ASSESSING INFORMAL CAREGIVER BURDEN AS WELL AS KNOWLEDGE ON POSITIONING AND FEEDING OF STROKE PATIENTS IN HOSPITAL USM

DR AL MIZAN B MUSTAPA @ AB RAHIM

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LIST OF ABBREVIATION

CKQ- MY	Caregiving Knowledge Questionaire Malay version
HUSM	Hospital Universiti Sains Malaysia
ICD 11	International Classification of Disease 11th Version
MRS	Modified Rankin Score
MCA	Middle Cerebral Artery
NG	Nasogastric Tube
MZBI	Malay Version of Zarit Burden Interview
WHO	World Health Organization
ZBI	Zarit Burden Interview

ABSTRAK (BAHASA MELAYU)

Pengenalan : Strok adalah salah satu penyakit yang lazim di seluruh dunia. Ia menyumbang kepada morbiditi dan kematian yang tinggi di Malaysia. Di Malaysia, majoriti penjaga pesakit strok adalah di kalangan penjaga yang tidak formal ataupun keluarga. Kebanyakan dari mereka tidak mendapat persediaan dan latihan yang mencukupi. Sehubungan dengan itu, ia boleh menyebabkan beban yang tinggi kepada penjaga. Sehingga sekarang maklumat mengenai korelasi diantara pengetahuan penjaga dan beban penjaga masih sangat kurang. Kajian ini adalah untuk mengkaji hubungan di antara beban, pengetahuan dan latar belakang penjaga pesakit strok di Hospital USM.

Kaedah : Kajian ini bersifat kajian lintang melibatkan penjaga pesakit strok yang datang ke Unit Rehabilitasi di Hospital USM. Pengetahuan penjaga dan beban penjaga dinilai menggunakan soalan yang telah disahkan dan dialih bahasa kepada bahasa melayu iaitu CKQ-My (pemberian makanan dan memposisi pesakit) dan Zarit Burden Interview. Latar belakang pesakit and penjaga juga diambil dan dikaji. Statistik deskriptif dan multivariat diguna untuk menganalisa maklumat.

Keputusan: Seramai 76 peserta di analisa, 87.8% diantara mereka adalah mempunyai pengetahuan yang rendah dalam memposisi pesakit strok. Manakala, 45 peserta yang menjaga pesakit stroke dengan tiub makanan diselidik mengenai pengetahuan pemberian makanan mempunyai pengatehuan yang baik (markah purata 15.69 ± 2.29). Keputusan juga menunjukkan, lebih kurang separuh dari penjaga tidak formal (47.88 %) menghadapi beban dalam menjaga pesakit strok dan majoriti daripada mereka dalam kategori ringan kepada sederhana. Penjaga yang menjaga pesakit strok yang teruk (MRS 4-5) . Keputusan regresi logistic berganda menunjukkan penjaga yang menjaga pesakit stroke dengan MRS 4-5 akan mengalami beban berbanding menjaga pesakit stroke MRS 1-3 (Adjusted OR= 4.9 ; 95% CI: 1.5 - 15.96; P=0.032). manakala bagi bukan penjaga utama kurang mendapat beban berbanding penjaga (Adjusted OR = 0.06 ; 95% CI: 0.02- 0.247 ; P= < 0.001).

Konklusi : Penjaga tidak formal bagi pesakit strok mempunyai kadar pengetahuan yang rendah untuk memposisi pesakit tetapi mempunyai kadar pengetahuan yang tinggi untuk pemberian makanan. Selain daripada itu, separuh daripada penjaga juga mengalami beban ringan ke sederhana. Hanya pesakit strok yang teruk (MRS 4-5) dan penjaga utama di dapati mempunyai kaitan dengan beban penjaga.

Kata kunci :
Pengetahuan, pemberian makanan, memposisi, beban penjaga

Abstract (English)

Background: Stroke contributes to high morbidity and mortality in both developed and developing countries. In a developing country like Malaysia, most stroke patients are taken care of by informal or family caregivers. Most of them did not receive adequate preparation and training. Hence may lead to an increase in caregiver burden. To date, there is a lack of information to correlate caregiving knowledge with the caregiver burden of stroke patients. This study examines the relationship between caregiver burden, caregiving knowledge, and demographic data of the informal caregiver of stroke patient in Hospital USM.

Method: This cross-sectional study involves informal caregivers attending Rehabilitation Unit in Hospital USM. Caregiving knowledge and caregiver burden were measured using previously translated and validated CKQ-My (on positioning and feeding) and Zarit Burden Interview. Socio-demographic data of patients and caregivers also were sampled and analysed. Descriptive and multivariate statistics were used for data analysis.

