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THE IMPACT OF SEVERITY OF DISABILITY OF STROKE ON THE QUALITY OF LIFE OF HOME-BASED FAMILY CAREGIVERS IN KELANTAN

by

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the requirements for the degree of
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CERTIFICATE

This is to certify that the dissertation entitled The Impact of Severity of Disability of Stroke on The Quality of Life of Home-Based Family Caregivers in Kelantan is the bonafide record of research work done by Fatin Nazihah binti Muhammed 87430 during the period of July 2008 to April 2009 under my supervision. This dissertation submitted in partial fulfillment for the degree of Bachelor of Health Sciences (Nursing). Research work and collection of data belong to Universiti Sains Malaysia

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THE IMPACT OF SEVERITY OF STROKE DISABILITIES ON QUALITY OF LIFE OF HOME-BASED FAMILY CAREGIVERS IN KELANTAN

ABSTRACT

This study examined the impact of severity of stroke disability on the quality of life (QoL) of home-based family caregivers in Kelantan. This study also examined the association between demographic characteristics of family caregivers with their quality of life. A random sample of caregivers (n=37) completed two questionnaires. Barthel Index (BI) was used to evaluate disability severity in stroke patients. Bakas Caregiving Outcomes Scale (BCOS) was applied to evaluate the quality of life among caregivers. On the BI, 37.8% (n=14) scored 0-59, indicating they were dependent. The BCOS with mean of 59.08 (SD=9.12), indicating overall slight change for the worst. There is no association between demographic characteristics regarding age, sex, race, marital status and educational level with family caregivers' quality of life. But, there is an association between family caregivers' job, total monthly income and caregiving duration with their quality of life. The correlation between disabilities in stroke patients and quality of life in their caregivers was determined in statistical analysis between BI and BCOS. There is a significant moderate relationship between BI total score and BCOS total score (r=0.645, p<0.001). Interventions aimed at improving the quality of life of family caregivers need further exploration.

KESAN KETERUKAN KETIDAKUPAYAAN STROK TERHADAP KUALITI HIDUP PERAWAT KELUARGA SEMASA DI RUMAH DI KELANTAN

ABSTRAK

Kajian ini dijalankan untuk mengkaji kesan keterukan ketidakupayaan pesakit strok terhadap kualiti hidup perawat keluarga mereka di rumah di Kelantan. Kajian ini juga menilai perkaitan antara ciri-ciri demografi perawat keluarga dengan kualiti hidup mereka. Persampelan rawak perawat keluarga (n=37) menamatkan dua borang soal selidik. Indeks Barthel (BI) digunakan untuk menilai tahap keterukan ketidakupayaan pesakit strok. Skala Hasil Penjagaan Bakas (BCOS) diaplikasi untuk menilai kualiti hidup perawat keluarga. Dalam Indeks Barthel, 37.8% (n=14) memperoleh skor 0-59, menunjukkan kebergantungan dengan perawat keluarga. BCOS dengan min 59.08 (SD=9.12) menunjukkan keseluruhan perubahan hidup ke arah lebih teruk. Tiada perkaotan antara cirri-ciri demografi perawat keluarga yg berkaitan dengan umur, jantina, etnik, status perkahwinan dan tahap pelajaran dengan kualiti hidup perawat keluarga. Bagaimanapun, terdapat perkaitan antara pekerjaan, jumlah pendapatan bulanan dan jangaka masa penjagaan dengan kualiti hidup perawat keluarga. Perhubungan antara ketidakupayaan pesakit strok dengan kualit hidup perawat keluarga ditentukan oleh analisis statistic antara BI dan BCOS. Terdapat perhubungan yang sederhana antara BI dan BCOS (r=0.645, p<0.001). Intervensi untuk meningkatkan kualiti hidup perawat keluarga perlu dieksplorasi dan diaplikasikan pada masa akan datang.

CHAPTER 1

INTRODUCTION

1.1 Background of the Study

Stroke is the third leading cause of death behind heart disease and cancer and is the leading cause of serious, long-term disability in the United States (*World Health Organization* (*WHO)*, 2008). According to the WHO, 15 million people suffer stroke worldwide each year. Of these, 5 million died and another 5 million are permanently disabled. Stroke strikes about 730 000 Americans each year - killing 160 000 and forever altering the lives of the 570 000 who survive (*American Heart Association* (*AHA)*, 2008).

