothesis. For reliability, it refers to the capability of the research in obtaining the same value when measurements are repeated (Chua, 2016). From the previous study by Neni, Latif, Wong & Luar (2010) shows that internal consistency reliability (Cronbach’s alpha) for overall each domain ranging from 0.775 to 0.811.

3.6 Variables

3.6.1 Variable measurement

The most common types of variables in the research study were independent variables and dependent variables. In this study, the measurements of the variables included in the independent and dependent variables are:

Table 3.1 Variables used in this study

Independent variable	• Caregivers at pediatric ward
Dependent variable	• Level of knowledge • Level of awareness • Level of practice

3.6.2 Variable scoring

Section A: Socio-demographic data

This section is used to identify socio-demographic data which are age, ethnicity, education level, marital status and occupation. Age was classified into 3 categories (<25; 25-40; >40). The ethnicity part in the questionnaire consists of four categories (Malay; Chinese; Indian; others) and educational level consists of four categories (primary; secondary; diploma; university). Marital status categories into 2 categories (married; single mother/widowed) while the occupations collapses into 3 categories (Government / private workers: Self-employed: Non-occupied/ housewife).

Section B: Awareness of Epilepsy

This section will be evaluated using a yes or no format. From that section, one mark will be given for ‘correct answer’ and no mark will be given for ‘wrong answer’. The overall score for this section is 5. Total maximum point to score is 5 and the minimum was 0. The original Bloom’s cut-off points, 80.0%–100.0%, 60.0%–79.0%, and ≤59.0%, were modified and adopted and from Nahida, 2007. Thus, score of 4-5 indicate the good awareness of epilepsy, 3 indicates satisfactory awareness of epilepsy and 0-2 indicates poor awareness of epilepsy.

Section C: Knowledge of Epilepsy

This section will be evaluated using the yes or no format as in Section B. From that section, one mark will be given for ‘correct answer’ and no mark will be given for ‘wrong answer’. The overall score for this section is 9. The maximum numbers of points point to be scored is 9 and the minimum is 0. Their score with their respective levels of knowledge are:

i. good knowledge: score 8-9
ii. satisfactory knowledge: score 6-7
iii. poor knowledge: score 0-5

Section D: Practice of Epilepsy

This section will be assessed using a yes or no format. From the section, one mark will be given for ‘correct answer’ and no mark will be given for ‘wrong answer’. The total marks for this section are 8 and the minimum was 0. Therefore, score 7-8 indicates good practice of epilepsy, 5-6 indicate the modest practice of epilepsy and 1-4 indicates the bad practice of epilepsy.

3.6.3 Translation of instrument

The original version of the questionnaire is in English version. It had been translated into the Malay version by the researcher to aid the understanding of the respondents. The translated version had been checked and validated by the Supervisor with a nursing background. Backward translation was used during the translation process so that the statements in the questionnaire maintained its original meaning.

3.7 Ethical consideration

The study will be conducted after getting the permission of the human research ethics committee (hrec), USM and the director of Hospital of USM, Kubang Kerian, Kelantan. Participants will be informed on the risks, their rights to voluntary participants and the right to discontinue the study at any time without a penalty or loss of benefits to which they were otherwise entitle. The informed written consent is obtained from each participant after they had agreed to join the study.

3.7.1 Privacy and Confidentiality

Participants' consent forms as well as the data collected from the questionnaire administration will be kept in a private and confidential manner and only be used for academic and research purpose. Data obtained from this study that does not identify you individually will be published for knowledge purposes. The records may be reviewed by the researcher, the Ethical Review Board for this study, and regulatory authorities for the purpose in verifying data. Participants' personal information may be held and processed on a computer.

3.7.2 Vulnerability Issue

Participants is voluntary and they are able to give their own consent.Participants may refuse to take part in the study or you may stop participation in the study at any time, without a penalty or loss of benefits to which you are otherwise entitled. The study is unlikely to pose any physical or biological threat to the participants.

3.7.3 Community Sensitivities And Benefits

Since these studies concern sensitive issues and experiences , it might cause uncomfortable situation during answer the questionnaire. Participants will be assured on the importance of the study that will benefits to community and health care providers in providing current data and help in managing stigma in epilepsy as well as improve the knowledge, awareness and practice of caregivers about the epilepsy.The information from this study will benefits to community nurses for health eduaction and in guiding the family members to improve their life.

3.7.4 Declaration of Interest

The researchers declare they have no conflict of interest.

3.7.5 Honorarium and Incentives

This study would not provide any incentive/ honorarium/ compensation to the respondents; however, participants were thanked verbally by the researcher for their involvement in this study after completion of the survey questionnaire.

3.8 Data collection plan

3.8.1 Procedure of data collection

The collection of data will be conduct after getting ethic approval from Human Research Ethical Committee (HREC) Universiti Sains Malaysia and permission for data collection from the Director of Hospital of USM, Kubang Kerian, Kelantan.

After that, the respondents were selected by the researcher with using the simple random sampling according to the inclusion and exclusion criteria, and then the researcher approached the respondents. Researchers approached the caregivers during the afternoon and evening visit time. Next, the researcher explained the purpose of the study and written consent obtained from them. Respondents were given brief and clear instruction on how the questionnaire should be completed.

Lastly, the time allotted to each respondent is around 20-30 minutes or less to complete the given questionnaire. Researcher wait while the questionnaire was completed to offer help if there are any questions about the questionnaire. The next step, the researcher will check if the question has been completely. If there any of the questionnaire is not filled by the respondents, then, the researcher should ask them to answer the unanswered question. The data collection was conducted from January 2020 until February 2020. There was a flow of process of data collection was exhibited in Figure 3.2.