Result: Total of 76 participants were analysed, 87.8% of them had poor knowledge in positioning of stroke patient. Otherwise, all 46 participant whose been assessed for feeding knowledge showed to had good knowledge (mean score 15.59± 2.29). About half of informal caregiver experience burden (47.88%) in taking care of stroke patient and majority of them categorized in mild to moderate (42.1 %). Multiple logistic regression demonstrated that caregivers who taking care of stroke patient with MRS 4-5 has 4.9 higher odd compared to stroke patient with MRS 1-3 to experience caregiver burden (Adjusted OR= 4.9 ; 95% CI: 1.5 - 15.96; P=0.032). For non-primary caregiver has 94% lower odd to get burden compared to primary caregiver (Adjusted OR = 0.06 ; 95% CI: 0.02- 0.247 ; P= < 0.001).

Conclusion: Informal caregivers of stroke patients at Hospital USM had poor knowledge on positioning, but good knowledge in feeding. Besides, they also experienced mild to moderate

burden. Only Modified Rankin Scale (MRS) of stroke patient and type of caregiver (primary vs. non-primary) was found to be associated with the caregivers' burden.

Keywords:
knowledge, feeding, positioning, caregiver burden

CHAPTER 1

INTRODUCTION

Stroke is one of the leading causes for disability and death in the world. According to the 4th National Health and Morbidity Survey (NHMS) in 2011, the overall prevalence of stroke in Malaysian population was 0.7% (IHSR, 2012). It was reported that the prevalence was significantly higher in older age (>75 years old) (7.8%), primary education level (2.3%), divorced/ widowed (2.5%) and lower income (<RM400) (1.2%) than their counterparts, while no significant differences were found across gender and ethnicity (IHSR, 2012). Moreover, National Neurology Registry (NNEUR) reported that the prevalence and incidence of stroke in Malaysia had increased more than 18% annually (ischemic stroke and hemorrhagic stroke) within 5-years duration from 2010 to 2014 (1). The ischemic stroke (79.4%) is the most common stroke occurred in Malaysia population, followed by hemorrhagic stroke (18.2%), transient ischemic attack (2.0%) and unclassified (0.4%) (1). Hypertension, diabetes mellitus, hyperlipidaemia, smoking and ischemic heart disease were the risk factors for stroke (2).

Stroke survivors often suffered with functional disabilities such as dysphagia, dementia, and balance dysfunction (2). About 54% of the stroke patients in Malaysia suffered with physical and cognitive disabilities upon discharge from the hospital (3). Therefore, they require long-term care and some form of assistance to perform daily activities after discharge from the hospital. In Malaysia, most stroke care is provided by informal caregivers such as family members of the patients (4). Many of them cannot afford to hire a formal or trained person to care for the patient. Besides, Malaysian culture hold strong family relationship, and thus most of the informal caregivers of stroke patients in Malaysia consisted of either children or spouse. The informal caregiver needs to learn the correct way in taking care of the post-stroke patient.

Without proper knowledge, the poor or wrong technique applied when caring for the stroke patients may lead to secondary complications such as pressure ulcers, aspiration pneumonia and shoulder pains (5).

The poor stroke knowledge and patients disability will increase the caregivers' burden and then negatively impacts patients' well-being, such as post-stroke depression, decreased cognitive function, physical disability, and general quality of life. It had been proved that adequate education, knowledge and training among caregivers can improve quality of care of stroke patients (6) Managing stroke patients also carries an economic impact on the country. The cost analysis study reported the mean cost of care for stroke patients in a teaching hospital in Malaysia is MYR 3696.40 ± 1842.17 per patient or 16% of the country's per capita gross domestic product (GDP), and the cost is varied across different stroke severity levels (7). We believe that preventing post-stroke complications may help reduce the country's economic burden.

The study of knowledge among stroke caregivers in Malaysia is very limited. To date, only one study has been done in assessing the level of specific knowledge among stroke caregivers. This study surveys the positioning knowledge among informal stroke caregivers in Klang valley. The result showed that most caregivers have poor knowledge in taking care of stroke patients, specifically on positioning (8). The study also recommends assessing based on locality. The caregivers of stroke patients face financial, emotional, social and physical burden (4). There are few studies on caregivers' burden in Malaysia but not specific to the caregiver of the stroke patient only. Studies on knowledge and caregivers burden in Malaysia were mostly done in the western region. We believe that cultural differences, financial status, education level, and social

support differed in the country's eastern part. Furthermore, to date, no data available in Malaysia correlate between knowledge and caregiver burden.

Measuring the level of knowledge among caregivers in HUSM focused on stroke patients' positioning and feeding will allow us to explore the level of their understanding regarding stroke patients' care. Knowing the correlation between the knowledge and caregiver burden will alert us to the importance of educating the caregivers. Consequently, we plan to use the findings of this study to design caregivers' education programs to benefit our local population.

