FAMILY CAREGIVER'S BURDEN IN CARING FOR STROKE PATIENTS AT HOSPITAL UNIVERSITI SAINS MALAYSIA (HOSPITAL USM)

by

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DECLARATION

I certify that this thesis does not incorporate without acknowledgement of any material previously submitted for a degree or diploma in any university, and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due references is made in the text.

CERTIFICATE

This is to certify that the dissertation entitled 'Family Caregiver's Burden in Caring for Stroke Patients at Hospital Universiti Sains Malaysia (Hospital USM)' is the been record of research work done by Siti Nor Adni Binti Ab Rahman , Matric Number: 105154, during the period of September 2012 to June 2013 under my supervision. This dissertation submitted in partial fulfillment for the degree of Bachelor of Science (Health) in Nursing. Research work and collection of data belong to Universiti Sains Malaysia.

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LIST OF ABBREVIATIONS

BPS	Behavioral and psychologic syndrome
CNS	Central Nervous System
Hospital USM	Hospital Universiti Sains Malaysia
HDL	High density lipoproteins
TCARE	Tailored Caregiver Assessment and Referral
TIA	Transient Ischemic Attack
WHO	World Health Organization
ZBI	Zarit burden interview

FAMILY CAREGIVER'S BURDEN IN CARING FOR STROKE PATIENTS AT HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRACT

Stroke is one of the chronic diseases that contributed to disabilities in many countries. Majority of stroke patients depend on their family for optimum recovery and survivor. The objective of this study was to measure the level of burden among family caregivers in caring for stroke patients at Hospital Universiti Sains Malaysia (Hospital USM). The socio demographic data of caregivers was assessed as the association factor for the level of burden among family caregivers. This study was a cross sectional study and Caregiver Identity theory was used in this study. The Zarit Burden Interview 12 questions short version Malay version questionnaire was used to measure the level of burden among 58 respondents from family caregivers of stroke patients in ward 2 Intan, 3 Utara, 7 Selatan and 7 Utara and also Rehabilitation Unit Hospital USM. The result showed that 93.1% of family caregiver for low burden whereas only 6.9% for high burden. Therefore, the level of burden among family caregiver is in low burden. There are no significant association between selected socio demographic data and level of burden among family caregiver who caring for stroke patient at Hospital USM. The age, gender, ethnicity, marital status, education level, occupation, family income and relationship to patient of 58 caregivers did not show any significant statistical difference in relation to their perceived burden.

Key term: Stroke, Family caregiver, Caregiver Burden, Zarit Burden Interview

BEBANAN MENJAGA PESAKIT STROK DALAM KALANGAN PENJAGA DI HOSPITAL UNIVERSITI SAINS MALAYSIA

ABSTRAK

Strok adalah salah satu penyakit kronik yang menyumbang kepada ketidakupayaan di kebanyakan negara. Majoriti pesakit strok bergantung kepada keluarga mereka untuk pemulihan yang optimum dan terus hidup. Objektif kajian ini adalah untuk mengukur tahap bebanan dalam kalangan penjaga yang menjaga pesakit strok di Hospital Universiti Sains Malaysia (Hospital USM). Data sosio demografi penjaga telah dinilai sebagai faktor perkaitan antara tahap bebanan dalam kalangan penjaga. Kajian ini adalah satu kajian keratan rentas dan teori Pengenalan Penjaga telah digunakan dalam kajian ini. Borang soal selidik Zarit Beban versi pendek mengadungi 12 soalan dalam Bahasa Melayu telah digunakan untuk mengukur tahap bebanan dalam kalangan 58 responden yang terdiri daripada penjaga pesakit strok di wad 2 Intan, 3 Utara, Selatan 7 dan 7 Utara dan juga Unit Pemulihan Hospital USM. Hasilnya menunjukkan bahawa 93.1% daripada penjaga keluarga merasai beban yang rendah manakala hanya 6.9% untuk beban yang tinggi. Oleh itu, tahap bebanan di kalangan penjaga adalah dalam beban rendah. Tiada hubungan yang signifikan antara data sosio demografi yang dipilih dan tahap bebanan yang dirasai dalam kalangan penjaga yang menjaga pesakit strok di Hospital USM. Umur, jantina, kumpulan etnik, status perkahwinan, tahap pendidikan, pekerjaan, pendapatan keluarga dan hubungan antara penjaga dengan pesakit dalam kalangan 58 penjaga tidak menunjukkan hubungan perbezaan statistik berhubung beban yang mereka rasai.

