# Functional Disability, Nurses' Expectation and Caregivers' Participation in Caring for Patients with Stroke During Hospitalization

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**Master of Nursing Science Thesis in Adult Nursing**

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# Abstract

This study aimed to identify levels of functional disability of stroke patients, nurses' expectation and caregivers' participation in caring for stroke patient during hospitalization. The study also aimed to examine the relationship between functional disability and caregivers' participation in caring and between nurses' expectation and caregivers' participation in caring.

A cross-sectional study was conducted at the medical and surgical wards of Hospital Universiti Sains Malaysia (HUSM) that provide care for stroke patients during the rehabilitation phase from July to August 2003. The instruments of this study consisted of Functional Independence Measure (FIM) of stroke patients, Caregivers' Participation in Care Questionnaire (CPIC) and Nurses' Expectation of Caregivers' Participation in Care Questionnaire (NECPC).

Of the 51 stroke patients enrolled in this study, most (88 %) were Malay with Islam religion. Thirty-one (61 %) had 20 (39 %) cerebral infarction and 39 percent had hemorrhagic stroke. The result shows that mean of the total FIM score was 62.5 ranged from 18 to 126 (SD=37.2), corresponding to the level as modified dependence,

i.e. requiring more than 50% assistance from others. The result shows that 47.0 % of stroke patients were completely dependent, 41.2 % were modified dependent and 11.8% were independent. The majority of caregiver's of stroke patients were women (84.3%). Twenty-six of the 51 caregivers (51%) were children's of stroke patients, and 31 % were the spouse and the others were their relatives. The result shows that caregivers scored at moderate level in their participation in caring for stroke patients during hospitalization. The mean level of caregivers' participation in caring was 109.8, range from 41 to 158 (SD=21.1). The result shows that 27 from 51 caregivers (52.9%) demonstrated a moderate level of participation, and the rest a high level of participation in caring. There were 51 nurses who worked in medical and surgical wards that provided care for stroke patients and responded to the questionnaire. Mean level of nurse expectation on caregiver' participation was 136.7 ranged from 41 to 158 (SD=13.3). The result shows that all nurses had scored high expectation on caregiver's participation in caring. However, in bivariate analysis using 'Pearson correlation' there was no significant correlation between functional disability and caregivers' participation in caring ($r = 0.04$, $p > 0.05$) or between nurses' expectation and caregivers' participation in caring ($r = -0.06$, $p > 0.05$).

Nurses should encourage caregivers to participate more in caring for stroke patients in hospital settings and also as a guide in planning strategies especially to increase the quality of nursing care by decreasing length of hospitalization and decrease readmission. Further research is needed on caregivers involvement in caring for stroke patients during hospitalization in relation to identifying caregivers' understanding about caring responsibility, their competencies and confidence in providing care for stroke patients after discharge.

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Sabarisah Hashim

# CONTENTS

Page

CHAPTER

## CONTENTS(Continued)

## CONTENTS(Continued)

# LIST OF TABLES

## LIST OF TABLES(Continued)

## LIST OF TABLES(Continued)

# LIST OF FIGURE

# CHAPTER 1

# INTRODUCTION

## 1. Background and Significance of Problem

Stroke is considered as one of the major chronic illnesses in Malaysia. It causes death and disability. According to Fauziah (1999), stroke is the third leading cause of death and the highest cause of disability in the state of Selangor, Penang and the Federal Territory and has the fourth highest level of mortality in other states in Malaysia. In the state of Kelantan, the result of a study on stroke patients who were admitted to the Hospital University Science Malaysia from 1997-1998 showed that the mortality rate was 37 percent while another 63 percent survived but were disabled due to the stroke (Fauziah, 1999). This is similar to the situation in the West, where stroke is also the third leading cause of death and a leading cause of disability. In the United States, more than 730,000 individuals suffered a stroke each year. While in the United Kingdom, the incidence has been reported be about 2-2.5 per 1000 per year, with a prevalence of about 6 per 1000 per year (Hafsteinsdottir & Grypdonck,1996).

Stroke causes chronic disablement of the individual. It affects virtually all systems: motor, sensory, autonomic nervous system, balance, ambulation, speech, perception, cognition and mood. Stroke also alter the ability of the individual to carry out activities of daily living from very little impairment to serious functional loss (Whitney cited in Backer, 1994; Beare, 1994; Black & Jacob, 1992).Because of that, stroke patients required long-term hospitalization for specific investigation, treatment and rehabilitation nursing care (Nilsson, Aniansson & Grimby, 2000; Stauffacher, Lindquist, & Sarik, 2000; Whitney cited in Backer, 1994; Beare & Mayer, 1994). Stroke patients frequently require a caregivers to help them in meeting their healthcare needs and to help in activities of daily living. The degree of dependency and assistance need is determined by the severity of the disability, concurrent cognitive and medical deficits, and behavioral problems (Ozer, 2000; Vanetzian & Corrigan, 1995). The result of one study reported that the need of stroke patients for rehabilitation care and support from a caregiver was related to disability in functional activities at moderate to high level of functional independence when assessed using the FIM tool (Nilsson, Aniansson & Grimby, 2000).

Recently, caregivers' participation in caring for the stroke patients during hospitalization became crucial. Plenty of literatures had been written about family participation in the caring process (Brereton & Nolan, 1997; Bowman, Rose, & Kresenic, 1988; Brillhart, 1988; Bull, Hansen & Gross, 2000a; Bull, Hansen & Gross, 2000b; Evans, Bishop, Matlock, Stranahan, Halar & Noonan,1987a; Evans, Bishop, Matlock, Stranahan, Smith & Halar, 1987b; Kenney, O'Connor & Enterlante, 2000; Moore, Maiocco, Schmidt, Gua, & Estes, 2002; Reimer, Haan, Rjinders, Limburg & Bos, 1998; Watson, 1992). Caregivers are encouraged to participate in caring for stroke patients starting with identification of the stroke patient's needs, setting their priorities, planning their care, and evaluating the outcome of the care (Bull, Hansen & Gross, 2000a). The literature survey showed that participation of caregivers in the caring process promoted awareness among caregiver about their rights to be involve in the care of their family members (Cahill, 1996; Pritchard, 1989), their responsibility in taking care of their family members who were disabled, and their ability to be competent in care giving.

It is important to make caregivers realize the importance of appropriate care for stroke patients, to receive knowledge and caring skill, and gain competency in providing care for the stroke patients.

Caregivers should realize that participation in caring activities and provision of treatment for their family member during hospitalization can promote early recovery of stroke patients. This can be as a lesson in protecting stroke patients during crisis from a variety of stroke complications, reducing amount of medication required, accelerating recovery, and facilitating compliance to prescribed medical regimens (Berspang, Asplund, Eriksson & Fugl-Meyer, 1987; Ozer, 2000). Studies showed that stroke patients who had families participating in caring during hospitalization were able to return home sooner and demonstrated a more favorable outcome compared to those did not have positive family participation (Watson, Modeste, Catolico & Crouch, 1998). According to Bull, Hansen & Gross (2000a), the participation consided success depending on level of caregivers' participation in identifying their needs, setting their priorities, planning their care and evaluating the outcome of care.

Nurses who care for stroke patients in the hospital setting expected families' or caregivers to participate in the caring process especially in meeting stroke patients' health care needs and helping patients to function in self-care activities of daily living (Brereton & Nolan, 2002; Bull, Hansen & Gross, 2000b; Watson, 1989). The nursing goals of caregivers' participation in caring are to improve the quality of care to the stroke patients (Stauffacher, Lindquist & Sarik, 2000; Ozer, 2000). Quality care is the care that has the best outcome such as enhancing the patient's condition and recovery of a stroke patient (Berspang, Asplund, Eriksson & Fugl-Meyer, 1987). However, it does not represent on over-utilization of available resources (Skippper, 1993) but it can decrease the length of hospital stay because patients can be discharged early (Baker & Stem, 1993), decrease the cost of medical service and family (Stauffacher, Lindquist & Sarik, 2000) and enhance self-care and self-efficacy of caregiver in caring for a stroke patient (Watson, 1989). The other nursing goals of caregivers' participation in caring are to enhance caregivers' knowledge about stroke and to learn the specific skills that relate to the management at home (Brereton & Nolan, 2000; Bull, Hansen & Gross, 2000a). Participation of caregivers in caring were expected to decrease economic burden of the health care system, stroke patients and their caregivers (Stauffacher, Lindquist & Sarik 2000; Ozer, 2000).

Failure of caregivers involvement in caring will cause an increased length of hospital stay (Ozer, 2000), increased rate of stroke complication such as pneumonia, skin break, urinary tract infection, and painful shoulder (Davenport, Dennis, Wellwood & Warlow, 1996), depression (Mumma, 1986) and increased rate of readmission (Bull, Hansen & Gross, 2000a). So it is important for nurses in the hospital setting who care for stroke patients to include family members in plan goals, decision-making (Poulton, 1999), implementing caring activities and evaluating outcome of care (Bull, Hansen & Gross, 2000a; Cahill, 1996). Nurses should ensure that caregivers are comfortable and take an effective role as care provider (Moore, Maiocco, Schmidt, Gua & Estes, 2002). This is because caregivers are central in assisting stroke patients' recovery within the hospital and at home. In sharing the responsibility of caring for the patient in the hospital, caregivers are encouraged to have a good partnership and relationship with nurses and other healthcare providers (Duncan & Morgan, 1994; Schwartz & Vogel, 1990).

There are other factors that may influence participation of the caregivers in caring for stroke patients. Laitinen and Isola (1998) stated that health status, age, attitudes and length of hospitalization of the patient contributed to caregivers' participation both positively and negatively. A stroke patient who is disabled in functioning causes a burden to the healthcare system and caregiver. Stroke patients frequently depend on others for care and assistance for many activities of daily living. Studies had also showed that caregivers reported that participation in caring for stroke patients was associated with feelings of burden, tensions and dilemmas (Brereton & Nolan 1997; Reimer, Haan, Rjinders, et al., 1998). According to Watson, Modeste, Catolico and Crouch (1998), there were relationships between functional disability (include motor and cognitive functions) and level of caregivers burden in involving in caring. The researcher's found that cognitive alteration demonstrated the strongest correlation with caregiver burden during participation in caring. The feeling of burden is also associated with unwillingness to participate in care during hospitalization of stroke patients.

Another factor that inhibit' caregivers' participation in caring was the little awareness among them about their rights to participate in caring, to acquire information and advice and being prepared for a care-giving role (Brereton & Nolan, 2002). In fact caregivers of stroke patients have a right to be involved in caring for their family members (Pritchard, 1989 and Cahill, 1996).

The other factor was informal caregivers often receive little or no preparation for the caregiving role (Bull, Hansen & Gross, 2000a; Bull, Hansen & Gross, 2000b; Congdon, 1994; Moore, Maiocco, Schmidt, Gua, et al., 2002). It is influence by characteristics and attitudes of nurses, attention and support provided by nurses and communication between relatives and nurses (Bull & Kane, 1996; Congdon, 1994; Laitinen & Isola, 1996). These studies showed that family caregivers need information about patient condition, progress and plan of care however caregivers' educational and support needs were being poorly addressed. Lack of caregiver involvement in care of hospitalized patient' reflected the healthcare professionals' failure to involve caregivers in caring process (Congdon, 1994; Davis, 1980; Schirm & Collier, 1992 cited in Bull, Hansen & Gross, 2000a).

In the Hospital University of Science Malaysia (HUSM), there is an increased realization among health care staff about the importance of participation of caregiver in caring for stroke patients during hospitalization. However, in the hospital setting there are no guidelines on how to involve the caregivers in caring for their family members. Recently, the nursing staff responsible in managing stroke patients in a clinical setting realized that participation of caregiver the in caring for stroke patient will provide benefits for health care delivery system, for the stroke patients, and for caregivers. The level of participation of caregivers' in care for stroke patients is, however, still not achieved to a satisfactory level. After reviewing the literature, no nursing study was conducted in Malaysia on this care of hospitalized stroke patients with the functional disability, or nurses' expectation and caregivers' participation. It is therefore very important to explore the level of these relationships. The researcher hypothesized that, firstly, an increased functional disability is not related in to an increase in level of caregiver participation in caring during hospitalization and secondly an increase in nurses' expectation on caregivers' participation is not related to an increase caregivers' participation in caring.

The purpose of this study was to determine the level of functional disability after having a stroke, nurses' expectation of caregivers' participation in caring and the levels of caregivers' participation in caring for stroke patient during hospitalization. This study also examined or determined what the relationships between functional disability, nurses' expectation of caregivers' participation in caring and caregivers' participation in caring for stroke patients during hospitalization.

## 2. Objectives of the Study

1. To identify level of functional disability of stroke patients during hospitalization in HUSM
2. To identify the level of caregivers' participation in caring for stroke patients during hospitalization in HUSM
3. To identify the level of nurses' expectations on caregivers' participation in caring
4. To explore the relationship between functional disability and caregivers' participation in caring for stroke patients
5. To explore the relationship between nurses' expectation of caregivers' participation in caring and caregivers' participation in caring for stroke patients

### 3. Research questions

The study was conducted to answer the following research questions:

1. What is the level of the functional disability of stroke patients during hospitalization?

2. What is the level of caregivers' participation in caring for stroke patients during hospitalization?
3. What is the level of nurses' expectations of caregivers' participation in caring for stroke patients?
4. Is there any relationship between functional disability and caregivers' participation in caring for stroke patients?
5. Is there any relationship between nurses' expectation on caregivers' participation in caring and caregivers' participation in caring for stroke patients?

## 5. Theoretical framework and related concept

The concept of caring is used in developing the framework of caregivers' participation in caring and nurses' expectation on caregiver participation in caring for stroke patients with disability during rehabilitation stage (Figure 1). Participation in caring in a hospital setting is a shared responsibility and a mutual relationship between caregivers and nurses (Duncan & Morgan, 1994).

Caring for stroke patients during the rehabilitation phase focuses on participation of caregiver in the caring process during hospitalization (Baker & Stem, 1993; Brereton & Nolan, 2002; Watson, 1989). Nursing care of stroke patients includes assessing and determining the patient's problems and needs, care-planning, intervention of caring activities and evaluation of the outcome of care (Kozier, Elb, Blais & Wilkinson, 1998).

Stroke patients are usually disabled in many areas of functional abilities which include mobility, activities of daily living, communication and psychosocial and they frequently depend on others in meeting their needs in maintaining health and in activities of daily living (Beare & Myers, 1994; Black & Jacob, 1992; Whitney cited in Backer, 1994). Disability is defined as a limitation in performing certain roles and tasks that society expects an individual to perform. Functional disability refers to a an inability to carry out the basic activities of daily living, which includes self-care activities, mobility, bowel and bladder management, locomotion, communication and psychosocial activities (Beare & Myers, 1994; Black & Jacob, 1992; Theuerkauf, 1996; Whitney cited in Backer,1994). Functionally disabled persons frequently need assistance in those activities. The assistance may include human assistance from another individual, structural assistance such as adaptive equipment and assistive devices, or prolonged time requirement (Derstine & Hargrove, 2001).

Caregivers' participation in caring for stroke patient during hospitalization is an active process, where caregivers are involve in identifying stroke patients' problems, taking part in care-planning and decision-making, performing clinical or daily living skills and evaluating outcome of care received from the time of admission until discharge (Cahill, 1996; Saunders, 1995). stated that participation means "getting involved or being allowed to become involved in the decision –making process or delivery of service or the evaluation of a service or even simply to become one of a number of people consulted on an issue or matter" (Brownlea, 1987, pp. 605).

Nurses expect caregivers to participate in caring activities during hospitalization of stroke patients in order to enhance the good care for them by minimizing the effects of disability (Derstine & Hargrove, 2001; Secrest, 2002). Stroke caregivers are encourage to participate in the caring process in relation to enhance caregivers' knowledge about stroke and to learn the specific skills that relate to the management at home (Brereton & Nolan, 2000, Bull, Hansen & Gross, 2000b). Congruency between caregivers' participation in caring and nurses' expectation on caregivers' participation in caring is essential in increasing an early recovery of stroke patients, decreasing the length of hospital stay and decreasing burden in medical and family cost. The positive relationship between caregivers' participation and nurses' expectation indirectly indicates caregivers' knowledge and skills in the caring activities provide to stroke patients. The more nurses expect caregivers to participate in care, the more nurses can provide knowledge and skill needed for care giving. As a result, the caregiver will be able to participate more in these caring activities. These relationships also true in an opposite direction. The more caregivers participate in caring activities, the more nurses expectation.

## 6. Definition of Terms

### 6.1 Stroke patients

Stroke patients are patients admitted to hospital after a stroke attack with diagnosis of cerebral hemorrhage or infarction and during the rehabilitation stage.

### 6.2 Functional disability

Functional disability is defined as the inability of individuals to function independently in self-care activities which include self-care in mobility, activities of daily living, bowel and bladder management, communication and psychological activities. The assessment tool used to measure the level of disability is the Functional Independence Measure (FIM). The FIM was developed in 1983 by a task force of the

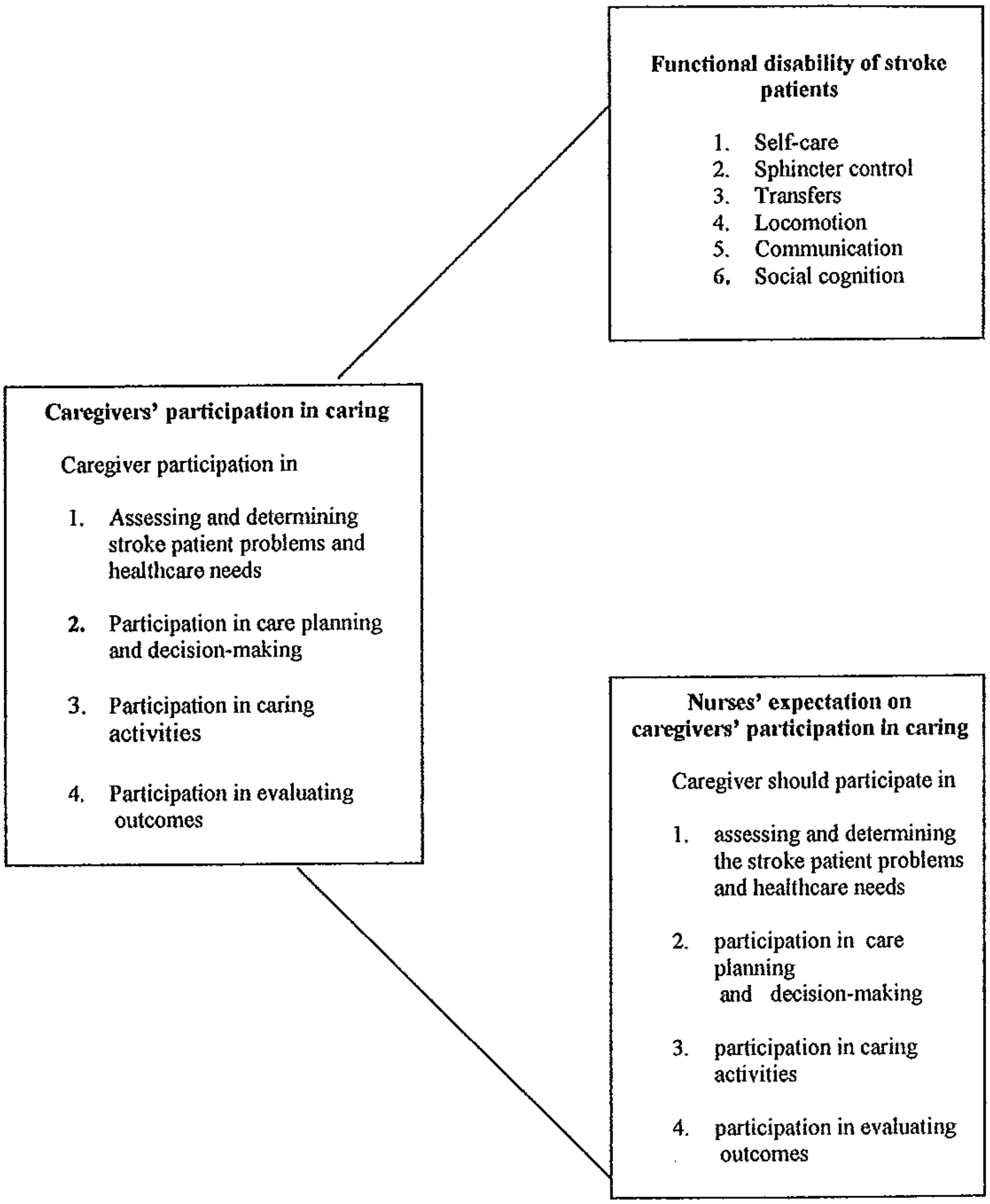

Figure 1 Framework to study the relationship between functional disability, nurses' expectation on caregivers' participation in caring and caregivers' participation in caring for stroke patients during hospitalization.

National Institute on Disability and Rehabilitation Research (NIDRR) and the American Congress of Rehabilitation Medicine (ACRM) see (Appendix B).

### 6.3 Caregiver

Caregiver is an individual (family member or significant other) who assumes primary responsibility for providing supportive actions that assist, support, or help stroke survivors in meeting their needs in activities of daily living and rehabilitation process during hospitalization.

### 6.4 Caregivers' participation in care

Caregivers' participation in care is defined as caregivers involving, sharing and interacting with nurses in participating in the caring process for stroke patients during hospitalization. It includes being involved in assessing stroke patient problems and healthcare needs, care planning and decision-making, caring activities and evaluating the outcomes of treatment and care. The levels of caregivers' participation in care are reflected in the items of a questionnaire developed by the researcher based on literature review in this study named as "Caregivers' Participation in Care" see (Appendix C).