LITERATURE REVIEW

Stroke carries long-term disability to the patients. According to Malaysia national stroke registry, about 50% of stroke patients discharged from the hospital after being diagnosed with acute stroke will experience functional dependence (9). Furthermore, it is being established that stroke patients with limb motor deficit, incontinence, and dysphagia are essential indicators of long-term disability and quality of life (10). Therefore, caregivers become crucial in managing stroke patients at home. Most stroke patients require high-level, long-term nursing care such as administration of medication or feeding, positioning knowledge, and emergency knowledge for stroke patients. Unable to give proper caregiving will arise various complications and burdens to patients, caregivers, and healthcare. This stroke patient had constant rate for readmission after diagnose of stroke because of stroke complication. (11)

It has been known that feeding and positioning in stroke patients are indicators of long-term disability and quality of life. Almost 41% of stroke patients experienced dysphagia at initial presentation and needed to be assisted in feeding. Associated factors like age ≥ 75 years, diabetes, and MCA infarct predict the occurrence of dysphagia after an acute stroke (1,12). This patient requires gastrointestinal access such as a nasogastric tube or percutaneous endoscopy gastrotomy tube. However, study among Malaysian healthcare professionals revealed that percutaneous endoscopy gastrostomy tube raised concerns of potential complications and body integrity interference despite being superior to NG tube (13). Failure to follow proper instruction and practice in nasogastric tube feeding, the stroke patient may cause malnutrition, pneumonia, and uncontrolled underlying comorbidities. Malnutrition is common among patients with stroke, with prevalence rates of 8 - 49% reported in the literature. Malnourished patients with stroke are recognized to develop more complications such as infections and pressure ulcers and require more extended in-hospital stays than well-nourished patients with stroke(14).

Additionally, the mortality rates of patient's post-stroke are affected by the degree of malnutrition in these patients.

Figure A : picture of Nasogastric Tube (Left) and Percutaneous Endoscopy Gastrotomy (Right) . (http://www.stroke4carers.org/?p=486)

According to Malaysia Stroke Registry 2009-2016, about 54% of the stroke population have varying degrees of physical disability (MRS 3-5). Physical disability, including spasticity, weakness, and contracture, imposes significant patient care challenges. Ideally, this type of stroke patient needs a knowledgeable caregiver in positioning the weak muscle. A recommended strategy to discourage physical complications of stroke and improve recovery is to encourage "reflex-inhibiting" patterns of posture. While there is consensus among clinicians that encouraging such positions is therapeutic and may enhance recovery, it is believed that only consistently good positioning will be effective(15). After a stroke, patients discharged from the hospital, responsible for being in good positioning will be taken by the primary caregivers.

