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# EDUCATIONAL NEEDS OF FAMILY CAREGIVER OF STROKE PATIENTS AS PERCEIVED BY THE FAMILY


**BY**

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## ABSTRACT

Stroke is one of the important causes of adult disability in many countries. The majority of stroke patients depend on their families for optimum recovery. The objective of the study was to identify the educational needs of family caregivers of stroke patient as perceived by the family. Needs of family caregiver was assessed as preparation for better care for stroke patient. This study was a cross-sectional study and Precede-Proceed model was used in this study. "The stroke caregiver assessment of educational needs survey" was used to measure the educational needs of stroke caregiver at Hospital Universiti Sains Malaysia (HUSM), Kelantan. The survey respondents were 53 family caregivers of stroke patients in ward 2 Intan, 3 Utara, 7 Selatan, and 7 Utara. The result showed that there were 13 topics chosen by stroke family caregiver which showed they needed a lot of education needs. The highest educational need was on "causes of stroke" and "treatment and medication", with 84.9% respectively. Meanwhile the lowest educational needs was on "how stroke may affect sexual activity" which was only 22.6%. Association between demographic data with "cause of stroke" and "treatment and medication" was also identified using chi-square test. The result showed that there was a significant association between "relation with patient" and "causes of stroke", with p value, 0.002. "Educational level" also showed a significant association with "causes of stroke", proved by p value, 0.028. Meanwhile, the result showed that there were no significant relationship between "demographic data" with "treatment and medication". The findings of this study showed that there are a few aspects in educational needs that family caregivers require. Therefore, a comprehensive and effective education needs to be carried out to fulfill their needs.

**Keyword: Educational needs, family caregiver, stroke**

**ABSTRAK**

Strok adalah salah satu punca terbesar yang menyumbang kepada ketidakupayaan dalam kalangan orang dewasa di kebanyakan negara. Majoriti pesakit strok bergantung kepada ahli keluarga untuk pemulihan yang optimum. Objektif kajian ini adalah untuk mengenalpasti keperluan pendidikan oleh ahli keluarga pesakit strok seperti yang dinyatakan oleh mereka. Keperluan pendidikan penjaga pesakit strok telah dikaji sebagai persediaan untuk penjagaan yang lebih baik untuk pesakit strok. Kajian ini adalah kajian keratan rentas dan model "Procede-Proceed" telah digunakan dalam kajian ini."Borang soal selidik berkaitan keperluan pendidikan tentang strok oleh penjaga pesakit strok" telah digunakan untuk menilai keperluan pendidikan dalam kalangan penjaga pesakit strok di Hospital Universiti Sains Malaysia (HUSM), Kelantan. Seramai 53 ahli keluarga pesakit strok di wad 2 Intan, 3 Utara, 7 Utara dan 7 Selatan telah mengambil bahagian dalam kajian ini. Keputusan kajian menunjukkan bahawa terdapat 13 topik telah dipilih oleh penjaga pesakit strok yang menunjukkan mereka memerlukan banyak pendidikan mengenai topik-topik tersebut. Keperluan pendidikan yang paling tinggi adalah pada topik "punca terjadinya strok" dan "rawatan dan ubat-ubatan" yang dibuktikan dengan 84.9% penjaga pesakit strok memilih topik tersebut. Manakala keperluan pendidikan yang paling rendah ialah pada topik "bagaimana strok boleh menjejaskan aktiviti seksual", dibuktikan dengan hanya 22.6% penjaga pesakit strok yang memilih topik ini. Perkaitan antara data demografik dengan "punca terjadinya strok" dan "rawatan dan ubat-ubatan" telah dikenalpasti menggunakan ujian "chi-square". Data menunjukkan bahawa ada perkaitan yang signifikan di antara "hubungan dengan pesakit" dan "punca terjadinya strok", dibuktikan dengan nilai p yang diperoleh iaitu 0.002. "Tahap pendidikan" juga

menunjukkan perkaitan yang signifikan dengan "punca terjadinya strok", dibuktikan dengan nilai p yang diperoleh iaitu 0.028. Manakala, data menunjukkan tiada perkaitan yang signifikan di antara data demografik dengan "rawatan dan ubat-ubatan". Penemuan dalam kajian ini mendedahkan bahawa terdapat beberapa aspek dalam keperluan pendidikan yang diperlukan oleh ahli keluarga yang menjaga pesakit strok. Oleh itu, pendidikan yang efektif dan komprehensif berkaitan strok perlu dilaksanakan untuk memenuhi keperluan mereka.