Family caregivers are terms that refer to unpaid individuals such as family members, friends and neighbours who provide care (*Family Caregivers Alliance (FCA),* 2008). They are often propelled into the caring role due to the sudden and unexpected nature of disease and family obligation. Family caregivers will likely continue to be the largest source of long-term care services in the U.S. and are estimated to reach 37 million caregivers by 2050, an increase of 85% from 2000 (*FCA,* 2008).

Family caregivers become central to the process of rehabilitation and to long-term outcome for stroke patients. Family caregivers play an important role in the lives of stroke patients. Many stroke patients are left with permanent physical and psychological disabilities and will be functionally dependent in activity daily living. It has been estimated that 68% to 74% of stroke patients depend on the daily care of family members once they return home (Dewey, Thrift, Mihalopoulos, Carter, Macdonell & McNeil, 2002). The support of family caregivers for their relatives with stroke has an important impact for patients.

Research shows that caregiving can have both deleterious mental and physical health consequences for caregivers (*FCA*, 2008). Stroke has the potential to affect the health and quality of life both to the individuals and their family caregivers which may subsequently affect the recovery of the stroke survivors (Han & Haley, 1999). Caregivers report feeling depressed, socially isolated, abandoned, burdened and stressed by the ways in which caregiving affects their daily schedule, physical and emotional health, and family relationships (Parag, Hackett, Yapa, Kerse, McNaughton, Feigin & Anderson, 2008). Stroke caregivers have to deal with not only stroke patients' difficulties in mobility, self-care, and communication, but also their cognitive impairment, depression, and personality changes (Han & Haley, 1999).

In Australia, stroke is the second single greatest killer after coronary heart disease and a leading cause of disability (Australian Institute of Health and Welfare (AIHW), 2008). According to AIHW also, about 346 700 Australians have had a stroke at some time in their lives in 2003. Reported by Dewey et al. (2002), about 88 percent of stroke survivors live at home and most of them have one or more disabilities such as impaired mobility, communication and dysphagia. Caregivers are now presented in 1 to 20 households (Dewey et al., 2002) and are acknowledged to play an important role in the care of stroke survivors.

The rapid industrialization of China now had making China to face the developed world diseases such as stroke. A survey of 7 cities in China between 1986 and 1990 yielded a yearly rate of age-adjusted stroke of 216 per 100,000, demonstrating that stroke is just as common a health problem in China as in other ASEAN nations (Cheng, Ziegler & Lai, 1995). Currently, the prevalence of stroke is about 5 million Chinese, 75 percent with varying degrees of incapacity. Incidence is 1.3 million new stroke patients per year and data sources suggest that there are between 1 and 1.5 million stroke deaths a year (*AHA*, 2008).

In the Asia-Pacific region, cardiovascular diseases have emerged as major public health concerns. In 2003, incidences of stroke in Asia increased by 25%. Although the study of the epidemiology of stroke in developed Western countries is extensive, in Asian countries it has been comparatively limited with the exception of Japan (Venketasubramaniam, 1998). There is little data on stroke incidence and prevalence in Southeast Asia. Since 1992, stroke has been among the top four leading causes of death in ASEAN countries (Venketasubramanian, 1998). It is the leading cause in Indonesia, third in the Philippines and Singapore, and fourth in Brunei, Malaysia, and Thailand. In ASEAN countries also, stroke accounted for 0.9 to 4.5 percent of total medical admissions and 9.2 to 30 percent of all admissions to the neurological wards. The prevalence of stroke has been documented as being in the range of 161 to 690 per 100 000 population (Venketasubramaniam, 1998).

Stroke is Singapore's third leading cause of death and accounts for 10 to 12 percent of all deaths in Singapore (Venketasubramanian, 1999). The number of deaths and admissions to Singapore hospitals for stroke has been rising; when standardized for age, however, mortality rates for stroke for both genders have fallen. Reported by Venketasubramanian (1999), as many as four in every 100 Singaporeans over the age of 50 has suffered a stroke The incidence of stroke is expected to double in the next 20 years as the population ages.