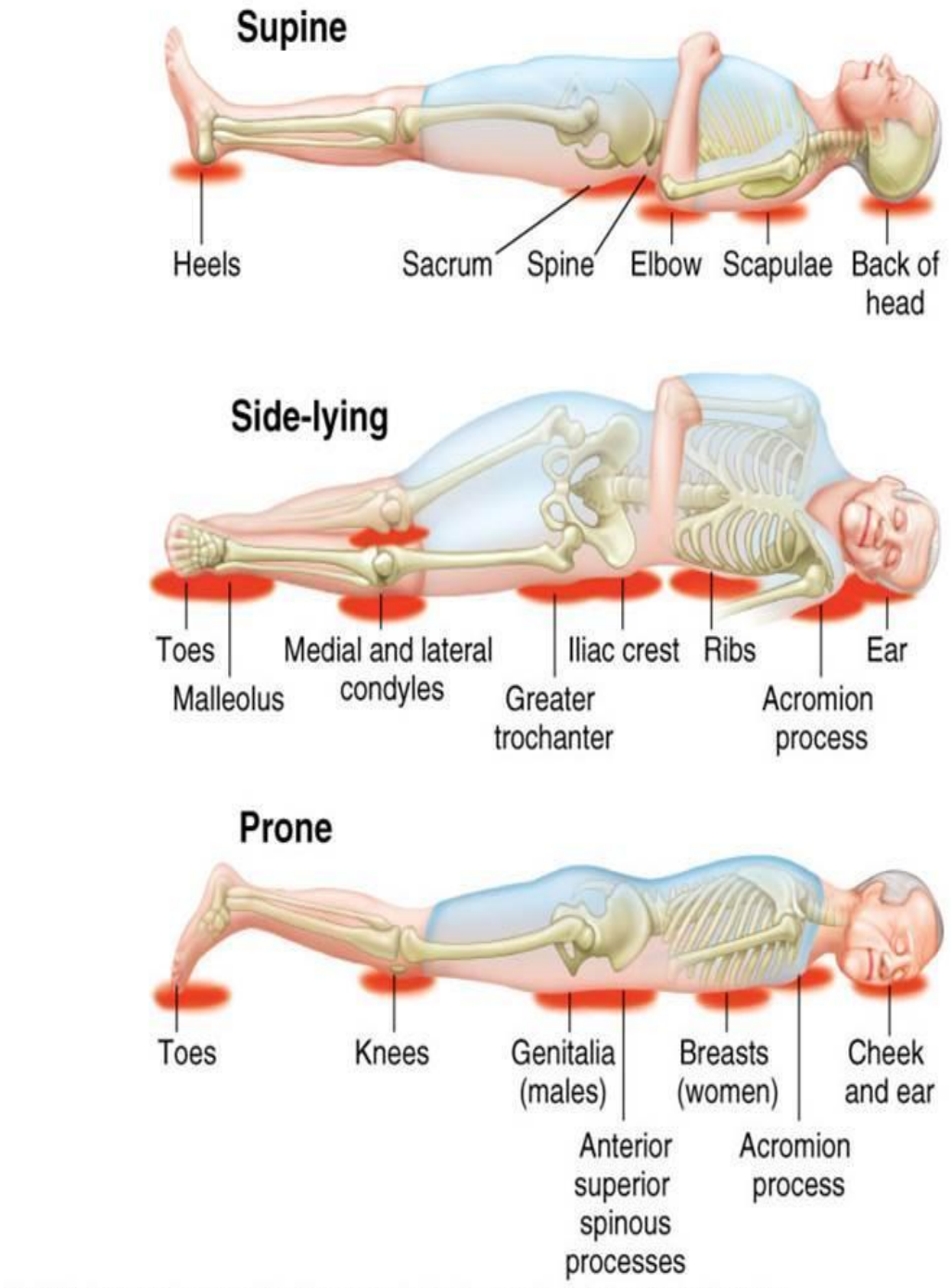


Fig. 33-2. Bony prominences subject to pressure, ischemia, necrosis, and ulceration in the supine, side-lying, and prone positions.

Figure B: picture of prominent area to develop pressure ulcer ((16))

Most stroke caregivers in Malaysia are informal caregivers, primarily due to the financial and availability of formal caregivers nearby. Informal caregiver refers to care provided by family, friends, and neighbours. These people had a variety of backgrounds and education. Hence, they

need basic caregiving knowledge and skills to care for stroke patients given these various disabilities and potential complications of the stroke. (8). Too often, caregivers are expected to perform these complex tasks alone, without any formal assessment of their level of efficacy related to caregiving or formal support (17). Recently investigators have suggested that family caregivers require both knowledge and skill to provide care and to reduce their own distress(12,13,14). A survey conducted among informal caregivers in the Klang Valley showed that 78% wanted to have more information to solve their problems, as well as 67%, wanted more information and advice from medical specialists(4). They were indirectly saying that the knowledge and training given are still not adequate.

Some study was done in assessing knowledge among either formal or informal caregivers. In Korea, surveyed for expertise in caring for a stroke patient among formal caregivers, specifically on feeding and positioning, showed that about one-third (33.8%) of caregivers did not have adequate knowledge of how to care for stroke patients properly. A significant number of caregivers demonstrated inappropriate and insufficient knowledge in several areas (1). A few studies involve informal caregivers worldwide. However, only one study has been published for informal caregivers in Malaysia to date. The study was done at Klang Valley using a validated questionnaire(21) measuring the knowledge of informal caregivers of a stroke patient, specifically in positioning. Among 128 caregivers sampled, 87.3% had poor knowledge of positioning (mean score 14.9 ± 4.32) of a stroke patient. (8). In Thailand, a study for stroke care assessing feeding and aspiration prevention, pressure ulcer prevention, fall prevention, mobility, and rehabilitation. This study compares the standard care and intervention group. Interventional groups are given more frequent training and teaching than usual practice. The result showed there were significantly improved stroke care skills in the intervention group compared to family caregivers in the control group ($F = 192.49$, $p < .001$)(22). This study also shows that stroke patients in the interventional group have fewer stroke complications. Few study

demonstrated a higher level of caregiving knowledge and skills was positively correlated with psychological well being of caregiver(15,16). Knowledge in stroke care is vital to the caregiver.