Kata kunci: Strok, keluarga penjaga, beban penjaga, Zarit Beban

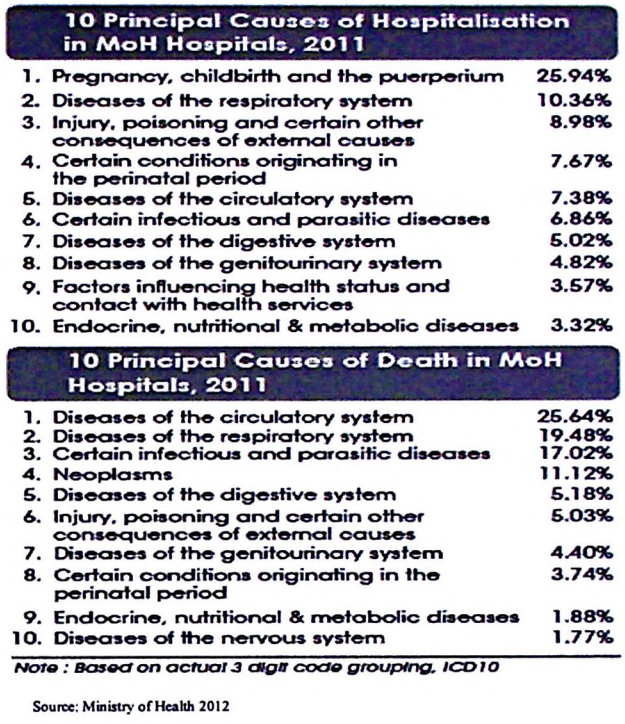
CHAPTER 1

INTRODUCTION

1.1 Background of the Study

'Stroke or cerebrovascular disorder is an umbrella term that refers to a functional abnormality of the central nervous system (CNS) that occurs when the normal blood supply to the brain disrupted' (Smeltzer, Bare, Hinkle and Cheever 2010). Stroke is the fourth leading cause of death in the United States in 2008 after more than five decades at number three in the ranking (Minino, Murphy, Jiaquan and Kochanek 2011). Stroke is also Singapore's fourth leading cause of death and is among the top 10 causes of hospitalization and approximately one-quarter of that is hemorrhagic stroke (Venketasubramanian and Chen 2008). Other than that, stroke is second leading cause of death in China (Wang, Wu, Liao, Zhang, Zhao, and Wang 2007).

The population of Malaysia in 2011 was 28.96 million (Department of Statistic Malaysia 2011). However, the prospective studies on stroke in Malaysia are limited. To date, neither the prevalence of stroke nor its incidence nationally has been recorded (Loo and Gan 2012). According to Ministry of Health (MoH) 2011, the disease that related to circulatory system is the fifth cause of hospitalization and first cause of death in Malaysia in 2011 as listed in Figure 1. According to Medical Record Department of Hospital Universiti Sains Malaysia (Hospital USM) 2012, from January until June 2012, there were 336 cases of stroke that admitted in Hospital USM.



10 Principal Causes of Hospitalisation in MoH Hospitals, 2011

1.	Pregnancy, childbirth and the puerperium	25.94%
2.	Diseases of the respiratory system	10.36%
3.	Injury, poisoning and certain other consequences of external causes	8.98%
4.	Certain conditions originating in the perinatal period	7.67%
5.	Diseases of the circulatory system	7.38%
6.	Certain infectious and parasitic diseases	6.86%
7.	Diseases of the digestive system	5.02%
8.	Diseases of the genitourinary system	4.82%
9.	Factors influencing health status and contact with health services	3.57%
10.	Endocrine, nutritional & metabolic diseases	3.32%

10 Principal Causes of Death in MoH Hospitals, 2011

1.	Diseases of the circulatory system	25.64%
2.	Diseases of the respiratory system	19.48%
3.	Certain infectious and parasitic diseases	17.02%
4.	Neoplasms	11.12%
5.	Diseases of the digestive system	5.18%
6.	Injury, poisoning and certain other consequences of external causes	5.03%
7.	Diseases of the genitourinary system	4.40%
8.	Certain conditions originating in the perinatal period	3.74%
9.	Endocrine, nutritional & metabolic diseases	1.88%
10.	Diseases of the nervous system	1.77%

Note : Based on actual 3 digit code grouping, ICD10

Source: Ministry of Health 2012

Figure 1: 10 Principal causes of hospitalization and death in MoH Hospitals 2011

Annually, 15 million people worldwide suffer a stroke. Of these, 5 million die and another 5 million are left permanently disabled, placing a burden on family and community (World Health Organization (WHO) 2012_a). Stroke survivors often suffer from various degrees of permanent disability and sustain impairments that significantly affect their personal, familial and social well-being. Due to its sudden and unpredictable onset, a stroke often leaves stroke survivors and their caregivers unprepared to deal with its impact on daily life (Rombough, Howse and Bartfay 2006).