Stroke is one of the leading causes of morbidity in Malaysia. According to the Asia Pacific Consensus on Stroke Management (1998), the burden of stroke will be increasing most in developing countries in the next 30 years. Cerebrovascular accident (CVA) contributed 10 percent of medically certified deaths and were the fourth leading cause of death in Malaysian Government Hospital in 2002 (*Ministry of Health Malaysia (MOH),* 2002). MOH statistics showed stroke consistently as the third leading cause of death in the 1990s, surpassed only by coronary heart disease and cancer. Data from

Ministry of Health (2002) showed cerebrovascular disease causing a mortality of 11.9 per 100 000 population (see Table 1.1). There is no incidence or prevalence data available for the country.

Table 1.1 : Top 5 Mortality Rate in MOH Hospitals 2002

Mortality (rate per 100 000 population)	
Septicaemia	22.60
Heart diseases and diseases of pulmonary Circulation	21.24
Malignant neoplasms	13.51
Cerebrovascular diseases	11.97
Accident	9.25

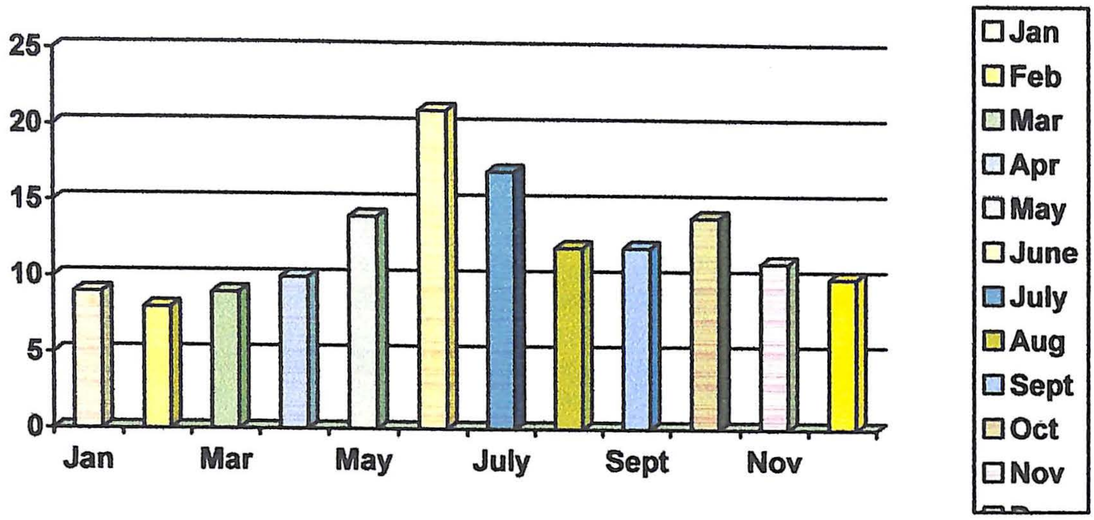
(Source: MOH Health Indicator, 2002)

In Hospital Universiti Sains Malaysia (HUSM), there were 491 stroke patients who had received treatment as in-patient from January 2004 to June 2008 (Record Unit of HUSM 2008). This number varies from year to year. Of this, 104 stroke patients died, 42 recurrent strokes, 80 old strokes while 265 for newly diagnosed for stroke or first ever stroke (see Table 1.2) while 2007 showed the highest number of stroke patients (see Figure 1.1).

Table 1.2 : Statistic of Stroke Patients in HUSM (2004 – Jun 2008)

Year	**Recurrent**	**Old**	**First-ever**	**Died**	**Total**
2004	9	16	42	21	88
2005	5	14	63	25	107
2006	9	15	42	26	92
2007	12	25	78	28	143
Till Jun 2008	7	10	40	4	61
Total	42	80	265	104	491

(Source: Record unit of HUSM, 2008)



(Resource: Record Unit of HUSM, 2008)

Figure 1.1: Statistic of Stroke Patients in HUSM from Jan – Dec 2007.