A study showed that one-third of caregivers carry a high burden in taking care of stroke patients. Caregivers who had not received appropriate medical assistance and information were not well prepared to care for family members or patients and would suffer from more significant stress and bear a greater burden of care (25). Taking care of haemorrhagic stroke give more higher burden to the caregiver(26). The caregiver burden is highly subjective. Numerous studies demonstrate that the prevalence of caregivers of stroke patients is about 24 – 54%, and the prevalence is increasing over time. A study done in the palliative centre in Malaysia showed that from a total of 280 informal caregivers, 47.4% experienced caregiver burden**,** whereby the majority have mild to moderate burden 90 (36.1%). Studies demonstrate caregiver burden was associated with education level, age, gender, duration of caregiving, and type of chronic illness. (27). Other study show significant correlation between caregiver burden and caregivers' education level, caregivers' relationship with care recipients, physical function of recipient and years of care (28–30). There is no such study in Malaysia that demonstrates an association between knowledge and caregiver burden. Generally, a high level of caregiving knowledge will enable the caregiver to resolve difficulties, thus reducing the burden and stress. The studies reported a previous increase in caregivers' knowledge with decreased the burden (31,32). Contrary to other few studies, for example, one study in China cannot show correlation caregiver knowledge with the burden (23).

CHAPTER 2

OBJECTIVES OF THE STUDY

Research Questions

Research Question(s)

1. What are the knowledge scores regarding positioning using the Malay Version of Caregiving Knowledge Questionnaire (CKQ-MY) form among informal caregiver of stroke patient in Hospital USM?
2. What are the knowledge scores regarding feeding using the Malay Version of Caregiving Knowledge Questionnaire (CKQ-MY) form among informal caregiver of stroke patient in Hospital USM?
3. What are the burden scores using Malay Version of Zarit Burden Interview (MZBI) among informal caregiver of stroke patient in Hospital USM?
4. What is socio-demographics factors associated with caregivers' burden among informal caregiver of stroke patient in Hospital USM?

Objective

General Objective

To determine the burden and knowledge of informal caregiver regarding positioning and feeding of stroke patients in Hospital USM

Specific Objective

1. To determine knowledge scores regarding positioning using the CKQ-MY form among informal caregiver of stroke patient in Hospital USM

2. To determine knowledge scores regarding feeding using the CKQ-MY form among informal caregiver of stroke patient in Hospital USM

3. To determine burden scores using MZBI among informal caregivers of stroke patient in Hospital USM

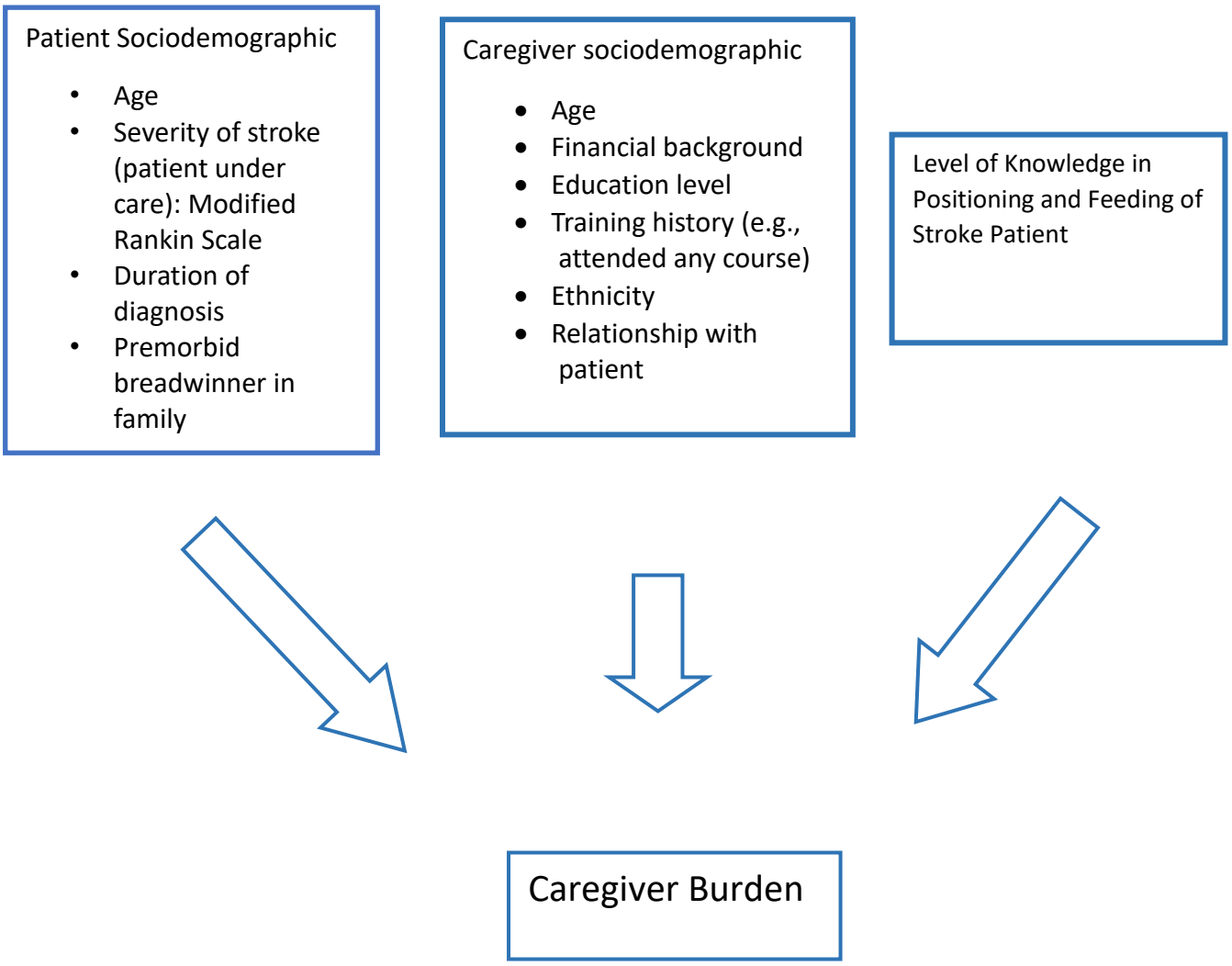
4. To determine socio-demographic factors associated with caregiver burden among Informal Caregivers of stroke in Hospital USM