### 6.5 Nurses' expectation of caregivers' participation in care

The nurses' expectation of caregivers' participation in caring for stroke patients during hospitalization in this study is defined as nurses' perception that caregivers should develop the capability in assessing and determining stroke patient problems and needs, care planning and decision-making, implementing nursing care for stroke patients, and evaluating the outcome of treatment and care. The level of caregivers participation in care is reflected in the items of a questionnaire developed by the researcher based on literature review in this study named as "Nurse Expectation of Caregivers' Participation in Caring' see (Appendix D).

## 7. Significance of the Study

The findings of this study will describe the level of functional disabilities of stroke patients, level of nurses' expectation of caregivers' participation in care and level of caregivers' participation in care. The results will be used to help nurses to understand the importance of caregivers' involvement in caring for stroke patients. The results of this study will be used as information in guiding nurses to develop a plan or as a model for caregivers' involvement in caring for stroke patients. Nursing management responsible for stroke management should use the results of this study as information to develop the capability required in involving caregivers in caring for stroke patients and also to plan strategies especially to increase the quality of nursing care, increase recovery of stroke patients, reduce the duration of hospitalization of stroke survivors, and decrease readmission.

# CHAPTER 2

# LITERATURE REVIEW

The literature related to the functional disability, nurse expectation and caregivers' participation in care for stroke patients in the rehabilitation phase during hospitalization was reviewed. The areas covered are the following sequence:

1. Overview of stroke
2. Impacts of stroke on functional ability of an individual
3. Caregivers' participation in caring for stroke patients during hospitalization
4. Nurses' expectation on caregives' participation in caring

## 1. Overview of the stroke

Cerebrovascular accident (CVA), or stroke, is an actual disruption of blood supply to a part of the brain resulting in ischemia and tissue death of that area of the brain and corresponding neurological deficits. The World Health Organization (WHO) defines stroke as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function with signs lasting 24 hours or longer or leading to death with no apparent cause other than of vascular origin" (Whitney cited in Backer, 1994). A stroke may be caused by one of two principal events: cerebral infarction or cerebral hemorrhage and classified as either ischemic or hemorrhagic. A national survey of stroke in the United States defined stroke more operationally, where stroke is a clinical syndrome consisting of a constellation of neurological findings, sudden or rapid in onset, which persists for more than 24 hours, and whose vascular origins are limited to: (a) thrombotic or embolic occlusion of a cerebral artery resulting in infarction, or (b) spontaneous rupture of a vessel resulting in intracerebral or subarachnoid hemorrhage. This definition excludes occlusion or rupture due to traumatic, neoplastic, or infection processes which produce vascular pathology (Whitney cited in Backer, 1994). Ischemic infarcts, which account for 85% of all strokes, include thrombotic and embolic strokes. Hemorrhagic strokes make up 15% of all strokes (Hock, 1999; Manzella, & Galante, 2000).

Thrombosis refers to a decrease in blood flow due to vessel stenosis or narrowing due to cholesterol or calcium build up in the vessel wall. A common area for thrombosis is at or above the bifurcation of the common carotid artery, but it can occur even in the smaller perforating vessels within the brain. Thrombotic strokes typically present with a gradual symptom onset. It can take hours to days for the full deficit to develop. Thrombotic stroke generally occurs during sleep; signs and symptoms are often present when the person arises in the morning.

Embolic strokes are caused by a sudden occlusion of an artery as a result of a clot that can originate from the heart (due to atrial fibrillation, a mechanical heart valve, or endocarditis) or from dislodgment of a thrombotic plaque. Embolic strokes occur suddenly and dramatically. Patients with histories of atrial fibrillation, valvular heart disease, coronary artery disease, hypercholesterolemia, diabetes, and cardiomyopathy are at risk for embolic strokes.

Hemorrhagic strokes are due to subarachnoid or intraparenchymal bleeding. A subarachnoid hemorrhage is due to a ruptured aneurysm, an arteriovenous malformation, or trauma. Intraparenchymal hemorrhages most frequently are caused by hypertension. Other causes are bleeding diathesis (for example, anticoagulant use) or vasculopathies. Hemorrhagic stroke occurs suddenly and without warning. The patient typically presents to the emergency room complaining of the "worst headache" of his or her life along with nausea and vomiting. They often have hypertension for 24 hours, but typically less than 20 minutes at the time.

A transient ischemic attack (TIA) is a neurological deficit that last less than 24 hours, but typically less than 20 minutes. TIAs are stroke-warning signs. Men have a 42% chance and women have a 24% chance of having a stroke within 5 years of having their first TIA (Hock, 1999; Manzella, & Galante, 2000)

Stroke affects people of all ages but predominantly the population over 60 years old (Manzella, & Galante, 2000). In East Malaysia, Fauziah (1999) who conducted a prospective study with first-ever stroke patients admitted to HUSM in 1997-1998, the results demonstrated that 56.3% of stroke was due to cerebral infarction, 33% was due to primary intracerebral hemorrhage and subarachnoid hemorrhage, and stroke of undetermined or uncertain type made up 7.6 % and 3.1% of stroke respectively.

Stroke causes alteration in motor, sensory, perceptual, and cognitive function of an individual. Alterations of motor function to the stroke patients are directly related to the cerebral blood vessel involved. After a stroke attack the patients frequently become hemiplegia or hemiparesis as a result from damage to the motor area of the cortex or to pyramidal tract fibers. Hemiplegia or hemiparesis may affect only the face, an arm, or a leg or may affect one entire side of the body and face but complete hemiplegia involves half of the face and tongue as well as the arm and leg of the same (ipsilateral) side of the body (Chin, Finocchiaro & Rosebrough, 1998).

Patients may also have sensory and perceptual alterations that are effects from hemispheric lesions such as hemianopsia, unilateral neglect, agnosia and specific deficits. The alterations occur through the visual, auditory, tactile or spatial sense. Hemianopsia or inability to see the whole or complete visual fields are visual deficits that is defective vision or blindness affecting the right or left halves of visual fields of both eyes (Chin, Finocchiaro & Rosebrough, 1998). Neglect is an alteration of the ability to reach to stimuli on the opposite side of the brain lesion, has been reported in 43 % of patients with stroke in the right hemisphere (Pederson, Jorgensen, Nakayama et al., 1997). Stroke patient may develop agnosia that is defined as a failure to recognize familiar objects perceived by the senses where there is no apparent sensory or intellectual impairment, it develop in 28 % of patients with right hemispheric lesion (Chin, Finocchiaro & Rosebrough, 1998).

After a stroke event, patients may have altered cognitive function. It occurs when the reticular activating system (RAS) is disrupted, leading to various neurobehavioral deficits such as; disorientation or confusion, memory loss, apathy, lack of initiation, decreased attention, impaired judgment, poor problem solving skills, inability to transfer learning from one situation to another and inability to calculate, reason, or abstract, emotional liability and lack of insight (Chin, Finocchiaro & Rosebrough, 1998).

Memory deficit can affect up to 95 percent of all stroke patients. Recognition of memory deficits can be complicated by aphasia (Lorish, Sandin, Roth, & Noll, 1994). Aphasia is a communication problem where the person has a defect in using and interpreting the symbols of language. Apraxia of speech occurs when a patient's ability to program speech muscles to produce sounds are impaired. Apraxia is usually associated with aphasia. Aphasia may involve any or all aspects of language use, such as speaking, writing, and understanding spoken language. It is associated with word apraxia usually resulting from damage to the left temporal and parietal lobes of the brain. Some patients demonstrate motor apraxia, a condition where an individual is either unable to perform a voluntary learned action on command, or may be able to perform the action spontaneously but cannot do so on command. Motor apraxia includes dressing apraxia- inability to dress self; limb apraxia- inability to plan and perform movements with arms and legs; and oral apraxia- inability to plan and perform movements with the tongue, jaw and lips (Bronstein, Popovich, & Steward-Amidei, 1991; Dittmar, 1989; Hickey, 1986).

### 2. Impacts of stroke on functional ability of an individual

Stroke causes some degree of disability of the individual to function as a normal human being, especially to function in activities of daily living include disability in self-care, mobility, communication and social interaction (Beare, 1994; Black & Jacob, 1992; Whitney cited in Backer, 1994). On impact from hemiplegia or hemiparesis initially following a stroke, a stroke patient is often immobile in bed, but as recovery occurs he begins to roll over in bed, then pulls himself into a sitting position, balances and finally transfers out of bed into a chair (Brandstater & Basmajian, 1987). Because of hemiplegia or hemiparesis a stroke patient is also at risk for developing complications such as skin breaks, pneumonia, urinary tract infection, and painful shoulder (Davenport, Dennis, Wallwood, & Warlow, 1996). A stroke patient needs to have regular exercises. Three joints must be exercised when performing a range of motions on the arm; the shoulder, the elbow, and the wrist. As the arm, three other major joints require exercise: the hip, the knee and the ankle (Bronstein, Popovich & Amidei, 1991).

Stroke patients are usually unable to perform basic activities of daily living (ADL), such as bathing, oral care, shaving, dressing, menstrual management, grooming, eating and using the toilet (Theuerkauf, 1996; Nilsson, Aniansson & Grimby, 2000; Hafsteinsdottir & Grypdonck, 1997; Chin, Finocchiaro & Rosebrough, 1998). The stroke patients need assistance in eating due to dysphagia or drowsiness. Results of studies with stroke patients showed incidence of dysphagia following stroke ranging from 50-59 percent. Stroke patients who are unable to eat need to be fed via a nasogastric tube. When the patients are free from tubes and intravenous cannulation, they need assistance to eat through oral feedings to maintain adequate nutritional status (Brandstater & Basmajian, 1987; Lorish, Sandin, Roth, et al., 1994). Caregivers need to learn how to feed the patient with caution in order to prevent aspiration of fluids or food into the bronchial tree that may unfortunately lead to debility, bronchopneumonia, delay rehabilitation program, death, or suffer nutritionally (Brandstater & Basmajian, 1987; Lorish, Sandin, Roth, et al., 1994). Lorish, Sandin, Roth, et al. (1994) stated that one third of dysphagia clients will aspirate, and 40 % of these will do so silently.

The stroke patients need assistance in urination due to incontinence. The incidence of urinary incontinence after stroke ranges from 38 to 60 percent in which the stroke patient may experience urinary retention, urinary incontinence, or urinary frequency (Gelber, Good, Laven & Verhulst, 1993). It is because a stroke patient with a persisting significant neurologic deficit has bladder dysfunction. A patient with hypotonic bladder may have difficulty initiating voiding, and the sacral reflexes mediating micturition are depressed. During hospitalization immediately after stroke, patients need an indwelling Foley's catheter which is usually inserted in order to prevent the bladder from filling beyond 500 ml, but its use leads to frequent complications such as cystitis, bladder stone, urethral ulcerations, periurethral abscess and epididymitis. After spontaneous voiding begins, a stroke patient can achieve better bladder control by using a posture that increases intraabdominal pressure, namely sitting on a commode or toilet seat, or standing to use a urinal (Beare & Myers, 1994; Black & Jacob, 1992; Brandstater & Basmajian, 1987; Whitney cited in Backer, 1994) however, Chin, Finocchiaro & Rosebrough (1998) stated that they still depend on others for bladder management because of the difficulty of transferring to the toilet or the inability to communicate-bladder fullness.

After a stroke, approximately 31 percent of all stroke clients experience alteration in bowel elimination. Problems most frequently encountered are constipation, fecal impaction, and bowel incontinence. A stroke patient usually becomes constipated in the first several weeks. Constipation and impaction happen because of problem of immobility, decreased fluid intake, low-fiber diet, or the patient's or family's inattention to bowel function. (Bronstein, Popovich, & Steward-Amidei, 1991). However, for the majority, bowel problems resolve spontaneously after 2 weeks (Lorish, Sandin, Roth, et al., 1994).

The other impact of stroke is contributes to difficulty in communication and social interaction, problem solving and memory (National Stroke Association, 1994 cited in Li Xiaoying, 1999). Inability to communicate can be both frightening and frustrating (Cochran, Flynn, Goetz, Potts-Nulty, Rece, & Sesenig, 1994). Mumma (1986) stated that ineffective communication can give a feeling of loneliness, stressful relationships with others, and social isolation, separating the stroke patients from pre-stroke recreational and social activities. Stroke patients often experience loss of control, depression and social isolation. As an effect from stroke, patients may have symptoms such as sadness, tearfulness, decreased interest in activities, weight gain and loss, insomnia or hypersomnia, fatigue, lack of energy, difficulty in concentration, restlessness, anxiety, constipation and hypochondriac preoccupation (Hayn & Fisher, 1997). That also may be misinterpreted as depression, cognitive impairment, or lack of motivation (Mumma, 1986). Dring, (1989); Galski, Bruno, Zorowitz & Walker (1993) stated that moderate or a severe higher level of cognitive deficits after a stroke event also causes difficulty in performing self-care activity, mobility and difficulty to learn new skills during the rehabilitation process.

It may cause them lose their jobs, recreational and social activities, which could make them dependent on their families in financial matters (Goodstein, 1983). Chin, Finocchiaro & Rosebrough (1998) found depression correlated significantly with failure to resume premorbid social activities, the depression patients reported a 67% decrease in social activities, while non depressed patients reported a 43% decrease in social activities. Johnson (1998) found that communication difficulties and confusion often experienced by stroke patients were a source of frustration to the caregiver. Stroke patients need support in order to cope with the emotional consequences after a stroke because successful coping with these feelings should result in acceptance and adaptation (Betehup cited in Barnett, 1987).

The life alteration experience of a stroke has long-term effect not only on stroke patients but also to healthcare delivery system and their caregivers. It causes a burden to healthcare delivery system and families in terms of caregiving and financial matters. Stroke patients need long-term nursing care not only during the acute, critical care but also during the recovery phase (Stauffacher, Lindquist & Sarik, 2000). After surviving from a critical condition following a stroke, stroke patients need appropriate treatment and care to prevent further neurological deterioration and need of specific medical and surgical therapy (Whitney cited in Backer, 1994). During the time when the physical movement increases, the rehabilitation usually starts. The rehabilitation phase for stroke patients begins after the medical and neurologic problem is stable from weeks to months (Ozer, 2000).

Assessment of the patients' functional abilities after stroke can be done during the rehabilitation phase to determine the level of disability faced by patients and level of dependence they need. Assessments of the patient's functional disability and independence of activities of daily living after stroke include mobility, self-care activities, elimination, communication and social cognition (Beare & Mayer, 1994). Mobility assessment is an evaluation of the patient's ability to move about in bed, sit and stand balance, walk, and transfer. Evaluation of self-care consists of the patient's ability to carry out dressing, grooming, toileting, bathing, eating and drinking. The elimination assessment consists of evaluating continence for both bowel and bladder. The patient's ability to communicate is assessed by evaluating his or her conversation as to intelligibility and appropriateness; the ability to read and write is also assessed. Cognitive assessment includes ability of the individual in social interaction, problem-solving and memory (Beare & Mayer, 1994). Several tools are available to measure functional abilities and changes over time for individual who are physically disabled after stroke such as Barthel Index, PULSES and Functional Independence Measure (FIM). According to Dittmar (1989), the FIM was developed in 1983 by a task force of the National Institute on Disability and Rehabilitation Research (NIDRR) and the American Congress of Rehabilitation Medicine (ACRM) (NIDRR, 1983; Guide for the Uniform Data Sets for Medical Rehabilitation (1993). The Functional Independence Measure (FIM) was designed to measure the degree of disability, which is relevant during inpatient medical rehabilitation. The FIM uses 18 items in which a patient's degree of disability and burden of care are apparent see (Appendix B). The FIM measures two domains of rehabilitation of motor and cognition function. Motor component consists of four dimensions: self care, sphincter control, locomotion, and mobility. Communication and social cognition in this tool constitute cognition function. Each item is rated according to the seven-level classification (Table 3.1). The patient's ability to perform the activities identified is scored on a seven–level scale representing gradations of independence and dependent behavior (Dodds, Martin, Stopor, & Dego, 1993).

### 3. Caregivers' participation in caring

Caregiver a an individual (usually family member) who assumes primary responsibility for providing supportive actions that assist, support, or help another person or group with evident or anticipated needs to improve a human condition or lifestyle (Leininger, cited in Wood, 1991).

Participation of caregivers in caring during hospitalization of stroke patient is a shared responsibility with a mutual relationship between caregivers and nurses (Duncan & Morgan, 1994). It shows that caregivers and nurses are able to share responsibility in caring for the patient during hospitalization (Schwartz & Vogel, 1990). Caregivers need to know what they are allowed to do and how they may do it in the somewhat frightening and strange enviroment of the hospital. An improved understanding of role definition would improve the quality of care (Schwartz & Vogel, 1990).

Participation in care demands the caregiver to develop capability to involve, share and interact with healthcare staff to assess and determine the stroke patients' problems and healthcare needs (Cahill, 1996). A key of participation is getting appropriate information (Brownlea, 1987; Cahill, 1996). It is important for caregivers to have an understanding about what had happened to stroke patients and be able to cope with the caring role (Watson, 1989). Caregivers should realize that they should have information and instructions from nurses on how to assess and determine changes in patient condition (Brauer, Schnidt & Pearson, 2001). Caregivers should know how to asesss neurologic change that is sufficient to cause alterations in the hemodynamics, balance, movement, and perception of the whole person (Brauer, Schnidt & Pearson, 2001). Brauer, Schmidt & Pearson (2001) stated that caregivers was identified the importance of getting clear information and understanding about medications, tests and treatments as well as wanting time for questions to be answered and resources. Information is an important aspect of learning new self-care behaviors related to helping to make intelligent decisions for patients under their care, and caregivers should be able to manage the chronic condition and prevention of recurrent stroke (Brauer, Schnidt & Pearson, 2001; Farzan, 1991; Watson, 1992). Caregivers wanted not only specific information about aspects of care management but also identified the need for more frequent contact with health professionals. Caregivers identified the desire to have time to ask questions regarding care issues, which can be time consuming. Caregivers needed and wanted written and verbal information on what had happened and what they could expect. Caregivers reported a need for good communication and support from nurses.

Participation in care planning implies a capability to make decisions and problem solving regarding patient' problems, need of treatment and care, ready to be involved in training programs (Brownlea, 1987; Cahill, 1996). Caregivers need to be as a consult person for stroke patient; they have to develop a capabilities to involve, share and interact with healthcare staff in participation in planning of care and decision-making for stroke patients. A consulted person's responsibilities are to identify patients' problems, to be able to select the appropriate consultant to ask about patient problems, to be able to communicate information about patient strength and problems, to be able to convey the information clearly and objectively and provide recommendations (Kozier, Elb, Blais & Wilkinson, 1998). They must keep themselves with adequate knowledge about stroke, treatment and care needed by stroke patients to facilitate decision-making. Poulton (1999) reported that participation in caring allowed caregivers to make decision in democratic situation. People were seen as being relevant to the decision-making process and problem solution and were seen as having some identification with those who might be affected by the decision (Brownlea, 1987). However, Congdon (1994) found that the decision-making usually were made by the health care professionals without participation of the family caregivers. Family caregiver voiced a lack of participation and control over decisions.

Caregivers also need to develop a capabilities to involve, share and interact with healthcare staff in participation in caring activities for stroke patients such as compliance with treatment plans , involve in providing medication, patient education and sharing information and taking part in physical care (Cahill, 1996). During hospitalization, patients are often unable to process new information and learn new skills because of illness or apprehension (Bowman, Rose & Kresenic, 1998). Family caregivers are encourage to participate in caring for stroke patients during hospitalization of stroke patients in order to have competency in providing care and support (Ozer, 2000). Participation of caregivers in caring for the stroke patient promotes capabilities among family members of their responsibility of their family member's health, and ability in caring and building self-efficacy (Watson, 1989). Stroke patients with hemiplegia usually depends on others in mobilizing for maintaining functional abilities, caregivers are demands to be involved in caring management such as transfer from chair to toilet, bathtub, encouraging patient to learn how to roll over in bed and pull himself or herself up to sit (Brandstater & Basmajian, 1987). Caregivers need to be involved and learn how to encourage patients to cooperate in performing range of motion exercises (ROM) several times each day to maintain strength in the muscles, reduce spasticity and to maintain joint mobility (Whitney cited in Backer, 1994). Caregivers should learn and practise with a nurse how to assist and facilitate self-care activities in general hygiene care and the physiological needs of the patients. They should help with simple activities such as bathing, shampooing, stripping, and managing bowel and bladder elimination. Caregivers should be involved in helping stroke patients to achieve better bladder control such as using a posture that increases intraabdominal pressure, namely sitting on a commode or toilet seat, or standing to use a urinal (Beare & Myers, 1994; Black & Jacob, 1992; Brandstater & Basmajian, 1987; Whitney cited in Backer, 1994). Besides being involved in bladder management, caregivers of stroke patient also have to be involved in bowel management. Caregivers involved in intervention to keep the patients with being adequately hydrated and ensuring an oral intake to keep the stool at the desirable level of fairly firm consistency can reduce the risk of bowel elimination problems. There should be sufficient fiber in the diet up to 15-20 gram daily (Beare & Myers, 1994; Black & Jacob, 1992; Brandstater & Basmajian, 1987; Whitney cited in Backer, 1994).

Caregivers need to assist the patients in eating and feeding such as enteral feeding via nasogastric tube because the stroke patient needs a consistency of the food in their diet. Caregivers should learn how to assist patients with dysphagia problems in eating and feeding therapy such as proper positioning when eating, exercises for strengthening the tongue and mastication, training breath control, and ice to stimulate movement and facilitate swallowing (Brandstater & Basmajian, 1987). After that they learn more complex activities such as changing positions, clapping patient's back and chest (to eliminate secretions), mobility as well as proper arm and leg exercises (Soparn, 2001).