1.2 Problem Statements

Stroke has become one of the most common causes of disability and handicap in the community. Each year about 780,000 people experience a new or recurrent stroke. About 600,000 of these are first attacks, and 180,000 are recurrent attacks (*AHA,* 2008). Once diagnosed of having stroke, many stroke patients require assistance in their activities of daily living which is provided by family members mostly.

Family caregivers reported to have significant changes in their quality of life from providing care to stroke patient. They aim to meet the needs of the dependent stroke patient while concurrently adjusting vocationally, socially, and emotionally to the sudden change in their own lifestyle. The needs of the disabled stroke survivor are often multiple and include help with physical activities (for example, moving, handling, and transferring from bed to chair, and chair to toilet).

Family members are usually placed suddenly in the caregiver role due to the stroke disease process. This new role may have the caregivers feeling unprepared and overwhelmed. The caregiving demands can have emotional and physical outcomes which could have implications in continuing the caregiving role. The lives of caregivers of persons with stroke may change just as the lives of the persons with stroke have changed. Some of the perceived life changes of caregivers may be positive, negative, or even unchanged (Parag et al., 2008).

Many studies evaluate the quality of life in caregivers as providing care towards stroke patients (Jostard, 2004; McCullough, 2005; White, 2006; & Khalid, 2008). There are needs to measure the severity of disability of stroke patients, measured by the Barthel Index (BI) to see any significance on family caregiver's quality of life. This is important to promote a good quality of life of family caregivers and to provide a more comprehensive assessment of caregiver outcomes.

Therefore, Roy Adaptation Model (RAM) by Sister Callista Roy has been modified and is used in this study. This theory is applied as it focuses on the person's ability to adapt to a problem or problems present in one or more of the adaptive modes. Responses to stimuli are dependent on levels of adaptation, which are continually changing (Roy & Roberts, 1981).

1.3 Objectives of the study

1.3.1 General Objectives

To explore the impact of severity of stroke disabilities on the quality of life of home-based family caregivers in Kelantan.

1.3.2 Specific Objectives

1. To identify the association between demographic characteristics (age, sex, ethnicity, education level, job, total monthly income and caregiving duration) of stroke patient's family caregivers with their quality of life.
2. To identify the relationship between severity of stroke disabilities with the quality of life of family caregivers.

1.4 Research Questions

1. Is there any association between demographic characteristics (age, sex, ethnicity, education level, job, total monthly income and caregiving duration) of stroke patient's family caregivers with their quality of life?
2. Is there a relationship between severity of stroke disabilities with the quality of life of family caregivers?

1.5 Hypotheses

1. H_A : There is a significant association between demographic characteristics of stroke patient's family caregivers with their quality of life.

   H_O : There is no significant association between demographic characteristics of stroke patient's family caregivers with their quality of life.
2. H_A : There is a relationship between severity of stroke disabilities (Barthel Index score) with the quality of life of family caregivers.

   H_O : There is no relationship between severity of stroke disabilities (Barthel Index score) with the quality of life of family caregivers.

1.6 Definition of Terms (Conceptual/Operational)

1.6.1 Person with stroke

A person with stroke is defined as an individual who experienced a type of cardiovascular disease (*American Stroke Association (ASA),* 2004). A stroke can occur when a blood vessel which carries oxygen and nutrients to the brain is either blocked by a clot or the blood vessel bursts. When either occurs, a part of the brain cannot receive the required oxygen and nutrients and, thus, the brain starts to die (*ASA,* 2004).

1.6.2 A first-ever stroke

A first ever stroke means a stroke that occurs in a person who never has had a stroke before. Previous Transient Ischemic Attack is not considered a stroke as these events last less than 24 hours (*ASA*, 2004).

1.6.3 Severity of Disability

Disability refers to physical or mental impairment that substantially limits one or more major life activities (*WHO*, 2008). In this study, the severity of disability of stroke patient was measured by Barthel Index.

1.6.4 Quality of life

A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (*WHO*, 2008). In this study, quality of life of family caregivers of stroke patient was measured by Bakas Caregiving Outcome Scale.