**Kata Kunci:**

**Keperluan pendidikan, keluarga pesakit, strok**

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# CHAPTER 1 INTRODUCTION

## 1.1 Introduction

A stroke, sometimes called a brain attack, occurs when a clot blocks the blood supply to the brain or when a blood vessel in the brain bursts (Centers for Disease Control and Prevention [CDC], 2011). Stroke or "brain attack" or also called Cerebrovascular Accident (CVA) refers to an acute onset of neurologic deficit lasting more than 24 hours or culminating in death caused by a sudden impairment of cerebral circulation. Stroke is the third leading cause of death in the United States, Europe, and most countries in the world (Warlow, Sudlow, Dennis, Wardlow, Sandercock 2003). In 2005, nearly 700,000 strokes and 160,000 stroke-related deaths will occur in the United States (American Heart Association, 2007). Fifty percent of patients experiencing a stroke will be left with moderate to severe residual deficits (MacIsaac, Harrison, Buchanan & Hopman, 2011). Because of the effect of stroke on stroke survivors and the accompanying burden of care that falls on caregivers, attention should be given to addressing caregiver needs (Connell, Baker & Prosser, 2003). However, the problem commonly voiced by stroke patients and their caregivers include professional stroke care-providers did not give sufficient information about the stroke and its consequences for daily life (Kaufmann, Schuling & Jong, 2005).

Successful reintegration of the individual back into the community is contingent upon careful preparation of the family caregiver (MacIsaac et al., 2011). Ideally, this preparation should begin upon admission and continue throughout the stay so that at discharge, the family member has the skills, knowledge, and confidence to care for the person with stroke at home ( MacIsaac et al., 2011).

## 1.2 Background of the Study

Stroke is the most important cause of severe and long-term disability in developed countries (American Heart Association, 2007). According to National Stroke Association of Malaysia (NASAM, 2011) stroke is the third largest cause of death in Malaysia.

Caregivers of individuals with stroke continue to experience long-term commitment with limited resources (Pierce, Gordon & Steiner, 2004). Although hospital discharge planning programs and rehabilitation facilities provide information, skills training, and emotional support for these caregivers, the need for caregiver support may become more complex and critical after discharge (Pierce et al., 2004). In a study done by MacIsaac et al. (2011) in certain hospitals in Canada to assess the needs of caregiver of stroke patients, the findings reveals that 50% of the caregivers reported having unmet informational needs, including a moderate to high need for understanding stroke treatment and prevention, and in accessing information regarding support for both the patient and the family.

Caregivers also identified the need to know what to expect during the hospitalization, such as the timing of diagnostic testing and therapy, timing of team rounds, when therapies were initiated, and what happens after acute treatment was

completed (MacIsaac et al., 2011). MacIsaac et al. (2011) stated that caregivers discussed how they were not considered part of the team with comments such as ''you want to help but they make you feel you are in the way and complicating things" (p. 136).

Several of the respondents described how various healthcare team members would enter the room and ''talk like I wasn't even there'' and how that experience affected them, ''felt like a fly on the wall-ignored" (MacIsaac et al., 2011, p. 136). Difficulties with a lack of awareness and understanding of the process resonated throughout many of these discussions, ''what are the next steps'' and ''need to know what to expect, the nurses should tell you'' (MacIsaac et al., 2011, p. 136). In her paper, MacIsaac et al. (2011, pg 136) also states that the lack of information set up a confrontational approach as more than one respondent reported having to ''fight'' for information, ''if you don't fight hard enough, you'll fall through the cracks''.

The purpose of this study was to assess educational needs of family caregiver of stroke patient in HUSM (Hospital Universiti Sains Malaysia).

## 1.3 Rationale for the Study

Patients with stroke face serious health problems not only in the acute phase, but also in the long-term or rehabilitation phase and the chronic phases (Hafsteinsdottir, Vergunst, Lindeman, & Schuurmans, 2011). Providing patients and caregivers with good education and information concerning stroke recovery is an important aspect of caring for stroke patients (Smith, Forster, House, Knapp, Wright & Young, 2008).

Furthermore, education has an important role in secondary stroke prevention and facilitating successful self management of this chronic disease (Tyson & Turner, 2000).