Mental deficit, especially where communication is affected, produces greater negative influence on the patient as compared with the physical (Bronstein & Stewart, 1991). Stroke patient with 'fluent' aphasia usually use countless words and jargon which have no meaning but may be able to understand speech and gestures. The person with "non-fluent" aphasia may not be able to speak well and they unable to make sounds. Patients with these problems need a firm and slow speaking tone and survivors also have to speak the same in order to regain effective communication. In receptive aphasia, the patient's comprehension is impaired; he speaks fluently, but his speech may not make sense, and he may repeat words. Caregivers need to use gestures and printed material or talk to make communication clear. In mixed or global aphasia, the patient who has problems associated with both expressive and receptive aphasia, the nurse and caregiver need to identify the best communication method that would work (Hayn & Fisher, 1997).

Caregivers need to develop a capabilities to involve, share and interact with healthcare staff in participation in involving in evaluating the outcomes of treatment and care for stroke patients. Caregivers who were involved in treatment and care for stroke patients, deliver of hands on care, almost all the time stay with the patient and should participate in the evaluation outcome care for stroke patient (Brownlea, 1987).

Participation of stroke caregiver in caring during hospitalization is very important because it can promote early recovery of stroke patient. To ensure of stroke patients recovery, caregivers' need to learn nursing care skill to enhance competence in providing care after discharge. Caregivers need to feel confident on their care skills, adequate to allay their fear and worries that they might be delaying the stroke patient's recovery (Brereton & Nolan, 2000). Wilson-Barnett and Obourne (1983) stated, if the family have confidence in their own ability and have some knowledge of the recovery process, they are less likely to over protect the patient and discourage independence. Family participation in caring is success if stroke patients show improvement in functional activities were able to return home and demonstrated more favorable outcomes compared to patients who did not have positive family involvement (Baker & Stem, 1993; Dejong & Branch, 1982, Brandstster & Basmajian, 1987).

### 3.1 Factors influencing caregivers' participation in caring

There are factors that influence caregivers' participation in caring such as attitude of caregiver, age of the stroke patient, severity of illness, communication, attention and attitude of nurses toward caregivers' participation in caring. Involvement by caregivers in caring will provide beneficial outcomes to caregivers and stroke patients. Unfortunately, the literature stated that informal caregivers often receive little or no preparation for the caregiving role. Current research showed that participation in caring during hospitalization is often perceived negatively by families (Schirm & Collier, 1992; Congdon, 1994). Congdon (1994) using a grounded theory design, obtained data from patients, families and nurses, and showed that patients were ready for discharge but families were not and nurses were uncertain. The results also showed that there was support for the patient but no support was offered to families and families were not involved in decision-making. Schirm and Collier (1992) stated that caregivers lacked involvement in care because health care staff failed to involve the caregivers in caring activities.

The problems of functional disabilities on stroke patients require long-term rehabilitation care and the patient frequently depended on families or caregiver for meeting their needs in activities of daily living after discharge from hospital (Galski, Bruno, Zorowitz & Walker, 1993; Nilsson, Aniansson & Grimby, 2000; Watson, Modeste, Catolico & Crouch, 1998). Nilsson, Aniansson and Grimby (2000) found that stroke patients need physical and psychosocial support from caregivers. A stroke patient with functional disability after stroke often relies on family members for physical care, social contacts, emotional support and financial aid after discharge from the hospital setting.

However, caregivers have reported being inadequately prepared for patients' discharge, particularly in terms of patients' conditions, limitations, and needs when returning home (Bull, Hansen & Gross, 2000a). Families complained that hospital staff did not listen to them and besides they reported that nurses did not educate and train patients and family caregivers during the caring process (Rosenthal, 1993)

Much has also been written about family participation in rehabilitation (Bishop & Evans, 1987; Bowman, Rose & Kresevic, 1998; Watson, 1992; Brillhart, 1988). The literature, however, revealed no direct information on the relationship between caregiver participation and functional ability during acute rehabilitation in hospital and nurse expectation on caregiver participation in caring, but many reported that participation in the caring process for stroke patients was associated with a burden in terms of providing care and financial aid. Study showed that there were correlations between the functional disabilities of stroke patients with caregivers' burden. There were relationships between functional disability (including motor and cognitive functions) and caregiver burden in participation in care giving, attitudes and overall perception of caregiver responsibilities (Vanetzian & Corrigan, 1995; Watson, Modeste, Catolico & Crouch, 1998). They also stated that social cognitive alteration demonstrated the strongest correlation with caregiver burden, because the feeling of burden was related to participation in caring so they tried to avoid participation in caring.

The level of caregiver participation in caring for stroke patients of caregiving can only be partly predicted from stroke severity or patient's dependency in performance of daily activities. Furthermore, caregiver perception of support from professional care services will likely influence the level of their participation in caregiving (Bowman, Rose & Kresevic, 1998). Bradley (2003), reported that a pilot study was initially conducted using nursing students' assessments of 51 family caregivers. It was found that 46 (90.2%) of these caregivers required health teaching, 48 (94.1%) required referrals to other health care providers or community agencies, and 14 (27.5%) required home health services themselves.

Lack of communication is a main factor in inhibiting caregivers' participation in care. Caregivers reported a need for more discussion, advice and information from nurses, mutual care planning, more cooperation, more trust and support (Laitinen & Isola, 1996). Problems often stem from lack of communication between family caregivers and hospital staff. Moore, Maiocco, Schmidt, et al. (2002) stated that patients and families were often unaware that hospital staff engaged in planning for discharged families and reported a lack of communication with and trust in hospital staff. Bowman, Rose and Kresevic (1998), stated that lack of concordance between family caregivers and nurse perceptions of information sharing. Nurses reported giving patients and caregivers much information and many choices as part of discharge planning, while caregivers reported that they and their relatives had received little information and few choices. This makes sharing information and training with family caregivers essential to discharge planning. Families of hospitalized stroke patients have complained about the lack of information provided by hospital staff. Families rated the need for information to be among the highest of their needs (Hickey, 1986). In fact, families rated the need for information as more important than emotional or personal needs (Kleinpell & Powers, 1992). Caregivers described health care professionals as poor sources of information about important caregiving issues and health care professionals did not share information automatically, feeling that patients and families should specifically ask for it (Bowman, Rose & Kresevic, (1998).

The other factors that inhibit caregivers' participation in caring are the emotional and cognitive support given by the nurses to them (Brereton & Nolan, 2000; Laitinen & Isola, 1996). Relatives usually need more encouragement. They also need information and advice from staff when participating in care. Caregivers were required to pay attention at all stages of transition to care and the support from the nursing staff to gain self-efficacy. However the characteristics and attitudes of nurses can affect participation by relatives. Caregivers felt that they had received very little preparation to provide physical care for the stroke patients at hospital because nurses were too busy and the focus was on the needs of the stroke victim only. The lack of attention to caregivers being difficult to adapt to that situation, made it all the more difficult to understand about the disease and what had happened to stroke patients and a reduced feeling of self-efficacy. Several caregivers reported that information and skills training were only given in response to their direct request to be shown (Brereton & Nolan, 2000 ; Laitinen & Isola,1996).

### 4. Nurses' expectation on caregivers' participation in care

The nursing goal in caring for stroke patients is to assist stroke patients toward optimal health and wellness while the goals of nursing care in rehabilitation phase are to re-establish community life by reducing the degree of disability, establish a support structure to the extent necessary, prevent recurrent stroke, prevent stroke complications, mobilize the client and resume self-care activities (Rosebrough, Chin, & Finocchiaro 1998; Secrest, 2002). Nurses must assist these stroke patients and caregivers in the transition of care from structured health care settings to home settings. Nurses help individuals and families find meaning in the changes and in the new adaptations and are pivotal in coordinating patient and family. An explicit goal of rehabilitation nursing is to improve the quality of life of people with disabilities (Secrest, 2002). Nurses believed that families have a role in caring for stroke patient during rehabilitation period, and consequently they include family members in planning goals and in making discharge plan. Inpatient rehabilitation programs routinely schedule time for family education and for family conferences. Some families, however, do not participate in the rehabilitation process (Bowman, Rose & Kresenic, 1998).

In nursing perspective, caregivers should develop a capability to assess and determine the stroke patients' problems and health care needs concerning stroke, seriousness of patient illness and the impairments, prognosis for recovery, need for treatments, stroke prevention, skill training in enabling the person with stroke to be cared for safely, and problem-solving capability, leading to self-confidence and independent initiative to access resources as needed (Brereton & Nolan, 2000; Stauffacher, Lindquist & Sarik, 2000; Ozer, 2000). Nurses have a responsibility in educating and supporting patients and caregivers by providing the information they need to understand and cope with the sudden changes in their lives resulting from the stroke. Some studies indicated that nurses perceived questions asked by the relatives, and their willingness to participate in care, as criticisms (Laitinen & Isola, 1996). Kleinpell and Power (1992) stated that nurses perceived families as not wanting to participate in in-patient care and they believed that family members are uncomfortable in asking questions.

The nurse's role in caring for stroke patients is to encourage patients and their families to participate in care planning and decision–making process. Clayton (1988) reported that giving caregivers opportunities to participate in care planning and decision–making was beneficial. However the study revealed that staff's unwillingness to share decision making with the family, especially if a care plan has been developed without the family input (Johnson, 1987). Clayton (1988) suggested that nurses should provide a resource that caregivers required in order to enhance active in participation in decision-making. In participation in care planning and decision-making caregivers are allowed to be as a consulted person. Consultation takes place as the process where caregivers' opinions are sought on issues relating to stroke patients health care needs (Poulton, 1999).

Nurses expected that caregiver should participate caring for stroke patients during hospitalization in relation increase quality of care to patients. Quality of care is care that has the best outcomes, which enhance patient's condition and but does enhance recovery of stroke patients (Berspang, Asplund, Eriksson & Fugl-Meyer, 1987), does not represent over utilization of available resources (Skippper, 1993), does increase length of hospital stay (Baker & Stem, 1993), does not increase cost of medical service and family (Stauffacher, Lindquist & Sarik, 2000), enhance self-care and self-efficacy of caregivers in caring for stroke patients (Watson, 1989). The problem of disability associated with stroke causes a need for hospitalization to improve functional abilities. It needs nurses to assist the patients in meeting their needs in transfer such as to the bathroom, helping in self-care activities of daily living (Skipper, 1993).

To enhance caregivers' participation the caregiver-nurse relationship in involvement in caring should be based on basic interpersonal skills of respect, trust, authenticity and courtesy (Gallant, 2002). Caregiver and nurse should maintain a good relationship between each other such as good communication. The interaction between relatives and nursing staff has to be based on co-operation and equality. A trusting relationship is established through interaction between caregivers and nurse with empathic understanding (Brauer, Schmidt & Pearson, 2001). Participation of caregiver in caring activities needs a warm atmosphere and trustful relationship between caregiver and nurse, privacy and flexible visiting times in participation in care (Laitinen & Isola, 1996). Lack of a warm atmosphere and trustful relationship between caregiver and nurse is considered as the main factor in limiting informal caregivers' participation in care. Communication between caregivers, patients and nurses is important and encourages caregivers' participation. They need better communication and discussion about their possibilities and capabilities for helping the patient. Relatives want more information about the condition, illness and limitations of the patient. The nurse has to be empathic and understanding and gives her time to relatives. Nurses perceive that caregivers should be ready to learn caring skills to enhance competence in providing care after discharge (Brereton & Nolan, 2000). The nurse expects the caregiver to participate in evaluation of outcomes of treatment and care for stroke patients. Usually those who are involved in the evaluation outcome of treatment and care for stroke patients recognized that those who deliver hands-on care, almost all the time stay with the patient, have both knowledge and skill, and are involved in care plan and decision-making (Brownlea, 1987; Congdon, 1994). Nurses should allow caregivers' participation in evaluating change or improvement of patient condition, and report and discuss with nurses or the physician about patient condition and treatment. It is believed that this will improve the relationship between caregivers and healthcare staff and increase caregiver satisfaction related to care and treatment provided to a stroke patient (Bull, Hansen & Gross, 2000b, Brereton & Nolan, 2002, Brauer, Schmidt & Pearson, 2001; Watson, 1992; Watson, Modeste, Catolico & Crouch, 1998).

## Conclusion

Stroke can cause alteration in the physical and the cognitive ability of individuals. Stroke patients are usually admitted to the hospital for life saving, treatment, care, rehabilitation and prevention of complications. The alteration to physical and cognitive ability will cause an impact to independence in self-care activities of daily living such as mobility, bladder and bowel management, communication and social cognition. The deficit in the functional ability makes the stroke patients depend on others in meeting their needs in the activities of daily living. Usually families come forward to be caregivers to help the patients in meetig their needs in activities of daily living and to gain mobility. However, family caregivers are usually uncertain about what had happened to the patient, knowledge about stroke illness and how to provide care to the patient. In relation to that, caregivers participate in caring activities in the hospital to enhance adaptation to the new caring role, enhance their knowledge to be involved in decision-making, care provision and evaluation of outcomes of care to the survivor. The nurse also expects caregivers to be involved in caring for the survivor in the hospital.

# CHAPTER 3

# METHODOLOGY

The study was a cross-sectional study conducted during July 2003 to August 2003 to describe relationships between the level of functional disability of stroke patients, nurses' expectation, and caregivers' participation in caring for stroke patients during hospitalization in Hospital University of Science Malaysia (HUSM).

## 1. Target population and setting

The population of this study were stroke patients who were hospitalized during 1st,July until 31st August 2003 with caregivers and staff nurses who were working in the surgical and medical wards of Hospital University Science Malaysia (HUSM), Kubang Kerian Kelantan. HUSM is a teaching tertiary care center in Kelantan, a state in Malaysia. The hospital is a center of stroke care for both hemorrhagic and infarction stroke. It provides a referral center on the east coast of Malaysia.

The majority of the sample were new cases of stroke, either hemorrhagic or infarction. They were referred to HUSM for special investigation such as for CT-scan, MRI, specific surgical and medical management and rehabilitation. When the conditions of stroke patients become stable after specific management, they are referred back to the area of referral for continuation of care and treatment. The study was conducted in acute male and female medical and surgical wards at HUSM that provided care for stroke patients during the rehabilitation and recovery stage. The wards were Ward 2 Intan (Male surgical ward ), ward 3 Utara (Female surgical ward), ward 7 Selatan (Male medical ward) and ward 7 Utara (Female medical ward).

## 2. Sampling method

The accessible population consisted of stroke patients who were admitted in surgical and medical wards during rehabilitation stage.

### 2.1 Inclusion criteria

2.1.1 **Stroke patients**

(1) Diagnosed as having stroke either infarction or hemorrhage

(2) Hospitalized more than three days

2.1.2 **Caregivers**

(1) 18 years old or older

(2) A primary caregiver of hospitalized stroke patient. He/ she was identified as a person with the responsibility to stay and help the patient during hospitalization

(3) Willing and being able to participate in caring during the hospitalization of stroke patients

(4) Able to communicate with the researcher

2.1.3 **Nurses**

(1) Registered nurses

(2) Working in surgical or medical ward

### 2.2 Exclusion criteria

The stroke patients who were admitted to surgical and medical ward after surviving from the acute stage but with no caregivers during data collection period.

### 2.3 Estimating sample size

The researcher used power analysis in determining the specific sample size to identify the relationships between functional disabilities, nurses' expectation of caregivers' participation in caring and caregivers' participation in caring for stroke patients during hospitalization.

The sample size of this study was estimated at .05 level of significance (α); the power of .80 (1-β); and with effect size .40, Alpha of .05 has been adopted as the standard for the α criterion, whereas a conventional standard for 1-β is .80, and (γ) gamma of .40 is the medium estimated effect size (Munro, 2001; Polit & Hungler, 1999,p 494). Based on these criteria, the sample for this study was 50 for each group. These numbers are considered as medium sample sizes to explain nature of existing relationship using power analysis (Polit & Hungler, 1999). According to Burn & Grove (2001), medium effects sizes are acceptable in nursing studies because large sample sizes are difficult to obtain and require a longer data collection period and are costly.

The sample was collected at Hospital University of Science Malaysia for two months. The total admission of stroke patients both infarction and hemorrhagic at HUSM was about 250 to 300 per year. Based on this estimate these would be about 50 stroke patients will be admit in the 2 month period. The data were collected from July –August 2003. A total of 67 stroke patients were admitted to HUSM due to hemorrhagic stroke or cerebral infarction during this period of time. Of these, fifty-one patients (76.1%) fulfilled the inclusion criteria of the study and had caregivers to help during hospitalization. All nurses who work at the medical and surgical wards both male and female that care for stroke patients during rehabilitation phase were invited to participate in this study. There were 56 nurses, and from these, 51 nurses completely responded to the questionnaires. Thus the total subjects were 51 stroke patients with their caregivers and 51 nurses who worked in surgical and medical wards.

## 3. Method of data collection

The level of functional disability was obtained by assessing stroke patients using the Functional Independence Measure Tool (FIM). The level of caregivers' participation was identified using Caregivers' Participation in Caring Questionnaire (CPCQ) and the level of nurses' expectation was identified using Nurses' Expectation of Caregivers' Participation in Caring Questionnaire (NECPC).

## 4. Instrumentations

The instruments of this study consisted of instruments for stroke patient, caregivers and nurses.

### 4.1 Functional Independence Measurement (FIM) Tool

Begin in the recovery stage a patient was scored on the FIM by the researcher see (Appendix B). In relation to the demographic data of stroke patients, the questionnaire was designed to identify the age, sex, religion, marital status and diagnosis/ type of stroke. The FIM consists of two domains, motor and cognitive function. Motor function is divided to 4 sub domains; i.e. self-care, sphincter control, transfers and locomotion. Cognitive function is divided to 2 sub domains; i.e. communication and social cognition (Dodds, Martin, Stopor, & Dego, 1993). Scores for each item within a subscale were added to make section scores; these scores summed up to produce a total FIM score.

The total FIM scores range from 126 for high independence to 18 for high dependence. The scoring levels are categorized into independent functioning range from 91.1–126, moderate dependence range from 54.1-91 and high dependence on a helper range from 18.0- 54.

The total FIM sub motor scores range from 91 for complete independence to 13 for complete dependence. The scoring level can also be categorized into independent functioning range from 65.1 – 91.0, moderate dependence range from 39.1 – 65.0 and high dependence on a helper 13.0 – 39.0.

Similar to the domain of motor function, the total FIM sub cognitive scores range from 35 for complete independence to 5 for complete dependence. The scoring level also can be categorized into independent functioning range from 25.1-35, moderate dependence range from 15.1–25.0 and high dependence on a helper 5–15 (Gross, Goodrich, Kain & Faulkner, 2001; Nilsson, Aniansson & Grimby, 2000).

The FIM tool was used to identify the functional independence of stroke patients in relation to determine the severity of disability (Ottenbacher, Gonzales, Smith, Liig, Fiedler & Granger, 2001). The FIM tool is intended to measure what a patient is actually able to do. The rating of individual items focuses on the amount of assistance needed by the person to complete the activity being evaluated (Ottenbacher, Gonzales, Smith, Liig, Fiedler & Granger, 2001).

The patient's ability to perform the activities is scored on a seven–level scale representing gradation of independence and dependent behavior (Dodds, Martin, Stopov, & Dego, 1993) as the following.

**Table 3.1** Functional Independence Measure

| | |
|---|---|
| **Independence**<br>7 - Complete Independence (Timely, Safely)<br>6 - Modified Independence | No Helper |
| **Modified Dependence**<br>5 - Supervision<br>4 - Minimal Assistance (Patient = 75%+)<br>3 - Moderate Assistance (Patient = 50%+))<br>**Complete Dependence**<br>2- Maximal Assistance (Patient = 25%+)<br>1 - Total Assistance (Patient = 0%+) | Helper |

In order to ensure the reliability of the FIM tool used in this study the condition of each level (1-7) has been described ( APPENDIX E shown some example of the description).

### 4.1.1 **Validity and Reliability**

#### (1) **Validity**

The FIM scale is a standardized tool, and has been tested for its validity. The FIM is considered valid because it has been tested for validity in more than 50 medical facilities across the United States and found to have face validity. Pilot, trial and implementation studies since 1984 assisted the developers in establishing face validity (Granger, Cotter, Hamilton, & Fiedler, 1993).

### (2) Reliability

The FIM scale is a standardized tool, which was tested for reliability. The inter-rater reliability was .91 (Kenney, O' Connor & Enterlante, 2000) and interval consistency of total items found with the correlation coefficient of .96 (Ottenbacher, Gonzales, Smith, Liig, Fiedler & Granger, 2001).

On individual items, there was a high correlation on self-care, sphincter control, transfer and locomotion items (r =. 85), and the range of .72 to .84 was found on the five items in communication and social cognition (Dittmarr, Gresham, Foreword & Granger, 1997). The reliability was tested before starting collecting data over a 4 -day period in a sample of 10 in-patients with head injury and the value of Cronbach's Alpha was .97. The reliability was also retested in a sample of stroke patients that was involved in this study. A significant correlation was found in all item and the value of Cronbach's Alpha for FIM was .96. This is considered as high reliability (Burns & Grove, 2001).

### 4.2 Questionnaire for Caregivers' Participation in Caring

This part consists of the demographic data form of caregivers which was designed to identify (1) age, (2) sex, (3) religion, (4) marital status, (5) level of education, (6) present occupation, (7) relationship with patients, and (8) past experience related to caring for stroke patients. Caregivers' participation was measured using the Caregivers' Participation in Caring for stroke patients Questionnaire (CPCQ). The CPCQ for stroke patients is a 41 item questionnaire. The items were constructed based on literature review related to stroke patient's care during rehabilitation and caregivers' participation in caring (Brownlea, 1987; Beare, 1994; Black & Jacob, 1992; Cahill, 1996; Whitney cited in Backer 1994). The items covered four processes of care participation which include capabilities to be involved in assessing the stroke patients problems and health care needs (No 1-14), to be involve in care planning and decision making (No 15-21), to be involve in caring activities (No 22-38) and to be involve in the evaluating outcome of care (No 39-41). The level of participation in caring activities was measured on a four-point Likert scale with response choices ranging from (0) not applicable (1) never participate (2) rarely participate (3) often participate and (4) always participate.