More adults with chronic conditions and disabilities like stroke are living at home than ever before and family caregivers have an even higher level of responsibility. Caring for loved ones was associated with several benefits, including personal fulfillment.

However, in providing the caregiving is also associated with physical, psychological, and financial burdens (Laurent, De Sèze, Delleci, Koleck, Dehail, Orgogozo and Mazaux 2011).

Advances in stroke care have decreased the rate of severe disabilities among stroke survivors, allowing more stroke survivors to live at home. However, these patients often require significant assistance with activities of daily living and instrumental activities of daily living. This condition may give impact for the family caregivers to prepare themselves as the caregiver for the stroke survivor in dealing with their daily life. Family caregivers will provide essential assistance for stroke survivor in providing rehabilitation and further treatment as well as adapt to community living. As a core person in assisting their stroke family members to achieve optimum recovery and quality of care, therefore it is important to assess and fulfill caregivers' needs related to caregiving role.

1.2 Problem Statements

For this study, the researcher want to give more focus on caregiver side that need to consider as important person who care for stroke patients. According to Das, Hazra, Khanti, Ghosal, Banerjee, Roy, Chaudhuri, Raut and Kumar (2010), caregiver is the unpaid person closely involved in physical (feeding, bathing, toileting, walking) and emotional care (emphatic listening, encouragement and motivation) to adhere to treatment and the caregiver commonly a family members living with the patient.

Caregiver burden can be differently perceived by people, depending on their society and culture in which where caregivers live and supportive from each other. A

study conducted by Das et al. (2010), in India among 199 stroke caregivers shows that financial, physical and mental stress experienced by stroke caregiver and the influence of their familial and social relationships among them in an urban community setting. With regard to financial burden, the total direct and indirect cost of cerebrovascular disease and stroke in the United States for 2008 was estimated to be $297.7 billion compared to all cancer and benign neoplasm was $228 billion (Roger, Go, Lloyd-Jones and Benjamin 2011). According to American Heart Association (2012), every Americans will pay about $73.7 billion in 2010 for stroke-related medical costs and disability. In Singapore, the costs about US$5000 for hospitalization and treatment for stroke patient in acute care (Venketasubramanian and Chen 2008).

Most of the previous studies discussed on quality of life of stroke survivors but not really focus on the caregivers as the important person in caring for stroke patients (Gunaydin, Karatepe, Kaya and Ulutas 2011; Laurent et al. 2011; Owolabi 2008; Singhpoo, Charerntanyarak, Ngamroop, Hadee, Chantachume, Lekbunyasin, Sawanyawisuth and Tiamkao 2008). However, the caregiver's life maybe change because of new responsibilities related to providing care for stroke patient that may cause the burden for them that need to measure in this study. It is because, caregiver burden can affect the quality of caregiving and caregivers' own quality of life (Rosdinom, Norzarina, Zanariah and Ruzanna 2011). Bastawrous (2013) critically discussed regarding on caregiver burden based on conceptual, methodological and theoretical elements of caregiver burden. Other than that, caregiver burden is used to describe the extent to which caregivers perceive their social life, physical health, emotional well-being and financial status as being affected as the result of providing care (Rosdinom et al. 2011).

Being a female is a factor that has been measure by Kwon, Kim, Kwon and Kim (2005) that give impact on the caregiver burden in caring for stroke patients. Whereas, Fatimang and Rahmah (2011), showed that lower burden recorded when the carer responsibility is a common duty for female but in Korea study, being a daughter-in-law as a carer was inversely associated with caregiver burden (Kwon et al. 2005). Other than that, many wives who care for their husband that have stroke appeared increased in stress and anxiety as they become fatigue from being constantly on guard because not enough sleep on night and over protectiveness because of afraid to let them go (Green and King 2009). In addition, no published study regarding on caregiver burden among stroke patient in Kelantan setting especially in Hospital USM has been done before. Therefore, the researcher wants to measure the level of caregiver burden in carry out their routine in caring for stroke patients in Hospital USM setting either patients who warded or undergoes rehabilitation.

Theoretical framework applied in this study was Caregiver Identity Theory introduced by Montgomery, Rowe and Kosloski (2007) that have identified five phases of the caregiving career that are linked to changes in the care recipient's need for assistance. This theory was closely related to this study that want to measure the level of family caregivers burden in caring stroke patients in Hospital USM. All the phases in this theory explained the underlying premise of the model is that caregiving is a dynamic change process over the time. This change process includes changes in care activities, changes in the relationship between the caregiver and the care recipient, and changes in the caregiver's identity.

1.3 Research Objectives

1.3.1 General objective

To measure the level of burden among family caregivers in caring for stroke patients at Hospital USM.