A lack of education for patients and caregivers can lead to misconceptions, anxiety, fear, poor health status and emotional problems like depression (Rodgers, Bond, Curless, 2001). A recent study showed that the lack of information is a key factor that prevents many European caregivers from adequately accessing support services (Hafsteinsdottir et al., 2011). This problem is especially true for isolated caregivers who are growing in number in Europe (Lamura, Mnich, Nolan, Wojszel, Krevers, Mestheneos et al., 2008).

## 1.4 Problem Statement

As stated by Hafsteinsdottir et al. (2011) a recent Cochrane review presents evidence that information improves patients' and caregivers' knowledge concerning stroke, increases satisfaction and leads to lower depression scores in patients; however, such information does not appear to reduce the number of patients with anxiety or depression, nor does it appear to influence caregiver mood, satisfaction or death (Smith, Forster, House, Knapp, Wright , 2008).

Bakas et al. (2002) reported various self-reported needs, concerns, strategies, and advice of the family caregivers of stroke patients within the first 6 months after hospital discharge (postactute rehabilitation phase). The needs were categorized into five areas: (1) Information, (2) emotions and behaviors, (3) physical care, (4) instrumental care, and (5) personal responses.

In Malaysia, stroke was consistently the 3$^{rd}$ commonest cause of death in the 1990s (SEAMIC data). In 2002, stroke was the 4$^{th}$ highest cause of death, following septicaemia, heart disease and cancer (Clinical Practice Guidelines, 2006). Loo & Gan (2012) stated that stroke is one of the top five leading causes of death and one of the top

10 causes for hospitalization in Malaysia. Stroke is also in the top five diseases with the greatest burden of disease, based on disability-adjusted life years (Loo & Gan, 2012).

However, prospective studies on stroke in Malaysia are limited, to date, neither the prevalence of stroke nor its incidence nationally has been recorded (Loo & Gan, 2012). Hypertension is the major risk factor for stroke. The mean age of stroke patients in Malaysia is between 54·5 and 62·6 years (Loo & Gan, 2012). Traditional medicine is commonly practiced, and according to the researcher, with the increasing number of stroke cases annually, more government and nongovernment organizations should be involved in primary and secondary prevention strategies (Loo & Gan, 2012). Stroke is one of the illness included as a Research Priority in the Health Sector for the 9th Malaysia Plan (Clinical Practice Guidelines, 2006).

A study done by Jaya et. al (2002) in HUSM that study about all patients with a first-ever stroke admitted to the HUSM (Hospital Universiti Sains Malaysia) from 1997 to 1998, reported that there were 158 cases of stroke admitted during the study period. The majority of the patients were Malays (86.1%), with a male preponderance (Jaya et. al, 2002). The mean age (SD) of the patients with stroke was 59.3 (12.28) years. The overall mortality was 37%, and most patients died in the 1st month after stroke (34%) (Jaya et. al, 2002).

As far as researcher concerns, limited study was done on caregiver of stroke patient in Kelantan. Most of the studies were about incidence and prevalence, types of stroke, mortality rates which focused more on patient. This study focused on educational needs of caregivers which are the most important people that take care of stroke survivor. So, they do need a lot of information regarding stroke, how to take care of stroke patient,

the effects of stroke on physical, and others. So, this study was done to identify educational needs of stroke family caregiver in HUSM, Kelantan.

## 1.5 Purpose of the Study

The purpose of this study was to identify the educational needs of family caregiver of stroke patients as perceived by the family. Other than that demographic data of the family caregivers were also being studied to identify any association between demographic background of the family caregivers and their educational needs.

## 1.6 Aims of the Study

### 1.6.1 General Objective

To identify the educational needs of family caregivers of stroke patient as perceived by the family.

### 1.6.2 Specific Objectives

1. To assess the educational needs of family caregiver of stroke patients.
2. To investigate the highest needs for education of family caregiver
3. To identify any association between demographic data of family caregivers and the highest educational needs.

## 1.7 Research Questions

The research questions are:

1. What are the educational needs of family caregiver of stroke patients?
2. What is the highest need for education of family caregivers?
3. Is there any association between the demographic background of family caregivers of stroke patients and the highest educational needs?

## 1.8 Research Hypothesis

$H_0$: There is no association between demographic background of family caregiver of stroke patients and the highest educational needs.

$H_A$: There is association between demographic background of family caregiver of stroke patients and the highest educational needs.

## 1.9 Significance of the Study

This study will provide information on the educational needs of family caregiver of stroke patients. This data can be used by many groups of people such as health care provider (doctors, nurses, physiotherapist and others), family caregiver, and researcher. Knowing this information, teaching materials can be develop that will help decrease the

caregiver's feeling of frustration and anxiety while providing care to the person with stroke at home.