CHAPTER 3:

Study Protocol

Research Title: The Study of Knowledge On Positioning And Feeding Of Stroke Patients And Factors Associated With Burden Among Informal Caregivers In Hospital USM.

Conceptual Framework



Research design

This is a non-interventional, cross-sectional study

Expected time frame: December 2021 – February 2022

Phase 1

a) Potential subject identified via inclusion and exclusion criteria

b) Explanation given and consent obtained

c) Administration of study tool

Phase 2

a) Data entry to Microsoft excel

Phase 3

a) Statistical analysis

Study area

The study will be conducted at the Hospital USM Rehabilitation Unit School of Medical Sciences, Universiti Sains Malaysia

Figure C: Rehabilitation Unit, Hospital USM

Study population

Reference population

Informal caregiver for stroke patient in Kota Bharu

Target population

Informal caregivers of stroke patients in Hospital USM

Source population / sampling pool

Informal caregivers who accompany stroke patient in Rehabilitation Unit in Hospital USM

Sampling frame

Informal caregivers who accompany stroke patient in Rehabilitation Unit in Hospital USM and fulfil the inclusion criteria and do not have any exclusion criteria

Subject criteria

Inclusion criteria

1. Aged 18-years-old and above
2. Informal caregiver of post stroke patient
3. The patient has been diagnosed with stroke for more than 3 months

Exclusion criteria

1. Caregiver unable to complete questionnaire due to e.g., illiteracy, language barrier etc.

Sample Size Estimation

Objective 1:

To obtain knowledge scores regarding positioning using the CKQ-MY form among informal caregiver of stroke patient in HUSM

Using single mean formula by sample size calculator (Ariffin,W.N. 2020)

Standard deviation	**precision**	**Power (1 - β)**	**n**	**Dropout rate 10%**	**Total sample size**	**Literature review**
4.22	0.05	0.80	117	130	130	C.-E. Tan *et al.*, 2020

Objective 2 :

To obtain knowledge scores regarding feeding using the CKQ-MY form among informal caregiver of stroke patient in HUSM

Using single proportion formula by sample size calculator (Ariffin,W.N. 2020)

Proportion	**Precision**	**Confident level (1 – β)**	**n**	**Dropout 10%**	**Total sample size**	**Literature review**
0.7	0.05	0.80	138	154	154	(Lee *et al.*, 2015)

Objective 3:

To determine proportion of burdened caregiver among informal caregivers of stroke patient in HUSM

Using single proportion formula by sample size calculator (Ariffin,W.N. 2020)

Proportion	**Precision**	**Confident level** $(1 - \beta)$	**n**	**Dropout 10%**	**Total sample size**	**Literature review**
0.47	0.05	0.80	150	164	183	(Ahmad Zubaidi *et al.*, 2020)

Objective 4

To determine socio-demographic factors associated with caregiver burden among informal caregivers in Hospital USM

Using two proportion formula by sample size calculator (Ariffin,W.N. 2020)

Factor	P_0	P_1	n	**2n+ 10%***	**Reference**
Education level	0.42	0.62	95	216	Ahmad Zubaidi *et al.*, 2020
Duration of care	0.6	0.4	95	216	(Koopman *et al.*, 2020)
Relationship	0.63	0.38	62	138	(Koopman *et al.*, 2020)

Thus, final sample size is 216 samples.