1.3.2 Specific objectives

- To measure the level of burden among family caregivers of stroke patients
- To identify the socio demographic characteristics of family caregivers of stroke patients
- To identify the relationship between selected socio demographic data and level of burden among family caregivers in caring of stroke patients at Hospital USM

1.4 Research Questions

- What is the level of burden among family caregivers of stroke patients?
- What are the socio demographic characteristics of family caregivers of stroke patients?
- What is the relationship between selected socio demographic data and level of burden among family caregivers of stroke patients at Hospital USM?

1.5 Hypothesis

1.5.1 Null hypothesis

H_o : There is no significant difference between selected socio demographic data and level of burden among family caregivers in caring for stroke patients in Hospital USM.

1.5.2 Alternative hypothesis

H_A : There is a significant difference between selected socio demographic data and level of burden among family caregivers in caring for stroke patients in Hospital USM.

1.6 Definition of Terms (Conceptual/Operational)

1.6.1 Family Caregiver

Caregiver is one who contributes the benefits of medical, social, economic, or environmental resources to a dependent or partially dependent individual, such as a critically ill person (Mosby 2009).

It also can be define as one family member serves as the primary source of care for an impaired elderly person, although others in the network of family and friends may serve as secondary caregivers (Montgomery, Rowe and Koloski 2007).

1.6.2 Burden

Burden is a load. It is a heavy, oppressive load, as a disabling clinical load (Mosby 2009).

1.6.2 Caregiver burden

Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness. For example, a person caring for someone with a chronic illness may experience such stressors as financial strain, managing the person's symptoms, dealing with crises, the loss of friends, or the loss of intimacy (Tull 2008).

1.6.3 Stroke patient

The patient that diagnosed as stroke which is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (WHO 2012) and cause disabilities according to the severity of the cerebrovascular accident.

1.6 Significance of the Study

In this study, the researcher want to discuss more about the caregiver burden who take a part actively in caring for survival stroke patients who have been observed from the experienced among neighborhood. In the long term period in caring of the stroke patients, the caregivers may face the difficulties and may cause burden for them. This problem was serious because stroke patient usually fully depend on the family caregiver in completing the activities of daily living such as feeding, walking, clothing and others every day. It is supported by the previous study (Fatimang and Rahmah 2011) that showed the prevalence of caregiver burden was 35.4% in

University Malaya Medical Centre setting. It is considered as high prevalence that occurred in the real situation.

Apart from that, the burden of family caregivers not only in physical and spiritual aspect, but also in other aspects such as marital status, gender, family income and patient condition (Fatimang and Rahmah 2011) also be the factors that cause burden among family caregivers. The socio demographic factors are major aspect that involve in caring stroke patients because every patients depend on treatment and fully depend on family caregivers because of their limitation and disabilities. Many studies that have been done before measure the socio demographic data as the baseline that contributes to burden for caregivers (Fatimang and Rahmah 2011; Isaac, Stewart and Krishnamoorthy 2011; McCullagh, Brigstocke, Donaldson and Kalra 2005) show the prevalence of these factors.

Therefore, in nursing field, all the factors that related to patient's condition need to be involve in our nursing intervention to provide holistic nursing care included their family caregivers which the first person who will be carry out our duty when patients can be discharge. The burden level needs to be one of the nursing considerations in the nursing care. Then, their burden level need to be measure to ensure the family caregivers ready to take part as the caregivers that really challenging especially in disable patient like stroke patients.

This finding of this study will provide an insight and awareness regarding the burden experienced by family caregivers in caring for stroke patients during recovery period. The findings will help health professionals, other family members as well as

policy makers in providing appropriate support or resources to reduce the burden of family caregivers.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

As discussed in the introductory chapter, stroke is one of the chronic diseases (WHO 2012_a) and need someone who can be a caregiver for them to survive. Reviewing the literature that is available is relevant in learning more about the nature of stroke, type of the stroke, risk factor for stroke and effect of it to patients and caregivers. Other than that, this literature review also will explore the previous research literature regarding caregiver burden in caring for stroke patients and other chronic illness. Furthermore, this literature reviews also explores the socio demographic factors that may associated with caregiver burden. The other section in this part is theoretical framework that will discuss further regarding theory use in this study that relevance to be measure.

The dimension of caregivers burden can be varieties depend on severity of patient's condition and the socio demographic factors among caregiver that need to contribute for the long term period in caring for stroke patient. Stroke affects physical, cognitive and emotional functioning (National Stroke Association 2012) among the stroke patient. Therefore, it will cause the caregiver affected in physically because stroke patient who paralysis, they have limited movement and need help in move. Caregiver need to transfer the patient with use all the energy. Other than that, stroke patient also will affect caregivers by psychologically because they tend to be more sensitive and need people treat them as a little child. In other conditions,

psychosocial of the caregivers affected because they need to give full time care on stroke patient and cannot be socialize as before. All of these will be discussing further in this literature review based on previous study and others references.