Not applicable: indicates that the item was not relevant

Never participate: indicates that the caregiver had never been involved in caring activities for stroke patients

Rarely participate: indicates that the caregiver seldom participated (1-2 days during hospitalization) in this caring activities for stroke patients

Often participate: indicates that the caregiver moderately participated (3-4 days) in this caring activities for stroke patients

Always participate: indicates that caregiver had a lot of participation (more than 5 day) in caring activities for stroke patients

The mean score of each item was categorized into four levels; 1= never participate, 1.1 – 2 = rarely participate and 2.1- 3 = often participate and 3.1 – 4 = always participate. The total score of CPCQ for stroke patients' caregivers ranged from 41-164, the score of 164 indicating complete caregivers' participation in care and the scores 41 indicating complete non-participation in care. The subtotal score and total score of caregivers' participation were described using three levels, low, moderate and high. The scoring levels are categorized into (1) high participation range from 123.1- 164 (2) moderate participation range from 82.1 -123 and (3) low participation range 41-82.

### 4.3 Nurses' Expectation of Caregivers' Participation in Caring Questionnaire

The questionnaire consist of demographic data of nurses including (1) age, (2) sex, (3) present working place, (4) level of nursing education, (5) length of care experience for stroke patients, and (6) course attended related to stroke care. Nurses' expectation on caregivers' participation in caring was measured using the Nurses' Expectation of Caregivers' Participation in Caring Questionnaire (NECPC) for stroke patients. The NECPC consist of 41 items and the questionnaire comprises of four processes of participation in caring for stroke patient during rehabilitation in hospital including expectation to be involved in assessing and determining the patients' problems and health care needs, care planning and decision-making, caring activities and evaluating outcomes of care. Most of these variables and items were based on literature review on nurses' expectation on caregivers' participation in caring (Brownlea, 1987; Brauer, Schmidt, & Pearson, 2001; Brereton & Nolan, 2000; Cahill, 1998; Clayton, 1988; Congdon, 1994; Laitinen & Isola, 1996; Stauffacher, Lindquist, Sarik, 2000; Ozer, 2000; Watson, 1992; Watson, 1998). A four-point Likert scale, with a response choice ranging from (0) Not applicable (1) Strongly disagree (2) Disagree (3) Agree (4) Strongly agree was used.

Not applicable: indicates that the item was not relevant

Strongly disagree: indicates that the nurse strongly disagrees that caregivers participate in caring for stroke patients

Disagree: indicates that the nurse somewhat disagrees that caregivers participate in caring for stroke patients

Agree: indicates that the nurse agrees that caregiver participate in caring for stroke patients

Strongly agree: indicates that the nurse strongly agree that caregiver participate in caring for stroke patients

Mean scores for each subscale were calculated (sum of subscale score divided by number of item in each subscale). The higher score indicates the greater expectation on caregivers' participation in caring in each process of participation. There are positive and negative statements of items. Items number 1, 3, 4, 16, 17, 18, 19, 24, 25, 26, 29, 37 and 40 are negative items and were recorded reversely (4=1, 3=2, 2=3,1=4). If the sample scored at "Not Applicable" , the total score of the scale were (41-n) X 4.

The total score of NECPC ranged from 41-164 with the highest score of 164 indicating that nurses highly expect caregivers to participate in caring for stroke patient and lowest score of 41 indicating that nurses do not expect caregivers to participate in caring. The subtotal scores and total score of caregivers' participation were described using three levels, low, moderate, and high that was obtained by dividing the score by 3. The scoring levels are categorized into: (1) high expectation range from 123.1- 164 (2) moderate expectation range from 82.1 –123, and (3) low expectation range 41-82.

### 4.3.1 **Validity and reliability**

Content validity and reliability of the Caregivers' Participation in Care and Nurse Expectation of Caregivers' Participation in Care questionnaires were tested before collecting the data.

**(1) Validity**

Content validity of the English version of the Caregivers' Participation in Care and Nurses' Expectation of Caregivers' Participation in Care questionnaires was reviewed and analyzed by 2 experts in medical-surgical nursing and 1 from community nursing of the Faculty of Nursing, Prince Songkla University, Thailand. Each item was evaluated on the degree of relevance with constructed variables of caregivers' participation in care and nurses' expectation of caregivers' participation in care for stroke patients. The instruments were revised according to the experts suggestions. The Bahasa Malaysia versions of the two instruments were developed by translating from the English versions by the researcher. The congruency of Malay version and English version were confirmed by a linguistic expert from Research Development Department, Health Campus, University of Science Malaysia, Malaysia.

### ii - Reliability

Reliability of both instruments (CPCQ & NECPC) of the Bahasa Malaysia version was tested among 12 caregivers and 10 nurses before data collection. Cronbach's alphas were calculated for internal consistency using correlation coefficients. Cronbach's Alpha coefficient of CPCQ was .94 and NECPC was .92. Reliability coefficients of .90 are considered as high reliability because of .70 is considered acceptable coefficient value for a newly developed instrument (Burns & Grove, 2001).

## Data Collection Procedure

The data collection started after permission obtaining from the Hospital Director of HUSM. Data collection procedures consisted of the following steps:

1). Selecting subjects both stroke patients and caregivers according to the sampling criteria

2). Explaining the objectives of the study to each subject and assuring them of confidentiality, anonymity and freedom to withdraw from the study.

3) Obtaining written consent for participation

4). Assessing the level of functional disability using FIM tool for stroke patients

5). Having caregivers answer the questionnaire (CPCQ)

6). Selecting nurses according to the inclusion criteria and having them answer the questionnaire (NECPC).

## 6. Ethical consideration

Permission for conducting data collection was obtained from Ethics Committee of Faculty of Nursing , Prince of Songkla University, Ethics Committee of Pusat Pengajian Sains Perubatan, USM, and the Hospital Director, HUSM. A consent form for respondents in this study includes statements about the researcher, purposes of the study, assurance of subjects' anonymity, the voluntary nature of participating in the study, freedom to withdraw from the study at anytime, anticipated usefulness of results, and the name, address of the researcher and other contact person. A code number was put on each questionnaire instead of using the subjects name. The questionnaires were coded according to the entering sequence of the samples. A code number was put on every questionnaire and was deleted thereafter. A new code number, which cannot identify the subject, is sustained.

## 7. Data analysis

All data was entered and analyzed using the Statistical Package for Social Science (SPSS) for Windows version 11.5 using the following procedures.

1). Demographic data of caregivers, stroke patients and nurses were presented as mean, standard deviation, frequency and percentage.

2). Mean and standard deviation were used to analyze subtotal and total scores of functional disability, nurse expectation of caregivers' participation in caring and caregivers' participation in caring. Normality was checked for all the scores.

3). Bivariate correlational analysis was conducted to determine whether functional disability level was associated with caregivers' participation level in caring.

4) Bivariate correlational analysis was conducted to determine whether nurses' expectation level was associated with caregivers' participation level in caring.

5) Level of relationship was examine using correlation coefficient ($r$). The level of significance for all analyze was at 0.05.

# CHAPTER 4

# RESULTS AND DISCUSSION

Results of this study were based on data from 51-patient/caregiver pairs and 51 nurses who worked in the surgical and medical wards where stroke patients were admitted. A total of 67 stroke patients were admitted at HUSM due to hemorrhagic stroke or cerebral infarction during July to August, 2003. While the patients with cerebral infarction were placed in the general medical ward, the patients with intra-cerebral hemorrhage were placed in general surgical ward. Critically ill patients were warded in medical or neurological intensive care unit. Among the 67 patients, fifty-one (76.1%) fulfilled the inclusion criteria of the study. Sixteen stroke patients (23.9 %) were excluded due to being critically ill and all nurses who worked in surgical or medical ward are invited to participate in this study.

The results of this study will be presented as follows:

1. Subject characteristics
2. Functional disability level of stroke patients during hospitalization
3. Caregivers' participation level in caring for stroke patients during hospitalization
4. Nurses' expectations level on caregivers' participation in caring
5. Relationships between functional disability level and caregivers' participation level in caring for stroke patients
6. Relationships between nurses' expectation level of caregivers' participation in caring and caregivers' participation level in caring for stroke patients

## 1. Subject Characteristics

### 1.1 Stroke Patients' Characteristics

A total of 51 stroke patients were diagnosed as having intra-cerebral hemorrhage or infarction based on CT scan report. Thirty-one patients (61 %) were diagnosed as having cerebral infarction and 20 (39 %) as having hemorrhagic stroke. Table 4.1 shows that the patient's aged ranged from 35 to 84 years (M = 61.39, SD = 11.55) with twenty-two (43 %) were over 65 years of age. There were 20 women (39 %) and 31 men (61%). All patients were married. Forty-five patients were predominantly Muslims or Malay (88 %) and 6 (12 %) were Buddhists (Chinese).

**Table 4.1** Frequency and percentage of stroke patients' characteristic (n=51).

| Characteristic | Frequency | Percent |
|---|---|---|
| Age | | |
| 35 - 44 | 4 | 7.8 |
| 45 - 54 | 9 | 17.6 |
| 55 - 64 | 16 | 31.4 |
| 65 - 74 | 14 | 27.5 |
| 75 - 84 | 8 | 15.7 |
| Gender | | |
| Male | 31 | 60.8 |
| Female | 20 | 39.2 |
| Religion | | |
| Muslim | 45 | 88.2 |
| Buddhist | 6 | 11.8 |
| Marital status | | |
| Married | 51 | 100 |

### 1.2 Caregivers' Characteristics

The total of 51 caregivers were recruited in this study. Caregivers' age ranged from 18 to 65 years (Mean = 39, SD= 13). Table 4.2 shows characteristics of caregivers. Most caregivers were women (84.3%). Majority of them were Muslims (90.2 %), followed by Buddhists (7.8 %) and Christians (2.0%). Most caregivers were married (68.6%). The majority of caregivers were low of socio-educational status, i.e., 74.4 % have primary and secondary level of education, 11.8% had no education or 68.6 % were unemployed. Most of caregivers were children of stroke patients (51.0%), whereas others were spouses (31.4 %) or close relatives or grandmother/father or parent of the stroke patients (17.7%) and 68.6 % reported having no previous experience of taking care of stroke patients.

**Table 4.2** Frequency and percentage caregiver's characteristic ( n =51).

| Characteristic | Frequency | Percent |
|---|---|---|
| Sex | | |
| Male | 8 | 15.7 |
| Female | 43 | 84.3 |
| Religion | | |
| Muslim | 46 | 90.2 |
| Buddhist | 4 | 7.8 |
| Christian | 1 | 2.0 |
| Marital Status | | |
| Single | 15 | 29.4 |
| Married | 35 | 68.6 |
| Widowed | 1 | 2.0 |

**Table 4.2 (continue)**

| Characteristic | Frequency | Percent |
|---|---|---|
| Education | | |
| None | 6 | 11.8 |
| Primary school | 11 | 21.5 |
| Secondary school | 27 | 52.9 |
| Diploma | 1 | 2.0 |
| Bachelor | 5 | 9.8 |
| Post graduate | 1 | 2.0 |
| Occupation | | |
| Government / private employee | 8 | 15.7 |
| Own businessman | 2 | 3.9 |
| Unemployed | 35 | 68.6 |
| Others | 6 | 11.8 |
| Relationship with patient | | |
| Spouse | 16 | 31.4 |
| Children | 26 | 51.0 |
| Parent | 3 | 5.9 |
| Relative | 5 | 9.8 |
| Grandmother/grandfather | 1 | 2.0 |
| Past experience caring with stroke patient | | |
| Yes | 16 | 31.4 |
| No | 35 | 68.6 |

### 1.3 Nurses' Characteristics

There were 56 nurses working in the surgical and medical wards and having experience in caring for stroke patients during recovery stage. Out of these, 51 nurses participated in this study. Thirty-one nurses (60.8 %) were from surgical wards (male and female) and 20 (39.2 %) from medical ward (male and female). The nurses' age ranged from 22 to 46 years (Mean =32 SD = 7.8). Table 4.3 shows characteristics of nurses. All of them were female. Thirty-one nurses (60.8 %) had a diploma in nursing while 20 samples (39.2 %) had a certificate in nursing. Twenty-six (51 %) had more than 6 years experience in caring for stroke patients and another 19 (37.3 %) had experience of between 1 and 5 years, while 6 (11.8 %) had less than I year's experience. Fifty nurses (98 %) did not attend a specific course for nursing care and rehabilitation care for stroke patients.

**Table 4.3** Frequency and percentage of nurses' characteristics (n=51)

| **Characteristic** | **Frequency** | **Percent** |
|---|---|---|
| Gender | | |
| Female | 51 | 100 |
| Education level in nursing | | |
| Certificate | 20 | 39.2 |
| Diploma | 31 | 60.8 |
| Duration of experience in providing care for stroke patient | | |
| < 1 year | 6 | 11.8 |
| 1 - 5 year | 19 | 37.3 |
| > 6 years | 26 | 51.0 |

## 2. Level of functional disability of stroke patients during hospitalization

All patients were assessed for their functional disability level by FIM . Table 4.4 shows minimal score, maximal score, mean, standard deviation of item scores, subtotal scores and total score of the variable. Table 4.4 shows the total FIM was 62.5

ranged from 18 to 126 (SD = 37.2), indicating moderate dependence that required moderate assistance from an other or a caregiver.

**Table 4.4** Minimal scores, maximal scores, mean, standard deviation of item scores, and subtotal score and total FIM score (n = 51)

| **Variables** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|
| Self-care | | | | |
| A. Eating | 1 | 7 | 3.22 | 2.17 |
| B. Grooming | 1 | 7 | 3.29 | 2.24 |
| C. Bathing | 1 | 7 | 3.16 | 2.21 |
| D. Dressing-Upper Body | 1 | 7 | 3.18 | 2.21 |
| E. Dressing-Lower Body | 1 | 7 | 3.18 | 2.23 |
| F. Toileting | 1 | 7 | 3.06 | 2.23 |
| 2. Sphincter Control | | | | |
| G. Bladder | 1 | 7 | 3.47 | 2.54 |
| H. Bowel | 1 | 7 | 3.47 | 2.54 |
| 3. Transfer | | | | |
| I. Bed, Chair, Wheelchair | 1 | 7 | 3.00 | 2.10 |
| J. Tub Shower | 1 | 7 | 2.94 | 2.10 |
| K. Toilet | 1 | 7 | 2.94 | 2.10 |
| 4. Locomotion | | | | |
| L. Walk, Wheelchair | 1 | 7 | 2.69 | 2.01 |
| M. Stair | 1 | 7 | 2.41 | 2.01 |
| **Motor subtotal score** | **13** | **91** | **40.0** | **27.6** |

Table 4.4 (Continued)

| Variables | Min | Max | Mean | SD |
|---|---|---|---|---|
| 5. Communication | | | | |
| N. Comprehension | 1 | 7 | 4.78 | 2.32 |
| O. Expression | 1 | 7 | 4.65 | 2.44 |
| 6. Social Cognition | | | | |
| P. Social Interaction | 1 | 7 | 4.29 | 2.41 |
| Q. Problem Solving | 1 | 7 | 3.59 | 2.29 |
| R. Memory | 1 | 7 | 5.16 | 2.48 |
| **Cognitive subtotal score** | **5** | **35** | **22.4** | **11.3** |
| **Total FIM Mean** | **18** | **126** | **62.5** | **37.2** |

The total FIM was categorized into 3 level of independence in order to examine the prevalence of independence or dependence. Table 5 shows the frequency of patients categorized by independence level of total FIM scores showed that 47.1% of stroke patients were in high dependence, 41.2 % were in moderate dependent of requiring assistance, and 12 % were in independence that is no assistance was required for functional activities.

**Table 4.5** Frequencies and percentage of patient categorized by functional independence level of total FIM score (n =51).

| Level of Functional Independence | Score | Frequency | Percent |
|---|---|---|---|
| High Dependence | 18.0 - 54.0 | 24 | 47.0 |
| Moderate Dependence | 54.1 – 91.1 | 21 | 41.2 |
| Independence | 90.2 - 126.0 | 6 | 11.8 |

In addition, Table 4.4 also shows the mean scores of individual items, subtotal motor and subtotal cognitive scores. The mean subtotal motor scores was 40.0 (SD =27.6), indicating moderate dependence that required moderate assistance from others or caregivers . The mean ability of stroke patients to complete the activities to meet their needs in activities of daily living i.e. to eating, grooming, bathing, dressing, toileting, controlling bowel and bladder, transfer from bed to chair or wheelchair, tub showering and walking or using wheelchair or climbing the stair, was 2.41 to 3.47 (ranged from 1 to 7 level of independence). Most stroke patients required moderate to maximal assistance from others or the caregiver in particular activities. The frequency of independence level in motor function shows that 54.9 % of stroke patients had high dependence, 31.4 % of stroke patients were in the category of moderate dependent, and 13.7 % were independence in physical activities due to alteration in motor function.

**Table 4.6** Frequency of independence level in motor subtotal score (n = 51)

| Level | Score | Frequency | Percent |
|---|---|---|---|
| High Dependence | 13.0 – 39.0 | 28 | 54.9 |
| Moderate Dependence | 39.1 – 65.0 | 16 | 31.4 |
| Independence | 65.1 – 91.0 | 7 | 13.7 |

For the cognitive subscale of FIM, the mean score was 22.4 ranged from 13 to 91 (SD = 11.3), indicating moderate dependence that required moderate assistance from others or caregivers in communication and social activities. The ability of stroke patients to function effectively in communication and social ability was 3.59 to 5.16 (ranged from 1 to 7). The frequency of independence level in cognitive function shows that 33.3 % were in level of high dependence, 29.4 % were in moderate dependence and 37.3 % were independent in cognitive function (Table 4.7).

**Table 4.7** Frequencies and percentage of patients categorized by independence level of cognitive subtotal score (n=51)

| **Level** | **Score** | **Frequency** | **Percent** |
|---|---|---|---|
| High Dependence | 5.0 – 15.0 | 17 | 33.3 |
| Moderate Dependence | 15.1 – 25.0 | 15 | 29.4 |
| Independence | 25.1 – 35.0 | 19 | 37.3 |

## 3. Level of caregivers' participation

Table 4.8 shows the total level of caregivers' participation was 109.8 ranged from 41 to 164, (SD 21.1) which indicate moderate participation. The score is categorized from high participation range from 123.1- 164, moderate participation range from 82.1 -123 and low participation range 41-82. bout half (52.9 %) of caregivers were in moderate level and 47.1 % were in high level (Table 4.9).

**Table 4.8** Minimal, maximal score, mean, standard deviation, skewness and kurtosis of caregivers' participation in caring (n = 51)

| Variables | Min | Max | Mean | SD | Skewness | Kurtosis |
|---|---|---|---|---|---|---|
| Caregivers' participation in caring | 67 | 158 | 109.8 | 21.1 | 1.72 | - 0.33 |

**Table 4.9** Frequencies and percentage of degree of caregivers' participation in caring (n= 51)

| Degree of Participation | Possible score | Frequency | Percent |
|---|---|---|---|
| Low participation | 41.0 - 82.0 | 0 | 0 |
| Moderate participation | 82.1 - 123.0 | 27 | 52.9 |
| High participation | 123.1 - 164.0 | 24 | 47.1 |

The level of caregivers' participation scores were analyzed. Tables 4.10, 4.11, 4.12 and 4.13 shows the mean, standard deviation and subtotal score for every part of caregivers' participation. All items of participation were scored by four levels, which were 1 = never participate, 1.1 – 2 = rarely participate, 2.1- 3.0 = often participate, and 3.1 – 4 = always participate. The score for each items were analyzed by three categories, 1-2 = low participation, 2.1-3 = moderate participation and 3.1 – 4 = high participation.

**Table 4.10** Mean, standard deviation and subtotal mean of caregivers' participation in assessing and determining stroke patients' problems and needs (n =51)

| **Variables** | **n** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|---|
| 1. Observe changes in patient's condition (e.g. breathing, sweating, consciousness, etc). | 51 | 1 | 4 | 3.35 | .91 |
| 2. Observe skin integrity | 49 | 1 | 4 | 2.96 | 1.10 |
| 3. Ask nurse concerning the severity of patient's illness | 51 | 1 | 4 | 2.65 | 1.11 |
| 4. Ask nurse about treatment(s) of stroke patient under your care | 51 | 1 | 4 | 2.41 | 1.21 |
| 5. Assess patients' ability to mobilize | 51 | 1 | 4 | 3.14 | .84 |
| 6. Assess patient's ability to perform hygienic care | 51 | 1 | 4 | 3.63 | .72 |
| 7. Assess swallowing ability by observing for choking | 50 | 1 | 4 | 3.04 | 1.18 |
| 8. Assess patient's ability to communicate | 50 | 1 | 4 | 3.33 | .93 |
| 9. Assess patient's needs in social interaction | 50 | 1 | 4 | 3.47 | .85 |
| 10. Assess patient's ability to make a decision | 50 | 1 | 4 | 3.33 | .95 |
| 11. Assess emotional response and needs of the patient | 50 | 1 | 4 | 3.02 | 1.12 |
| 12. Report change(s) of patient's condition(s) to nurses or physician | 51 | 1 | 4 | 2.51 | 1.23 |

**Table 4.10(Continued)**

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 13. Report patient's ability to perform activities of daily living to nurses or physician | 51 | 1 | 4 | 2.24 | 1.24 |
| 14. Report emotional and social need of the patient to nurses or physician | 51 | 1 | 4 | 1.96 | 1.14 |
| **Subtotal score** | | **14** | **56** | **41.03** | **8.6** |

* Subtotal score Low participation = 14 - 28
Moderate participation = 28.1 – 32
High participation = 32.1 – 56

Table 4.10 shows them mea subtotal mean items score of caregiver's participation in assessing and determining stroke patients' needs was 41.03 (SD = 8.6), indicating high participation when the score was categorized into 3 levels of participation (Low = 14 to 28 , moderate =28.1 to 42 and high = 42.1 to 56). The caregivers participate at high participation (3.02 to 3.63) in observed changes in patient's condition, assess patient's ability to mobilize, perform hygienic care, swallow, communicate and to make decision, the patients' emotional response and also the patient's need in social interaction (range from 1 to 4 in participation). Caregivers scored at moderate participation (2.24 to 3.0) in observed skin integrity, asking nurses concerning the severity of the patient's illness, treatment(s) and patient condition(s) under their care and reporting the patient's ability to perform activities of daily living to the nurse. Caregivers showed low participation (1.96) in reporting emotional and social need of the patient to nurses.