Sampling Method and Subject Recruitment

This study is questionnaire-based research. Adult caregivers (aged 18 years and above) of stroke patients diagnosed for more than 3 months and attending rehabilitation activities at the Rehabilitation Unit were recruited for this study. Caregivers were each approached individually at different times using a non-probability, convenience sampling. They were given explanations and a participant information sheet regarding the study. Those who expressed interest to participate were screened for the inclusion and exclusion criteria and were asked to give written informed consent. Subjects who meet the inclusion criteria and do not have exclusion criteria were identified and invited to join the study by interviewer. To protect patients' private information, each patient will be de-identified and assigned a unique identification (ID) code (example 1001, 1002). This ID code will be used to label their samples and subsequent work.

Research tool

1. Proforma Checklist
2. CKQ – My on Positioning and Feeding
3. Malay Version of Zarit Burden Interview

Operational definitions

Stroke - According to WHO ICD 11, cerebral ischaemic stroke is acute focal neurological dysfunction, caused by focal infarction at single, of multiple site of the brain or retina. Evidence of acute infarction may come either from:

i) symptom duration lasting more than 24 hours
ii) neuroimaging or other technique in clinically relevant are of the brain.

Informal Caregiver – People who provide care to those who need it within the context of an existing relationship, such as a family member, a friend, or a neighbour.

Formal Caregiver – Caregivers who are being paid for their services and have certificate in providing care to disable person such as physiotherapist, nurse or other healthcare worker

Modified Rankin Scale (MRS): The most widely scale used to measure functional outcome (level of disability or dependence). The mRS is an ordinal scale that ranges from 0 – 6.

0: No symptoms

1: No significant disability. Able to carry out all usual activities, despite some symptom

2: Slight disability. Able to look after own affairs without assistance, but unable to carry out all previous activities.

3: Moderate disability. Requires some help, but able to walk unassisted.

4: Moderately severe disability. Unable to attend to own bodily needs without assistance, and unable to walk unassisted.

5: Severe disability. Requires constant nursing care and attention, bedridden, incontinent

6: Dead

Primary caregiver: The family member, friend or neighbour, who spends the most time providing unpaid care to stroke patient and who is perceived by themselves and others as the principal person responsible for caring for them (33,34)

Non primary caregiver: family members, friends or neighbours who undertake some unpaid caregiving tasks or provide support to primary caregivers, but who are not perceived by themselves or others as having principal responsibility for the cared-for person

Positioning: Recommended postures base on underlying physiological activity for post stroke patients to discourage post stroke spasticity, contracture, and other related complication

Feeding/ Nasogatric tube Feeding: a flexible, fine-bore, radio-opaque tube passed into the stomach via the nose. It is used to deliver nutritional support and medications to patients who are unable to swallow or are unable to meet their nutritional requirements by mouth

Caregiver Burden: Strain borne by a person who cares for a chronically ill, disabled, or elderly person.

Premorbid breadwinner: The main person who provided financial support to family before diagnosing of stroke.