1.6.5 Family Caregiver

Family caregiver was an individual, such as a family member, who provided care to a person with stroke (Bakas, Champion, Perkins, Farran, & Williams, 2002).

1.6.6 Care giving

Care giving is assistance in routine activity daily living provided to family members or friends because of long-term mental and physical condition impairment, diseases or disabilities, which cause hardship to the individual to take care of themselves (Anderson, Linto & Stewart-Wynne, 1995).

1.7 Significance of the study

Recent years have seen increasing awareness of the role of caregivers in the management of stroke patient. The important role of the caregivers in maintaining their disabled family members in the community is becoming increasingly recognized. Once these health problems occur, assistance is needed to continue the activities of daily living. Due to the disease process of those persons who have experienced a stroke, the caregivers assumed new roles and responsibilities.

There is growing literatures on the care giving burden, poor care giving outcomes, lack of caregiver support, and equivocal success, with interventions aimed all alleviating the caregiving outcome (Han & Haley, 1999). The caregivers may struggle with keeping the patients alive, minimizing their suffering, and respecting patient's wishes.

This study focused on the impact of severity of stroke disabilities on the quality of life of family caregivers. Physical deficit in the stroke can be challenging for the family members, who can experience limited strength themselves. This study is significant to nursing to help develop interventions that can be implemented for the caregivers of persons with stroke. During the difficult time of adjustment for the family unit to the stroke disease process, nurses are urged to provide support in many aspects of cares. For example, nurses have a responsibility to provide stroke education and supply information regarding coping strategies to caregivers of persons with stroke. Nurses are practicing from a holistic framework recognizes and intervenes in self-care deficits for all members of the family unit. Nurses need to be educated to see their patients as human beings with social needs. Quality care will increase the quality of life for stroke patients as well as increase the family caregivers' satisfaction.

CHAPTER 2

LITERATURE REVIEW

2.1 Overview of Stroke Disease

Stroke is the primary cerebrovascular disorder in the United States and in the world (*AHA,* 2000). A stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue (*WHO,* 2008).

Stroke can be divided into two major categories; ischemic stroke and hemorrhagic stroke (*AHA,* 2008) (see Figure 2). Ischemic stroke is the most common type, accounts for about 87 percent of all strokes. It occurs when a blood clot (thrombus) forms and blocks blood flow in an artery bringing blood to part of the brain. Blood clots usually form in arteries damaged by fatty buildups, called atherosclerosis (*AHA,* 2008). Hemorrhagic strokes are primarily caused by bleeding into the brain tissue, the ventricles, or the subarachnoid space. (*AHA,* 2008).