# CHAPTER 2 LITERATURE REVIEW

## 2.1 Introduction

In this chapter, incidence and prevalence, risk factor, warning signs, complication of stroke is discussed. It also includes discussion about concept of needs. Other than that, previous studies on educational needs of patients and families following stroke are reviewed. Studies on educational needs of patients as perceived by health professional are also reviewed.

## 2.2 Incidence and Prevalence of stroke

According to National Stroke Association of Malaysia (NASAM) (2011) stroke is the third largest cause of death in Malaysia and it is considered to be the single most common cause of severe disability, and every year, an estimated 40,000 people in Malaysia suffer from stroke.

The *Disease Burden Study* indicated that stroke is ranked third behind ischemic heart disease and mental illness (Ministry of Health [MOH], 2005). The number of stroke patients admitted to the Malaysian Ministry of Health (MOH) hospitals has been increasing (MOH, 2006) from 13,868 in 2000 to 16,805 in 2004 (National Institutes of Health, Malaysia [NIHM], 2006).

## 2.3 Risk factors, symptoms and complications of stroke

According to World Health Organization (WHO) there are five major modifiable risk factors of stroke that are high blood pressure, abnormal blood lipids, physical inactivity, unhealthy diets, and diabetes mellitus. Other modifiable risk factors are low socioeconomic status, psychosocial stress, and alcohol intake. Meanwhile, non modifiable factors include advancing age, ethnicity and heredity or family history (WHO, 2011).

Findings from Ong and Raymond study done in 2002 revealed that risk factors of stroke are hypertension (71.5%) was the commonest risk factor for stroke, followed by diabetes mellitus (40.2%), hyperlipidaemia (37%), smoking (35%), ischaemic heart disease (23.2%), previous transient ischaemic attack (5.3%) and atrial fibrillation (4.5%).

Symptoms of a stroke are sudden numbness or weakness of face, arm, or leg, especially on one side of the body, sudden confusion or trouble speaking or understanding speech, sudden trouble seeing in one or both eyes, sudden trouble walking, dizziness, or loss of balance or coordination and sudden severe headache with no known cause (National Institute of Neurological Disorders and Stroke, [NINDS], 2008).

In a study done by Doshi, Say, Young, and Doraisamy (2003), the researcher discussed about complication of stroke based on a study by Davenport, Dennis, wellwood (1996). The complications studied were recurrent stroke, epileptic seizure, urinary tract infection (UTI), chest infection, pressure sores, falls, deep vein thrombosis (DVT), pulmonary embolism (PE), limb pain, depression, cardiovascular (CVS) complications, uncontrolled hypertension, acute retention of urine (ARU), bleeding from the

gastrointestinal tract (BGIT), constipation and drug rash (Doshi, Say, Young, & Doraisamy, 2003).

Doshi et al. (2003) conducted a study on complication in stroke patients in Singapore. The aim of the study was to look at the type and frequencies of complications after an acute

stroke in an inpatient rehabilitation setting. They also looked at the type of complications which required the transfer of patient care back to the primary referring physician. The result from the study revealed that, sixty four patients (45.7%) did not have any complications, thirty two patients (22.9%) had at least one complication, twenty-five patients (17.9%) had three or more complications each. The researcher states that the most common complications were constipation (complicating 22.9% of strokes), Acute Retention of Urine (ARU) (20.9%), Urinary Tract Infection (UTI) (14.3%), depression (9.3%) and limb pain (8.6%).

## 2.4 Educational needs of patients following stroke

There have been studies about educational needs of patients following stroke. Choi-Kwon et al. (2005) studied the educational needs of patients in the acute phase of stroke and compared these needs to the perceptions of health care professionals. The educational needs of patients differed considerably from the perceptions of professionals (Choi-Kwon, Lee, Park, Kwon, Ahn, 2005). Compared with doctors, patients viewed the topics of possibility of cure with medical treatment, stress management, general medical knowledge and post stroke diet management to be more important (Choi-Kwon et al.,

2005). However, compared with patients, doctors and nurses believed stroke risk factors and medical issues were more important than did patients.