2.2 The Nature of Stroke

According to WHO (2012_a), stroke is defined as rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin. The simple definition of stroke is a disruption of blood flow to the brain (Green and King 2009). Stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (WHO 2012_a).

Stroke also known as brain attack which occur when a blood clot blocks the blood flow in a vessel or artery or when a blood vessel breaks, interrupting blood flow to an area of the brain. When either of these things happens, brain cells begin to die (Alexander, Gorelick, Malone, Rao, Rymer and Zorowit 2003). The term "brain attack" is being used to suggest to health care practitioners and public that stroke is a medical emergency issue similar to a heart attack (Smeltzer et al. 2010). Therefore, it needs to be handling even more urgently than heart attack. It is because, every minute people lose getting treatment increases the chances of them experiencing stroke-related disabilities or death (Alexander et al. 2003).

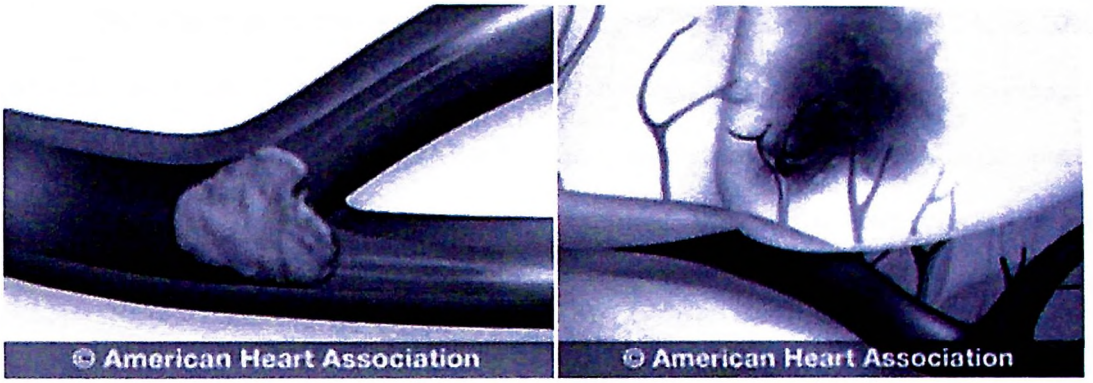
The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include

confusion, difficulty speaking or understanding speech, visual disturbance, difficulty walking, dizziness, loss of balance or coordination, severe headache with no known cause fainting or unconsciousness (Smeltzer et al. 2010).

According to a study that have been done by Hanun, Azidah and Monniaty (2012) in Kota Bharu regarding on recovery of stroke patient, the finding from that study indicates that majority of the patients achieved good functional outcome at 6 months, although only 19.4% had rehabilitation. The rehabilitation services in this country are low. Therefore, stroke patient are depending on the caregiver. However, majority of the patients lived with carer which means they had good social support. Study shows that people who have good social support after a stroke positively associated with good functional status (Hanun, Azidah and Monniaty 2012).

2.3 Types of Stroke

There are two types of brain attacks which is ischemic and hemorrhagic stroke (WHO 2012_a). With ischemic strokes, a blood clot blocks a blood vessel in the brain. With hemorrhagic strokes, a blood vessel in the brain breaks or ruptures. Figure 2 illustrate the types of stroke.



Ischemic stroke Hemorrhagic stroke

Figure 2: Types of stroke

Source: (American Heart Association 2012)

Ischemic stroke is most common. Ischemic stroke occurs when a blood vessel that supplies blood to the brain is blocked by a blood clot. This may happen in two ways where a clot may form in an artery that is already very narrow called a thrombotic stroke. The other way is a clot may break off from another place in the blood vessels of the brain, or from some other part of the body, and travel up to the brain. This is called cerebral embolism, or an embolic stroke (Zieve 2012). Ischemic strokes are subdivided into five different types based on the causes which are large artery thrombotic strokes, small penetrating artery thrombotic strokes, cardiogenic embolic strokes, cryptogenic strokes and other. The left hemispheric stroke can cause paralysis or weakness on right side of body, right visual field deficit, aphasia, altered intelectual ability and slow cautious behavior. Whereas, the right hemispheric stroke can cause paralysis or weakness on left side of body, left visual field deficit, spatial-perception deficit, increased distractibility and lack of awareness of deficits (Smeltzer et al. 2010).