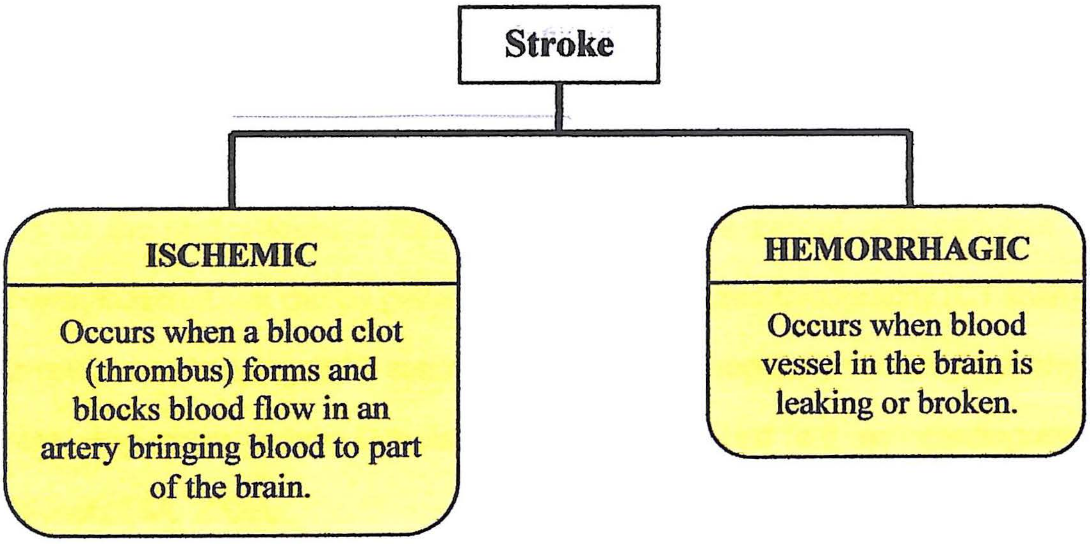


Figure 2.1 : Categories of Stroke

The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include: confusion, difficulty speaking or understanding speech; difficulty seeing with one or both eyes; difficulty walking, dizziness, loss of balance or coordination; severe headache with no known cause; fainting or unconsciousness (*WHO,* 2008).

Overall, the most common risk factors for stroke are high blood pressure, high cholesterol, smoking, diabetes and increasing age (Wedro, 2008). From American Heart Association (2008), some stroke risk factors are hereditary. Others are a function of natural processes. Still others result from a person's lifestyle. Those resulting from lifestyle or environment can be modified with the help of a healthcare professional.

The effects of a stroke depend on which part of the brain is injured and how severely it is affected (*ASA*, 2008). A very severe stroke can cause sudden death. Stroke can affect patients physically, mentally, emotionally, or a combination of the three (*ASA*, 2008). Some of the physical disabilities that can result from stroke include paralysis, numbness, pressure sores, pneumonia, incontinence, apraxia (inability to perform learned movements), difficulties carrying out daily activities, appetite loss, speech loss, vision loss, and pain. If the stroke is severe enough, or in a certain location such as parts of the brainstem, coma or death can result (*WHO,* 2008).

There are several techniques and tools used to diagnose stroke. A stroke is diagnosed as the doctor takes a medical history from the patient, and performs a physical examination. Data can be gathered from computerized tomography (CT scan), magnetic resonance imaging (MRI scan), computerized tomography with angiography, conventional angiogram, carotid Doppler ultrasound, heart test (e.g. echocardiogram) and blood test (*ASA*, 2008).

Surgery, medications, hospital care and rehabilitation are all accepted stroke treatments (*AHA,* 2008). There is opportunity to use tissue plasminogen activator (TPA) as a clot-buster drug to dissolve the blood clot that is causing the stroke. Drugs to thin the blood (anticoagulation; for example, heparin) are also sometimes used in treating stroke patients in the hopes of improving the patient's recovery (Wedro, 2008). In certain patients, aspirin given after the onset of a stroke does have a small, but measurable effect on recovery (Wedro, 2008). Other treatments include managing other medical problems such as hypertension and hypercholesterolemia. Blood pressure and cholesterol control are keys to prevention of future stroke events (*ASA*, 2008). In patients with diabetes, the blood sugar (glucose) level is often elevated after a stroke. Controlling the glucose level in these patients may minimize the size of a stroke. Finally, oxygen may be administered to stroke patients when necessary. When a patient is no longer acutely ill after a stroke, the healthcare staff focuses on maximizing the patient's functional abilities (Wedro, 2008).

Rehabilitation can take place after stroke patients discharged from ward. The rehabilitation process can include some or all of the following:

1. Speech therapy to relearn talking and swallowing;
2. Occupational therapy to regain dexterity in the arms and hands;
3. Physical therapy to improve strength and walking; and
4. Family education to orient them in caring for their loved one at home and the challenges they will face.

(Wedro, 2008)

2.2 Caregivers of Person with Stroke

Family caregivers are an important resource in the promotion of successful health outcome in stroke survivors. Recent years have seen increasing awareness of the role of caregivers in the management of stroke patients, and there is growing literature on the caregiving burden, poor caregiver outcomes, lack of caregiver support, with interventions aimed at alleviating the caregiving burden (Han & Haley, 1999).

