The effect of a nurse led Supportive Educative Learning program for Family caregivers (SELF) on outcomes for stroke survivors and the family carers in Thailand

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A thesis submitted in fulfillment of the requirements for the degree of

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School of Nursing
College of Health and Science

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I, Roshinee Oupra hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

................................................
(Signature)
Dedicated to:

This study is dedicated to the survivors of stroke and their families I have known in Thailand.
Acknowledgements

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<tr>
<td>ADLs</td>
<td>Activity of Daily Living</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ARNA</td>
<td>Australasian Rehabilitation Nurses’ Association</td>
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<tr>
<td>AUD</td>
<td>Australian Dollar</td>
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<td>BI</td>
<td>Barthel Index</td>
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<td>CBR</td>
<td>Community Base Rehabilitation</td>
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<tr>
<td>CSI</td>
<td>Caregiver Strain Index</td>
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<tr>
<td>CT</td>
<td>Computerized Axial Tomography</td>
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<tr>
<td>CVA</td>
<td>Cerebrovascular accident</td>
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<tr>
<td>CVD</td>
<td>Cerebrovascular disease</td>
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<tr>
<td>DALYs</td>
<td>Disability –Adjusted Life Years</td>
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<td>Diabetes Mellitus</td>
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<td>GCS</td>
<td>Glasgow Coma Scale</td>
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<tr>
<td>GHQ-28</td>
<td>General Health Questionnaires</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>HT</td>
<td>Hypertension</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>IHD</td>
<td>Ischemic Heart Disease</td>
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<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<tr>
<td>MRI</td>
<td>Magnetic Resonance Imaging</td>
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<td>MOPH</td>
<td>Ministry of Public Health</td>
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<td>mRS</td>
<td>Modified Rankin Scale</td>
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<td>NHS</td>
<td>National Health Services</td>
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<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>QoL</td>
<td>Quality of life</td>
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<tr>
<td>SELF</td>
<td>Supportive Educative Learning program for Family caregivers</td>
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<tr>
<td>THB</td>
<td>Thai Baht</td>
</tr>
<tr>
<td>TIA</td>
<td>Transient Ischemic Attack</td>
</tr>
<tr>
<td>USD</td>
<td>United States Dollar</td>
</tr>
<tr>
<td>UTI</td>
<td>Urinary Tract Infection</td>
</tr>
<tr>
<td>UWS</td>
<td>University of Western Sydney</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Abstract

In Thailand, the crude death rate from stroke is 10.9/100,000 population, and increasing. Complications due to stroke account for a significant proportion of admissions to medical wards in Thailand. Unlike Western countries where community rehabilitation programs have been established to provide services following the acute stage of stroke recovery, there is no stroke rehabilitation team in the community and family caregivers are the primary source for ongoing care and support. While family members accompany patients during their hospitalisation, they received little information about how to assist their relatives, and as a result feel inadequately trained, poorly informed and not satisfied with the support that is available after discharge. As results, many family caregivers suffer both physically and psychologically and find themselves overwhelmed with strain, suffering burden and exhaustion.

This research was a comparative study with concurrent controls, using a two-group pre-test and post test design. The aims of this study were to develop and implement a nurse led supportive-educative learning programme for caregivers of stroke survivors, and to evaluate outcomes for patients and their carers.

This study was conducted in two hospitals in different cities in Thailand. The intervention consisted of didactic group education sessions, caregivers education booklet, and demonstration and practice sessions for carers while the patient was hospitalized during the acute phase of the stroke, and follow up support by telephone for three months following discharge.
Data were collected at three stages: stage one following admission, stage two prior to discharge and stage three at three months after discharge. The Mini Mental State Examination (MMSE) was used as a pre-recruitment screening test to evaluate the cognitive status of stroke survivors and their family caregivers. In addition to demographic data, functional ability was assessed by using the Barthel Index (BI) and modified Rankin scale (mRS). The General Health Questionnaire-28 (GHQ-28) was used for assessing the quality of life in the stroke survivors as well as their family caregivers and family caregivers’ strain was collected by using the Caregiver Strain Index (CSI). Finally, readmission and mortality rates were recorded.

One hundred forty stroke survivors and 140 family caregivers (70 from each of the two study sites) were recruited and completed the stage one data collection. Patients admitted to site A hospital comprised the intervention group and patients admitted to site B hospital were the control group. At the three month follow-up, data were obtained from 64 patients and 70 carers who received the intervention and 63 patients and 67 caregivers in the control group. Findings demonstrated that the stroke survivors in the intervention group scored better for functional outcome and quality of life (BI $t=2.43$, $p=0.017$; mRS $Z=3.176$, $p=0.001$; and GHQ-28 $t=5.17$, $p=0.000$) and had fewer readmissions for management of stroke-related complications (intervention $n=10$ [14.3%]; control $n=34$ [48.6%]). The family caregivers in the intervention group also had better quality of life (GHQ-28 $t=6.80$, $p=0.000$) and less strain (CSI $t=7.17$, $p=0.000$). In addition, it was found that family caregivers’ quality of life and strain have an effect on stroke survivors’ functional outcome.
This study demonstrated that providing education and support to the family caregiver of stroke survivors does benefit both the survivors and caregiver by empower carers to make decisions about the care they provide which has a follow on effect of reducing carer stress and burden. It is recommended that programs to provide carers with skills and knowledge to assume an active and therapeutic role in the management of family members who suffer a stroke be established and appropriately supported. Furthermore, implementing this research in other regions of Thailand is recommended.
Anthology of Publications

Conference Presentations


Newspaper Article

Chapter One

Background and significance of the study

1.1 Introduction

This chapter presents the background to the study, an explanation of the significance of the study to people in Thailand and describes developments in primary care within the Thai health system. The research questions and aims that direct this study are stated and an overview of the structure of the study is presented.

1.2 Background to the study

This section will provide an overview of stroke in general and situations of stroke in Thailand, followed by the Thai context which includes a profile of stroke patients, the Thai health care systems and stroke rehabilitation in Thailand

1.2.1 Stroke

Stroke or cerebrovascular accident (CVA) results from a defect of the vessels in the brain including occlusion due to thrombi / emboli, or haemorrhage caused by vascular rupture (Poungvarin, 2001a, 2001b). Unlike a transient ischemic attack (TIA) which is caused by a temporary interruption to the blood supply to the brain causing symptoms and signs that recede completely within 24 hours (Poungvarin, 2001b, p.165), symptoms of stroke persist for longer than 24 hours and may lead to death (Boysen & Truelsen, 2000).
Stroke is the leading cause of death worldwide, (WHO Guidelines Subcommite, 1999), attributing to the death of around 20 million people around the world a year (Mendis, Porter, Mackay & O’Brien, 2004). This number is predicted to rise to 24 million deaths per year by 2030 (Mendis et al., 2004). Stroke survivors (stroke patients discharged home from hospital) usually have some degree of disability which makes the condition a particularly costly disorder for individuals, the health system and society. In the United State of America (USA), stroke is the third leading cause of death and physical impairment. Approximately 700,000 Americans suffer a stroke each year, with 40% of the stroke survivors left with moderate impairment and 15-30% living with severe disability (American Heart and Stroke Association, 2004).

Similar to the USA, Australian data indicates that 40,000 Australians suffer a stroke each year (Corbett, 2003), ranking stroke as the third most common cause of death. Disability is also a major concern in Australia with 1/3 of stroke survivors dying in the first year, and around 10% requiring long term high-level care (Corbett, 2003).

In Thailand, the prevalence rate for stroke is 690/100,000 which is comparable to developed countries (Venketasubramanian, 1998). The incidence of stroke is increasing and currently one new stroke is diagnosed every four minutes (Ministry of Public Health Thailand, 2004), with stroke being the third leading cause of death in Thailand (Ministry of Public Health Thailand, 2004). In addition, data from the National Statistical Office Thailand regarding the death rate due to stroke demonstrates an increasing mortality (National Statistical Office Thailand, 2004a). For the six years 1999 to 2004 the number of people who died due to stroke
increased dramatically (Figure 1.1) with men having a higher incidence than women. The study claims 12,636 men and 9,120 women died from stroke in 2004 (Figure 1.2).

**Figure 1.1:** Number of deaths due to stroke in Thailand 1999-2004

**Figure 1.2** Comparison of deaths due to stroke for Thai males and females 1999-2004
Stroke carries a high rate of morbidity with 150,000 people becoming disabled each year in Thailand (Asian Acute Stroke Advisory Panel, 2000). Stroke also ranks in the top twenty causes of disability burden in the country (Ministry of Public Health Thailand, 1999). It is estimated that the management of stroke costs at least 15,000 million Thai baht (THB)/year (500 million USD) (Ministry of Public Health Thailand, 1998). Complications due to stroke account for a significant proportion of admissions to medical wards in Thai hospitals, the most common complications being pneumonia, urinary tract infections and decubitus ulcers (Poungvarin, Prayoonwiwat & Senanarong, 2000).

Stroke can have devastating consequences for patients and their families. It can result in physical, perceptive, cognitive, intellectual, communicative, emotional and behavioural changes and abnormalities. This in turn affects all aspects of the person’s physical and psychological life, including their economic situation, and results in the need for support and access to services on a long-term basis (Anemaet, 2002; Jaracz, Jaracz, Kozubski & Rybakowski, 2002; McCullagh, Brigstocke, Donaldson & Kalra, 2005).

While the incidence of stroke is increasing, the mortality rate has decreased considerably (Elkins & Johnson, 2003). This situation is attributed to improved identification and reduction of stroke risk factors (Elkins & Johnson, 2003; Poungvarin, 2001a). Advances in approaches to treatment during the acute phase and rehabilitation have also successfully reduced severe impairment and hospitalization (Altieri, Rocco & Lenzi, 2005; Kalra, Evans, Perez, Melbourn, Patel,
Returning home or to the community can be a traumatic experience for stroke survivors. This situation compounds when there is inadequate or insufficient support available to ease their transition to home, and to assist them to modify their lives according to the degree of disability experienced. In some countries, community care programs, established to assist people to remain living in their own homes, are provided by health professionals.

However, in developing countries where health services do not meet the acute needs of the majority of the community, families must assume responsibility for rehabilitation and long term care. This situation has a significant impact on the survivors’ quality of life, and the wellbeing of the entire family. As a result, the family member or family caregiver has to adjust their schedule in order to provide more complex care in the home which, ideally, should be provided by health care professionals (Keer & Smith, 2001; O’Connell & Baker, 2004). This responsibility is assumed frequently without any preparation for, or support to continue in, the caregiver role. Formal programs to provide members of the family, in particular the primary caregiver, with the skills and knowledge necessary to provide care and to identify situations that may require input by health professionals to prevent deterioration in the stroke survivor’s condition, are paramount to ensure optimal quality of life for all concerned (Jullamate, Azeredo, Paul & Subgranon, 2006).
Nurses play an important role in providing education and instruction to patients and families during hospitalisation (Australasian Rehabilitation Nurses' Association, 2003; Pryor & Smith, 2002), as they are the professional group likely to have the most contact with stroke survivors during the acute phase of their illness and during rehabilitation. Nurses also have a significant role in the assessment of home care giving situations, and in supporting and assisting family caregivers as they prepare to become caregivers (Australasian Rehabilitation Nurses' Association, 2003; Brillhart, 2001; Pryor & Smith, 2002).

After discharge from hospital, family caregivers are the main people who care for stroke survivors. Although patients return home for long term care, the majority of family caregivers in several studies (Banks, 1999; Brereton & Nolan, 2000; Jullamate, Azeredo, Paul, & Subgranon, 2006; Lui & Mackenzie, 1999) indicated that they had insufficient information concerning the care of people following stroke and they lacked the knowledge and training to take care of their post stroke relatives (Banks, 1999; Brereton & Nolan, 2000; Jullamate et al., 2006; Lui & Mackenzie, 1999). In addition, the majority of caregivers need education programs which contain simple and understandable information and they also need advice to assist them with their care giving role (Jullamate et al., 2006; Louie, Liu & Man, 2006; O'Connell & Baker, 2004; O'Connell, Baker & Prosser, 2003; Yoon & Byles, 2002). Therefore, it is considered very important that nurses educate stroke survivors’ family caregivers so that they can provide effective ongoing care at home.

Negative experiences for family caregivers are to be avoided because they can lead to negative outcomes for stroke survivors (Teel, Duncan & Lai, 2001).
In Thailand, stroke survivors usually stay in hospital until their medical condition is stable and then return home to be cared for by the family (approximately three days to two weeks) (data taken from medical record from intervention and control hospital). About 50% of stroke survivors return home to the community before they reach full recovery, and as a consequence many have lasting functional deficits which impede their ability to participate in their usual or pre-stroke activities of living (Anderson, Rubenach, Mhurchu, Clark, Spencer & Winsor, 2000). The family is considered to be the main caregiver following discharge from hospital although no support or instruction is provided to prepare the family for the caregiving role. The situation is made more difficult for the individual and family because there is no therapeutic support or care service for stroke patients in the community in Thailand.