**Table 4.11** Means, standard deviations and subtotal mean scores of caregivers' participation in care planning and decision-making (n =51)

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 1. Be a consulted person in care planning and decision- making | 51 | 1 | 4 | 2.65 | 1.19 |
| 2. Give suggestions to nurses/physicians during care planning | 51 | 1 | 4 | 1.53 | .94 |
| 3. Make a decision regarding treatment for stroke patient | 51 | 1 | 4 | 1.73 | 1.13 |
| 4. Make decision regarding the cost of treatment | 51 | 1 | 4 | 1.61 | 1.11 |
| 5. Identify other resources in helping you in caring for the stroke patient (money, equipment, etc) | 51 | 1 | 4 | 2.61 | 1.15 |
| 6. Create a good relationship with nurse or physician | 51 | 1 | 4 | 3.24 | .88 |
| 7. Inform nurses that you take responsibility and accountability for the outcome of treatment | 51 | 1 | 4 | 2.00 | 1.29 |
| **Subtotal score** | | **7** | **28** | **15.35** | **4.92** |

| * Subtotal score | Low participation = 7 -14 |
|---|---|
| | Moderate participation = 14.1 - 21 |
| | High participation = 21.1 -28 |

Table 4.11 shows that the mean subtotal score of caregivers' participation in care planning and decision-making was 15.35 (SD = 4.92), indicating moderate level. Caregivers scored at low to moderate participation ( 1.53 to 2.61) in many items of participation in care-planning and decision-making except item number 20, where the caregivers' shows that they highly participated highly in creating a good relationship with nurse or physician (mean 3.24).

**Table 4.12** Means, standard deviations and subtotal mean caregivers' participation in caring activities (n =51)

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 1. Position the patient properly | 48 | 1 | 4 | 2.61 | 1.20 |
| 2. Change position every two hours. | 45 | 1 | 4 | 1.80 | 1.09 |
| 3. Help nurses during suctioning procedure | 33 | 1 | 4 | 1.25 | 1.32 |
| 4. Monitor oxygen administrative device(s) | 33 | 1 | 4 | 1.41 | 1.44 |
| 5. Assist patient to meet nutritional need such as monitor intravenous administration/tube feeding/oral feeding | 47 | 1 | 4 | 3.20 | 1.26 |
| 6. Mobilize stroke patient such as from bed to chair or vice versa using correct transfer techniques and by using a wheelchair | 50 | 1 | 4 | 2.33 | 1.30 |
| 7. Encourage stroke patient to perform movement as early as possible after stroke | 50 | 1 | 4 | 2.37 | 1.09 |
| 8. Perform exercise on patient's limbs | 50 | 1 | 4 | 2.31 | 1.19 |
| 9. Help patient to meet hygienic needs including bathing, grooming and dressing | 50 | 1 | 4 | 3.71 | .83 |
| 10. Help patient in defecation | 50 | 1 | 4 | 3.51 | 1.06 |
| 11. Help patient in urination | 50 | 1 | 4 | 3.67 | .90 |
| 12. Help patient to communicate with other | 50 | 1 | 4 | 2.84 | 1.10 |
| 13. Listen and be with patient when she/he expressing their feeling(s) | 51 | 1 | 4 | 3.51 | .83 |
| 14. Give emotional support by touching, praying for stroke patient(e.g. depend on your culture) | 51 | 1 | 4 | 3.39 | .80 |

**Table 4.12 (Continued)**

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 15. Provide means to promote or improve patient orientation(e.g. speak with stroke patient, provide music). | 51 | 1 | 4 | 2.22 | 1.18 |
| 16. Help nurses to give oral medication to the patient | 51 | 1 | 4 | 2.53 | 1.31 |
| 17. Prevent fall injury (e.g. raising siderails) | 48 | 1 | 4 | 3.22 | 1.22 |
| **Subtotal score** | | **17** | **68** | **45.88** | **9.9** |

* Subtotal score
Low participation = 17 - 34
Moderate participation = 34.1 -51
High participation = 51.1 -68

Table 4.12 shows that the mean subtotal score of caregiver participation in caring activities was 45.9 (SD = 9.9), indicating moderate participation when the score was categorized into 3 level of participation (Low = 17 to 34 , moderate = 34.1 to 51and high =51.1 to 68 ). Caregivers scored at high participation in activities of daily living skill such assisting the patient to meet nutritional need, defecation and urination, intervention to prevent fall and psychosocial support (range of mean from 3.20 to 3.71). Skill that needed proper technique, however, were scored at moderate participation such as positioning, mobilizing the patient, exercising, helping patient to meet hygienic needs include bathing, grooming and dressing, promoting orientation and helping nurses to give oral medication (ranged of mean from 2.22 to 2.61). Caregivers also showed low participation in changing position every 2 hours, suctioning procedure and monitoring oxygen administration (range of mean from 1.25 to 1.80).

**Table 4.13** Mean, standard deviation and subtotal mean scores of caregivers' participation in evaluation outcome of care (n = 51)

| **Variables** | **n** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|---|
| 1. Observe changes/improvement of patient conditions after care | 51 | 2 | 4 | 3.71 | .61 |
| 2. Discuss with nurse or physician regarding treatment and care provided | 51 | 1 | 4 | 2.02 | 1.30 |
| 3. Report your certain difficulty(ies) about your participation in care to nurse or physician. | 51 | 1 | 4 | 1.80 | 1.14 |
| **Subtotal score** | | **4** | **12** | **7.52** | **2.28** |

* Subtotal score
Low participation = 3 - 6
Moderate participation = 6.1 - 9
High participation = 9.1 – 12

Table 4.13 shows the mean subtotal scores of caregivers' participation items in evaluating outcome of care was 7.52 (SD = 2.28), indicating moderate participation when categorized into 3 level of participation (Low 3 to 6 =, moderate = 6.1 to 9 and high = 9.1 to 12). Caregivers had high participation in observing changes/ improvement of patient condition and moderate participation in interacting with nurse or physician regarding treatment and care and provided.

## 4. Level of nurses' expectation

Table 4.14 shows the total score of nurses' expectation on caregivers' participation in caring was 136.7 ranged from 41 to 164 (SD = 13.35). The total scores indicate high level of expectation when the score was categorized into high expectation ranged from 123.1- 164, moderate expectation range from 82.1 -123 and low expectation range 41-82. Nurses (100 %), scored high expectation that the caregiver should participate in caring activities (Table 4.15).

**Table 4.14** Minimal, maximal scores, mean, standard deviation, skewness, and kurtosis of nurses' expectation on caregivers' participation (n =51)

| Total Score | Min | Max | Mean | SD | Skewness | Kurtosis |
|---|---|---|---|---|---|---|
| Nurses' expectation on caregivers' participation | 112.0 | 163.0 | 136.7 | 13.35 | 0.71 | -1.17 |

**Table 4.15** Frequency and percentage of nurses' expectation on caregivers' participation in caring for stroke patients

| Degree of Expectation | Range | Frequency | Percent |
|---|---|---|---|
| Low Expectation | 41.0 - 82 | 0 | 0 |
| Moderate expectation | 82.1 - 123.0 | 0 | 0 |
| High expectation | 123.1 - 164 | 51 | 100 |

The level of nurses' expectation on caregivers' participation scores was analyzed. Tables 4.16, 4.17, 4.18 and 4.19 show the mean, standard deviation and subtotal scores for every part of nurses' expectation. Each item of expectation was scored at four levels: 1= Strongly disagree, 1.1 – 2 = Disagree, 2.1- 3 = Agree and 3.1 – 4 = Strongly agree. The score for each items were analyzed by three categorized, which 1-2 = low expectation, 2.1-3 = moderate expectation and 3.1 – 4 = high expectation.

**Table 4.16** Mean, standard deviation and subtotal of nurses' expectation on caregivers' participation in assessing and determining stroke patient need (n = 51)

| **Variable** | **n** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|---|
| 1. Caregiver should allowed to observe changes in patient's condition. | 51 | 1 | 4 | 3.57 | .85 |
| 2. Caregiver should observe skin integrity | 51 | 1 | 4 | 3.39 | .66 |
| 3. Caregiver should allowed to ask concerning the severity of patient's illness. | 51 | 1 | 4 | 3.49 | .73 |
| 4. Caregiver should allowed to ask nurse about treatment(s) of stroke patient under his/her care. | 51 | 1 | 4 | 3.39 | .75 |
| 5. Caregiver should assess patients' ability to mobilize | 51 | 1 | 4 | 3.14 | .77 |
| 6. Caregiver should assess patient's ability to perform hygienic care. | 51 | 1 | 4 | 3.29 | .64 |
| 7. Caregiver should assess swallowing ability by observing for choking. | 51 | 1 | 4 | 3.20 | .74 |
| 8. Caregiver should assess patient's ability to communicate. | 51 | 1 | 4 | 3.10 | .78 |
| 9. Caregiver should assess patient's need in social activities. | 50 | 1 | 4 | 3.1 | .92 |
| 10. Caregiver should assess patient's ability to make a decision. | 49 | 1 | 4 | 2.82 | .05 |
| 11. Caregiver should assess emotional response and need of the patient. | 51 | 1 | 4 | 3.25 | .77 |
| 12. Caregiver should report change(s) of patient condition(s) to nurses or physicians. | 51 | 1 | 4 | 3.67 | .65 |

**Table 4.16 (Continued)**

| Variable | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 13. Caregiver should report patient's ability to perform activities daily living to nurses or physicians. | 51 | 1 | 4 | 3.37 | .66 |
| 14. Caregiver should report emotional and social need of the patient to nurses or physicians. | 51 | 1 | 4 | 3.22 | .75 |
| **Subtotal score** | | **14** | **56** | **45.92** | **6.11** |

* Subtotal score
Low expectation = 14 -28
Moderate expectation = 28.1- 42
High expectation = 42.1 -56

Table 4.16 shows that the mean subtotal score of nurses' expectation on caregiver participation items in assessing and determining stroke patient's need was 45.9 (SD = 6.11), indicating high expectation when categorized into 3 level of expectation (low = 14 to 28, moderate = 28.1 to 42 and high = 42.1 to 56). Nurses highly expected that caregivers should participate in most items of nurses' expectation on caregivers' participation in assessing and determining stroke patient's needs.

**Table 4.17** Mean, standard deviation and subtotal mean of nurses' expectation on caregivers' participation in care-plan and decision making (n = 51).

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 1. Caregiver should become consulted person in care planning and decision-making. | 51 | 1 | 4 | 2.49 | 1.06 |

**Table 4.17 (Continued)**

| Variables | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 2. Caregiver should be allowed to give suggestions to nurses/physicians during care planning. | 50 | 1 | 4 | 2.96 | .99 |
| 3. Caregiver should be allowed to make a decision regarding need of treatment for stroke patient. | 51 | 1 | 4 | 2.78 | 1.0 |
| 4. Caregiver should be allowed to make decision regarding the cost of treatment | 50 | 1 | 4 | 2.96 | .93 |
| 5. Caregiver should identify other resources in helping her/he in caring for the stroke patient (money, equipment, etc). | 51 | 1 | 4 | 3.43 | .70 |
| 6. Caregiver should create a good relationship with nurses or physicians | 51 | 1 | 4 | 3.73 | .66 |
| 7. Caregiver should inform nurses that she/he take responsibility and accountability for the outcome of treatment. | 50 | 1 | 4 | 2.86 | .96 |
| **Total sub score** | | **7** | **28** | **21.21** | **3.46** |

* Subtotal score
Low expectation = 7- 14
Moderate expectation = 14.1 -21
High expectation = 21.1 -28

Table 4.17 shows that the mean subtotal score of nurses' expectation on caregivers' participation items in care-plan and decision-making was 21.21(SD = 3.46), indicating high expectation when the score was categorized into 3 level of expectation (low = 7 to 14, moderate 14.1 to 21 and high 21.1 to 28). Majority of nurses moderately expected caregivers to participate in care-planning and decision-making such as to become consulted person, being allowed to give suggestion, being allowed to make a decision regarding treatment, being allowed to make decision regarding the cost of treatment and informing nurses that they take responsibility and accountability for the outcomes of treatment (2.49- 2.96). However, nurses had high expectation of caregivers to identify other resources in helping them in caring for the stroke patient and to always create a good relationship with nurses or physicians.

**Table 4.18** Mean, standard deviation and subtotal mean of nurses' expectation on caregivers' participation in caring (n = 51)

| **Variables** | **n** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|---|
| 1. Caregiver should be able to position the patient properly. | 51 | 1 | 4 | 3.41 | .53 |
| 2. Caregiver should be able to change patient's position every two hours. | 51 | 1 | 4 | 3.41 | .60 |
| 3. Caregiver should be allowed to help nurses during suctioning procedure. | 50 | 1 | 4 | 3.27 | .89 |
| 4. Caregiver should allowed to monitor oxygen administrative device(s). | 51 | 1 | 4 | 3.24 | .76 |
| 5. Caregiver should allowed to assist patient to meet nutritional need such as monitor intravenous administration/tube feeding/oral feeding. | 51 | 1 | 4 | 3.41 | .69 |
| 6. Caregiver should mobilize stroke patient such as from bed to chair or vice versa using correct transfer techniques and by using a wheelchair. | 51 | 1 | 4 | 3.61 | .49 |
| 7. Caregiver should encourage stroke patient to perform early movement after stroke. | 51 | 1 | 4 | 3.41 | .72 |

**Table 4. 18 (Continued)**

| Variable | n | Min | Max | Mean | SD |
|---|---|---|---|---|---|
| 8. Caregiver should allowed to perform exercise on patient's limbs. | 51 | 1 | 4 | 3.33 | .89 |
| 9. Caregiver should help patient to meet hygienic needs including bathing, grooming and dressing. | 51 | 1 | 4 | 3.69 | .46 |
| 10. Caregiver should help patient in defecation. | 51 | 1 | 4 | 3.61 | .49 |
| 11. Caregiver should help patient in urination. | 51 | 1 | 4 | 3.57 | .50 |
| 12. Caregiver should help patient to communicate with others. | 51 | 1 | 4 | 3.39 | .60 |
| 13. Caregiver should listen and be with patient when she/he express their feeling(s). | 51 | 1 | 4 | 3.76 | .42 |
| 14. Caregiver should give emotional support by touching, praying for stroke patient (e.g. depend on your culture). | 51 | 1 | 4 | 3.80 | .40 |
| 15. Caregiver should provide means to promote or improve patient orientation (e.g. speak with stroke patient, provide music). | 51 | 1 | 4 | 3.65 | .68 |
| 16. Caregiver should be allowed to help nurses to give oral medication to the patient. | 51 | 1 | 4 | 3.41 | .75 |
| 17. Caregiver should prevent fall injury (e.g. raising siderails). | 51 | 1 | 4 | 3.73 | .60 |
| **Sub total score** | | **17** | **68** | **59.74** | **5.62** |

* Subtotal score Low expectation = 17 - 34
Moderate expectation = 34.1 -51
High expectation = 51.1 - 68

Table 4.18 shows that the mean subtotal score of nurses' expectation on caregivers' participation items in caring activities was 59.74 (SD 5.62), indicating high expectation when the score was categorized into 3 level of expectation (low = 17 to 34 , moderate 34.1 to 51 and high = 51.1 to 68). Nurses scored at high expectation that caregivers should participate in all items of expectation on participation in caring activities including that needed proper techniques such as feeding via nasogastric tube, oxygenation, positioning, mobilizing the patient, exercising, suctioning, and activities of daily living skills such as bathing, dressing, defecation, urination, intervention to prevent fall, promoting communication and social support.

**Table 4. 19** Mean, standard deviation and subtotal mean nurses' expectation on caregivers' participation in evaluation outcome of care (n = 51)

| **Variables** | **n** | **Min** | **Max** | **Mean** | **SD** |
|---|---|---|---|---|---|
| 1. Caregiver should observe changes/ improvement of patient conditions after care. | 49 | 1 | 4 | 3.25 | .91 |
| 2. Caregiver should be allowed to discuss with nurses or physician regarding treatment and care provided. | 51 | 1 | 4 | 3.45 | .73 |
| 3. Caregiver should report your certain difficulty(ies) about your care to nurses or physician. | 49 | 1 | 4 | 3.14 | .98 |
| **Sub total score in Evaluation outcome of care** | | **3** | **12** | **9.84** | **2.09** |

* Subtotal score
Low expectation = 3 -6
Moderate expectation = 6.1 - 9
High expectation = 9.1 -12

Table 4.19 shows the subtotal mean score of nurses' expectation on caregiver participation items in evaluation outcome of care was 9.84 (SD = 2.09), indicating high expectation when the score was categorized into 3 level of expectation (low = 3 to 6, moderate = 6.1 to 9 and high = 9.1 to 12). Nurses highly expected that caregivers should participate in observing changes/ improvement of patient, discussing with nurses or physician regarding treatment of stroke patient and participating in interaction with nurses or physician.

## Bivariate Analyses

### 5. Relationships between functional disability and caregivers' participation in caring for stroke patients

Pearson correlation coefficient was calculated to examine the relationships between the total FIM scores and total scores of caregiver participation level in caring (Table 4.20). These 2 set of scores were normally distributed. There was no significant correlation between total FIM scores and total scores of caregivers' participation level in caring (r = 0.04, $p > 0.05$). The finding indicated that the level of functional disability was not correlated with caregivers' participation in caring.

### 6. Relationships between nurses' expectation on caregivers' participation in caring and caregivers' participation in caring for stroke patients

Pearson correlation coefficient was also used to examine the significant relationships between the nurses' expectation and level of caregiver participation in caring (Table 4.20). The data for both scores were normally distributed. Table 4.20

showed that there was no-significant correlation between nurses' expectation and caregivers' participation in caring (r = -0.06, p > 0.05).

**Table 4.20** Correlation coefficient (*r*) between functional disability, nurses' e expectation and caregivers' participation in caring

| **Variable** | **Correlation coefficient (*r*) with Caregivers'participation** | |
|---|---|---|
| | *r* | *p* |
| Caregivers' participation | – | – |
| Functional disability | 0.04 | NS |
| Nurse expectation | -0.06 | NS |

* NS, not significant

## Discussion

This study aimed to describe the level of functional disability of stroke patients during the recovery stage, caregivers' participation in caring of the stroke patients, and nurses' expectation on the caring participation hospital of the University Sciences Malaysia. This study also aimed to identify the relationship between patients' functional disability and caregivers' participation in caring, and also the relationship between nurses' expectation and caregivers' participation in caring.

The discussion will be on (1) functional disability of stroke patients (2) caregivers' participation in caring (3) nurses expectation on caring participation (4) relationship between functional disability and caregivers' participation and relationship between nurses' expectation on caring and caregivers' participation in caring.

**Functional disability of stroke patients**

In this study stroke patient's age ranged from 35 to 84 years (M = 61.39, SD = 11.55) which almost 60 % in between 55 to 74 years old. This result indicates that elderly person were at risk of stroke attack. This result similar to previous study stated that elderly person were at risk of stroke attack due to underlying diseases such as hypertension, heart disease or diabetes mellitus (Fauziah, 1999). However, young persons between 35 to 54 is also at risk for stroke attack especially hemorrhagic stroke. In this study showed that 61 % were diagnosed as having cerebral infarction and 39 % as having cerebral hemorrhage. The majority of patients that were diagnosed as hemorrhagic are between age 35 to 54 years old. The percentage is quite similar to a previous study by Fauziah (1999) in the same setting, which demonstrated that 56.3 % of stroke was due to cerebral infarction, and 33 % were due to primary intracerebral or subarachnoid hemorrhage.

The mean score of total Functional Independence Measure (FIM) that measured the level of functional disability after stroke was 62.5 (SD = 7.2), indicating modified dependence. Forty seven percent of stroke patients in this study were not able to function as normal person and required assistance from others and 41% were moderately disabled and require assistance to function as a human being.

A previous report stated that a patient with persisting neurological alteration following a stroke usually suffers a degree of disability to function as a normal person (Brandstater & Basmajian,1987).

The reasons why stroke patients suffered a degree of functional disability and required assistance to function as normal person after stroke were due to hemiplegia or hemiparesis and neurobehavioral deficits. Examination of the motor function of the patients found that the majority were unable to move from the bed, walk, use the wheelchair or climb the stairs during hospitalization. They were completely or moderately dependent on others to help in meeting their needs in daily living activities such as self-care, sphincter control, transfers, and locomotion during recovery stage. They required a specific care throughout the recovery stage in order to prevent any poststroke complication and a long-term rehabilitation period to gain independence in functioning. According to Brandstater & Basmajian (1987), Hafsteinsdottir and Grypdonck (1997), Nilsson, Aniansson and Grimby (2000), Rosebrough, Chin and Finocchiaro (1998), and Theuerkauf (1996), after a stroke attack patients frequently become hemiplegic or hemiparesis as a result of damage to the motor area of the cortex or the pyramidal tract fibers.

In terms of a cognitive function, the result of this study showed that a majority of stroke patients were moderately in able to communicate effectively, interact with another person and environment, solve problems and remember previous event. According to Chin, Finocchiaro and Rosebrough (1998), stroke sometimes caused disruption to the reticular activating system (RAS), leading to various neurobehavioral deficits such as disorientation or confusion, memory loss, apathy, lack of initiation, decreased attention, impaired judgment, poor problem-solving skill, inability to transfer learning from one situation to another and inability to calculate, reason, or abstract, emotional liability and lack of insight. Due to these reasons, stroke patients could not function in the cognitive domain effectively and required moderate assistance (50%) from others during the rehabilitation phase.