The other type of stroke is hemorrhagic stroke which is account for 15 % to 20% (Smeltzer et al. 2010) caused by intracranial or subarachnoid hemorrhage. Hemorrhagic stroke are caused by bleeding into brain tissue, the ventricles or subarachnoid space. Subrachnoid hemorrhage resulted from a ruptured intracranial aneurysm. Another common cause of intracerebral hemorrhage in the elderly is cerebral angiopathy caused by beta-amyloid protein in the blood vessel in the brain. Secondary intracerebral hemorrhage is associated with arteriovenous malformation, intracranial aneurysms, intracranial neoplasms or certain medication such as anticoagulants (American Heart Association 2012).

2.4 Stroke Risk Factors

Stroke can attack anyone no matter their age, gender or race. However, the chances of having a stroke increase for people with certain risk factors or the criteria that can cause stroke. The risk factor of stroke can be divided into two which is modifiable risk factors and non modifiable risk factors (American Heart Association 2012).

2.4.1 Modifiable Stroke Risk Factors

The modifiable risk factors generally falls into two categories which is lifestyle and medical risk factors where it can be change and treat. The medical modifiable risk factors are hypertension, hyperlipidemia, diabetes mellitus and atrial fibrillation. Whereas, the lifestyles modifiable risk factors are obesity, sedentary lifestyle, smoking, and excessive alcohol consumption (WHO 2012_a).

For medical modifiable risk factors, hypertension or high blood pressure (140/90 mmHg or higher) is major risk factor for stroke. High blood pressure can damage blood vessels called arteries that supply blood to the brain (American Heart Association 2012). In addition, hyperlipidemia or high blood cholesterol and lipid also high risk factor for stroke. High cholesterol levels can contribute to atherosclerosis (thickening or hardening of the arteries) caused by a build-up of plaque (deposits of fatty substances, cholesterol, calcium). Plaque build-up on the inside of the walls of arteries can decrease the amount of blood flow to the brain. A stroke occurs if the blood supply is cut off to the brain. Atherosclerosis is a slow, progressive disease that may start as early as childhood (WHO 2012_b). Diabetes mellitus or high blood sugar also major risk factor for stroke because people with diabetes have two to four times the risk of having a stroke than someone without diabetes. Atrial fibrillation or an irregular heartbeat is the most powerful and treatable heart risk factor of stroke. About 15 percent of strokes occur in people with atrial fibrillation (Smeltzer et al. 2010).

The lifestyle modifiable risk factors, obesity or excessive body weight is the most common risk factor for stroke. Obesity is more likely can cause hypertension, diabetes and hyperlipidemia. Sedentary lifestyle or not active lifestyle also can contribute to obesity add with non healthy diet will contribute high risk factors of stroke. Smoking is doubles the risk factor for stroke when compared to a nonsmoker. When smoking, it reduces the amount of oxygen in the blood, causing the heart to work harder and allowing blood clots to form more easily. Smoking also increases the amount of build-up in the arteries, which may block the

flow of blood to the brain, causing a stroke (WHO 2012$_a$). Lastly, excessive alcohol consumption will raises levels of high density lipoproteins (HDL) cholesterol, often called "good" cholesterol. HDLs carry cholesterol to the liver where it is filtered out of blood and eliminated. Too much cholesterol in the blood causes plaque to accumulate in blood vessels and arteries, slowing blood flow and possibly leading to stroke. Alcohol is also considered to be a mild blood thinner, which may prevent clots from forming in blood vessels and causing a stroke (American Heart Association 2012). All the modifiable risk factors either medical or lifestyle can be treat and change to reduce the risk to have stroke.

2.4.2 Non Modifiable Stroke Risk Factors

Another type of risk factors of stroke is non modifiable risk factors. It is include the advance age, gender, ethnicity, family history and history of previous stroke or Transient Ischemic Attack (TIA). People with age more than 55 years old have higher risk. Men have a higher rate of stroke than that of women. Another risk factor is ethnicity, where African Americans are almost twice comparing to Caucasian Americans (Smeltzer et al. 2010). Family history and have history of previous stroke also give higher risk to get recurrent stroke.

2.5 The Effect of Stroke on Patients and Families

Stroke affects many dimensions of health and the effect of stroke on patients and families is complex and multifaceted, even for patients with the minor stroke. Therefore, the recovery from stroke is a process occurring over time (Green and King 2009).

However, stroke patients who survive from the acute illness frequently depend on informal caregivers for practical and emotional support. Stroke caused physical, cognitive and behavioral dysfunction of stroke victims (Das et al. 2010). In a study done in Korea, stroke patient may develop aphasia, dysarthria and cognitive dysfunction that contribute to burden among caregiver (Kwon et al. 2005). One aspect of stroke that has received limited attention in stroke caregiving is the cognitive changes that are a common consequence of stroke (Cameron, Cheung, Streiner, Coyte and Stewart 2006). Other than that, initial stroke severity was associated with more behavioral symptoms that will effect more functional impairment in stroke patient (Rush, McNeil, Gamble, Luke, Richie, Albers, Brown, Brott and Meschia 2010).