A qualitative study conducted in Thailand involved interviews with 20 informal caregivers of stroke survivors regarding their needs in providing care (Jullamate et al., 2006). The findings revealed that the three main needs of caregivers were assistance, information and social support. Despite this information, caregivers’ needs are often given low priority in the management of stroke. The absence of any form of support contributes to the burden on family caregivers who will provide care to meet the physical and emotional needs of the stroke survivor (Subgranon & Lund, 2000).

Providing care to a stroke survivor at home, that includes rehabilitation and prevention of complications, places considerable physical and psychological burdens on the caregiver (Gasemgitvatana & Tulyatorn, 1999; Subgranon & Lund, 2000;
Family caregivers of stroke survivors have been shown to have higher depression scores than non-caregivers, which can in turn have negative implications for continuation of the care giving role (Teel et al., 2001).

It is vitally important that family caregivers of stroke survivors have sufficient knowledge and skills to provide appropriate care to assist them to overcome their functional deficits and complications that may develop as a result of disability. Caregivers require specific knowledge of procedures and an understanding of the particular complications that may develop. This is supported by the humanistic psychologists, who claim that training which combines knowledge and skills would enable the development of knowledge that evolves from experience into practice (Curson, 1997). Additionally, rehabilitation practice can enhance functional recovery, prevent further dysfunction, improve subsequent health care utilization, and also promote quality of life of patients and their caregivers (Hoenig, Honner, Duncan, Clipp & Hamilton, 1999). Therefore, early and ongoing rehabilitation may help to prevent complications and promote the best possible outcomes for the person.

Providing sufficient knowledge is a key support to prepare people for their new role as family caregiver and this can be achieved by a specific teaching program (Hammer & Collinson, 2000). Such a program could benefit both survivors and family caregivers as it would help them to feel more confident in looking after the stroke survivor and help to reduce their stress and burden. It is also potentially an effective way to ensure stroke survivors receive the rehabilitation required, to promote quality of life and restore maximum function (Burton & Gibbon, 2005; Kalra et al., 2004).
1.2.2 The Thai context

This study was undertaken in Thailand therefore it is important to understand the demographics, and the social, cultural and health context of the country.

(i) Geographic and administrative system

Thailand (Figure 1.3) is a country in South-East Asia covering an area of 514,000 square kilometres. Bangkok is the capital city of Thailand, a country which is bordered by Burma, Lao, Cambodia and Malaysia. Thailand is classified into four geographic regions: central (include Bangkok Metropolitan region), northern; north eastern; and southern. Additionally there are 76 provinces, 870 districts, 7,197 tambons sub district and 69,523 villages.

Thailand is a democratic country, having the king as Head of the State, a constitutional monarchy under the Constitution of the Kingdom of Thailand. The constitution is regarded as the first people’s constitution of the nation. The constitution establishes three independent powers namely the Legislative, the Executive and the Judiciary powers.

Thailand’s administrative system comprises the following major administrative categories:

(a) Central administration is through the King, who is the head of the state. The council of Ministers is the government body responsible for administrative or governmental functions under the parliament system and there are 20 ministries and departments.
(b) Provincial administration is the function of the ministries and departments, who delegate to the regional or provincial level, under the supervision of the provincial governor with assigned officials from various central administrative agencies.

(c) Local administration is the autonomous administrative authority of the people in each administrative locality, under the law.

Figure 1.3: Map of Thailand

(ii) Population and language

Thailand has a population of 63.08 million (surveyed in 2005) (Wibulpolprasert, 2006). Almost all residents (99.3%) are of Thai nationality and the rest are of other nationalities, such as Chinese, Myanmar and Lao. Most of the population (40,100,000) live in rural areas; around 22,729,000 live in urban areas (Institute for Population and Social Research, 2007). For communication purposes, the official language, Thai, is used for spoken and written communication.
(iii) Economic and education

In the past, the Thai economy was mostly subsistence farming for household consumption and not commercial or export markets. Regarding industry, the production was previously of local or village handicraft type. The Thai economy began to development during 1961-1966, i.e. from the first National Economic and Social Development Plan (1961-1966) through to the current 9th plan (2002-2006) (Wibulpolprasert, 2006).

Bangkok and its metropolitan region have the highest per capita income in the country and the north-eastern provinces have the lowest. Average monthly income per household in Thailand is 14,963 baht (554.20AUD; 427.50USD) (National Statistical Office Thailand, 2004b). However, benefits have accrued faster in occupations closely linked to the international economy, for example manufacturing parts of electronic goods for export markets such as the USA and Japan. For those who remain in the domestic economy, such as small-scale farmers, income continues to be low and poverty is still a main concern in rural Thailand.

The Thailand Government provides 12 years of elementary education (basic education), comprising six years of primary education (starting at age 7), three years of lower secondary education and three years of upper secondary education. However, only the first nine years is compulsory and this is reflected in school enrolment rates; 86% in primary school and 55% in secondary education (Wibulpolprasert, 2006). The literacy rate for those aged 15 and over is 97% for males and 94% for females (Earth Trends Country Profiles, 2003).
(iv) Cultural context

The majority of Thai people (95%) are Buddhist (Poungvarin, 2003). Buddhism plays a significant role in Thai life and is pervasive in the Thai culture. Two major concepts, “katanyu” and “katavethi” are of particular relevance to this study. Katanyu is a sense of awareness and gratitude towards someone who has done something that has benefited you. Katavethi relates to doing something in return for those benefits (Royal Thai Scholars Dictionary, 1982). These concepts are strong within the Thai family and are fundamental principles of their beliefs. This means that when Thai children grow up they are responsible to pay back, or look after, their parents to reciprocate the benefits they received from their parents (Panyanunthaphikhu, 2000; Suwanno, 1997).

Senior or elderly persons are respected in Thai culture and elderly family members live with their children in the extended family structure which strengthens the bond between them and other family members (Suwanno, 1997). Family member interaction and interdependence characterises rural lifestyle. The close relationships among family members and people in rural areas are influenced by their agricultural work patterns, which require all family members to participate.

(v) Health

The health status of Thai people has been improving, with life expectancy at birth being 67.9 years for males and 73.9 years for females (Wibulpolprasert, 2006). Though higher than that of developing countries and world population (66.9 years), life expectancy of Thai people is still lower than those for several other southeast Asia countries (Wibulpolprasert, 2006).
The major and rising causes of death among Thai population are non-communicable diseases, accidents and human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS). For all age groups, the leading cause of death is diseases of the circulatory system (18.6% of all causes), more than half of which were due to cerebrovascular disease; the second leading cause was cancer and tumours (16.2%); the third leading cause was infectious disease (15.5%), most of which were HIV infections (Wibulpolprasert, 2006).

In measuring the health status of Thai people using DALYs (Disability-Adjusted Life Years: one DALY is one lost year of healthy life) as the indicator, it was found that HIV/AIDS is the leading cause of DALYs lost in both males and females (17% for males; 10% for females), followed by road traffic injuries, cerebrovascular disease and diabetes respectively (Bureau of Policy and Strategy, 2002).

(vi) Profile of stroke patients in Thailand

Studies of stroke survivors conducted in Thailand demonstrate a profile consistent with stroke survivors in western countries (Moonkrtkklang, 1999; Nakara, 1999; National Statistical Office Thailand, 2004a; Nicoletti, Sofia, Giuffrida, Bartoloni, Bartalesi & Bartolo, 2000; Niyomthai, 2002; Pungvarin, 2001a; Thipsamniag, 2000; Thornvaldsen, Davidsen, Bronnum-Hansen & Schroll, 1999; Williams, Jiang, Matchar & Samsa, 1999). Stroke is more common in males than females, and as the age of the people in the country increases, the incidence of stroke also increases (Pungvarin, 2001a). The average age of stroke patients is 60 years or older and this is similar to the Western countries (Moonkrtkklang, 1999; Nakara, 1999;
The majority of stroke patients in Thailand are married and have completed elementary education (nine years of schooling) (Chantawatchai, 1999; Moonkrthkklang, 1999; Nakara, 1999). In terms of family role, 66.4% of the stroke patients were leaders of the family therefore their illness has a significant impact on their role in the family (Nakara, 1999). Mental health is also compromised following stroke, with patients reporting stress and anxiety resulting from feeling ill-informed about their disorder and limited access to ongoing care (Nakara, 1999; Thongtang, 2001).

The majority of stroke patients in Thailand suffer from ischaemic stroke (Chantawatchai, 1999; Moonkrthkklang, 1999; Nakara, 1999; Poungvarin, 2001b), with the most common precipitating factor being hypertension. Additionally, heart disease, diabetes mellitus and hyperlipidemia were also found as causes of stroke in the Thai population (Chantawatchai, 1999; Moonkrthkklang, 1999; Nakara, 1999; Poungvarin, 2001b; Rajborirug, 2002). In a study conducted in Thailand by Poungvarin et al., (2000), data were analyzed from all stroke patients who were admitted to the study hospital during May 1997 to October 1998. The most common risk factors of stroke (Figure 1.4) were hypertension (57.58%), hyperlipidemia (33.88%), diabetes mellitus (30.58%), smoking (21.49%), ischaemic heart disease (16.53%), previous stroke (14.33%) and alcohol consumption (13.22%).
(vii) Thai health care system

The Ministry of Public Health, Thailand (MOPH) is responsible for the Thai health service. In general, there are two sectors that provide health care; one is the government sector and the other is the private sector. The four regions and 76 provinces are used for health administration (Figure 1.5). There are large regional hospitals typically providing 500 to 1000 beds in each region. These regional hospitals are responsible for the provincial hospitals in their region. Community hospitals are normally located in small provinces and in big districts. For the tambon level and villages, there are community health care centres responsible for primary health care.
Figure 1.5: Levels of health service administration in Thailand.
It can be seen that the structure and pattern of health service provided in rural and urban areas are quite different. In rural areas, in particular, the community health centre is a village level health service unit that is expected to be the first line of contact. Each health centre's role includes health promotion, disease control and prevention, treatment and care of minor illness and rehabilitation (Ministry of Public Health Thailand, 1998). Although these health centres were established in rural areas and sub-districts throughout the Kingdom, the quality of care is not consistent across the health centres. As a result people distrust the services that are provided and are reluctant to use them (Sriwanichakorn, 1999). Therefore, the health care system is not effective in helping the health centre serve the public as a first line contact (Sriwanichakorn, 1999). The lack of attention to developing the quality of care at the health centre has also contributed to this problem.

At the district level, the community hospital provides services that include primary medical care and care of patients who are referred from the health centres. It also provides health promotion, disease prevention, and gives supervision and help to health centres (Sriwanichakorn, 1999). However, the percentage of patients in rural areas visiting community hospitals increased from 24.37% in 1997 to 36.7% in 1999 (Ministry of Public Health Thailand, 2000). The problem is that the people who distrust the health centre service tend to use the services at the community hospital, even when the health problem could actually have been managed at the health centre. Patients have a strong belief that by going to a hospital and consulting a doctor they will receive higher quality care than is available at a health centre (Sriwanichakorn, 1999). Hence, the health centre as a first line of service is under-utilised.
In urban areas, there are metropolitan public health centres and municipal public health centres. These two types of centres provide primary care services, health promotion and disease prevention to people in Bangkok and to those who live in the municipal areas. Nurses often lead the multidisciplinary teams in these centres. Some people with minor health problems bypass these health centres to go to the district or province hospital, thus these hospitals are crowded and quality of care is jeopardized (Boontong, 2000).

When people in the rural areas require medical attention, their first source of care is the health centre in their village. In the rural health centres there are no doctors or registered nurses. Technical nurses and community health care workers provide care. Technical nurses are those who have completed two years’ study in nursing college after high school to obtain a diploma in nursing and midwifery. Community health care workers have completed two years' training in public health after high school graduation. They are considered to be one of the most important categories of health personnel as they are working at district level, and are the interface between government health facilities and the people.

Severely ill patients are transferred first to the district hospital and if more complex care is required they will be transferred to a provincial hospital or a regional hospital depending on the level of care that is required. Patients with medical insurance are required to follow that system if they wish to claim for their expenses or receive free services.
The concept of the referral pathway in the Thai health care system is not clearly defined and there is a lack of continuity of care as people move between the levels of care. Consequently, health care teams aim to help patients to recover from critical conditions and maintain stability as much as possible, however, after discharge, community based rehabilitation is rarely provided.

There are no data on the time course of functional recovery and related factors of stroke patients in Thailand although researchers have reported that 91% of stroke survivors are dependent on others to complete their activity of daily livings (ADLs) following discharge from hospital (Taboonpong, Pansena & Takviriyanan, 1994). People require assistance with bathing, dressing, eating, eliminating, moving, recovering and protection from various kinds of danger (Hiranchunha, 1998). Additionally, in most hospitals there are insufficient beds for patients, providers of all types with specialist training as well as the lack of medical equipment.