Younger patients found aspects concerning exercise and sexual activities to be more important than did older patients (Choi-Kwon et al., 2005). Tooth (2004) done a study about the educational needs of patients in the rehabilitation phase. The study shows that patients wanted information about the following topics, which are medications and side effects, specific medical information about their type of stroke and specific symptoms like dizziness, pain and loss of taste (Tooth, 2004). Other study is done by Hanger, Walker, Paterson, McBride (1998) that explore about if patients had unanswered questions concerning the stroke. The findings from the study shows that that common questions were related to communication difficulties, the nature of the stroke, fear of recurrent stroke, recovery, stroke prevention, memory problems, driving and tiredness (Hanger, Walker, Paterson, McBride, 1998).

There are two studies done that investigated the unmet needs of young stroke survivors in the chronic phase (Hafsteinsdottir et al., 2011). One of it is a study done by Kersten, Low, Ashburn, George, 2002. The study reveals that the most commonly reported questions in the first study were related to stroke, stroke prevention, treatment, and recovery (Kersten, Low, Ashburn, George, 2002). Another one is done by the same researcher Low, Kersten, Ashburn, George in 2003. The second study shows that the most commonly reported questions were related to the causes of stroke, stroke prevention, and returning to work (Low, Kersten, Ashburn, George, 2003).

## 2.5 Educational needs of caregivers

A systematic review of the literature of educational needs of patients with a stroke and their caregiver by Hafsteinsdottir et al. (2011) shows that nine studies investigated the educational needs of caregivers. Van der Smagt-Duijnstee, Hamers (2000) found that during the first days of admission, most caregivers focused on the patient and his or her illness but then, after 2 weeks, most caregivers seemed to have accepted the stroke but not its consequences. Four categories of needs were identified which are information, communication, support and accessibility to the patient and the health care professional (Van der Smagt-Duijnstee, Hamers, 2000).

In 2001, Van der Smagt-Duijnstee, Hamers and Abu-Saad reported that all caregivers found that it is very important to have questions answered honestly and for professionals to take time to answer their questions. Caregivers considered it important to have contact with the nurses, and to speak with the same nurse (Van der Smagt-Duijnstee, Hamers, Abu-Saad, 2001). A study reveals that caregivers identified the following educational needs before and after discharge from a stroke unit which are dealing with psychological, emotional and behavioral problems and local service information (MacKenzie, Perry, Lockhart, Cottee & Cloud, 2007).

Meanwhile, result of a study done in 2004 shows that the most reported educational needs were fall prevention, maintaining adequate nutrition, staying active, managing stress, and dealing with emotional and mood changes (Pierce et al., 2004). Caregivers wanted information concerning the following issues: preventing recurrent stroke, helping with communicating problems, coping with feeding problems, preventing

a patient's cognitive and physical deterioration and handling a patient's changing moods (Mak & MacKenzie, 2007).

Hafsteinsdottir et al. (2011) noticed that after 6 months, most caregivers wanted more education about the signs and symptoms of stroke, complications and how to manage them, as well as the possibility of another stroke recurrence (Bakas, Austin, Okonwo, Lewis, 2002). King and Semik (2006) found that the most difficult time experienced by caregivers was during the hospitalization and the first months after discharge. Their difficulty was due to uncertainty, new responsibilities, survivor's impairments and emotions, lack of confidence, lack of information and skills, uncaring staff and travel to the hospital (King, 2006).

Kim (2007) found that the need for information was more important in the acute rehabilitation phase than in the post-acute rehabilitation phase. Caregivers of patients in inpatients facilities found health information more important than caregivers of patients in outpatient clinic services or day hospitals. Finally, the ninth study reviewed by Hafsteinsdottir et al. (2011) shows that 22–50 percent of caregivers needed for information related to the stroke recovery, other important topics identified included prescriptions and medications, safety issues, managing behavior, managing emotional instability and the changing relationship with a patient (Pierce et al., 2004).

## 2.6 Conceptual /Theoretical Framework

The framework used in this study is PRECEDE model. PRECEDE stands for Predisposing, Reinforcing, and Enabling Factors in Educational Diagnosis and Evaluation (Ransdell, 2001). This framework offers a quantifiable means of conducting an educational program (Haske van Veenendaal, Doris. Grinspun & Adriaanse, 1996). Ransdell (2001) states that, the PRECEDE-PROCEED model was developed as a planning framework from which health education and health promotion programs could be designed.

Predisposing factors include knowledge, attitudes, beliefs, personal preferences, existing skills, and self-efficacy toward the desired behavior change (Ransdell, 2001). Meanwhile, reinforcing factors include factors that reward or reinforce the desired behavior change and enabling factors are psychological/emotional or physical factors that facilitate motivation to change behavior (Ransdell, 2001).