The FIM result demonstrated that stroke patients in this study were generally functionally disabled at levels between modified dependence and complete dependence especially in activities of daily living including in self-care, elimination, mobility, locomotion, communication and social interaction. The stroke patients required a long term rehabilitation care to gain independent in all functional activities.

**Caregivers' participation in caring**

The result of study showed that the total level of caregivers' participation was 109.80 (SD 21.1), a moderate level of participation. Caregivers' participation in caring was categorized into three level of participation and there were factors influencing the level of caregivers' participation in caring such as socio-demographic variables, caregiver' uncertainty about the state of illness, lack of communication between caregiver and nurses, lack of attention from nurses to caregivers, level of caregivers knowledge and experience, caregivers' attitude in caring for stroke patients and length of hospitalization of the patient.

Caregivers in this study highly participated in caring for their sick family member especially on simple activities, i.e. observation of changes in patient condition such as assessed the ability of stroke patient to mobilized, performing hygienic care, assessing ability to swallow, assessing patient ability to communicate, assessing patient needs in social interaction, and assessing patient ability to make decision and emotional response. They also tended to participate in daily living skills activities such as assessing patients to meet nutritional needs, to meet hygienic needs, defecation and urination and provided psychosocial support and intervention to prevent fall.

The reason why they highly participated in these caring activities was because of family relationship and culture. Most of the caregivers were member of the stroke patients family for example most of caregivers were children of stroke patients (51%), whereas others were spouses (31.4 %) or close relatives or grandmother/father or parent of the stroke patients (17.7%). Due to family ties, most of caregivers were willing to participate in providing care and most of them perceived that they were responsible to stay and help their family member who was sick. Most of caregivers I this study were Malay (Muslim); where in the Malay culture and as Muslim practice, they were taught to respect and help a person who was sick.

The other reason why caregivers highly participated in caring was that during hospitalization of a stroke patient, they were usually in a state of uncertainty concerning the severity of the illness, the complexity of treatment and care systems, and lack of information about the diagnosis and seriousness of the illness of their family member. They might not understand what had happened to their family member and sometimes could not accept the condition of the disabled family member. Previous study stated that caregivers of stroke patients were usually unable to understand and cope with the sudden changes of their family member's life resulting from the stroke and suggested that nurses have a responsibility in educating and supporting caregivers by providing information (Laitinen & Isola, 1996). Because of the uncertainty, during their stay with the patients in the hospital they participated in giving care to stroke the patients i.e. observing of changes in patient condition and being involved in providing simple activities such as assisting the patient in eating, bathing, elimination and mobilizing and giving psychosocial support. The finding is also congruent with the previous studies where family members assumed extensive responsibilities for the performance of most tasks especially in six areas relevant to activities of daily living that includes nutrition, hygiene, elimination, medication, environment care and mobility (Congdon, 1994; Kurki, Paunonen & Lehti, 1997; Laitenen & Isola, 1996; Moore, Maiocco, Schmidt, et al., 2002).

However, caregivers moderately participated in caring activities that required an interaction with nurses and the skills requiring some knowledge and training. The majority of caregivers reported that they fewer opportunities to ask nurses the concerning severity of the illness of their family members or to ask about their treatment. They were shown less opportunity to report patient's ability to perform activities of daily living to nurses, to be a consulted person for the stroke patient, to be involved in identifying other resources in helping them in caring for stroke patients and to take responsibility and accountability for the outcomes of treatments. The result also showed that their participation was at moderate level for skills that required some knowledge and experience such as observation of skin integrity, mobilizing the stroke patient such as from bed to chair or wheelchair or vice versa using correct transfer techniques, encouraging the patient to do exercises for example movement or limb exercises and encouraging stroke patient to communicate or improving patient orientation.

The possible explanation for less participation in these caring activities is that the communications between caregiver and nurse are not achieved at a higher level of agreement and no attention is given to family caregivers. The result showed that caregivers do not have opportunities to communicate with nurses and physicians, especially in getting information from the nurse or physician about what had happened to the stroke patients, interaction related to care planning and decision regarding treatment and care needed. This result is similar to previous studies which stated that caregivers did not participate in caring because of lack of communication and attention provided by nurses and there was no warm, friendly atmosphere and trustful relationship between caregiver and nurse (Brereton & Nolan, 1997; Laitenen & Isola, 1996). It is also supported by another study which showed healthcare staff usually did not have time to give attention to caregivers and suggested that healthcare staff and caregiver should have a mutual relationship in order to provide a good quality of care to stroke patients (Brereton & Nolan, 2002, Bowman, Rose & Kresenic, 1998; Brauer, Schmidt & Pearson 2001; Laitinen & Isola, 1996; Watson, Modeste, Catolico, et al., 1998; Watson, 1992).

The other reason why they moderately participated in some caring activities was that they to lack of knowledge or experience and they needed some training to cope with caring activities for example mobilizing the patient using correct transfer technique, performing exercises and helping patient to improve communication skills. However, in the real situation nurses in this setting were 'too busy' and nurses only focused on the needs of the stroke patients, so the caregiver did not have opportunities to learn from nurses how to provide good care. Other finding also stated that caregivers were unable to provide good care and needing assistance with physical care and education and skill training regarding mobility of physical care, the common difficulties occurred with lifting and incontinence management (Brereton & Nolan, 2000; McLeann, Hall, Mayer & Main, 1991) and speech therapy (McLeann, Hall, Mayer & Main, 1991).

Caregivers' participations was low especially in complicated activities that required special training such as doing positioning every two hour, suctioning procedure, feeding the stroke patient via tube and monitoring oxygen administration. The reason was that they had no experience in these caring skills and the majority of caregivers felt difficult to participate in these caring activities for stroke patients because they lacked of knowledge and experience. This finding was supported from the demographic result that showed the majority of caregivers were of low educational background, about 86% of them had lower level of education (none to secondary school), so they may have difficulty to learn the most high technical caring skills. Brereton & Nolan (2000) also reported that the reasons caregivers did not participate in providing physical care were they did not have knowledge and caregivers also reported that information was only given in response to their direct request.

Our results showed that caregivers require specific educational program related to stroke illness and training in order to be able to participate in these procedures. However, nurses or healthcare staff did not schedule specific educational session to provide information about illness, treatments, care needs to the stroke's caregivers and caring skill training. This finding was supported by previous study that nurses did not provide information about stroke, what sort of treatment was being given nor what was to happen in the future to the caregivers (McLeann, Hall, Mayer & Main, 1991). This was also supported by a study of Moore, Maiocco, Schmidt, et al., (2002), who stated that caregivers of stroke patients usually needed some skill training, for example in positioning technique, helping in suctioning procedure, monitoring oxygen administration, monitoring intravenous administration or nasogastric feeding, mobilizing the patient using correct transfer technique, performing exercise and helping patients to improve the communication.

Their participation was also low in the activities that required an ability to give opinions and make decisions such as giving suggestions to nurses or physicians, making decision regarding treatment, cost of treatment and reporting certain difficulties in providing care for the stroke patient. The possible reason why they participate only poorly in giving opinions, suggestions and making decisions is that they were itself not have confident or were not provided opportunity to participate in discussion with nurses and physicians about the patient condition, treatment and care needed. In some condition nurses sometime did not allowed caregivers to involve in decision-making and care plan. Similarly, Congdon (1994) reported that caregivers had barriers to communicate and make decisions regarding treatment during hospitalization of the patients. Previous study stated that making-decisions regarding treatment and cost of treatment usually were made by healthcare professionals and without the participation of the patient's caregiver (Congdon, 1994).

The other explanation why caregivers' participation was at level of moderate participation might be the problem of disability of the stroke patient. Disability after stroke created a feeling of burden to the family members to participate in physical care, social contacts, emotional support and financial aid during hospitalization. The family caregivers have to suffered with unexpected hospitalization, the prognosis of outcome and preparing for the long-term of rehabilitation due to disability. Many reported that participation in the caring process for stroke patients was associated with burden in terms of providing care and financial aid. Study has shown that there were correlations between the functional disabilities of stroke patients and caregivers' burden. There were relationships between functional disability (include motor and cognitive functions) and caregiver burden in participation in care giving, attitudes and overall perception of caregiver responsibilities. It was also stated that social cognitive alteration demonstrated the strongest correlation with caregiver burden, because the feeling of burden was related to participation in caring so they there was a tendency to avoid participation in caring (Vanetzian & Corrigan, 1995; Watson, Modeste, Catolico, et al., 1998).

The last reason why the level of caregivers' participation in care only achieved a moderate level of participation might be related to the length of hospitalization of stroke patients. In this study the average length of hospital stay for the majority of stroke patient was in between 7-10 days. Seven to ten days is not enough for caregivers to understand about stroke illness and learn about caring skill. However if there is proper program for stroke caregivers, 7 -10 days of hospitalization would be major problem.

**Nurses' expectation on caregivers' participation**

In caring for stroke patients during the rehabilitation stage, nurses in the hospital setting expected caregivers to participate in providing care for stroke patients. The total mean score of nurses' expectation on caregiver participation was 136.7, ranging from 41 to 164 (SD = 13.35). It can be concluded that the majority of nurses, highly expected that caregivers should participate in caring for stroke patients during hospitalization. The nurses goal in encouraging caregivers to participate in caring activities for stroke patients was to prepare them to be knowledgeable about stroke illness and care needs. The second goal was to prepare caregivers to be competent in caring skill in relation to promoting early recovery of stroke patient and preventing stroke complication. The other reason was to decrease nurses' workload and decrease the burden on the healthcare delivery system.

The most important reason why nurses expected caregivers to participate in caring for stroke patients during hospitalization was to increase caregivers' knowledge concerning stroke: the impairments, prognosis for recovery and need for stroke prevention. The result of this study showed that nurses highly expected that caregivers had to participate in assessing and determining stroke patient problems and healthcare needs: caregivers should be involved in knowing what had happened to their family member such as observing changes in patient's condition, gaining information concerning stroke illness, seriousness of patient illness, the impairment in physical and psychosocial health, prognosis for recovery and treatment required, skin integrity of the stroke patient, assessing patients' ability in self-care activities of daily living, promoting communication and providing support in psychosocial needs. Nurses expected that caregivers should develop an ability to ask questions and be able to report the status of stroke patients to nurses or physician. The reason of encouraging the caregivers to participate in assessing and determining stroke patient problems and healthcare needs was to prepare caregivers to be able to identify the stroke patients problems, health care needs, severity of illness, degree of disability, prognosis for recovery and needs for treatment. This was supported by previous results by Brereton and Nolan (2000); Stauffacher, Lindquist and Sarik (2000) and Ozer (2000) who showed that caregivers should participate in the caring process to ensure that they gained enough knowledge and knew the patients' problems and health care needs.

The second reason was to enhance caregivers' competency in providing care for the stroke patient after discharge from the hospital. The result of this study showed that the majority of nurses expected caregivers to learn the caring skills provided for the stroke patient i.e. positioning technique, maintaining the patient with enough oxygenation such as suctioning procedure and monitoring oxygen administration, mobilizing and transfer technique, exercising, activities of daily living activities such as eating, hygiene needs, defecation and urination, promoting communication and provide psychosocial support to the stroke patient. Brereton and Nolan (2000); Stauffacher, Lindquist and Sarik 2000; Ozer (2000) suggested that caregivers should participate in caring skill training. This is important for preparing them to have self-confidence in providing care and being able to find resources in helping stroke patients have early recovery and for preventing stroke complications. Studies also stated that caregivers needed skills-training in enabling the person with stroke to be cared for safely, capability in problem solving, leading to self-confidence, and independent initiative to access resources as needed (Brereton & Nolan, 2000; Brillhart & Johnson, 1997; Hafsteinsdottir & Grypdonck, 1997; Stauffacher, Lindquist & Sarik , 2000; Ozer, 2000).

The other possible reason why nurses in this study expected caregivers to participate in caring was that they perceived that participation of caregivers in caring for stroke patients would decreased nurses workload. As understand, caring for disabled patient usually associated with increase workload in term of providing care. Nurses have to provide a rehabilitation nursing care, for example giving specific treatment and care, assisting the stroke patient who is disabled in meeting their needs for transfer such as to the bathroom, helping in self-care activities of daily living and promoting exercises. However, nurses in this setting could not provide a quality of rehabilitation care to stroke patients and also could not provided a proper educational program and skill training for stroke caregivers during discharge planning due for many reasons. The major problem was because stroke patients were not placed in a specific rehabilitation ward during this stage, but were warded in a general surgical or medical ward during the rehabilitation stage. In fact, in this setting, care was provided specifically for acute medical and surgical patients, but not specific rehabilitation care. The other reason was that nurses lacked the time and energy to provide a quality of care to the patient in the ward. Nurses in these settings are also very busy with other patients that need acute care in both medical and surgical wards. There were also not enough nurses working in each shift of duty and nurses' workload was very heavy. The other reason was because of nurses in these settings also do not have specific knowledge and training on stroke management. The result of this study showed that 51 % had experienced more than 6 years in caring for stroke patients and another 37.3 % had experience between 1 to 5 years. Even though the majority had been working more that 5 years in these settings but the majority of them reported that had never attended any specific course about rehabilitation management for stroke patients.

The other reason why nurses expected caregivers to participate in caring was that it was believed these such participation could decrease length of hospital stay, and so will decrease the burden of healthcare services in terms of money and manpower in providing care for stroke patients. This is because recently, it is the strategy of healthcare services to overcome the economic crisis, where the length of stay for stroke patients has been shortened. However, healthcare staff believed if rehabilitation care could be continued effectively at home this would decrease readmission of stroke patients due to stroke complications. In relation to that, caregivers were expected to participate in providing care for stroke patients during hospitalization in order to prepare them to be able and be ready to continue rehabilitation care at home safely. This is supported by Ozer (2000) who stated that caregivers should be ready and encouraged to learn caring skill for stroke patients during hospitalization so that they could provide a good quality of care at home after discharge.

The result of study showed that nurses expected that caregivers should be more comfortable to ask questions, to report and discuss with the nurses or physicians about the treatments and care provided to the stroke patients. They were expected to be able to report the difficulties during participation in caring. Nurses believed that if there was a mutual relationship between nurse-caregiver such as good interaction and cooperation in providing care for stroke patient, caregivers' participation in caring would be achieved to the optimal goal of participation. This is supported by the result of previous study that expected the caregiver-nurse relationship in the hospital setting should be based on basic interpersonal skills of respect, trust, authenticity and courtesy, and needs a warm atmosphere, privacy and flexible visiting times in participation in care (Laitinen and Isola, 1996).

However, regarding the nurses expectation on caregivers' participation in care planning and decision-making, the result showed that the majority of nurses in this study moderately expected caregivers to become a consulted person for stroke patients, to give suggestion to nurses during care-planning, decision-making about treatment and cost. The possibly reason might be that nurses were unwilling to allow caregivers to be involved in care-planning and make decision regarding treatment and care needed. The reason why nurses had an unwilling attitude to allow caregivers to participate in care-planning and decision-making may be that they felt threatened that the caregiver would disrupt their power in caring responsibility. This supported by previous study, stated that nurses and health care providers were unwilling to shared decision-making with the family, for example care-plan has been developed without the family input (Johnson, 1987).

Generally, nurses' expectation on caregivers' participation provided a positive benefit to stroke patients, nurses and caregivers. Nurses' believed that caregivers' participation in caring would enhance caregivers' knowledge, caring skill, relationship between nurse-caregiver and would decrease nurses' workload and burden of healthcare services.

### Relationship between caregivers' participation and functional disability and between caregivers' participation and nurses' expectation

It was hypothesized that there would be relationships between caregivers' participation and functional disability and between caregivers' participation and nurses' expectation. The bivariate analyses showed that there were no significant correlation between level of functional independence and caregivers' participation in caring ($r = .04$, $p > 0.05$) (Table 4.20) and the result of correlation between nurses' expectation on caregivers' participation in caring and caregivers' participation in caring for stroke patients gave a small negative non-significant correlation ($r = -.060$, $p > 0.05$).

These may be many explanations for the non-significant correlation between caregivers' participation in caring with level of disability and nurses' expectation, beginning from the caregivers, such as socio demographic variables, caregivers' uncertainty about state of illness, lack of communication between caregiver and nurses, lack of attention from nurses to caregivers, level of caregivers' knowledge and experience, caregivers' and nurses' attitude in caring for stroke patients, length of hospitalization of patients and also might be due to too small a sample size however to have a significant correlation and the need for a longer period of collecting data.

Even though the relationships were not statistically significant, the trend was that the caregivers' participation in caring was possibly correlated with level of disability and nurses' expectation on caregivers' participation in care if the strategies of encourage caregivers to participate in caring for stroke patients was well implemented. The researcher strongly suggests that the results should be used in our setting as information and guidance to enhance the quality of care for stroke patients. It is predicted, if nurses have an organized plan in involving caregivers in caring activities starting from admission of stroke patient until the rehabilitation phase such as providing an educational program, skill-training for high caring skill and psychosocial support, caregivers' participation goal may be achieved to the maximal level and the correlated with functional disability and nurses' expectation.

# CHAPTER 5

# SUMMARY AND RECOMMENDATIONS

A cross-sectional study was done from 1 July 2003 to 31 August 2003 with 51 stroke patients, 51 caregivers and 51 nurses in the medical and surgical wards in HUSM. The objectives of this study were to the determine level of functional disability after stroke during recovery phase, level of caregivers' participation in caring and level of nurses' expectation on caregiver participation in caring for stroke patients. This study also aimed to determine the correlation between functional disability and caregivers' participation and between caregivers' participation and nurses' expectation on caregivers' participation in caring.

## 1. Summary of study findings

Stroke is sudden and causes disability. It is also a disease that has profound effects on stroke patients, their caregivers and also on the healthcare system (Ozer, 2000). Mean level of FIM was 62.5 (SD = 37.2). The majority of stroke patients at the recovery stage were categorized on having moderate disability and needing moderate assistance from others. The result showed that 47.0 % of stroke patients were highly dependent, 41.2 % were moderate dependent and 11.8 % were independent. Caregivers in this study showed moderate level of participation in caring for stroke patients during hospitalization. The total level of participation in caring was M=109.8, ranged from 18 to 126, and SD = 21.1. About half of the caregivers (52.9 %) demonstrated a moderate level of participation, and another 47.1% a high level of participation in caring. The result of nurses' expectation on caregivers' participation in caring for stroke patients during hospitalization showed that nurses' scored at high level of expectation. Mean level of nurses' expectation on caregiver' participation was 136.7 (SD = 13.3).

In bivariate analysis using Pearson correlation there was no significant correlation between functional disability and caregivers' participation in caring (r = .04, $p > .05$) and or between nurses' expectation and caregivers' participation in caring ($r = -.06, p > .05$).

## 2. Limitations of the Study

The medium sample size calculated for this study was 88 for each sample. According to Burn & Grove (2001) medium effects sizes are acceptable in nursing studies because large sample sizes are difficult to obtain, and require a longer data collection period and are costly. However, the researcher could not achieve the target sample size due to the time, manpower and cost limitation. In addition, this was a cross-sectional study and the sample was only collected at Hospital University of Science Malaysia during July to August. The researcher could not expand the setting as planned due to time limitation to follow the regulation and ethical review in order to have permission from the director of the nearest hospital as planned during the proposed study.

## 3. Implications and Recommendations

With an increasing prevalence of stroke and an increasing admission of stroke patients in our setting, it is important to increase the capacity required in involving caregivers in caring and to guide planning strategies especially to increase the quality of nursing care, recovery of stroke patients and short-term hospitalization of stroke survivors and decrease readmission. Participation of the caregiver in caring for the stroke patient will be more effective if caregivers are well prepared for their role.

1. The nurse manager who has responsibilities in providing care for stroke patients should develop a policy to have a proper assessment in determining the degree of independence or disability of stroke patients during admission, before discharge and at discharge time. It is important to determine the level of disability and how much a stroke patient requires a helper, so the nurse can use this data in planning the nursing care and support for stroke patients and their caregivers.

2. Information from this study will help nurses to understand what are the caring activities that caregivers are willing to participate in and what are the caring activities that caregivers and less participating and how to make change. The nurse should measure the families willingness to help with patient care, family knowledge of the illness or disability and understanding of what has happened, and there must be accurately determined. Nurses also should encourage family participation in the rehabilitation process and assess caregiver's level of participation in caring. Nurses are in an important position to encourage family caregivers to participate in caring for stroke patients during hospitalization, because they spend the most time with patients and their family members during hospitalization and often continue to interact with them after discharge.

3. The results of this study will be used as information to guide nurses to develop a plan or a model for caregivers' involvement in caring for stroke patients. The nursing manager who is responsible for stroke management should use the results

of this study as information to develop a plan or model in involving caregivers in caring for stroke patients.

a) The nursing manager should provide an inpatient rehabilitation program that routinely schedules time for family education and conferences. This is because caregivers of stroke patients with first-time stroke were unsure how to provide care for the patient. Nurses and other rehabilitation professionals need to focus on teaching caregivers about caring aspects for the stroke patient and providing information about stroke illness, treatment, care need and how to prevent stroke complication. They should provide specific information about aspects of care management with educational material such as booklets or pamphlets. This is because caregivers show that they need clear information about stroke illness, how to prevent recurrent stroke and complication, medications, tests and treatments, and also expected questions to be answered and information resources to be provided.

b) The nursing manager should provide training in some caring skill to ensure that caregivers will be competent and confident in providing care for stroke patient at home after discharge. Nurses should allow or encourage caregivers to participate in simple activities such as self-care activities of daily living for stroke patients. The nurse should provide a training program for the skill that needs proper technique, such as positioning, mobilizing the patient, exercising, helping the patient to meet hygiene needs including bathing, grooming and dressing, promote orientation and to give oral medication, change position, performing suctioning procedure and monitoring oxygen administration.