There is no history of a universal government administered health insurance scheme in Thailand, although private companies are required to provide health insurance for their employees and the employee will be sent usually to the hospital of the company's choice. In addition, those who work for the government are reimbursed for their medical fees by the government. Additionally, individuals can purchase their own private health insurance. Thailand does not have a system similar to general medical practitioners in Australia, rather when a person is ill, they attend a hospital. As a result, medical specialists attached to hospitals mostly treat patients in urban areas.
The system of health insurance is undergoing some change with the introduction of the 30 baht health policy (1 USD equal to 30-37 baht, 1 AUD equal to 27 baht). The system seeks to ensure that all people are able to access health care facilities without being worried about the cost. Only 30 baht is paid for each health care visit. This scheme was piloted in six provinces in Thailand from 2001 (Ministry of Public Health Thailand, 2001) and was implemented nationally in 2002 (Pokpermdee, 2006). This system provides a universal health card or gold card for people living in the pilot areas who were not in any health scheme and whose names were in the house registration in those provinces. This card must be shown with the individual’s identification card every time they access the government health service, or any private sector health service that has registered with this project. The provider health service has to follow the referral health system from the primary health care centre or the nearby hospital, which are registered under the project. For emergencies and accidents, the insured can access any government health service. To access health services, the insured must contribute a co-payment of 30 baht per episode. Under this 30 baht Universal Coverage Policy, the insured receives the same quality health service as offered by other health schemes. At present, the service package includes almost all health services, except cosmetic care, obstetric delivery beyond two pregnancies, drug addiction treatment, haemodialysis, organ transplantation, infertility treatment and other high cost interventions. The government funding is paid by capitation. The total payment per person paid from tax revenue is 1,404 baht per year, part of which is paid to the health care facilities, according to the number of local residents who are registered with them. This capitation includes the cost for curative, preventive, and health promotional care as well as the administration.
However, not all of the people who were eligible for the gold card and the 30 baht scheme access health services via the required mechanism. This applies particularly to people who migrate and/or have no specific address and therefore are not registered with the scheme. There are still some concerns about this project, in particular the sustainability, quality and processes have been questioned (Secretary of Public Health, 2001).

The financial sustainability of the program has been questioned due to inadequate hospital management of the budget. Moreover, this problem may occur from uneven patient distribution, for example, some hospitals have a higher percentage of chronic patients, which is costly. At present the government is attempting to compel all hospitals to participate in the Hospital Accreditation Program to ensure quality of care. Clinical practice guidelines are being developed to assist this process.

(viii) Stroke rehabilitation in Thailand

Thailand is estimated to be ten years behind the USA and Britain in regard to stroke care (Auamkul, Kanshana & Phiranggapaura, 1999). The majority (90%) of health expenditure is allocated to curative services rather than supportive and preventive care, and the majority of hospitals and community health centres focus on curative and symptomatic treatment (Chavanichkul & Tangcharoensathien, 2006; Wiboolpolprasert, Pradumbuk, Riewpaiboon, Rujakom & Pengpaiboon, 1996). There is only one stroke unit, which is in Siriraj Hospital in Bangkok (capital of Thailand). Only 150 facilities provide Computerized Axial Tomography (CT) and 20 provide Magnetic Resonance Imaging (MRI) in the whole Kingdom (Asian Acute Stroke Advisory Panel, 2000). The financial and social benefits of
rehabilitation are not recognised and little attention is given to restorative treatment in acute or community settings, nevertheless many of the provincial hospitals will have a rehabilitation team. There is no stroke rehabilitation team in the community in Thailand and many post stroke patients have to be readmitted to the hospital for treatment of complications arising because of the lack of appropriate rehabilitation (Jullamate et al., 2006; Komjakraphan, 2000). Activity limitation has become the major category of disability in Thailand and stroke is one of the main causes. Nevertheless, 80% of the services provided aim to prevent complications, which is only one objective of rehabilitation (Wiboolpolprasert et al., 1996).

As a consequence of the financial and service focus on curative care, few providers understand the essentials of rehabilitation or have the skills required to lead development of these services. Thus, patient education is largely neglected and little attention is directed towards understanding the needs of stroke survivors following discharge or assisting caregivers to fulfils their roles. There are also limited positions to train stroke rehabilitation professionals. In 1998, the Ministry of Public Health surveyed a number of specialists in health care based on the actual field positions and found there were only 293 physical therapists and 597 physical therapist assistants (Ministry of Public Health Thailand, 1998). Finally, the funding in the community is insufficient to meet the demand for services.

A minority of patients are followed up in the community. People living close to hospitals and/or those who have retained a naso-gastric tube or tracheotomy tube will be followed up by the home health care teams, which are usually led by nurses. Acute stroke patients stay in the hospital until their medical condition is stable.
When the doctor feels the patient is ready for rehabilitation, they are sent to a rehabilitation unit for several hours (or the physiotherapist may see the patient in the ward) and then discharged home. Family members are asked to attend and observe in the rehabilitation unit. After discharge, stroke patients are on their own with their caregivers unless any complications arise, in which case they are readmitted to the hospital. At the same time, strain on family caregivers is great due to shorter hospital stays, the absence of a referral system for ongoing care and the absence of support for caregivers (Jullamate et al., 2006). It is not surprising to find that many family members of stroke survivors are suffering from lack of care and support as neither has been provided to them (Jullamate et al., 2006). Stroke survivors frequently have complications which require readmission. During readmission patients will receive symptomatic treatment for a few days and then be discharged. With the trend of shorter hospital stays, patients often return home before their recovery is complete. Assistance from family members is thus required for caring at home.

1.3 Significance of the study

This study was conducted in Thailand where there is no stroke rehabilitation service in the community. The majority of studies conducted in Thailand focus on the factors of strain on the family caregivers, communication problems in stroke patients, epidemiology of stroke, risk factors of stroke, aetiology of stroke, caregiving process, well-being of family caregivers and health status of the caregivers (Jatupornpat, 2000; Niyomthai, 2002; Rajborirug, 2002; Rattanawijit & Kunsonkiet, 1998; Sangboon, 2002; Subgranon & Lund, 2000; Thipsamniag, 2000;
There is no previous research that investigates the effect of education for family caregivers on outcomes for stroke survivors and this study will address that gap in the literature. Education for caregivers will be the intervention.

In a situation where management of acute stroke is provided in the hospital setting and there is no primary care for rehabilitation or follow-up, people living in rural areas away from city hospitals are particularly compromised. Consequently, these patients often end up with disability, complications and readmission to hospital. The burden of care that must be assumed by the family places strain on stroke survivors and their families. A training program for family caregivers of stroke survivors, designed and delivered by nurses, is long over due in Thailand especially given the worldwide focus on primary care and community programs.

Appropriate rehabilitation practices can enhance functional recovery, prevent further dysfunction, improve subsequent health care utilization, as well as promoting quality of life for stroke survivors and their caregivers (Hoenig et al., 1999). Nurses are closely involved in helping stroke survivors manage personal care issues, which could possibly be done more effectively if patients remained in hospital for an extended period of time. However, in reality, patients in Thailand are discharged as soon as their condition is stable. This is due to the high cost of care, budget limitations, and lack of human resources. This may leave patients unable to perform daily activities and complications may follow. As a result, family members assume responsibility for the provision of care.
To reduce caregiver stress and burden, one of the approaches involved in rehabilitation nursing is providing education and training to families (Brillhart, 2001; Pryor, 2005). This helps families feel more confident in looking after stroke survivors. Besides this, adult learning theory suggests that adults learn what they consider realistic and important to them and what can be applied in their real lives (Knowles, 1984; Speck, 1996). Hence, providing education support to the caregivers of stroke patients could benefit both stroke survivors and caregivers.

Participating in such a program will provide caregivers with skills and knowledge to provide day to day care, contribute to the rehabilitation of stroke survivors and reduce the incidence of complication and readmission to hospital. The intervention is also intended to reduce the caregivers’ burden by providing them with resources, skills and information to assist them to provide care for stroke patients.

This research is significant because it will help to develop a new way to improve care for stroke patients in rural areas or communities and reduce caregivers’ strain in Thailand.
1.4 Research question

What is the effect of a nurse-led supportive, educative learning program on the outcomes for stroke survivors and their family caregivers in rural Thailand?

1.5 Aims of the study

1. To develop and implement a nurse led supportive educative learning program for family caregivers (SELF) of stroke survivors in Thailand

2. To evaluate the effect of the SELF program on:
   • functional ability and quality of life of stroke survivors
   • family caregivers’ strain and quality of life

3. To reduce the incidence of complications among stroke survivors.

1.6 Hypotheses

H1: Participation by family carers of stroke survivors in the SELF program will improve the functional level of stroke survivors compared to those whose carers have not participated in the program.

H2: Participation by family carers of stroke survivors in the SELF program will improve quality of life of stroke survivors compared to those whose carers have not participated in the program.
H3: Family carers of stroke survivors who participate in the SELF program will have lower levels of strain compared to family carers who have not participated in the program.

H4: Family carers of stroke survivors who participate in the SELF program will have higher quality of life compared to family carers who have not participated in the program.

H5: Stroke survivors whose family carers have participated in the SELF program will have fewer readmissions to hospital for management of stroke related complications compared to stroke survivors whose carers have not participated in the program.

1.7 Structure of the thesis

This thesis will be organized as follows:

• **Chapter two**: is a review of the literature relevant to stroke. The effect of stroke on patients and their families, the aims of stroke rehabilitation, and the role of nurses in stroke rehabilitation as described in the literature is presented. This chapter also profiles stroke patients in Thailand, and describes current practices in stroke rehabilitation in Thailand. A combination of Orem’s Theory of Self-care (Orem & Taylor, 1986) and adult learning theory (Knowles, 1984) provide the philosophical underpinnings for the assumptions upon which this study was based (conceptual framework). Orem’s theory and adult learning theory were critically reviewed and discussed and their applicability to the study aims established.
- **Chapter three - Method:** in this chapter the design and implementation of the study is described including sampling, developing of the intervention and instruments for data collection, including validity and reliability, and the process for data collection and data analysis.

- **Chapter four - Results:** this chapter reports the findings of this study including the flow chart of participants through the trial.

- **Chapter five - Discussion:** the main findings from the study are discussed along with the strengths and limitations of the study. The implications of this study for practice and research are considered. This chapter concludes with the final recommendation to take forward to health professionals and the Ministry of Public Health Thailand for discussion in order to improve strategies of providing health care services in stroke survivors and improve the quality of life for both the stroke survivors and their family caregivers.

1.8 **Summary**

This chapter has presented the background and significance of the study by introducing the effect of stroke on stroke survivors and their family caregivers, followed by the problem of stroke in Thailand. The research questions and aims of the study were given. In the next chapter, the conceptual framework of this study will be discussed and the relevant literature to the study will be critically reviewed and discussed.
Chapter Two

Literature review

2.1 Introduction

A comprehensive search strategy was developed to identify relevant literature for this study. MEDLINE, CINAHL, OVID, EMBASE, PsycInfo, WHO and Cochrane Library electronic databases were searched using the key terms of stroke, cerebrovascular disease (CVD), cerebrovascular accident, stroke patients, stroke survivors family caregivers, caregivers, carers, informal care giving, rehabilitation, epidemiology, incidence, Orem’s theory of nursing, education, training, adult learning theory, community based rehabilitation (CBR), nursing roles, functional outcome and International Classification of Functioning, Disability and Health (ICF). Some of the key terms were then combined to get the relevant literature. The most recent literature were selected however, it is noted that some of the included literature predated this. This is because this literature provides original terms and definitions about stroke, rehabilitation, adult learning theory and Orem's self-care-deficit theory.

This literature review is divided into three sections. The first section explores the definition of stroke, signs and symptoms, the effect on stroke survivors, time course of functional recovery, factors related to functional abilities in ADLs among stroke survivors, stroke rehabilitation, and effects of stroke on family caregivers. The second section discusses the basic concepts of rehabilitation, the International Classification of Functioning, Disability and Health, community based rehabilitation
and the nurse role in rehabilitation. The third section reviews literature relating to adult learning theory and Orem’s theory of self-care. Finally, the conceptual framework or the theoretical framework of this study is presented. The following chapter will be presented in the following sections:

2.2 Stroke

2.2.1 General aspects of stroke
2.2.2 Effect of stroke
2.2.3 Time course of functional recovery among stroke patients
2.2.4 Factors related to functional abilities in ADL among stroke patients
2.2.5 Stroke rehabilitation
2.2.6 Effects of care giving on stroke family caregivers
2.2.7 Self-management of chronic conditions

2.3 Rehabilitation

2.3.1 Rehabilitation
2.3.2 The International Classification of Functioning, Disability and Health
2.3.3 Community based rehabilitation
2.3.4 Nursing’s role in rehabilitation
2.3.5 Rehabilitation nursing competence

2.4 Conceptual Framework

2.4.1 Conceptual framework
2.2 Stroke

2.2.1. General aspects of stroke

According to the World Health Organization, stroke is defined as “rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin” (Aho, Harmsen, Hatano, Marquardsen, Smirnov & Strasser, 1980, p 114). This definition includes most cases of sub-arachnoid haemorrhage, intracranial haemorrhage, and cerebral infarction, but not TIA. The term “global” in the definition refers to disturbances of cerebral function in patients with sub-arachnoid haemorrhage without focal neurological deficits (Aho et al., 1980). In addition, a recent WHO MONICA (World Health Organization Monitoring Trends and Determinants in Cardiovascular Disease) project has given the definition of stroke or cerebrovascular disease (CVD) as:

“the acute illness precipitated by local derangement of the blood supply to the brain, either by obstruction to the artery concerned (ischaemic stroke) or rupture and bleeding into the brain (haemorrhagic stroke) or the membrane around it (sub-arachnoid haemorrhage)” (Tunstall-Pedoe, Kuulasmaa, Tolonen, Davidson & Mendis, 2003, p.xix).