All of the chronic disorder that changed patient's disabilities like stroke will affect their family caregivers as well as other family members. Caregivers who live with chronically ill persons can experience consequences in four areas which are their personal life strain, social isolation, financial burden and intrinsic reward where physical impairments are associated with greater personal life strain and financial burden, while social impairment has a high impact on all four factors (Limpawattana, Theeranut, Chindaprasirt, Samanyawisuth and Pimporm 2012). The other domains in the study conducted by Cameron et al. (2006), shown that apathy, depression, and irritability of stroke patient did not make a significant contribution to caregiver depression.

2.6 The Experience of Family Caregivers in Caring for Stroke Patients

According to Limpawattana et al. (2012), high burden is face for the caregivers who care for the dementia, cerebrovascular disease (stroke) and advanced cancer patients. Among caregivers, there are 95% finding show that the family caregivers who face burden may show the abusive behavior to stroke patients out of frustration (Adika et al. 2012) and also happen in Malaysia when abusing happen for those caregivers who cannot continue care the patients but present of welfare house give the different perception when two of three from caregivers able to solve the caregiver burden (Fatimang and Rahmah 2011).

The lack of public financial support for stroke survivors because of their disability and limited employment opportunities, poses problems for caregivers in India especially among slum dwellers and less educated caregivers (Das et al. 2010). Unemployment of either patients or caregivers was a factor that affecting caregiver burden (Kwon et al. 2005). Similar situation also happen in Malaysia when economic factors contributed caregiver burden from the family who low income compare to higher income background that face low burden level in caring stroke patients (Fatimang and Rahmah 2011). It is because, most of a particular attention was paid need to provide by caregivers to calculation of cost of inpatient stay, cost of physicians and therapists, diagnostic visits, tests and drugs in the acute phase, together with an analysis of expenses for residential, nursing or sheltered home (Carlo 2009) that will impact their economic burden if they come from low income family.

In the other side, the factors of caregiver which is female, being unemployed, being patient's daughter in-law, having more than 15 hours of caregiving a day (Kwon et al. 2005), anxiety, depression and change in health status give high score in burden among family caregivers of stroke (Kwon et al. 2005; Adika et al. 2012). The respondents or caregivers who already married face lower burden in caring stroke patient's family because they may have own support from husband, child, family in-law and others that will support them in caring stroke patients (Fatimang and Rahmah 2011).

2.7 Stroke Caregiver Burden

Stroke patients who survived from acute phase usually need person that can give fully support during recovery period. Informal caregivers usually from family members who be the central to the process of post stroke care includes all treatment during hospitalization and home care after discharge from hospital (Cameron and Gignac 2008; Hung, Huang, Chen, Liao, Lin, Chuo and Chang 2012). Usually, stroke survivors' impairment and dependency often result in family caregivers feeling overwhelmed by new responsibilities as a caregiver.

Stroke survivors returning to the community often have difficulties performing every day activities like dressing, eating and mobility that can last well into the first year post-stroke. Generally, caregivers rarely receive preparation for their role and as a result, they often experience stress and negative health consequences that can additionally contribute to poor patient rehabilitation outcomes or threaten the sustainability of home care (Cameron and Gignac 2008).

A study in China revealed that caregiver's burden was independently associated with the severity of their depressive symptoms as well as patient's education level (Tang, Lau, Mok, Ungvari and Wong 2011). A few published studies demonstrated that family caregivers experience depression while caring for their stroke family members (Adika et al. 2012; Cameron and Gignac 2008; Epstein-Lubow, Beevers, Bishop and Miller 2009; Kwon et al. 2005). Inability to provide adequate care for their stroke family members caused depression and burden among the caregivers (Adika et al., 2012). Apart from that Denno, Gillard, Graham, DiBonaventura MGoren, Varon, and Zorowitz (2013) indicated that caregivers are more likely to have anxiety and depression when their burden increases. In other factors, the memory and comprehension behavioral and psychologic syndroms (BPS) of poststroke were strongly associated with depression symptoms in caregivers where lifestyle of caregivers interference due to caregiving, less personal control, and providing less caregiving assistance in care of stroke patient (Cameron et al. 2006)

Family functioning has an important influence on caregiver burden. According to Epstein-Lubow et al. (2009), conducted the study among 192 family caregivers to determine whether family functioning is associated with caregiver depressive symptoms during acute stage of stroke and the finding shows that 41% of caregivers experienced significant acute depressive symptoms were more pronounced for women, who less education and for those caregivers who experienced worse general health. Depressive symptoms also increase for caregivers who caring for a patient who was male or more functionally impaired and poor family functioning. It is supported by the study conducted

by Chiou, Chang, Chen and Wang 2009, shown that caregiver burden was likely to be higher when the caregivers had lower levels of family function and social support.