4. Nurses and caregivers should develop a mutual relationship between each to ensure that the goal of participation in caring for the stroke patient will be effective.

The communication between nurses and caregivers should be improved to prevent barriers to caregivers' participation in caring.

5. Further research in the area of stroke care is needed, such as studies that involve caregivers in caring for stroke patient during hospitalization in order to get deeper understanding about caregivers' needs and problems in participation in caring.

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# APPENDICES

# APPENDIX A

## Consent Form

Dear Participant,

I am Sabarisah Binti Hashim, a Nursing Student in Master Degree in Nursing Science, Faculty Of Nursing, Prince Of Songkla University, Thailand. To fulfill the requirement for Degree of Master in Nursing Science (Adult Nursing), I have to do a research study. I am doing a research about Functional disability, Nurses' Expectation on Caregivers' Participation in caring and Caregivers' Participation in Care for Stroke Patients during hospitalization at Hospital University of Science Malaysia.

The information will help nurses in planning appropriate nursing care and rehabilitation program immediately after acute stroke which will include caregivers to be involved in care, in relation to prepare them to be knowledgeable, competent and confident to give a quality of care at home after discharge.

As a part of this study, I would like to do an assessment on stroke patients. The assessment will take 40 minutes to finish.

For the second part, I would like to assess caregivers' participation in care and also assess nurses' expectation of caregivers' participation in care.

At any point if you do not want to participate, you have the right to refuse and you can stop at any time you wish. Your signature on this form indicates that you understand and you agree to participate in my research.

| | | |
|---|---|---|
| ---------------------- | ------------------------ | -------------------------- |
| Name of Participant | Signature | Date |
| ---------------------- | ------------------------ | -------------------------- |
| Name of Researcher | Signature | Date |

If you have any inquiries, please contact:

Nursing Education
Pusat Pengajian Sains Kesihatan
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International Program,
Prince Songkla University,

# APPENDIX B

## Functional Independence Measure (FIM)

### PART 1

### BAHAGIAN 1

Subject No. _______
*(No. Subjek)*
Date ___________
*(Tarikh)*

### 1 . 1 Stroke Patient's Demographic Information

1.1.1 Age ____________ years
*(Umur)* *(Tahun)*

1.1.2 Gender *(Jantina)*
[ ] Male *(Lelaki)*
[ ] Female *(Perempuan)*

1.1.3 Religion *(Agama)*
[ ] Islam *(Islam)*
[ ] Buddhist *(Buddha)*
[ ] Christian *(Kristian)*
[ ] Other (identify) ______________________
*Lain-Lain (Nyatakan)*

1.1.4 Marital Status *(Taraf Perkahwinan)*
[ ] Single *(Belum Berkahwin)*
[ ] Married *(Berkahwin)*
[ ] Widowed *(Janda/Duda)*

1.1.5 Diagnosis/ type of stroke *(Diagnosis/Jenis Strok)*
[ ] cerebral hemorrhage
[ ] cerebral infarction

**1.2 : FIM Instrument: Assessment level of functional disability of stroke patients**

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Independence *(Berkeupayaan)*<br>7 Complete Independence (Timely, Safely) (Keupayaan Penuh)<br>6 Modified Independence ( Berkeupayaan Dengan Bantuan) | NO HELPER *(TIDAK PERLU PEMBANTU)* | | | | | | |
| U<br>K<br>U<br>R<br>A<br>N | Modified Dependence *(Ketidakupayaan Dan Perlu Bantuan Separuh)*<br>5 Supervision *(Perlu Pengawasan Penuh)*<br>4 Minimal Assist (Pesakit = 75%+) *(Perlu Bantuan Minimal)*<br>3 Moderate Assist (Pesakit = 50%+) *(Perlu Bantuan Separa)*<br>Complete Dependence *(Ketidakupayaan Penuh)*<br>2 Maximal Assist (Pesakit = 25%+) *(Perlu Bantuan Maksima)*<br>1 Total Assist (Pesakit = 0%+) *(Perlu Bantuan Penuh)* | HELPER *(PERLU PEMBANTU)* | | | | | | |
| **No** | **Variable *(Perkara)*** | **1** | **2** | **3** | **4** | **5** | **6** | **7** |
| 1 | Self-Care *(Penjagaan Diri)*<br>A. Eating *(Makan)*<br>B. Grooming *(Berpakaian/Bersolek)*<br>C. Bathing *(Mandi)*<br>D. Dressing-Upper Body *(Berpakaian-Paras Atas Tubuh)*<br>E. Dressing-Lower Body *(Berpakaian-Paras Bawah Tubuh)*<br>F. Toileting *(Membuang air di tandas)* | | | | | | | |
| 2. | Sphincter Control *(Mengawal Sphincter)*<br>G. Bladder *(Mengawal pundi kencing)*<br>H. Bowel *(Mengawal Usus Besar)* | | | | | | | |
| 3 | Transfers *(Berpindah)*<br>I. Bed, Chair, Wheelchair *(Katil, Kerusi, Kerusi Roda)*<br>J. Tub, Shower *(Bekas Kolah Mandi, Pancur Air)*<br>K. Toilet *(Mangkuk Tandas)* | | | | | | | |
| 4. | Locomotion *(Pergerakan)*<br>L. Walk/ Wheelchair *(Berjalan/ Kerusi Roda)*<br>M. Stair *(Anaktangga)* | | | | | | | |
| | *Motor Subtotal Score (Skor Motor Subtotal)* | | | | | | | |
| 5 | Communication *(Komunikasi)*<br>N. Comprehension *(Kefahaman)*<br>- Auditory *(Pendengaran)* ☐<br>- Visual *(Penglihatan)* ☐<br>- Both *(Kedua-duanya)* ☐<br>O. Expression *(Luahan)*<br>- Vocal *(Vocal)* ☐<br>- Non Vocal *(Tanpa Vocal)* ☐<br>- Both *(Kedua-duanya)* ☐ | | | | | | | |
| 6. | Social Cognition *(Kepintaran Bersosial)*<br>P. Social Interaction *(Interaksi social)*<br>Q. Problem Solving *(Penyelesaian Masalah)*<br>R. Memory *(Ingatan)* | | | | | | | |
| | Cognitive Subtotal Score *(Skor Kepintaran Sosial Subtotal)* | | | | | | | |
| | TOTAL *(JUMLAH)* | | | | | | | |

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## APPENDIX C

## Caregivers' Participation in Care Questionnaire

### PART 2

Subject No. ______
*No. Subjek*
Date ___________
*Tarikh*

### 2.1 Caregivers' Demographic Information *(Maklumat Demografi Penjaga)*

Direction: The following items are to obtain some information about you. Please write and tick appropriate answers. Thank you.

*Arahan : Butir-butir di bawah adalah untuk mendapat maklumat tentang diri anda. Sila jawab dan tandakan [ / ] di petak yang sesuai. Terima kasih.*

2.1.1 Age ___________ years
*Umur* *Tahun*

2.1.2 Gender *Jantina*
[ ] Male *Lelak)* [ ] Female *Perempuan*

2.1.3 Religion *Agama*
[ ] Islam *Islam* [ ] Christian *Kristian*
[ ] Buddhist *Buddha* [ ] Others (identify) ______________
*Lain-lain*

2.1.4 Marital Status *Taraf Perkahwinan*
[ ] Single *Belum Berkahwin*
[ ] Married *Berkahwin*
[ ] Widowed *Duda/Janda*

2.1.5 Education level: *Tahap Pendidikan*
[ ] None *Tiada*
[ ] Primary School *Peringkat Sekolah Rendah*
[ ] Secondary School *Peringkat Sekolah Menengah*
[ ] Diploma *Diploma*
[ ] Bachelor *Ijazah Pertama*
[ ] Post graduate level *Pos graduate*

2.1.6 Present occupation: *Pekerjaan*
- [ ] Government Officer/Public Enterprise Employee *Kerajaan/Pekerja Awam Sykt*
- [ ] Owns Enterprise *Syarikat Persendirian*
- [ ] Farmer *Petani*
- [ ] Unemployed *Tidak bekerja*
- [ ] Others *Lain-lain* ________

2.1.7 Relationship with this patient *Hubungan dengan pesakit*
- [ ] Spouse *isteri/suami*
- [ ] Parent *ibu/bapa*
- [ ] Children *anak*
- [ ] Sibling *abang, kakak atau adik*
- [ ] Relative *saudara mara*

*2.1.8* Past experience of caring for stroke patient *Pengalaman lepas menjaga pesakit strok*
- [ ] Yes *Ya* ______ years *tahun*
- [ ] No *Tidak*

## 2.2 Caregivers' participation in care

Instruction: The following questionnaires describe the process of caregivers' participations in caring for stroke patient during hospitalization. There are four processes of participation in caring that includes caregiver involve in assessing and determining the patients' problems and health care needs, involve in care planning and decision-making, involve in caring activities and involve in evaluating outcomes of care. For each statement, there are four possible choices according to your participation in care. There is no RIGHT or WRONG answer. Your honest choice is the only correct answer.

***Penglibatan penjaga dalam penjagaan pesakit***

*Arahan: Soalan-soalan di bawah adalah berkaitan dengan proses penglibatan penjaga dalam penjagaan pesakit strok semasa di hospital. Terdapat empat(4) proses penglibatan penjaga dalam penjagaan pesakit strok iaitu menilai, dan mengnalpasti masalah dan keperluan penjagaan kesihatan, perancangan penjagaan dan membuat keputusan, aktiviti penjagaan dan penilaian hasil dari penjagaan dan rawatan.Bagi setiap kenyataan/soalan terdapat empat(4) pilihan mengikut tahap penglibatan anda. Tiada jawapan BETUL atau SALAH. Kejujuran pilihan anda adalah jawapan yang BETUL.*

Please "*Circle*" in the space available according to four level of choice.
*Sila " Bulatkan" dalam ruangan yang disediakan berpandukan empat tahap pilihan*

1 = Never *(Tidak pernah)*:

2 = Rarely *(Jarang-jarang)*:

3= Often *(Kadang-kadang)*:

4 = Always *(Selalu*

N/A = Not Applicable *(Tidak Berkaitan)*

## SESSION A: ASSESSING AND DETERMINING STROKE PATIENT PROBLEMS AND HEALTHCARE NEEDS.

**In this session, you are asked about level of your participation in assessing and determining problems and health care need of stroke patient under your care during hospitalization. For each item of participation listed, please circle in the relevant choice that you think appropriate for you or your situation. Please select only one from 1 (never) to 4 (always) N/A (Not Applicable).**

## *SESSI A : MENILAI DAN MENGENALPASTI MASALAH PESAKIT STROK DAN KEPERLUAN KESIHATAN*

***Dalam sessi ini, anda dikehendaki menyatakan tahap penglibatan anda dalam menilai dan mengenalpasti masalah pesakit strok dan keperluan penjagaan kesihatan. Bagi setiap soalan adalah berkenaan penglibatan, sila' bulatkan ' jawaban yang anda fikir sesuai untuk anda dan situasi anda. Sila pilih hanya satu dari 1 (tidak pernah) hingga 4 (selalu) atau N/A (Tidak Berkaitan).***

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 1. Observe changes in patient's condition. (e.g. breathing, sweating, consciousness, etc)<br>*Perhati perubahan keadaan pesakit (contoh. : bernafas, berpeluh, paras sedar diri dan sebagainya).* | 1 | 2 | 3 | 4 | N/A |
| 2. Observe skin integrity.<br>*Perhati integriti kulit pesakit.* | 1 | 2 | 3 | 4 | N/A |
| 3. Ask nurse concerning the severity of patient's illness.<br>*Menanya jururawat berkaitan dengan keterukan penyakit pesakit.* | 1 | 2 | 3 | 4 | N/A |
| 4. Ask nurse about treatment(s) of stroke patient under your care.<br>*Menanya jururawat berkaitan dengan rawatan untuk pesakit strok yang di bawah jagaan anda.* | 1 | 2 | 3 | 4 | N/A |

5. Assess patients' ability to mobilize

*Menilai keupayaan pergerakan pesakit.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

6. Assess patient's ability to perform hygienic care.

*Menilai keupayaan penjagaan kebersihan diri pesakit.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

7. Assess swallowing ability by observing for choking.

*Menilai kebolehan pesakit menelan dan pemerhatian untuk masalah tercekik.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

8. Assess patient's ability to communicate.

*Menilai kebolehan pesakit berkomunikasi.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

9. Assess patient's need in social interaction

*Menilai keperluan pesakit semasa berinteraksi dengan orang lain.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

10. Assess patient's ability to make a decision.

*Menilai kebolehan pesakit membuat keputusan.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

11. Assess emotional response and need of the patient

*Menilai tindakbalas dan keperluan emosi pesakit.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

12. Report change(s) of patient condition(s) to nurses or physician.

*Lapor sebarang perubahan ke atas pesakit kepada jururawat atau pengamal perubatan.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

13. Report patient's ability to perform activities daily living to nurses or physician.

*Lapor kebolehan pesakit menjalankan aktiviti harian kepada jururawat atau pengamal perubatan.*

Never *Tidak pernah* — Always *Selalu*
1 2 3 4 N/A

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 14. Report emotional and social need of the patient to nurses or physician.<br>*Lapor keperluan emosi dan sosial pesakit kepada jururawat dan pengamal perubatan.* | 1 | 2 | 3 | 4 | N/A |

**B. PARTICIPATION IN CARE PLANNING AND DECISION- MAKING**

**In this session, you are asked about level of your participation in care planning and decision-making of stroke patient under your care. For each item of participation listed, please circle in the relevant choice that you think appropriate for you or your situation. Please select only one from 1 (never) to 4 (always) or N/A (Not Applicable)**

***Penglibatan Dalam Perancangan PenjagaanDan Membuat Keputusan***

**Dalam sessi ini, anda dikehendaki menyatakan tahap penglibatan anda dalam perancangan penjagaan dan membuat keputusan bagi pesakit strok di bawah jagaan anda. *Bagi setiap soalan adalah berkenaan penglibatan, sila ' bulatkan' jawaban yang anda fikir sesuai untuk anda dan situasi anda. Sila pilih hanya satu dari 1 (tidak pernah) hingga 4 (selalu) or N/A (Tidak Berkaitan).***

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 15. Be a consulted person in care planning and decision-making.<br>*Menjadi perujuk dalam perancangan jagaan perawatan dan membuat keputusan.* | 1 | 2 | 3 | 4 | N/A |

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 16. Give suggestions to nurses/physicians during care planning.<br>*Memberi cadangan kepada jururawat/pengamal perubatan semasa perancangan penjagaan.* | 1 | 2 | 3 | 4 | N/A |

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 17. Make a decision regarding treatment for stroke patient.<br>*Membuat keputusan berhubung rawatan untuk pesakit strok yang di bawah jagaan anda.* | 1 | 2 | 3 | 4 | N/A |

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 18. Make decision regarding the cost of treatment.<br>*Membuat keputusan berhubung kos rawatan pesakit.* | 1 | 2 | 3 | 4 | N/A |

| | Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|---|
| 19. Identify other resources in helping you in caring for the stroke patient (money, equipment, etc).<br>*Mengenalpasti sumber-sumber lain bagi membantu anda dalam penjagaan pesakit (kewangan, peralatan, dan lain-lain).* | 1 | 2 | 3 | 4 | N/A |

20. Create a good relationship with nurse or physician.

*Menjalin hubungan baik dengan jururawat/ pengamal perubatan.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

21. Inform nurses that you take responsibility and accountability for the outcome of treatment.

*Memaklumkan kepada jururawat bahawa anda bertanggungjawah atas sebarang hasil rawatan.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

## SESSION C: PARTICIPATION IN CARING ACTIVITIES

**In this session, you are asked about level of your participation in caring activities provided to stroke patient under your care. For each item of participation listed, please circle in the relevant choice that you think appropriate for you or your situation. Please select only one from 1 (never) to 4 (always) or N/A (Not Applicable).**

## *SESSI C: PENGLIBATAN DALAM AKTIVITI PENJAGAAN*

**Dalam sessi ini anda dikehendaki menyatakan tahap penglibatan anda dalam aktiviti penjagaan yang diberi kepada pesakit strok di bawah jagaan anda. *Bagi setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk anda dan situasi anda. Sila pilih hanya satu dari 1 (tidak pernah) hingga 4 (selalu) atau N/A (Tidak Berkaitan).***

22. Position the patient properly.

*Membuat posisi pesakit dengan betul.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

23. Change position every two hours.

*Menukar posisi pesakit setiap 2 jam*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

24. Help nurses during suctioning procedure.

*Membantu jururawat semasa prosedur penyedutan*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

25. Monitor oxygen administrative device(s).

*Memantau peralatan pemberian gas oksigen*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

26. Assist patient to meet nutritional need such as monitor intravenous administration/tube feeding/oral feeding.

*Membantu pesakit dalam memenuhi keperluan pemakanan pesakit seperti mengawasi pemberian cecair intravena/ melalui tube/makan melalui mulut.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

27. Mobilize stroke patient such as from bed to chair or vice versa using correct transfer techniques and by using a wheelchair.

*Membantu pesakit strok berpindah seperti dari katil ke kerusi atau sebaliknya dengan menggunakan teknik yang betul dan dengan menggunakan kerusi roda.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

28. Encourage stroke patient to perform movement as early as possible after stroke .

*Mengalakkan pesakit strok melakukan pergerakan seawall yang boleh selepas strok*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

29. Perform exercise on patient's limbs.

*Melakukan senaman pada anggota badan pesakit*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

30. Help patient to meet hygienic needs including bathing, grooming and dressing.

*Membantu pesakit memenuhi keperluan kebersihan termasuk mandi, bersolek dan berpakaian*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

31. Help patient in defecation.

*Membantu pesakit membuang air besar*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

32. Help patient in urination.

*Membantu pesakit membuang air kecil*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

33. Help patient to communicate with other.

*Membantu pesakit berinteraksi dengan orang lain*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

34. Listen and be with patient when she/he express their feeling(s).

*Mendengar dan berada disisi pesakit apabila pesakit meluahkan perasaannya*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

35. Give emotional support by touching, praying for stroke patient(e.g. depend on your culture).

*Memberi sokongan emosi dengan memegang tangan pesakit, berdoa kepada pesakit strok, dll*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

36. Provide means to promote or improve patient orientation(e.g. speak with stroke patient, provide music).

*Menggunakan pelbagai kaedah untuk mempertingkatkan orientasi pesakit contohnya bercakap dengan pesakit strok, memperdengarkan muzik dll.*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

37. Help nurses to give oral medication to the patient

*Membantu jururawat memberi ubat melalui mulut kepada pesakit*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

38. Prevent fall injury (e.g. raising siderails).

*Menjaga pesakit dariter jatuh contohnya dengan menaikkan pengadang katil*

| Never<br>*Tidak pernah* | | | Always<br>*Selalu* | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | N/A |

## D. PARTICIPATION IN EVALUATION OUTCOMES OF CARE

**In this session, you are asked about level of your participation in evaluation outcome of care provided to stroke patient under your care. For each item of participation listed, please circle in the relevant choice that you think appropriate for you or your situation. Please select only one from 1 (never) to 4 (always) or N/A (Applicable).**

## *SESSI C: PENGLIBATAN DALAM PENILAIAN HASIL PENJAGAAN PERAWATAN DAN RAWATAN*

***Dalam sessi ini anda dikehendaki menyatakan tahap penglibatan anda dalam penilaian keberhasilan jagaan perawatan dan rawatan yang diberi pada pesakit strok di bawah jagaan anda. Bagi setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk anda dan situasi anda. Sila pilih hanya satu dari 1 (tidak pernah) hingga 4 (selalu) atau N/A (Tidak Berkaitan).***

| | | | | | |
|---|---|---|---|---|---|
| 39. Observe changes/improvement of patient conditions after care.<br>*Memerhati perubahan/tahap pemulihan pesakit selepas rawatan* | Never<br>*Tidak pernah*<br>1 | 2 | 3 | Always<br>*Selalu*<br>4 | N/A |
| 40. Discuss with nurses or physician regarding treatment and care provided<br>*Berbincang dengan jururawat atau pengamal/ perubatan berkenaan rawatan dan keperluan jagaan perawatan* | Never<br>*Tidak pernah*<br>1 | 2 | 3 | Always<br>*Selalu*<br>4 | N/A |
| 41. Report your certain difficulty(ies) about your participation in care to nurses or physician.<br>*Melaporkan sebarang kesulitan anda semasa penglibatan anda dalam penjagaan pesakit kepada jururawat atau pengamal perubatan)* | Never<br>*Tidak pernah*<br>1 | 2 | 3 | Always<br>*Selalu*<br>4 | N/A |

# APPENDIX D

## Nurses' Expectation on Caregivers' Participation in care

## Questionnaires

**PART 3**

Subject No. ______
Date __________

### 3.1 Nurses Demographic Information

Direction: The following items are to obtain some information about you. Please write or tick the appropriate sections. Thank you.

3.1.1 Age ______________ years
*(Umur)* *(Tahun)*

3.1.2 Gender *(Jantina)*
[ ] Male *(Lelaki)*
[ ] Female *(Perempuan)*

3.1.3 Present working place *(Tempat kerja)*
[ ] Hospital USM *(Hospital USM)*
[ ] General Hospital Kota Bharu *(Hospital Kota Bharu)*
[ ] District Hospital *(Hospital Daerah)*

2.1.4 Education level/status in nursing
[ ] Certificate *(Sijil)*
[ ] Diploma *(Diploma)*
[ ] Bachelor *(Ijazah Pertama)*
[ ] Post graduate level *(Pos graduate)*

3.1.4 Duration of being a nurse in providing care for stroke patients
____________ years
*(Berapa lamakah anda menjadi jururawat yang memberi perawatan kepada pesakit strok)*

3.1.5 Did you attend any courses or continued your education regarding nursing care and rehabilitation of stroke patients after finishing your basic nursing education? *(Adakah anda pernah mengikuti kursus atau melanjutkan pengajian dalam perawatan dan penjagaan pesakit strok selepas tamat dari kursus asas kejurawatan).*

[ ] Yes *(Ya)*
If yes, please state where/ when, and for how long.
*(Jika Ya, nyatakan di mana/bila, dan berapa lama)*

______________________________________________

Type of courses______________________
*(Nyatakan tajuk kursus)* .