Stroke, therefore, is a condition that is caused by insufficient blood supply to the brain due to obstruction, or rupture of a blood vessel in the brain, which causes a sudden onset of neurological deficits (Poungvarin, 2001a). When stroke occurs, the brain tissue can be damaged or destroyed due to insufficient oxygen supply to the cells (Poungvarin, 2001a, 2001b). Stroke is classified as the main public health problem in the world and a leading cause of disability (American Heart Association,
Stroke survivors tend to suffer from physical and emotional impairments that contribute to disability; with almost 50% of stroke survivors being discharged home with limitations in various body functions (Andersen, Schultz-Larsen, Kreiner, Forchhammer, Erikson & Brown, 2000; Doyle, 2002; O'Connell, Hanna, Penney, Pearce, Owen & Warelow, 2001). For example, the most common effects of stroke are weakness or paralysis on one side of the body, numbness, aphasia (impairment of language), dysphasia (reduced ability to communicate), homonymous hemianopia (decreased vision or changes in visual field), dizziness, loss of balance or loss of coordination, dysphagia (difficulty in swallowing), motor deficit which is often associated with increased resistance to passive extensions and muscle contracture in the wrist, problems with bladder or bowel control and problems with movement and self-care generally (American Family Physician, 1997; Poungvarin, 2001b). Stroke does not only affect the physical condition; it also affects mental health contributing to depression, anxiety, confusion, disorientation, amnesia, psychosis and frustration (Thongtang, 2001). The mental health condition of the stroke survivors often results in greatest burden on family caregivers as they have a feeling of heavy responsibility and uncertainty about the needs of the stroke survivors who are dependent on their care (Han & Haley, 1999; Scholte op Reimer, de Haan, Rijinders, Limburg & Van den Bos, 1998; Teel et al., 2001).
In general, stroke is classified into two main types according to the aetiology: ischaemic stroke and haemorrhagic stroke (Figure 2.1) (Pajaree, 2004; Poungvarin, 2001b). Many studies report that haemorrhagic stroke patients have a more difficult recovery period and tend to have a higher incidence of physical and sensory limitations when compared with ischaemic stroke (de Freitas, Devuyst, van Melle & Bogousslavsky, 2000; Su, Chang, Chen, Su, Chien & Huang, 2000). Moreover, a retrospective case series design study conducted by Lipson, Sangha, Foley, Bhogal, Pohani and Teasell (2005), recruited 819 stroke patients (110 patients with haemorrhagic stroke and 709 patients with ischaemic stroke) and found that haemorrhagic stroke patients are likely to develop medical complications more than ischaemic stroke patients.

**Figure 2.1:** Classification of stroke

Ischaemic stroke is caused by occlusion of an artery, which decreases blood flow to the brain, thereby starving the tissues of oxygen (ischaemia). The most common subtypes of ischaemic stroke are thrombotic and embolic strokes. Thrombotic
stroke is the most common type of ischaemic stroke, caused by development of atherosclerosis of the blood vessel wall. Thrombotic stroke tends to have a slow onset with thrombus formation extending along the interior of the artery, gradually occluding the lumen of the artery. An embolic stroke occurs when an embolus breaks off from one area of the body and travels to the cerebral arteries via the carotid artery (Pajaree, 2004; Poungvarin, 2001b). The morality rate was the highest in embolic stroke when compared with thrombotic stroke in a study by De Jong, Van Raak, Kessels, and Lodder (2003) that followed 998 stroke patients with first cerebral infarction.

Haemorrhagic stroke is caused by rupture of blood vessels in the sub-arachnoid space or bleeding into brain tissues (Poungvarin, 2001b). Haemorrhagic stroke is classified into two subtypes, sub-arachnoid haemorrhage (SAH) and intracerebral haemorrhage (ICH). Sub-arachnoid haemorrhage is caused by rupture of a cerebral aneurysm or arteriovenous malformation. Sub-arachnoid haemorrhage is often characterized by sudden severe headache, vomiting, and change in level of consciousness. Intracerebral haemorrhage is caused by hypertension (Poungvarin, 2001b). It is believed that hypertension (elevated systolic and diastolic pressures) causes changes in the arterial wall that leave it prone to rupture (Poungvarin, 2001b). Intracerebral haemorrhage occurs when blood leaks into the brain tissue through the rupture in the vessel wall (Pajaree, 2004; Poungvarin, 2001b). Signs and symptoms of both types of stroke are presented in Table 2.1.
Table 2.1: Sign and symptoms of ischaemic and haemorrhagic stroke

<table>
<thead>
<tr>
<th><strong>Ischaemic Stroke</strong></th>
<th><strong>Haemorrhagic Stroke</strong></th>
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<tbody>
<tr>
<td>• weakness or paralysis in the arm or leg, sometimes sudden falls may occur</td>
<td>• sudden onset severe headache</td>
</tr>
<tr>
<td>• tingling or numbness in the mouth, cheeks or gums</td>
<td>• nausea /vomiting</td>
</tr>
<tr>
<td>• difficulty swallowing</td>
<td>• altered mental state</td>
</tr>
<tr>
<td>• aphasia (language deficits)</td>
<td>• seizures</td>
</tr>
<tr>
<td>• neglect (hemi-inattention)</td>
<td>• sensitivity to light (photophobia)</td>
</tr>
<tr>
<td>• severe ataxia, often with nausea and vertigo</td>
<td>• loss of consciousness</td>
</tr>
<tr>
<td>• gaze palsy</td>
<td>• decreased level of consciousness</td>
</tr>
<tr>
<td>• visual field loss</td>
<td>• neck stiffness</td>
</tr>
<tr>
<td>• slurred speech</td>
<td>• focal neurological symptoms similar to ischaemic stroke</td>
</tr>
<tr>
<td></td>
<td>• the eyes may become fixed in one direction or lose vision</td>
</tr>
<tr>
<td></td>
<td>• stupor, rigidity and coma</td>
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</tbody>
</table>

Source: Adapted from Carrozzella and Jauch (2002, p 38)

Stroke risk factors include high blood pressure, diabetes mellitus, heart disease, transient ischaemic attack (TIA), carotid artery disease, smoking, inactivity and obesity, excessive alcohol intake, age more than 55 (however, stroke does affect people of all ages), male gender and ethnicity (American Stroke Association, 1999; Poungvarin, 2001a). The effects of stroke depend on the anatomic site of the brain, the rate of onset, the size of lesion, and the presence of collateral circulation. The neurological deficits reflect both the location and size of the infarction or haemorrhage (Poungvarin, 2001b). The most visible sign of stroke is hemiplegia; stroke survivors with hemiplegia often demonstrate abnormal muscle tone to some degree, affecting the limbs and the trunk (Poungvarin, 2001b). Moreover, more than 50% of stroke survivors are at risk of developing a wide range of complications secondary to their stroke (Doshi, Say, Young & Doraismay, 2003; Langhorne, Stott, Robertson, MacDonald, Jones, McAlpine, Dick, Taylor & Murray, 2000; Roth,
Lovell, Richard, Heinemann, Semik & Diaz, 2001). Doshi, et al. (2003) conducted a retrospective review of complications from 140 case notes during January 2001-June 2001. They found that the overall complications rate was 54.3%; the more common complications were constipation, acute retention of urine, urinary tract infection, limb pain, epileptic seizure, chest infection, pressure sore, fall, deep vein thrombosis (DVT), depression, uncontrolled hypertension, and bleeding from the gastrointestinal tract. The findings from this study are similar to the previous studies by Langhorne et al., (2000) and Roth et al., (2001). Because the presence of even one of these complications can result in poor outcomes and poor prognosis for stroke survivors, it is very important that the person and their family caregivers are given information in order to prevent them (Johnston, Li, Lyden, Hanson, Feasby, Adams, Faught & Haley, 1999; Langhorne et al., 2000).

2.2.2. Effect of stroke on stroke survivors

Following acute stroke, the pathology that remains has various effects on the stroke survivor. It may affect almost all functions such as motor and sensory functions, autonomic nervous system, balance, speech, cognition, ability to perform ADLs as well as mental health status. Common problems are presented in the following sections.

(i) **Cognitive problems or memory disorders** may manifest as recent and remote memory deficits, a short attention span, poor judgment, inability to calculate, and/or inability to correlate learning with the real situation (Tosayanon, 2001). Moreover, stroke survivors may have difficulties understanding information, often have uncontrollable behaviour and have a high risk of accident (Tosayanon, 2001).
There are significant differences in cognitive abilities between patients with left and right hemiplegia (Anderson, 1990; Tosayanon, 2001). The patient with left hemiplegia often demonstrates visual motor perceptual impairment, loss of visual memory, left–side neglect, and poor insight and judgment. However, this patient may retain verbal fluency but lack insight into these problems (Tosayanon, 2001). The patient with right hemiplegia is not able to communicate effectively because both the vocabulary and auditory retention span have been reduced (Poungvarin, 2001b; Tosayanon, 2001). The reported prevalence of cognitive deficit within the first month after stroke ranges from 18-22% (Rasquin, Lodder, Ponds, Winkens, Jolles & Verhey, 2004)

(ii) The major communication problems are dysarthria and aphasia (Pajaree, 2004). Dysarthria is the condition in which stroke survivors understand the language but have difficulty with pronunciation, which may be due to weakness or paralysis of the muscles that control the lips, tongue and larynx (Poungvarin, 2001b). Stroke survivors with dysarthria often have difficulty with chewing and swallowing food (Pajaree, 2004; Poungvarin, 2001b). Aphasia is a deficit in using and interpreting the symbols of language; aphasia is a typical characteristic of left hemispheric lesion (Pajaree, 2004). Greener, Enderby and Whurr (1999) reviewed 12 trials about speech and language therapy for aphasia following stroke, and found that aphasia normally appeared in the first week in about one quarter of survivors of stroke. Fifty percent of all spontaneous recovery from disability occurs over the first month and can continue up to six months. About 12% of all survivors are still aphasic at six months.
(iii) **Motor weakness** affecting the extremities or the whole body, may cause postural and movement difficulties. Hemiplegia and hemiparesis are the most common symptoms found after the onset of stroke (Pajaree, 2004; Poungvarin, 2001b). Hemiparesis is apparently the most striking characteristic of stroke, with a prevalence of 70% to 85% in the acute stage (Pajaree, 2004; Poungvarin, 2001b). Many stroke survivors with persistent hemiparesis are often found suffering from spasticity that affects functional mobility and ADLs (Pajaree, 2004). It is very important that stroke survivors should be treated immediately because spasticity can cause secondary complications, such as joint deformities (Lagalla, Danni, Reiter, Ceravolo & Provinciali, 2000). Shoulder subluxation, often caused by incorrect handling, is another common complication resulting from poor recovery of arm function (Tosayanon, 2001). However, there is evidence that rehabilitation could improve function and reduce morbidity. To illustrate, Platz, Winter, Muller, and Pinkoskiet (2001) conducted a randomized control trial of 28 patients to test the ability of arm training to improve arm function following stroke and traumatic brain injury in patients with mild arm paresis. Although this study used a small sample size, the results demonstrated that arm function can be improved with exercise.

(iv) **Sensory and visual problems** are commonly associated with lesions in the parietal and temporal lobes resulting from interruption to the visual fibre of the optic tract which produce visual deficits (Pajaree, 2004; Tosayanon, 2001). Visual disorders may reduce the stroke survivor’s ability to relearn motor skills and increase the risk of accidents (Pajaree, 2004). Visual problems are associated with a poor outcome (Pajaree, 2004; Poungvarin, 2001b). This is of particular importance in stroke rehabilitation because as many as 20% to 80% of stroke patients may have
visual problems (Pajaree, 2004). The common visual problems that affect stroke survivors are as follows.

(a) Homonymous hemianopia is defective vision or visual loss in the same half of the visual field of each eye, in which stroke survivors can see only one half of normal vision and cannot see past the midline toward the opposite side of the lesion without turning toward that side (Schnell, 1993). Patients with hemianopia complain mainly of difficulties with reading and scanning scenes fast enough to make sense of things as a whole. Consequently, they fail to notice relevant objects or avoid obstacles on their affected side and may collide with approaching people or cars (Pajaree, 2004).