2.8 Theoretical Framework

The caregiver identity theory was developed by Montgomery and Kosloski in year 2000 (Montgomery, Rowe and Kosloski 2007). This theory addresses both the challenges and opportunities in providing assistance to family caregivers. This theory is an extension of the caregiver marker framework, which was advanced as a tool useful for guiding the design and delivery of support services. This theory show that the dynamic change process. It is includes change in care activities, change in the relationship between the caregiver and patient (care recipient) and changes in the caregiver's identity.

According to this theory, the caregiver role is out from the existing role in relationship, usually a familial role such as daughter, wife or husband. As the needs of the patient especially stroke patients increase in quantity and intensity over time, the initial familial relationship gives way to a relationship characterized by caregiving and changes in the caregiver's role and identity in relation to the patients. This identity change occurs because the care tasks that required in maintain the health of the patient become inconsistent with the expectations associated with the caregiver's initial familial role. This shift in identity is cause by significant increase in level of dependency of patient which is care recipient. This is important in part in this study which is related to dependency of patient on caregiver that may cause burden in caregiver that researcher want to measure in this study.

Montgomery and Kosloski have identified five phases for the caregiving career that are linked to changes in the patients that need for assistance. Figure 3 illustrates the five phases of caregiving career.

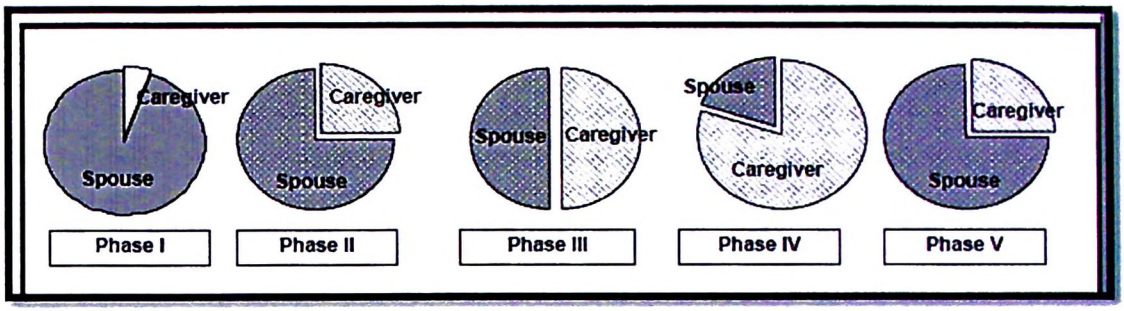


Figure 3: Caregiver identities mapped to phases of caregiving career

Source: (Montgomery, Rowe and Kosloski 2007)

Phase 1 is the period of career role onset. This period begins at the point that caregiver assists the care of patient in a manner that is not usually a part of the family caregiver's role. In this phase, caregivers are rarely aware of their caregiving role identity.

Phase 2 begins when the caregivers acknowledges that her or his care activities are beyond the normal scope of initial familial role. During this phase, caregiver is still maintaining her or his primary familial identity in relation to the patient but acknowledges the presence of the caregiver role. This point also the phase that career make self identification as a caregiver.

Phase 3 begin when the care needs of the care recipient increase in quality and intensity to a level that requires assistance that is substantially beyond the normal boundaries of the initial familial relationship. The caregiver is often confused between maintaining his or her initial identity as a relative and assuming the role of caregiver as a

primary identity. Caregivers who choose to continue with their caregiving tasks through Phase 3 usually increase the intensity of care they that provide over time to such an extent that the caregiver role comes to dominate the relationship between each other.

In Phase 4, in many family members they can continue for an extended time period during which the caregiver continues to revisit the option of nursing home placement.

The final phase which is Phase 5 in caregiving career, it's begin when the patient is moved to a setting that relieves the caregiver of primary responsibility for care, most often in a nursing home, assisted living facility or the home of another family member. During this final phase, the caregiver is often able to shift his or her primary identity back to initial familial role.

This theory is close related to this study regarding the caregiver burden in caring stroke patients in Hospital USM that researcher want to measure. It is because in this theory mention that in every phase for the caregiver that change their life and responsibilities from a special relation which is as family become a caregiver. In phase 1, the family involve need to accept the reality for the condition of the family members that diagnosed by stroke and their role immediately change to the caregiver for a disable person that really need help from the caregiver. For the next phase, the demands for the care that patient need may increase due to their condition that make the caregiver face a burden to take care of their family members. This is what the researcher wants to measure when someone takes care for someone who really depends on the caregiver. Then the final phase of this theory mention about the caregiver may send their relatives for other institution of nursing that will take their role as the caregiver in ensure the patient will