[ ] No *(Tidak)*

Instructions: The following questionnaires describe the nurses' expectations of caregivers' participation in caring for stroke patient during hospitalization. There are also 4 phases of nurse expectations on caregivers' participation that include seeking information, involvement in decision-making, involvement in caring activities, having a mutual relationship with staff and involvement in evaluating the progress of care. For each statement, there are four possible choices according to your participation in care. There is no RIGHT or WRONG answer. Your honest choice is the only correct answer. Please read each statement carefully and then tick your choice.

*Arahan: Soalan-soalan di bawah adalah berkaitan dengan ekspektasi jururawat terhadap penglibatan penjaga dalam penjagaan pesakit strok semasa hospitalisasi. Terdapat empat(4) proses penglibatan penjaga dalam penjagaan pesakit strok iaitu menilai, dan mengenalpasti masalah dan keperluan penjagaan kesihatan, perancangan penjagaan dan membuat keputusan, aktiviti penjagaan dan penilaian hasil dari penjagaan dan rawatan.*

*Bagi setiap kenyataan/soalan terdapat empat(4) pilihan mengikut tahap penglibatan anda. Tiada jawapan BETUL atau SALAH. Kejujuran pilihan anda adalah jawapan yang BETUL.*

Please "*Circle*" in the space available according to four level of choice.
*Sila "* ***Bulatkan*** *" dalam ruangan yang disediakan berpandukan empat tahap pilihan*

1= Strongly disagree *(Amat Tidak Setuju)*

2= Disagree *(Tidak Bersetuju)*

3= Agree *(Bersetuju)*

4= Strongly agree *(Amat Bersetuju)*

N/A = Not Applicable *(Tidak Berkaitan)*

## SESSION A: ASSESSING AND DETERMINING STROKE PATIENT PROBLEMS AND HEALTH CARE NEEDS.

**This session, you are asked about your expectation toward caregivers' participation in assessing and determining problems and health care need of stroke patient under their care. Please circle the relevant choice according to your level of expectation. Please select only one from 1 (strongly disagree) to 4 (strongly agree) or N/A (Not Applicable).**

## SESSI A: EKSPEKTASI JURURAWAT TERHADAP PENJAGA MELIBATKAN DIRI DALAM MENILAI DAN MENGENALPASTI MASALAH DAN KEPERLUAN KESIHATAN PESAKIT STROK

***Dalam sessi ini, anda dikehendaki menyatakan ekspektasi anda terhadap penglibatan penjaga dalam menilai dan mengenalpasti masalah pesakit strok dan keperluan penjagaan kesihatan. Bagi setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk tahap ekspektasi anda. Sila pilih hanya satu dari 1(amat tidak setuju) hingga 4(amat setuju) atau N/A (Tidak Berkaitan).***

| | | | | | |
|---|---|---|---|---|---|
| 1. Caregiver should not be allowed to observe changes in patient's condition. (e.g. breathing, sweating, consciousness, etc)<br>*Penjaga sepatutnya tidak dibenarkan membuat pemerhatian pada perubahan keadaan pesakit (contoh. : bernafas, berpeluh, paras sedar diri dan sebagainya).* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 2. Caregiver should observe skin integrity<br>*Penjaga sepatutnya membuat pemerhatian pada integriti kulit pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 3. Caregiver should not be allowed to ask concerning the severity of patient's illness.<br>*Penjaga sepatutnya tidak dibenarkan menanya berkaitan dengan keterukan penyakit pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 4. Caregiver should not be allowed to ask nurse about treatment(s) of stroke patient under his/her care.<br>*Penjaga sepatutnya tidak dibenarkan menanya jururawat berkaitan dengan rawatan untuk pesakit strok yang di bawah jagaannya.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

| | | | | | |
|---|---|---|---|---|---|
| 5. Caregiver should assess patients' ability to mobilize<br>*Penjaga sepetutnya menilai keupayaan pergerakan pesakit* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 6. Caregiver should assess patient's ability to perform hygienic care.<br>*Penjaga sepatutnya menilai keupayaan pesakit untuk menjaga kebersihan diri.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 7. Caregiver should assess swallowing ability by observing for choking.<br>*Penjaga sepatutnya menilai kebolehan pesakit menelan pesakit dan pemerhatian masalah tercekik.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 8. Caregiver should assess patient's ability to communicate.<br>*Penjaga sepatutnya menilai kebolehan pesakit berkomunikasi.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 9. Caregiver should assess patient's need in social activities.<br>*Penjaga sepatutnya menilai keperluan pesakit dalam berinteraksi dengan orang lain.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 10. Caregiver should assess patient's ability to make a decision.<br>*Penjaga sepatutnya menilai kebolehan pesakit membuat keputusan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 11. Caregiver should assess emotional response and need of the patient.<br>*Penjaga sepatutnya menilai tindakbalas dan keperluan emosi pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

12. Caregiver should report change(s) of patient condition(s) to nurses or physicians.

*Penjaga sepatutnya melapor sebarang perubahan ke atas pesakit kepada jururawat atau pengamal perubatan.*

| | | | | |
|---|---|---|---|---|
| strongly disagree<br>*Amat tidak setuju* | | | strongly agree<br>*Amat setuju* | |
| 1 | 2 | 3 | 4 | N/A |

13. Caregiver should report patient's ability to perform activities daily living to nurses or physicians.

*Penjaga sepatutnya melapor kebolehan pesakit menjalankan aktiviti harian kepada jururawat atau pengamal perubatan.*

| | | | | |
|---|---|---|---|---|
| strongly disagree<br>*Amat tidak setuju* | | | strongly agree<br>*Amat setuju* | |
| 1 | 2 | 3 | 4 | N/A |

14. Caregiver should report emotional and social need of the patient to nurses or physicians.

*Penjaga sepatutnya melaporkan keperluan emosi dan sosial pesakit kepada jururawat dan pengamal perubatan.*

| | | | | |
|---|---|---|---|---|
| strongly disagree<br>*Amat tidak setuju* | | | strongly agree<br>*Amat setuju* | |
| 1 | 2 | 3 | 4 | N/A |

## SESSION B. PARTICIPATION IN CARE PLANNING AND DECISION-MAKING.

**This session, you are asked about your expectation toward caregivers' participation in care planning and decision-making for stroke patient under their care. Please circle the relevant choice according to your level of expectation. Please select only one from 1 (strongly disagree) to 4 (strongly agree) or N/A (Not Applicable).**

## SESSI B: EKSPEKTASI JURURAWAT TERHADAP PENJAGA MELIBATKAN DIRI DALAM PERANCANGAN JAGAAN PERAWATAN DAN MEMBUAT KEPUTUSAN

**Dalam sessi ini, anda dikehendaki menyatakan ekspektasi anda terhadap penglibatan penjaga *dalam perancangan jagaan perawatan dan membuat keputusan. Bagi setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk tahap ekspektasi anda. Sila pilih hanya satu dari 1 (amat tidak setuju) hingga 4 (amat setuju) atau N/A (Tidak Berkaitan).***

15. Caregiver should become consulted person in care planning and decision-making.

*Penjaga sepatutnya menjadi perujuk dalam perancangan jagaan perawatan dan membuat keputusan.*

| | | | | |
|---|---|---|---|---|
| strongly disagree<br>*Amat tidak setuju* | | | strongly agree<br>*Amat setuju* | |
| 1 | 2 | 3 | 4 | N/A |

| | | | | | |
|---|---|---|---|---|---|
| 16. Caregiver should not be allowed to give suggestions to nurses/physicians during care planning.<br>*Pejaga sepatutnya tidak dibenarkan memberi cadangan kepada jururawat/pengamal perubatan semasa perancangan penjagaan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 17. Caregiver should not be allowed to make a decision regarding need of treatment for stroke patient.<br>*Penjaga sepatutnya tidak dibenarkan membuat keputusan berhubung rawatan untuk pesakit strok yang di bawah jagaan anda.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 18. Caregiver should not be allowed to make decision regarding the cost of treatment<br>*Penjaga sepatutnya tidak dibenarkan membuat keputusan berhubung kos rawatan pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 19. Caregiver should not identify other resources in helping her/he in caring for the stroke patient (money, equipment, etc).<br>*Penjaga tidak sepatutnya dibenarkan mendapat sumber-sumber lain bagi membantunya dalam penjagaan pesakt strok (kewangan, peralatan, dan lain-lain).* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 20. Caregiver should create a good relationship with nurses or physicians<br>*Penjaga sepatutnya menjalin hubungan baik dengan jururawat/ pengamal perubatan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 21. Caregiver should inform nurses that she/he take responsibility and accountability for the outcome of treatment.<br>*Penjaga sepatutnya memaklumkan kepada jururawat bahawa dia bertanggungjawah atas sebarang hasil rawatan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

## SECTION C. PARTICIPATION IN CARING ACTIVITIES

**This session, you are asked about your expectation toward caregivers' participation in caring activities provided to stroke patient. Please circle the relevant choice according to your level of expectation. Please select only one from 1 (strongly disagree) to 4 (strongly agree) or N/A (Not Applicable).**

## SESSI C: EKSPEKTASI JURURAWAT TERHADAP PENJAGA MELIBATKAN DIRI DALAM AKTIVITI PERAWATAN

**Dalam sessi ini, anda dikehendaki menyatakan ekspektasi anda terhadap penglibatan penjaga dalam aktiviti perawatan.** ***Setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk tahap ekspektasi anda. Sila pilih hanya satu dari 1 (amat tidak setuju) hingga 4 (amat setuju) atau N/A (Tidak Berkaitan).***

| | | | | | |
|---|---|---|---|---|---|
| 22. Caregiver should be able to position the patient properly.<br>*Penjaga sepatutnya boleh membuat posisi pesakit dengan betul.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 23. Caregiver should be able to change patient's position every two hours.<br>*Penjaga sepatutnya boleh menukar posisi pesakit setiap 2 jam.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 24. Caregiver should not be allowed to help nurses during suctioning procedure.<br>*Penjaga sepatutnya tidak dibenarkan membantu jururawat semasa prosedur penyedutan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 25. Caregiver should not allowed to monitor oxygen administrative device(s).<br>*Penjaga sepatutnya tidak dibenarkan memerhatikan peralatan pemberian gas oksigen.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 26. Caregiver should not allowed to assist patient to meet nutritional need such as monitor intravenous administration/tube feeding/oral feeding.<br>*Penjaga sepatutnya tidak dibenarkan membantu dalam memenuhi keperluan pemakanan pesakit seperti mengawasi pemberian cecair intravena/ melalui tube/makan melalui mulut.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

| | | | | | |
|---|---|---|---|---|---|
| 27. Caregiver should mobilize stroke patient such as from bed to chair or vice versa using correct transfer techniques and by using a wheelchair.<br>*Penjaga sepatutnya membantu pesakit strok berpindah seperti dari katil ke kerusi atau sebaliknya dengan menggunakan teknik yang betul dan dengan menggunakan kerusi roda.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 28. Caregiver should encourage stroke patient to perform early movement after stroke.<br>*Penjaga sepatutnya mengalakkan pesakit strok melakukan pergerakan seawal yang boleh selepas strok.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 29. Caregiver should not allowed to perform exercise on patient's limbs.<br>*Penjaga sepatutnya tidak dibenarkan melakukan senaman pada anggota badan pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 30. Caregiver should help patient to meet hygienic needs including bathing, grooming and dressing.<br>*Penjaga sepatutnya membantu pesakit memenuhi keperluan kebersihandiri termasuk mandi, bersolek dan berpakaian.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 31. Caregiver should help patient in defecation.<br>*Penjaga sepatutnya membantu pesakit untuk membuang air besar.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 32. Caregiver should help patient in urination.<br>*Penjaga sepatutnya membantu pesakit untuk membuang air kecil.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 33. Caregiver should help patient to communicate with others.<br>*Penjaga sepatutnya membantu pesakit berinteraksi dengan orang lain.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

| | | | | | |
|---|---|---|---|---|---|
| 34. Caregiver should listen and be with patient when she/he express their feeling(s).<br>*Penjaga sepatutnya mendengar dan berada disisi pesakit apabila pesakit meluahkan perasaannya.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 35. Caregiver should give emotional support by touching, praying for stroke patient (e.g. depend on your culture).<br>*Penjaga sepatutnya memberi sokongan emosi dengan memegang tangan pesakit, berdoa kepada pesakit strok, dll.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 36. Caregiver should provide means to promote or improve patient orientation (e.g. speak with stroke patient, provide music).<br>*Penjaga sepatutnya menggunakan pelbagai kaedah untuk mempertingkatkan orientasi pesakit contohnya bercakap dengan pesakit strok, memperdengarkan muzik dll.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 37. Caregiver should not be allowed to help nurses to give oral medication to the patient.<br>*Penjaga sepatutnya tidak dibenarkan membantu jururawat memberi ubat melalui mulut kepada pesakit.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 38. Caregiver should prevent fall injury (e.g. raising siderails).<br>*Penjaga sepatutnya menjaga pesakit dari terjatuh contohnya dengan menaikkan pengadang katil.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

## SESSION D. PARTICIPATION IN EVALUATING OUTCOMES OF CARE

**This session, you are asked about your expectation toward caregivers' participation in evaluation outcomes of care provided to stroke patient under their care. Please circle the relevant choice according to your level of expectation. Please select only one from 1 (strongly disagree) to 4 (strongly agree) or N/A (Not Applicable).**

## SESSI D: EKSPEKTASI JURURAWAT TERHADAP PENJAGA MELIBATKAN DIRI DALAM MENILAI HASIL RAWATAN DAN JAGAAN PERAWATAN

**Dalam sessi ini, anda dikehendaki menyatakan ekspektasi anda terhadap penglibatan penjaga dalam menilai hasil rawatan dan jagaan perawatan.** ***Setiap soalan adalah berkenaan penglibatan, sila' bulatkan 'jawaban yang anda fikir sesuai untuk tahap ekspektasi anda. Sila pilih hanya satu dari 1 (amat tidak setuju) hingga 4 (amat setuju) atau N/A (Tidak Berkaitan).***

| | | | | | |
|---|---|---|---|---|---|
| 39. Caregiver should observe changes/ improvement of patient conditions after care.<br>*Penjaga sepatutnya memerhati perubahan/tahap pemulihan pesakit selepas rawatan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 40. Caregiver should not be allowed to discuss with nurses or physician regarding treatment and care provided.<br>*Penjaga sepatutnya tidak dibenarkan berbincang dengan jururawat atau pengamal/perubatan berkenaan rawatan dan keperluan jagaan perawatan.* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |
| 41. Caregiver should report your certain difficulty(ies) about your care to nurses or physician.<br>*Penjaga sepatutnya melaporkan sebarang kesulitan anda semasa penglibatan anda dalam penjagaan pesakit kepada jururawat atau pengamal perubatan).* | strongly disagree<br>*Amat tidak setuju*<br>1 | 2 | 3 | strongly agree<br>*Amat setuju*<br>4 | N/A |

# APPENDIX E

## The description levels of functional independence measure tool

The description levels of function using a seven–level scale that representing gradation of independence and dependent behavior of FIM tool to assess stroke patient's during erly stage of rehabilitation in hospital. The outlined below :

| FIM LEVELS | | |
|---|---|---|
| **NO HELPER** | | |
| 7 | Complete Independence (Timely, Safely) | indicating independence |
| 6 | Modified Independence (Device) | indicating independence with the use of aids |
| **HELPER** | | |
| | *Modified Dependence* | |
| 5 | Supervision | indicating need for supervision |
| 4 | Minimal Assistance (Subject = 75%+) | indicating minimal assistance |
| 3 | Moderate Assistance(Subject = 50 %+) | indicating moderate assistance with patient providing 50% effort |
| | *Complete Dependence* | |
| 2 | Maximal Assistance (Subject= 25%) | defined as complete dependence |
| 1 | Total Assistance( Subject =0%+) | defined as complete dependence |

(Dodds, Martin, Stopov, & Dego, 1993).

The examples of the use of, FIM to measure gradations in independent and dependent behavior of stroke patient using seven-point scale.

Example 1: EATING
Able to;
Grasp fork/spoon/ food container
Spear food with fork
Scoop food into utensil
Place food inside mouth
Drink water without spilling
Chewing
Swallowing

| Level | Descriptive |
|---|---|
| 7- Complete Independence (Timely, Safely) | Subject able to eat safely without requiring an assistant or help from other person, or adaptive equipment and assistive device to:<br>Take the food, prepare eating utensils and environment<br>Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing<br>Subject also able to perform eating in reasonable amount of time for normal eating behavior. |
| 6- Modified Independence (Device) | Subject able to perform eating independently with the use of assistive device. Subject able to eat effectively using eating utensil with built-up handle, subject able to:<br>Take the food, prepare eating utensils and environment<br>Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing<br>Subject takes more than a reasonable time for normal eating behavior. |
| 5- Supervision or Setup | Subject able to eat but requires helper to supervise her/him to perform eating. Subject requires helper to standby, observe, cue or coax, set up the eating utensil needed or help to apply orthoses or assistive/adaptive devices before eating to:<br>Take the food, prepare eating utensils and environment<br>Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing |

| | |
|---|---|
| 4 - Minimal Assistance | Subject has 75% or more of the ability to perform eating by her/himself. Subject requires a little assistance or help from other person to:<br>Take the food, prepare eating utensils and environment<br>Subject able to:<br>Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing |
| 3 - Moderate Assistance | Subject has 50% or more but less than 75% of ability to perform eating. Subject requires half assistance to:<br>Take the food, prepare eating utensils and environment<br>Grasp knife, fork/spoon, food container<br>Cut food<br>Spear food with fork<br>Scoop food into utensil<br>Subject able to:<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing |
| 2 - Maximal Assistance | Subject expends less than 50% of the effort, but has at least 25 % of ability to perform eating. Subject unable to:<br>Take the food, prepare eating utensils and environment<br>Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing<br>Subject usually conscious but require assistance in oral or tube feeding |
| 1 - Total Assistance | Subject expends less than 25% of the effort in eating in ability to:<br>Take the food, prepare eating utensils and environment |

| | |
|---|---|
| | Grasp fork/spoon, food container<br>Spear food with fork<br>Scoop food into utensil<br>Place food inside mouth<br>Drink water without spilling<br>Chewing<br>Swallowing<br>Subject usually unconscious and requires assistance in tube feeding. |

Example 2: TRASFER FROM BED TO CHAIR OR WHEELCHAIR AND BACK

Able to:

Sit on the side of the bed or chair
Move the feet flat of the floor
Stand up
Sit on the chair/bed/wheelchair.

| Level | Descriptive |
|---|---|
| 7- Complete Independence (Timely, Safely) | Subject able to transfer from bed, chair and wheelchair independently without requiring an assistance or help from other person, or use adaptive equipment and assistance device such as walking aids. Subject able to:<br>Sit on the side of the bed or chair<br>Move the feet flat o the floor<br>Stand up<br>Sit on the chair/bed/wheelchair.<br>Subject also able to do transfer within a reasonable amount of time. |
| 6- Modified Independence (Device) | Subject able to transfer from bed, chair and wheelchair independently with the use of assistive device such as using walking aids to transfer . Subject also able to:<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Stand up<br>Sit on the chair/bed/wheelchair.<br>Subject takes more than a reasonable time to transfer. |
| 5- Supervision or Setup | Subject able to move from bed to chair or wheelchair with the use of walking aids and back but require helper to supervise during performing this activity for example require helper to standby, |

| | |
|---|---|
| | observe, cue or coax. Subject also able to:<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Stand up<br>Sit on the chair/bed/wheelchair. |
| 4 - Minimal Assistance | Subject has 75% or more the ability to move from bed to chair or wheelchair by her/himself. Subject requires one person to assist him/her to transfer :<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Stand up<br>Sit on the chair/bed/wheelchair. |
| 3 - Moderate Assistance | Subject expends 50% or more but has less than 75% of ability to move from bed to chair or wheelchair by her/himself. Subject requires one assistance to :<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Subject unable to:<br>Stand up<br>Sit on the chair/bed/wheelchair. |
| 2- Maximal assistance | Subject expends less than 50% of the effort, but has at least 25 % of ability to move from bed to chair or wheelchair; Subject requires two assistance: Subject unable to:<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Stand up<br>Sit on the chair/bed/wheelchair.<br>Subject conscious but unable to move the body by him/herself. |
| 1-Total Assistance | Subject expends less than 25% of the effort in moving from bed to chair or wheelchair. Subject require two assistance: Subject unable to:<br>Sit on the side o the bed or chair<br>Move the feet flat on the floor<br>Stand up<br>Sit on the chair/bed/wheelchair.<br>Subject unconscious. |

# APPENDIX F

## LIST OF EXPERTS

The content validity of Caregivers'Participation in Care Questionnaire and Nurses' Expectation on Caregivers'Participation in Care Questionnaire was analyzed by three expert from Faculty of Nursing, Prince Songkla University and two from Health Campus, Universiti Sains Malaysia, Kubang Kerian Kelantan.

1. Dr. Wongchan Petpichetchian, Assistance Professor RN, Ph.D
   Associate Dean for Academic Affairs and International Relations,
   Faculty of Nursing, Prince Songkla University, Hat Yai Thailand.

2. Dr. Sunuttra Taboonpong, RN, Ph.D.
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   Faculty of Nursing, Prince Songkla University, Hat Yai Thailand.

3. Dr. Sang-arun Ismalai,RN, Ph.D.
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4. Professor Madya Dr.Jafri Malim Dato' Abdullah MD,Ph.D
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