(b) Agnosia refers to the inability to recognize people or objects even when basic sensory modalities, such as vision are intact (Pajaree, 2004). There are basically three different forms of agnosia. The first, visual agnosia, is where the person has difficulty recognizing objects, faces and words. Stroke survivors may see some objects but are unable to recognize or attach meaning to them. For example, patients with visual agnosia may not recognize an object upon visual presentation even though they can describe its shape and other visual characteristics. The second is auditory agnosia, which involves the inability to recognize sounds and thirdly, somatosensory agnosia where the person has difficulty perceiving objects through tactile stimulation (Pajaree, 2004). Disorientation occurs because of the inability to recognize environmental cues, familiar faces or symbols. This can cause considerable self-care deficits when common or necessary objects such as silverware, clothing or toilet articles are unfamiliar (Schnell, 1993).
(v) **Dysphagia** is caused by a deficit of the nerve control centre around the throat and oesophagus causing difficulty in chewing, swallowing and movement of tongue and lips (Pajaree, 2004). People with dysphagia have a high risk of aspiration which leads to complications including pneumonia and infection (Pajaree, 2004). It is estimated that 42-76% of patients with acute stroke develop dysphagia and about half will experience aspiration, but not all will develop pneumonia (Katzan, Cebul, Husak, Dawson & Baker, 2003). Medical complications like pneumonia are known to be life threatening (Kelly, Hunt, Rudd & Lewis, 2002), with pneumonia associated with 15-25% of deaths following stroke (Adams, 2003).

(vi) **Common bladder and bowel problems** are incontinence and urinary retention due to decreased urinary bladder muscle tone (Pajaree, 2004). Incontinence has been recognized as one of the most common disabilities following stroke (Sze, Wong, Or, Lum & Woo, 2000). The main type of bowel problem is constipation, which may be due to inadequate food and water intake, muscle weakness and decreased mobility. A review of current knowledge of the association between urinary incontinence and stroke by Brittain, Peet and Castleden (1998) found the prevalence of urinary incontinence ranged from 32% to 79% in predominantly hospital–based studies. Studies with higher rates of incontinence (69% to 79%) excluded younger patients. Similarly, in a later study in a multi-ethnic population in London found that the prevalence of urinary incontinence was 50% (Lawrence, Coshall, Dundas, Stewart, Rudd, Howard & Wolfe, 2001).
(vii) Behaviour and emotional aspects Depression is common following stroke and has been shown to exert a more comprehensive adverse effect on health related quality of life than other functional limitations (Kwok, Lo, Wong, Wai-Kwong, Mok & Kai-Sing, 2006). A Malaysian study (Glamcevski & Pierson, 2005) investigated the prevalence and factors associated with post stroke in 80 stroke patients who were admitted to hospital. Results indicated that 66% of stroke survivors were depressed within 3-6 months post stroke. Moreover, the occurrence of depression was significantly related to age, ethnicity and poor performance in the ADLs (Glamcevski & Pierson, 2005). Signs of depression included slow or inconsistent recovery, poor cooperation or clinical deterioration of a previously stable neurological deficit (Thongtang, 2001).

2.2.3. Time course of functional recovery among stroke patients

There are two types of recovery in completed stroke namely neurological recovery and functional recovery.

Neurological recovery may be due to the resolution of local factors such as the reduction of cerebral oedema, the absorption of damaged tissue and the improvement of local circulation (Pajaree, 2004; Poungvarin, 2001b; Young & Forster, 2007). The process of neurological recovery has been divided into stages as follows (Pajaree, 2004; Poungvarin, 2001b): (a) immediately following the acute episode, flaccidity is present, with no movement of the limbs on the affected side; (b) as recovery begins, the basic limb synergies or some of their components may appear as associated reactions or minimal voluntary movement responses may be present, spasticity appears at this stage; (c) the stroke patient gains voluntary control
over spasticity increases; (d) some movement patterns out of synergy are mastered and spasticity begins to decline; (e) if progress continues, more difficult movements are learned as the basic synergies lose their dominance over motor acts; (f) with the disappearance of spasticity, the stroke patient begins to be able to move their joints and co-ordination approaches normal. A patient demonstrating this form of recovery presents with improvement in motor control, language ability or other primary neurological functions (Pajaree, 2004).

Generally it is agreed that 90% of neurological recovery occurs by the end of three months after the onset of stroke (Jorgensen, Nakayama, Raaschou, Vive-Larsen, Stoier & Olsen, 1995; Pajaree, 2004; Poungvarin, 2001b). However, this does not include some types of haemorrhagic stroke which may have a longer recovery period (Pajaree, 2004; Poungvarin, 2001b).

**Functional improvement** of the stroke survivors depends upon their environment, amount of training or rehabilitation and their motivation for them to learn and become independent regarding self-care and mobility (Pajaree, 2004). Improvement in the functional abilities of stroke survivors can be expected within one year after onset. A patient, who has sensorimotor, cognitive or behavioural deficits due to stroke, may regain the capacity to carry out ADLs such as eating, dressing, bathing and toileting, even if some degree of residual physical impairment remains. The ability to perform these tasks can improve through adaptation and training in the presence or absence of natural neurological recovery. Therefore, rehabilitation is very important for functional improvement (Pajaree, 2004; Poungvarin, 2001b).
Several studies have examined functional and neurological recovery and have documented that the most rapid recovery is in the first three months after the onset of stroke (Jorgensen et al., 1995; Zhou, Li & Liu, 2005). Jorgensen et al. (1995) conducted a prospective, consecutive, and community based study in Copenhagen, Denmark. They recruited 1,197 patients with acute stroke. The main outcome measures were neurological deficits (using the Scandinavian Neurological Stroke Scale) and functional disabilities (using the Barthel Index). The measurements were performed from the time of acute admission to the end of rehabilitation (six months post stroke). They found that the best ADL function was reached within nine weeks in patients with initially mild stroke, 13 weeks for those with moderate strokes, 17 weeks for severe strokes and 20 weeks for patients with very severe strokes.

Time course of motor function is also reported in many studies. For example Broeks, Lankhorst, Rumping and Prevo (1999) studied arm function after stroke and found that most of the improvement occurred during the first 16 weeks after stroke. Half of the patients had fair to good functional ability of the hemiplegic arm four years after stroke. Similarly, in a recent study by Zhou, et al. (2005) 423 stroke patients were investigated to determine whether the time lag between onset of the stroke and commencement of rehabilitation influences recovery of motor functions. The patients were divided into three groups according to time from onset of stroke to the beginning of rehabilitation: from 0-29 days, 30-89 days, and 90-180 days. The outcomes were measured by using Brunnstrom (for hand function and walking ability) and Barthel Index. The results revealed that the people who started rehabilitation within 30 days after onset of stroke achieved the best outcome. Additionally, it was found that the duration of three months induced the best
outcome when rehabilitation commenced within the first 90 days after the onset of stroke.

Therefore, it can be concluded that the best possible neurological and functional recovery depends on the severity and type of stroke, and will also be influenced by the rehabilitation that is available. While recovery does vary between individuals, rehabilitation should be provided as soon as possible in order to achieve the best results (Zhou et al., 2005).

2.2.4. Factors related to functional abilities in Activities of Daily Living among stroke survivors

Spontaneous recovery of stroke survivors occurs within the first month after onset and continues up to one to two years in some cases depending upon many related factors. These factors are explained below.

(i) Level of consciousness upon admission: The level of consciousness on admission is the most sensitive indicator of neurological function and is related to mortality risk in critically ill patients (Poungvarin, 2001b). For any type of stroke, consciousness upon admission is clearly the main factor in determining the chances of survival. This variable acts as a measure of severity of the stroke and the function remaining in the damaged tissue, which is a major underlying factor of increased mortality (Pajaree, 2004; Poungvarin, 2001b). A research study (Fanshawe, Venkatesh & Boots, 2002) in Australia investigated the mortality rate and functional outcomes of stroke patients admitted to the intensive care unit as well as identified factors that related to poor outcomes. They found that the mean Barthel score was
significantly different \((P< 0.001)\) between the independent \((94\pm6)\) and dependent \((45\pm26)\) survivors \((0-24 = \text{total dependence};\ 25-49 = \text{severe dependence};\ 50-74 = \text{moderate dependence};\ 75-90 = \text{mild dependence};\ 91-99 = \text{minimal dependence})\). Lower Rankin scores were related with considerable numbers of patients with good functional outcomes. Patients with haemorrhagic stroke, who had a Glasgow Coma Scale score <10 during assessment, had increased mortality and poor functional outcomes. From this study, it seems that the functional ability or level of independence, in the acute phase of stroke, could be a potential predictor of survival and functional outcome of the patients.

(ii) **The time from onset to treatment:** Stroke is considered a medical emergency. The importance of early hospital admission with acute stroke has been increasingly recognized because of the ongoing clinical trials of new promising drugs with narrow therapeutic time windows (Diez-Tejedor & Fuentes, 2001; Fogelholm, Murros, Rissanen & Ilmavirta, 1996; Poungvarin, 2001b). Furthermore, clinical and experimental studies suggest that cerebral ischaemia persisting for more than six hours can lead to permanent neurological damage (Ringelstein, Biniek, Weiller, Amneling, Nolte & Thron, 1992). Most thrombolytic and neuroprotective drug trials include patients who are present at the hospital within this short period of time (Davalos, Castillo & Martinez-Vila, 1995). A meta-analysis (41,399 stroke patients) of anticoagulation for cerebral sinus thrombosis revealed that providing aspirin once daily, starting within 48 hours of onset of stroke, significantly decreased the rates of death and dependency at six months. In addition, the treatment also decreased the incidence of recurrence of stroke and pulmonary emboli (Sandercock, Gubitz, Foley & Counsell, 2004).
(iii) **Age**: A person is most likely to suffer a stroke after the age of 60 years (Teel et al., 2001; Zwygart-Stauffacher et al., 2000). The ability of the body to function decreases with age, therefore age is an index of both therapeutic self-care demands and the abilities and limitations of individual self-care (Chekryn & Dewis, 1999). Degeneration of cardiovascular function also contributes to the increase of stroke attributed to ageing. In older people, there is an increase in peripheral vascular resistance due to decreased elasticity of the vasculature because of increased collagen and cross-linking of connective tissue elements. The increased vascular resistance causes increased blood pressure and sometimes lack of adequate blood flow to the heart muscle, thus causing angina or heart attack (Heath & Schofield, 1999). As a person ages, atherosclerosis increases narrowing of the lumen of the large vessels, predisposing them to aneurysms and possible rupture of the vessels, and reduced arterial circulation to all organs including the brain and kidney. Immobilization and inactivity also contribute to the increased incidence of stroke in elderly people (Heath & Schofield, 1999).

Paolucci, Antonucci, Troisi, Bragoni, Coiro, De Angelis, Pratesi, Venturiero, and Grasso (2003) investigated the relationship of patients’ age and the rate of recovery and found that age had an inverse correlation with the recovery of functional abilities. They conducted a study on 150 stroke inpatients using a case comparison method. Patients were divided into five subgroups according to age ($\leq 50$, 51-64, 65-74, 75-84 and $\geq 85$) and time of admission after onset of stroke. The data demonstrated that increasing age was associated with greater disability in ADLs and mobility. Moreover, the response in ADLs in patients aged $\geq 85$ years was almost ten times lower when compared with the other groups. It could be seen that older
people not only have a higher risk of stroke, but they also have greater disability and slower response to rehabilitation.

(iv) Gender: Gender is a factor that is related to the ability to self-care. Several studies (Bonita & Beaglehole, 1988; Dombovy, Basford, Whisnant & Bergstralh, 1987; Wade, Hewer & Wood, 1984) mention the relationship between self-care agency and gender in hemiplegic patients and found no relationship between gender and functional recovery in ADLs of stroke patients. In addition, a critical review about prediction of function after stroke authored by Jongbloed (1986) found no statistically significant effect of gender on functional recovery.

However, all these studies are almost two decades old. Important changes in the epidemiology of stroke have occurred during this period with different patterns emerging for men and women regarding mortality, incidence and distribution across subtypes of stroke (Wyller, Sodring, Ljunggren & Bautz-Holter, 1997). The World Health Organization (WHO) MONICA project indicates higher case fatality rates in female than in male stroke patients in the general population (Thorvaldsen, Asplund, Kuulassmaa, Rajakangas & Schroll, 1995). Several other reports have indicated that there is a relationship between gender and stroke. For instance, Wyller, et al. (1997) studied gender differences in functional outcomes assessed by the Barthel Index (BI) and found that men achieved a significantly better score than women. This may be because men perceived physical therapy sessions as physical training and were keener to attend (Kvigne, Kirkevold & Gjengedal, 2005). Conversely, women were unlikely to attend the physical therapy sessions, perceiving their bodies as being
unpredictable, demanding and needing a different kind of help to adapt (Kvigne & Kirkevold, 2003; Kvigne et al., 2005).

In addition, a European study (Di Carlo, Lamassa, Baldereschi, Pracucci, Basile, Wolfe, Giroud, Rudd, Ghetti & Inzitari, 2003) regarding gender differences found that when compared with male stroke patients, female patients were significantly older, more frequently institutionalized before stroke and had worse pre-stroke Rankin scores. Female stroke patients also had a significant history of hypertension and arterial fibrillation more frequently than male patients. Moreover, during the acute phase, female stroke patients were more likely than male patients to have coma, paralysis, aphasia, urinary incontinence, and swallowing problems. In addition, at three month follow-up, female gender was a significant predictor of disability, however, there were no significant gender effects on three months survival. Despite several studies finding that males suffer from stroke more than females, the study by Di Carlo et al. (2003) found that female stroke patients tended to have a higher risk of complications and disability. However, it could be noted that female stroke patients recruited to the study were older than the male patients, which could be a confounding factor influencing the results. Therefore, when comparing genders, it is very important to match the age of subjects.