Family caregivers aim to meet the needs of the dependent stroke survivor while concurrently adjusting vocationally, socially, and emotionally to the sudden change in their own lifestyle (Han & Haley, 1999). The needs of the disabled stroke survivor are often multiple and include help with physical activities, for example, moving, handling, and transferring from bed to chair, and chair to toilet; nursing activities such as facilitation of activities of daily living such as feeding; communication - verbal and non-verbal interaction with family, friends, and the outside world; psychological and emotional support - to adapt to the effects of the stroke; and social reintegration into society (Hankey, 2004)

Unfortunately, this commitment to care often posses a significant risk to the caregivers' own health and well-being (White, Poissant, Cote-LeBlanc, Wood-Dauphinee, 2006). Understanding the effects of caring on health and how caregivers cope with the demands and stresses of their role enables nurses and other health care providers to better meet the needs of this growing population.

The experiences of caregivers have received considerable attention over the last two decades. Han and Haley (1999) noted that the main focus of this attention has been on Alzheimer's dementia (AD) caregiving. Less research has been conducted on the experiences of caregivers of persons with stroke, despite the high prevalence of stroke and the potentially high burden associated with caring for those it affects (Han &

Haley, 1999). Clearly there is a need to increase our knowledge about the unique experiences of caregivers of persons with stroke. Due to the nature of the disease, many caregivers of stroke survivors enter the caring role abruptly, with little time to adapt to their new circumstances (Kerr & Smith, 2001). Many caregivers feel inadequately prepared to face the emotional and physical challenges of caring for someone with a disability (Bakas, et al., 2002; Kerr & Smith, 2001), suggesting that the early weeks and months after discharge are an uncertain and vulnerable time for caregivers.

2.3 The Impact on Family Caregivers Quality of Life

The consequences of care giving can be numerous and cumulative. Caregivers might experience chronic burden of physical, psychological, social, and financial stress, coupled with erosion of precious family and leisure time and lack of external recognition and support, contribute to anxiety, depression, and a decline in the quality of life of the care giver (Dewey et al., 2002). Providing care on persons with stroke may give impact on caregivers' quality of life. Family caregivers have a high risk of depression and psychological morbidity, and they perceive caregiving as a burden in terms of feelings of heavy responsibility, uncertainty about care needs, constant worries, restraints in social life, and feelings that the affected persons totally rely on their care (McCullaugh, Brigstocke, Donaldson, & Kalra, 2005).

Study by Emily McCullagh (2005) aimed to identify determinants of caregiving burden and quality of life in caregivers of stroke patients. The contribution of these variables to caregiver burden score (CBS) and quality of life (QOL) measures at 3 months and 1 year was analyzed using regression models. Caregiver burden in the immediate aftermath of stroke was determined by patient and caregiver anxiety rather than by the level of disability, age, gender, or support from family or social services. In addition, caregiver QOL was adversely influenced by patient disability and caregivers' age, male gender, and physical health. Social services support had little effect on caregiver burden or QOL but reduced the need for institutional care. In conclusion, this study showed that advancing age and anxiety in patients and caregivers, high dependency, and poor family support identify caregivers at risk of adverse outcomes, which may be reduced by caregiver training.

Study by Varsha Parag (2008) aimed to describe the positive and negative impact of providing care for stroke survivors and to identify independent predictors of poor carer outcome. This study was conducted in a prospective population based stroke incidence in Auckland, New Zealand over a 12-months period. Stroke survivors and their unpaid carers were assessed at 6 and 18 months after stroke onset using the Short Form 36 questionnaire and the Bakas Caregiving Outcomes Scale. Results showed that unpaid carers reported lower health-related quality of life at 6 months after stroke than their age- and sex-matched counterparts in the New Zealand population. The impact of providing care was predominantly negative; however, approximately one third of the carers had improved relationships with the stroke survivor. No reliable predictors of carer burden were identified.

Han and Haley (1999) revealed that older caregivers are less likely to have depression at 6-9 months post-stroke. Those caregivers with higher incomes were also less likely to be depressed at 6-9 months post-stroke. Caregivers concerned for the future, before the chronic phase of the stroke, were found to have higher levels of depression. Caregivers had greater depression with symptoms of their own illness, the depression of the person with stroke, and the perception of the survivor's cognitive hassles, such as disruptive or inappropriate behavior. Female caregivers noted higher levels of anxiety than did male caregivers.