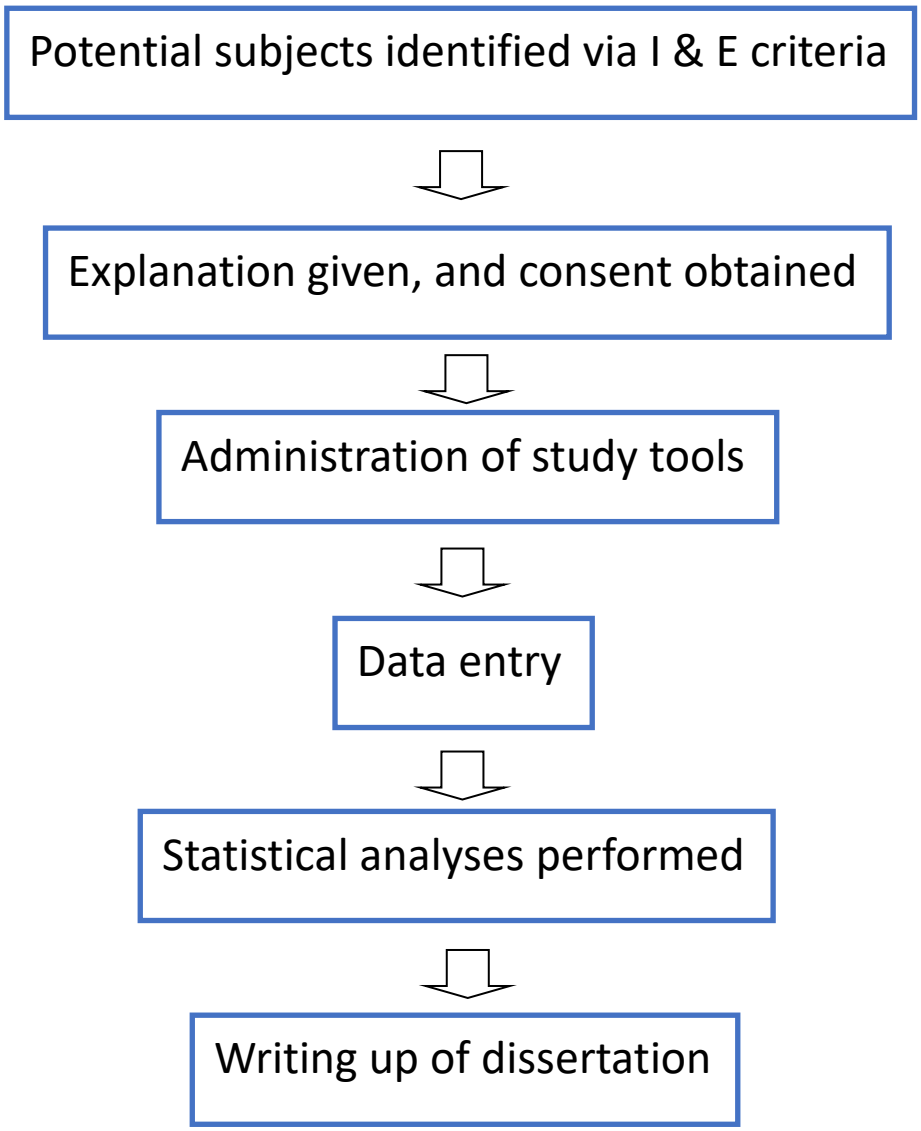
Data Collection Method

Data Collection

Details of data collection:

1. Primary data collection
2. Study participants will be identified by anonymous code number
3. Potential subjects recruited from stroke and rehabilitation clinics
4. Briefing on study and consent (2 minutes)
5. Administration of proforma form, CKQ-My and MZBI (10 minutes)
6. Data will be entered in Microsoft Excel, then exported to SPSS v24 for further statistical analyses

Study Flowchart



Data Analysis

Statistical Analysis Plan

All the data collected were entered into a database. The statistical analysis was done using the SPSS software version 26 for data entry and statistical analysis.

For objective numbers 1, 2 and 3, Descriptive statistic were presented by using mean and standard deviation for continuous variables. Then using frequency and percentage for categorical variables

For objective number 4. Multiple logistic regression was applied to determine the association between sociodemographic status, knowledge, and impact on caregiver's burden

Expected result(s)

Objective 1 and 2: To measure score of knowledge in positioning and feeding among informal caregiver of stroke patient in HUSM

Knowledge for positioning	
Mean score (sd) Median score (IQR)	
Knowledge for feeding	
Mean score (sd) Median score (IQR)	

Objective 3: To assess burden scores using the MZBI among informal caregivers of stroke patient in HUSM

	Burdened		Not burdened	
	N(%)	Mean (sd)	N(%)	Mean (sd)
prevalance				

Age			
Gender	Male		
	Female		
Ethnicity	Malay		
	Chinese		
	indian		
Education level	Primary		
	Secondary		
	Tertiary		
Household income	<RM1000		
	RM1000-RM4999		
	>RM5000		
Caregiving	Primary caregivers		
	Non primary caregiver		
Relationship with patient	Spouse		
	Children		
	others		

Modified rankin score	1-3		
	4-5		
Receive extra training	yes		
	No		

Objective 4: To determine factors association with Caregiver Burden Among Informal Caregivers in Hospital USM

		Univariate analysis		Multiple logistic regression	
		crude OR (95% CL)	P value	Adjusted OR (95% CL)	p- value
Age					
Gender	Male				
	Female				
Ethnicity	Malay				
	Chinese				
	Indian				
Education level	Primary				
	Secondary				
	Tertiary				
Household	<RM1000				

income	RM1000-RM4999		
	>RM5000		
Caregiving	Primary caregiver		
	Non primary caregiver		
Relationship with patient	Spouse		
	Children		
	others		
Modified rankin score	1-3		
	4-5		
Receive extra training	yes		
	No		
Knowledge on posisioning	Good		
	Poor		
Knowledge on feeding			

Gantt chart

SUBJECTS	2021							2022					
	J	J	A	S	O	N	D	J	F	M	A	M	J
Preparation for proposal													
Submit proposal to Ethics Committee													
Data collection													
Data entry													
Analysis of data													
Thesis writing													
Thesis submission (first draf)													
Correction of thesis submission													
Submission of final research													
Presentation for viva													