In summary, stroke survivors may be left with severe mental and physical activity limitations and participation restrictions, although most of the stroke survivors do experience some levels of neurological and functional recovery. Previous studies mentioned above demonstrated that stroke recovery generally begins early with the fastest improvement occurring over the first three months, but continues as long as
six to 12 months after stroke. Functional recovery may be related to many factors, such as age, gender, level of consciousness on admission and the time from onset to treatment. From the literature reviewed, many studies confirmed the relationship between these factors and functional outcomes. Therefore, it is very important that stroke survivors commence rehabilitation as soon as possible and their family caregivers are trained in order to help the survivor rehabilitate effectively.

2.2.5. Stroke rehabilitation

Stroke rehabilitation does not reverse the damage caused by stroke, but is likely to be one of the main approaches to maintain function, restore lost ability, and prevent further disability and complications (The Ohio State University Medical Centre, 2005). It has been clearly identified that the optimum time to commence rehabilitation is as early as possible (Cadilhac, Ibrahim, Pearce, Ogden, McNeill, Davis & Donnan, 2004; Pollack & Disler, 2002). Further, as demonstrated in the International Classification and Functioning, Disability and Health (ICF) and others (Pajaree, 2004; World Health Organization, 2002a) rehabilitation aims to do more than just impact on impairment or pathology, but also facilitate the return to employment, leisure and participation in a meaningful life.

Rehabilitation includes assessment of an individual’s functional limitations caused by stroke and helps the patient to relearn the life skills (Pajaree, 2004), for example, the ability to perform ADLs, such as one hand dressing, feeding oneself with one hand or using walking aids. These activities, in turn, should be planned with the survivors and their family caregiver in order to set and achieve achievable goals (Fawcus, 2000). It is important that the rehabilitation team, stroke survivors and
their family caregivers should agree and set goals and agree to use the therapeutic approach in order to meet that goal (Intercollegiate Stroke Working Party, 2004).

Goal setting is one of the most important and beneficial aspects of rehabilitation. To illustrate, a quasi-experimental study by Ljungberg, Hanson, and Lovgren (2001) investigated the effectiveness of a home rehabilitation program for stroke patients. They aimed to develop a rehabilitation program that focused on the stroke patient's functional ability and life satisfaction from a holistic viewpoint. Patients and their families were involved in setting achievable goals with the stroke team. This rehabilitation process began in hospital and then continued up to four weeks after discharge in the stroke patient's home. As a result, the intervention group improved in functional ability after four weeks at home. They also participated in activities and were generally more active than the control group. Ninety percent of the families in the intervention group experienced high life satisfaction levels after the training period. Although the intervention did include both carers and patients, there were limitations to this study. There was no randomisation due to its quasi-experimental design, the sample was small and the groups were unevenly allocated (32 in the intervention group and nine in the control group). These factors limit the generalisability of the results. Nevertheless, this study has provided some evidence of the benefits of goal setting in stroke rehabilitation. Other studies, whilst not specifically investigating stroke survivors, provide evidence of the benefit of goal setting in rehabilitation for chronic airway limitation patients (Vallet, Ahmaidi & Serres, 1997), student with learning disability (Johnson, Graham & Harris, 1997) and high school student (Bar-Eli, Tenenbaum & Pie, 1997). In addition, it is
believed that goal setting is good practice in rehabilitation (McGrath, Marks & Davies, 1995; Rockwood, Joyce & Stolee, 1997).

Besides the studies mentioned above, there is evidence from clinical trials supporting claims that rehabilitation prevents complications and hospital readmission. To illustrate, Anderson et al. (2000) conducted a randomised control study in Denmark with 155 stroke patients with persistent impairment and disability. The patients were divided into three groups, the first group received follow–up home visits by a physician, the second group was provided instructions by a physiotherapist in their home and the third group received only standard after care which included outpatient rehabilitation by a hospital physician or the general practitioner, and home care to compensate for disability. The standard after care did not include follow-up home visits by the physician or instructions by the physiotherapist. The patients were free to contact their general practitioner and the social service centre. As a result, the readmission rates within six months after discharge were significantly lower in the intervention group (first and second groups) than in the control group (third group). This supports the view that follow–up and rehabilitation after discharge could be the way to prevent hospital readmission due to complications and to help stroke patients regain functional abilities.

The need for and benefits of assistive devices and environmental modifications among long-living stroke survivors was investigated with a particular focus on whether the need continued and increased over time (Sorensen, Lendal, Schultz-Larsen & Uhrskov, 2003). The study recruited 155 stroke survivors who were
discharged home with functional limitations. The patients were provided with assistive devices and/or environmental modifications at discharge. The researchers then followed up the patients after six months and three to five years after discharge. The results revealed that almost all of the survivors were still dependent on assistive devices at five years. Moreover, they needed changes to their devices and needed more assistance and environmental modifications over time. This research has presented particularly significant results providing the evidence to suggest that stroke rehabilitation is a continuing process and it is important that stroke survivors receive ongoing follow-up to assess and meet their changing needs.

From the studies reviewed above (Andersen et al., 2000; Fawcus, 2000; Ljungberg et al., 2001; Pollack & Disler, 2002; Reddy & Reddy, 1997; Sorensen et al., 2003), it could be concluded that the early commencement of rehabilitation and goal setting involving carers and patients enhances outcomes for both. Moreover, it is critical that the goals are relevant to the needs of patients and the family caregivers are able to provide support. During the rehabilitation process, it is important that the health care staff provide consistent and continuous reinforcement and support.

The benefit of early rehabilitation was demonstrated in a well designed RCT conducted by Kalra et al. (2004). Caregivers were trained to assist stroke survivors with their ADLs. The training program included instruction on common stroke related problems and their prevention, management of pressure areas, continence, nutrition and positioning, as well as advice on local services. In addition, instruction related to lifting and handling technique, continence, assistance with ADLs was provided. The results revealed that the burden of family caregivers in the
intervention group was less than that of the control group. They also found that training improved psychosocial outcomes in both patients and caregivers in the intervention group at one year. This RCT had a large sample (300 stroke patients and 300 family caregivers) and a significant number was followed-up at three months (141 stroke survivors and 141 family caregivers in the intervention group and 140 stroke survivors and 140 family caregivers in the control group) and at 12 months (134 stroke survivors and 134 family caregivers in each groups). The results of this study could be generalized for the population as this study has provided evidence that providing information and emotional support for family caregivers with basic training in skills, such as facilitation of ADLs improves the outcomes for the stroke survivors and their family caregivers. Significant findings of that study were that family caregivers reported high quality of life, with reduced burden in the intervention group when compared with the control group. Furthermore, it was found that training caregivers during rehabilitation of patients reduced costs of care and improved overall quality of life in family caregivers at one year (Patel, Knapp, Evans, Perez & Kalra, 2004). This study demonstrates that rehabilitation and care of stroke survivors should be broadened to include the proposed family caregivers by actively involving them in setting goals, rehabilitation and ensuring that they are adequately trained, supported and followed–up.

An early systematic review (Langhorne, 1997) of the randomised trials of organised inpatient (stroke unit) care included 19 trials with 3249 patients. The aims of the review were to identify the characteristics contributing to the effectiveness of organised inpatient care (a service provided by a stroke team working exclusively in the care of stroke patients; a team with expertise in the assessment and rehabilitation
of disabling illness) compared with conventional care in reducing death, dependency and the requirement for long term institutional care after stroke. The results demonstrated that the organised unit care reduced the death rate, patients were more independent and the need for institutional care was reduced. Although this systemic review provided the results of RCTs which may have important clinical effects, the majority of the papers included in the review, were retrospectively analysed and, in some cases, specific questions were not explicitly stated in the original published report. However, this review has provided evidence that stroke survivors do need special care, especially rehabilitation, as it could be seen from the study that those in the stroke unit had better outcomes in all aspects and the review does provide a convincing argument.

A structured nursing intervention (Nir, Zolotogorsky & Sugarman, 2004) conducted in Israel, recruited 155 elderly stroke survivors who were admitted to a geriatric rehabilitation department (GRD). The nursing intervention was carried out by senior nursing students as part of a research seminar. The students were trained in the GRD during one semester in implementation of the intervention program and in the use of the study instruments to maximize homogeneity and to minimize bias due to personal attitudes. The intervention consisted of 12 consecutive weekly meeting (once a week and 1-2 hours for each session) and a written guidebook. The senior nursing students provided 12 consecutive weekly meetings with routine rehabilitation to the elderly stroke survivors and their family caregivers in the intervention group (73 stroke survivors and 73 family caregivers), while the control group received only routine rehabilitation. The meetings were held in the GRD of a university medical centre in southern Israel in the first week after admission to GRD.
and continued to home after discharge. The meeting were based on the written guidebook, which was based on Orem’s Model of Self-care and was modified to meet the needs of the stroke patients and their caregivers. The nursing intervention was guided by the three domains from Orem’s model: affective domain (aiming to create an atmosphere of mutual trust between the patient, caregiver and nurse), cognitive domain (focusing on the patient’s perception of his or her illness, attitude towards illness, understanding of rehabilitation and the recovery process), and instrumental domain (directed at increasing the stroke patients’ self-care skills and if patients were incapable, family caregivers were taught). The guidebook included topics that addressed common problems that arise after stroke. Each topic was organised around goals, guidelines for achieving those goals and a feedback form. The patients were followed-up after three months and again at six months. The outcome were measure by using FIM, Instrumental Activities of Daily living Scale, Short Geriatric Depression Scale, Internal-External Locus of control Scale, Rosenberg Self-esteem Scale and interview about dietary habits and self-perception of health. The intervention group demonstrated better scores in functional status, depression, self-perceived health, self-esteem and dietary adherence when compared with the control group. The results of this study are applicable in the clinical setting as the study had adequate sample size, robust design, and the participants were randomized by a stratified random technique, distributed equally in both groups. In addition, the measurements used were validated and reliable, for example the FIM instrument was well known and had been used widely (Bottemiller, Bieber, Basford & Harris, 2006) and the Short Geriatric Depression Scale has demonstrated evidence of reliability and validity in an older population in Israel (Cwikel & Ritchie, 1989). A similar study by (Mant, Carter, Wade & Winner, 2000) involved 323 stroke
survivors with first or recurrent stroke who had a family carer (267 carers). A family support worker was assigned to support each family within six weeks of stroke. The carers were assessed for knowledge about stroke, Frenchay activities index, GHQ-28, CSI, SF-36, Dartmouth co-op charts and satisfaction scores. The patients were assessed for knowledge about stroke and use of service, functional ability (BI), Rivermead mobility index, Frenchay activities index, London Handicap scale, hospital anxiety and depression scale, Dartmouth co-op charts and satisfaction. The results showed significant psychological benefits for carers, but did not find any difference in the patients. The support was provided only four times within six months in each family (two home visits and two telephone calls) which may have reduced the effect of the intervention. This support might have been insufficient to improve the outcome, as the stroke survivors may need more intensive support and rehabilitation. This can be seen in a review (Pollack & Disler, 2002) of rehabilitation of patients after stroke which found that 75% of stroke survivors who survived the first month after stroke required specialized rehabilitation continuously. Although the outcome measure used in the study conducted by Mant et al. (2000) may not be sufficiently sensitive to detect the difference in the patient outcomes, it did demonstrate that support helped the family caregivers in their psychological health. Family caregivers are the people who provide care to the patients, therefore they require support to fulfil their role. The benefit is improved outcomes of stroke survivors.

The majority of interventions described above, which could be implemented in clinical practice, demonstrated significant improvement. In addition, the results from these studies support rehabilitation and demonstrate advantages to stroke
patients and their family caregivers. Therefore, it could be concluded that rehabilitation is very important for stroke patients and their family caregivers, as it is the process of rehabilitation that helps to recover many abilities lost or impaired through stroke.

2.2.6. Effects of care giving on stroke family caregivers

The caregiver (sometimes referred to as the informal caregiver or family caregiver) is the person who is involved in providing care to the patient at home. The caregivers could be a father, mother, wife, husband, son, daughter, sister, brother, friend or significant other. In addition, the caregiver focuses on providing care without wages or reward (Sirapongam, 1996; Suwanno, 1997). Caregivers can be divided also into two categories based on the level of care provided, namely primary caregiver and secondary caregiver (Sirapongam, 1996).

(i) A Primary caregiver is the main person who provides direct care and spends time continuously with the care recipient. The services provided mainly include personal care such as bathing, feeding and toileting, and home health care activities such as administering medication and changing dressings.

(ii) A Secondary caregiver is the person(s) who provides indirect care and does not spend time continuously with the care recipient. The services provided may range from shopping, transportation and running errands. The service may include occasional direct care when the primary caregiver is not available, but the amount of time spent in performing care giving activities is less than the primary caregiver provides.
It can be seen that the role of family caregivers is complex, especially for the family caregivers of stroke survivors. This is because stroke occurs suddenly and both the survivor and their family caregivers do not have time to prepare themselves for the unexpected change that occurs (Exall & Johnston, 1999). When the survivors’ condition is stable and rehabilitation has begun, they will be discharged home into the care of the family caregivers. The family caregivers need to provide care which includes ADLs, like feeding, personal hygiene care, grooming, dressing, toileting, help in moving and prevention of complications and accidents. At this stage, many family caregivers are uncertain about the survivors’ future, do not know what to do or how to help survivors perform the tasks and may not be informed about how to deal with survivors’ emotions (Belciug, 2006).

Undertaking the role of caregiver for stroke survivors with limitations in engaging in daily activities is a long-term commitment (Hoyert & Seltzer, 1992; Newman, 1997). The role may be exhausting and time consuming because caregivers have to deal with not only the stroke survivors’ physical limitations, but also their psychological health problems. Moreover, many studies report that family caregivers continue to express a lack of understanding about the cause of stroke and its effects, and are dissatisfied with information on how to provide care to the stroke survivor (Banks, 1999; Close & Procter, 1999; Forster, Smith, Young, Knapp, House & Wright, 2004; Jullamate et al., 2006; Rodgers, Atkinson, Bond, Suddes, Dobson & Curless, 1999; Smith, Lawrence, Kerr, Langhorne & Lees, 2004). Consequently, supporting the stroke survivor can disrupt all aspects of the caregiver’s life potentially leading to physical, financial and emotional problems, leisure time reduction, family relationship stress, and occupational problems.
(Dennis, O'Rourke, Lewis, Sharpe & Warlow, 1998; Han & Haley, 1999; Kotila, Numminen, Waltimo & Kaste, 1998; Low, Payne & Roderick, 1999). This may result in the caregiver experiencing stress, frustration and psychological burden (Dennis et al., 1998; Grant, Glandon, Elliott, Giger & Weaver, 2004; Han & Haley, 1999; Teel et al., 2001; Van Exel, Koopmanschap, Van den Berg, Brouwer & Van den Bos, 2005). This may result in role strain in the family caregivers. According to Archbold, Stewart, Greenlick and Harvath (1990), caregivers’ role strain consists of role conflicts, role mismatched expectation, increased tension and global strain. Yang and Kirschling (1992) add that caregiver role strain is the feeling of difficulty in fulfilling the caregiving role.

To support this, there are many research studies about caregiver stress and strain regarding direct care that have reported on the negative and detrimental aspects of the care giving process (Jonsson, Lindgren, Hallstrom, Norrving & Lindgren, 2005; Sit, Wong, Clinton, Li & Fong, 2004; Teel et al., 2001). For example, the study by Teel et al. (2001) studied care giving experiences after stroke. They found that most caregivers felt their physical health was adversely affected by tiredness, sleeplessness, back pain and weight loss. Their mental health was also affected as they experienced stress, recurrent sorrow, as well as depressive state symptoms at 1, 3, and 6 months. A study (Sit et al., 2004) regarding stroke care in the home has reported similar findings that home care for the stroke survivor is heavy, demanding work with health-related care tasks being the most stressful. Around 40% of family caregivers reported somatic symptoms for example, fatigue and low back pain. Moreover in the longitudinal study (Jonsson et al., 2005) concerning quality of life in stroke survivors and their informal caregivers, changes in quality of life covering
physical and mental factors were examined in 304 stroke survivors and 234 informal caregivers. They found that informal caregivers’ quality of life scores on emotional and mental factors had improved at the 16 month follow-up compared to at the commencement of the care giving role.

Assuming the role of family caregiver of a stroke survivor means more burden and responsibilities and this can lead to changes in living patterns and family life. As a result, family caregivers may suffer from role strain (Bugge, Alexander & Hagen, 1999; Garity, 1999). Strain has been the most common concern for caregivers providing care to demented or disabled persons (Garity, 1999). Strain is defined as the stress that is generated within a person when they cannot comply or have difficulty in complying with the expectations of their role or set of roles (Almberg, Grafstrom & Winblad, 1997). For example, family caregivers have to dedicate their time to providing care to the stroke survivors, which otherwise may have been allocated to performing their former role effectively (Enterlante & Kern, 1995). Additionally, they may not be able to maintain their previous work in addition to providing care and as a consequence may experience career disruption (Robinson-Smith & Mahoney, 1995; Watcharapichat, 2000). Moreover, the expectation of the caregiver's role from other relatives may make the caregiver confused, as a result the caregiver may experience strain from mismatched expectations (Watcharapichat, 2000). Strain is also an independent risk factor for the development of depression (Almberg et al., 1997; Watcharapichat, 2000).

Hoyert and Seltzer (1992) studied factors underlying happiness and family activities and found that there were differences between family caregivers who had more
responsibilities (those who worked outside the home as well as providing care) with those who did not have to work outside the home (providing care only). For example, family caregivers who had to work as well as care for the incapacitated family members reported higher levels of stress than those who do not have to work outside the home. Caregivers of family members with chronic disorders often had poorer health status, less self-satisfaction, and more depression than those who do not. Additionally, when assessing the effects of caring, it was found that being a caregiver had negative aspects which included problems in household management, occupation, social activities, marital satisfaction and health problems. Similarly, Perkdetch (2002), conducted a study in Thailand investigating the impact on caregivers' role strain on the amount of care, communication problems and individual factors. She interviewed 100 stroke patients’ caregivers and found that the amount of care and stroke survivor communication problems negatively influenced family caregiver strain, which means that the more care required, the more the strain increases (Van Exel et al., 2005).

Based on these studies it was concluded that family caregiver role strain results from taking responsibility for the care of a stroke survivor. Role strain can adversely affect family caregiver in many ways, including changes in daily living, such as loss of privacy or social activities, and change in health status.

Besides the amount of care, financial problems can also sometimes cause strain for family caregivers (Han & Haley, 1999; Hatthakit, 1999; Jullamate et al., 2006; Low et al., 1999). Some have to resign from the workforce or take time off from work. As a result, an additional source of family income is frequently lost (Hatthakit,
Income or financial status is one component in the support system of individuals, which directly affects health status. Income indicates an individual’s economic and social status, and it can be used as an indicator of financial needs. Economic problems can lead to conflict in the family as well as neglect of stroke survivors (Watcharapichat, 2000). Money is an important factor in treatment, as it is needed to pay for medical care, medication, transport to and from hospital, and other necessities. Additionally, family caregivers with high incomes have more opportunities to seek information, support and care which are beneficial for the stroke survivors.

Caregivers who have adequate financial resources tend to perceive the caring burden differently when compared with caregivers who do not have financial stability. This can lead to different stressful conditions. For example, Gasemgitvatana and Tulyatorn (1999) explored predictive health factors of wives who were the caregivers of husbands with chronic illness in Thailand. They found that 94% of economic problems were related to health problems or health status which means that the more health problems faced by the wives, the more economic problems they experienced.

Social isolation also impacts on general wellbeing. Caregivers report that lack of social activities such as missing church attendance and fewer visits from family members and friends affected their social relationships (Low et al., 1999; Natechang, 2002; Sangboon, 2002). Although some caregivers became closer to their family members due to working together, they may still experience conflict. This may be due to the caregivers lacking time for their personal concerns (Han &
Haley, 1999; Low et al., 1999; Periad & Ames, 1993). To support this, Anderson, Linto and Stewart-Wynne (1995) found that 35% of family caregivers stated adverse effects on family relationship for a variety of reasons such as tension, misunderstanding, or feeling neglected among family members because of the physical and emotional demands of the stroke survivors. Additionally, family caregiver frustration and anger towards stroke survivors was displaced onto other members in the family.

Notwithstanding the negative effects of caregiving (Kramer, 1997), studies have addressed the rewards of caregiving and positive factors that motivate caregivers to continue to give care to their relatives (Riedel, Fredman & Langenberg, 1998). Although not particularly in stroke survivors, positive effects of caregiving have been demonstrated. A sense of fulfilment, feeling of closeness and a pleasure and satisfaction in day to day interactions with the care recipient have been reported (Kinney, Stephens, Franks & Norris, 1995; Riedel et al., 1998). Additionally, a study by Johnson (1998) also report that the experience of caregiving allows caregivers to receive both rewards and pleasure.

It is very important that family caregivers be supported in order to adapt to their new role and develop coping strategies that will help them to function effectively and maintain their positive feeling towards their care giving role. Providing support could help to reduce the negative effect of caregiving and influence the positive feeling which supports their well being as well as recovery of stroke survivors (Kotila et al., 1998; Scholte op Reimer et al., 1998). There is some evidence (Table 2.2) which suggests that training family caregivers, providing specialist services,
telephone follow-up, counselling and participation in stroke education groups may improve outcomes for family caregivers of stroke survivors. Improved knowledge, quality of life and mental health, maintaining adaptive change in family function, improving problem solving, coping strategies and ability to seek social support have been reported (Boaro & Velji, 2005; Clark, Rubenach & Winsor, 2003; Forster et al., 2004; Grant, 1999; Grant, Elliott, Weaver, Bartolucci & Giger, 2002; Hartke & King, 2003; Johnson & Pearson, 2000; Kalra et al., 2004; Louie et al., 2006; Mant et al., 2000; Stevenson, 2004; Van den Heuvel, de witte, Nooyen-Haazen & Sanderman, 2000).

Although the extensive research mentioned (Table 2.2) has suggests that upskilling carers to assist rehabilitation improves family caregivers’ and stroke patients’ outcomes, the effectiveness of the interventions could not be conclusively demonstrated. For example, a systemic review conducted by Forster et al. (2004) found some evidence that information combined with education sessions improved knowledge and was more effective than information provision alone. However, the strength of the evidence is underpinned by low trial quality and variability among outcome measures.

Similarly, the more recent review by Visser–Meiley, et al. (2005) reported the effectiveness of an intervention for family caregivers of stroke survivors with significant improvement in caregivers’ knowledge, satisfaction with care, emotional health, adaptive change in family function, problem solving skills, less depression, active coping strategies and seeking social support. However, the included RCTs of specific stroke interventions did not adequately assess the contribution of differences
between family caregivers on the outcomes. In addition, there were no studies investigating the best possible timing in the stroke recovery process or duration of the caregiver intervention.

However, there were several studies (Grant et al., 2002; Kalra et al., 2004; Mant et al., 2000; Van den Heuvel et al., 2000) that detected significant differences between treatment and control groups, offering some progress in this area of research. These studies were well designed, had sufficient sample size to represent the populations, the participants were distributed equally and the measurements used were reliable.

Nevertheless, while all the studies mentioned have some limitations they provide a rationale for the caregiver providing rehabilitation and also provide an outline of content that the intervention could be used in hospital and community settings.
<table>
<thead>
<tr>
<th>Author</th>
<th>Study design and Sample</th>
<th>Interventions</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Louie et al., 2006)</td>
<td>Quasi-experimental design with pre and post test. n= 54 stroke patients and 32 family caregivers</td>
<td>Stroke education group</td>
<td>Significant increase in stroke-related knowledge in the patients and their caregivers. There were a significant association between the total scores in the stroke knowledge test and the admission scores in the Mini Mental State Examination of the patients. However, there were no improvement on perceived health status and care-giving stress.</td>
</tr>
<tr>
<td>(Visser-Meily et al., 2005)</td>
<td>A Review of 18 RCTs and 4 non-randomised studies</td>
<td>Providing specialist service; Psycho-education; Counselling and peer support</td>
<td>Significant improvement in caregivers’ knowledge, satisfaction with care, emotional health, adaptive change in family function, problem solving skills, less depress, active coping strategies and seeking social support. However 1 RCT found family caregivers’ dissatisfaction with information provided and 1 RCT found worst state of general health among family caregivers.</td>
</tr>
<tr>
<td>(Kalra et al., 2004)</td>
<td>RCT with 300 stroke survivors and their family caregivers</td>
<td>Family caregivers in the intervention group have training in assistance of ADL with their relatives and follow-up at home</td>
<td>Training reduces costs and family caregivers’ burden and improves psychosocial outcomes in patients and care-givers at one year.</td>
</tr>
<tr>
<td>(Mant et al., 2000)</td>
<td>RCT with 323 stroke survivors; n=267 family caregivers.</td>
<td>Family support</td>
<td>Family support significantly increased social activities and improved quality of life for carers, with no significant effects on patients.</td>
</tr>
<tr>
<td>Author</td>
<td>Study design and Sample</td>
<td>Interventions</td>
<td>Results</td>
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<tr>
<td>(Grant et al., 2002)</td>
<td>RCT with =74 family caregivers</td>
<td>Telephone</td>
<td>Caregivers in telephone support group had better problem solving abilities, greater preparedness less depress and significant improvement in measures of vitality, social functioning, mental health and role limitation related to emotional problem</td>
</tr>
<tr>
<td>(Grant, 1999)</td>
<td>RCT with 30 caregivers</td>
<td>20 family caregivers receiving either telephone contact or home visits</td>
<td>Telephone group showed significant reduction in caregiver depression at 2nd week after discharge. They were improved in terms of problem solving skills and were more prepared in the 2nd and 5th week after discharge.</td>
</tr>
<tr>
<td>(Forster et al., 2004)</td>
<td>Review: Meta-analysis consist of 9 RCTs and CCTs: that recruited stroke survivors and caregivers</td>
<td>Leaflet, manuals, booklets and lectures</td>
<td>The evidence from the review suggested that providing information combined with education sessions is more effective than information alone.</td>
</tr>
<tr>
<td>(Johnson &amp; Pearson, 2000)</td>
<td>Quasi-experimental study/n=41 stroke survivors</td>
<td>Structures education course over 4 weeks</td>
<td>Positive effect on depression and hope but no effect on coping.</td>
</tr>
<tr>
<td>(Van den Heuvel et al., 2000)</td>
<td>CCT/ n=257 family caregivers</td>
<td>Group support vs home visits vs control</td>
<td>Group support and home visits increased in knowledge, better in coping and seeking for support. No differences were found between the treatment groups.</td>
</tr>
<tr>
<td>(Hartke &amp; King, 2003)</td>
<td>RCT/ n= 88 family caregivers</td>
<td>8 sessions regarding psycho-educational and telephone group</td>
<td>Significant increase in competence in the intervention group</td>
</tr>
<tr>
<td>(Clark et al., 2003)</td>
<td>RCT/n=62 stroke patients and their spouses</td>
<td>Stroke information package and 3 visits from a trained social working in providing family counselling.</td>
<td>Improved family functioning and social recovery in the intervention group. There were no effect on depression, anxiety or health status</td>
</tr>
</tbody>
</table>
The studies reviewed also affirmed that the needs of stroke survivors and their family caregivers are exceeding the current resources available in health care services. However, it is not impossible to help the stroke survivors and their family caregivers to meet their needs. Based on the trials reviewed, health care professionals can adapt strategies to find the most effective methods to support family caregivers. Providing support to both family caregivers and stroke survivors is crucial to maintain home care and protect the health of family caregivers. This is particularly important during the first 12 week transitional period following hospital discharge (Sit et al., 2004).

Since nurses work closely with stroke survivors and their family caregivers, it is important that nurses assist caregivers to develop skills for caring for stroke survivors appropriately. Additionally, it is important that nurses understand the needs and experiences of family caregivers in order to provide optimal support (Moore, Maiocco, Schmidt, Guo & Estes, 2002). It is anticipated that the outcome of this research will have long term benefit for stroke survivors and their caregivers in Thailand. The program being tested in this research will provide nurses with a model/stroke rehabilitation program that can be implemented by the family following discharge to reduce complications for the stroke survivor and reduce burden and stress for the caregivers.
2.2.7. Self-management of chronic conditions

A key component of self-management of chronic conditions is patient education and regular medical review (Battersby, 2005). Self-management aims to increase patients’ involvement in their own care (Battersby, 2005). A major emphasis is to improve the quality of care and quality of life for people with chronic conditions. The incorporation of self-management education into care activities could empower patients to take a more proactive role in managing their illness and improving their quality of life.

It is important to distinguish self-management education from conventional patient education as they are not the same. The differences between them are outlined in Table 2.3 (Bodenheimer, Wagner & Grumbach, 2002a, 2002b).
Table 2.3: Overview of self-management education and conventional patient education.

<table>
<thead>
<tr>
<th>Topics</th>
<th>Self-management education</th>
<th>Conventional patient education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Content</td>
<td>Problem–solving skills that can be adapted to chronic conditions in general</td>
<td>Disease specific, information and technical skills</td>
</tr>
<tr>
<td>Definition of the problem</td>
<td>Patient formulates the problem which may or may not be directly related to disease</td>
<td>Inadequate control of disease is the problem</td>
</tr>
<tr>
<td>Theoretical construct underlying the education</td>
<td>Patient self–efficacy (learned through setting short-term actions plans) leads to improved clinical outcomes</td>
<td>Disease-specific knowledge produces behaviour change and leads to improved clinical outcomes</td>
</tr>
<tr>
<td>Goal</td>
<td>Increased self-efficacy will improve clinical outcomes</td>
<td>Patient compliance with prescribed behaviour changes will improve clinical outcomes</td>
</tr>
<tr>
<td>Educator</td>
<td>Health professional or peer leader and other patients in the group</td>
<td>Health professional</td>
</tr>
</tbody>
</table>

Source: (Bodenheimer et al., 2002a, 2002b)

A number of controlled trials have been conducted to measure the effectiveness of self-management education programs or chronic disease self-management program (CDSM) which combines training and development of key self-management task (Jones, 2006; Kendall, Catalano, Kuipers & Posner, 2007).

To illustrate, Kendall et al., (2007) conducted a longitudinal, randomised controlled trial regarding recovery following stroke which aimed to examine the efficiency of
the Chronic Disease Self-Management (CDSM) course as a way of promoting progressive psychosocial recovery pathways among people following stroke. The participants were 100 people with stroke (58 in the intervention group and 42 in the control group), from an acute inpatient unit at a major hospital in south-east Queensland, Australia. The CDSM course involved a small group education process with a maximum of 15 participants, conducted over a six week period, for approximately two hours each week. The course was implemented within the first few months of discharge and was delivered in community settings and facilitated by two trained health professionals using the highly structured course protocol. Course content introduced participants to a range of topics: regaining, maintaining health and well-being, group interaction and support, problem solving, goal setting, communication with the health care team and management of chronic. Data were collected by telephone interview four times over a 12 month period at 3, 6, 9 and 12 months. The instruments used for data collection were Stroke Specific Quality of life scale (SSQOL) and the Self-efficacy scale. The study reported a significant difference between the control and the intervention groups. The intervention group scored better regarding self-efficacy levels across all times (p=.003). In addition, the control group reported declines in functioning during the first year following stroke in the area of family roles, ADLs, self-care and work productivity which were not reported in the intervention group. However, the intervention did not appear to have its impact through self-efficacy and failed to influence outcomes such as mood or social participation. Although there were more than 30 participants in each group, the power analysis was not reported. Moreover, the study did not clearly describe data collection procedures, for example if the assessors were blinded to the intervention and control group, which may have caused bias during data collection.
In addition, data about clinical status of the participants (stroke severity, level of disability and co-morbidity) were not provided. Therefore the generalisability of the results is dubious. However, the study has provided insight into how some areas of adjustment may be maintained following stroke by offering an education program focused on self-management.

Similarly, a longitudinal cohort study (Huijbregts, Teasell, Streiner & Myers, 2005) developed the Stroke Self-Management Program (SSMP) and evaluated in comparison to the Canadian Heart and Stroke Foundation’s Living With Stroke (LWS) education program. Data was collected at baseline, completion of program, and at three month follow-up. The primary outcomes were Reintegration to Normal Living Index (RNL) and participation in formal exercise. Other data were collected using a battery of stroke outcomes assessments, participant focus groups and program records. Thirty stroke survivors and 16 family caregivers participated. The results demonstrated that at discharge (p=.02) and follow-up (p=.04), the client attended SSMP attended more exercise classes and significantly improved in RNL (p=.04). Additionally, the participants attended SSMP reported benefits from individual goal setting and problem solving. This study has provided an evidence of how SSMP could improve the stroke survivors’ outcome, and fill the existing gap in the continuum of stroke care. In addition, it has potentially provided evidence that the self-management approach is associated with post stroke indicators of improved well-being and participation. However, this study has small sample which diminished power for some analyses. Therefore, the initial findings should be replicated with a larger sample.
It could be seen from the study that the chronic disease self management program (CDSM) or stroke self-management program (SSMP) is the facilitation of personal resources such as enhanced confidence and self-efficacy, goal setting, problem solving and decision making skills, deliver within a setting of peer support (Lorig, Ritter, Stewart, Sobel, Brown & Bandura, 2001). Nevertheless, its application in the stroke population has been minimal (Jones, 2006; Kendall et al., 2007), as the course is likely to offer an important psychosocial aspects to current rehabilitation (Kendall et al., 2007).

However, the studies mentioned above (Huijbrgts et al., 2005; Kendall et al., 2007) were carried out in different developed countries. Therefore, there was cultural diversity, participant literacy levels as well as differences in the health care systems which should be considered if the self management or SSMP is to be implemented in developing countries. In addition, self-management of chronic condition or SSMP is a western approach and not applicable in this study. This is because following the acute stage of stroke, the patient might have lost their functional ability as well as the ability to think critically, which might affect their ability to perform an act competently or looking after themselves. The aim of this current study is to reduce complication following stroke, improve functional ability of the stroke survivors, it is important that the family caregivers is provided with skills to provide care as soon as the patients have been discharge home. Therefore self-management is not applicable for acute stroke patient in this setting.
2.3 Section Two

2.3.1. Rehabilitation

Health care reform in Western countries has seen a paradigm shift from a focus on the management of acute illness to an emphasis on health promotion, disease prevention and rehabilitation in service development and research. The health reform strategies emphasise maintaining a healthy population and supporting people to return to as full and productive life as is possible (Department of Health, 2001; World Health Organization, 2001). Within this context, rehabilitation is one of the main processes for helping persons with physical impairments, activity limitations and participation restrictions to achieve the highest level of independence, through restoration of former abilities, prevention of complications and adjustment to their new situation (Ebrahim & Harwood, 1999; World Health Organization, 2001). Additionally, rehabilitation includes secondary and tertiary prevention, which aims to prevent the further progress of recent ill health through early assessment, treatment and prevention of complications rising from an enduring condition (Naidoo & Willis, 2000).

In this study, the definition by Murphy and Williams (1999) is appropriate as it highlights that rehabilitation involves the total needs of the client, sees each person as unique, aims for economic self-sufficiency and integration into society. As such, the rehabilitation process is:

- a systematic approach to assessing and addressing the total needs of a person with disabilities. Each person is seen as a unique individual with assets that can be developed. The ultimate goal of the rehabilitation
process is to promote functional independence where
the individual is capable of economic self-sufficiency
and integration into society (Murphy & Williams,
1999, p.29).

The scope of rehabilitation is broadening from a focus on physical function to a
holistic approach to assist people with disabilities and chronic illness maintain their
social roles and functions (Edwards, 2002; Nolan & Nolan, 1998). However, in
practice the focus continues to reflect physical function. Rehabilitation comprises a
range of services including specialist rehabilitation and general facilities delivered by
residential and day care services as well as community care (Pajaree, 2004). The
interventions are individualised to each (Pajaree, 2004).

The fit between patients' abilities and environmental demands is very important
(Jette, 1997). However, there are many variables that could influence the outcome of
rehabilitation, for example the participants, the activities and the setting where the
activities take place each contribute to the gains an individual can achieve from
participation in a rehabilitation program (Pryor, 2000). In addition, the success of
rehabilitation depends on factors such as, the nature and severity of the condition,
disorder, or injury; the type and degree of any resulting impairment and activity
limitations; the overall health of a client and the nature and extent of family support.
2.3.2 The International Classification of Functioning, Disability and Health

The International Classification and Functioning, Disability and Health (ICF) (World Health Organization, 2001) is gaining acceptance internationally as a framework for understanding functioning and disability. It focuses on how people live with their health conditions rather than focusing on disease and mortality (Press Release WHO/48, 2001). The ICF is a classification of health components which represent disability and function as outcomes of interactions between health conditions (disorder, disease and injuries) and contextual factors (environment and personal factors) (World Health Organization, 2001). The ICF comprises two parts, each with two components (Table 2.4) (World Health Organization, 2002b, p.10).
Table 2.4: Overview of ICF components and definitions

<table>
<thead>
<tr>
<th>Part</th>
<th>Component</th>
<th>ICF definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Part 1. Functioning and disability</strong></td>
<td>(a) Body functions and structure</td>
<td>In the context of health:</td>
</tr>
<tr>
<td></td>
<td>(b) Activities and Participations</td>
<td><strong>Body functions</strong> are the physiological functions of body systems (including psychological functions).</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Body structures</strong> are anatomical parts of the body such as organs, limbs and their components.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Impairments</strong> are problems in body function or structure such as a significant deviation or loss.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Activity</strong> is the execution of a task or action by an individual.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Participation</strong> is involvement in a life situation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Activity limitations</strong> are difficulties an individual may have in executing activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Participations restrictions</strong> are problems an individual may experience in involvement in life situations</td>
</tr>
<tr>
<td><strong>Part 2. Contextual factors</strong></td>
<td>(a) Environmental factors</td>
<td><strong>Environment factors</strong> make up the physical, social and attitudinal environment in which people conduct their lives.</td>
</tr>
<tr>
<td></td>
<td>(b) Personal factors</td>
<td><strong>Personal factors</strong> or internal factor include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual.</td>
</tr>
</tbody>
</table>

Source adapted from World Health Organization (2002b, p.10)
The aims of ICF are:

- to provide a scientific basis for understanding and studying health and health-related states, outcome and determinants
- to establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities
- to permit comparison of data across countries, health care disciplines, services and time
- to provide a systematic coding scheme for health information systems

(World Health Organization, 2002b, p.5)

The rehabilitation literature contains many examples of projects informed by ICF, for example, Mayo, Wood–Dauphinee, Cote, Duncan and Carlton (2002) investigated activity, participation, and quality of life six months post stroke. The aims of the study were to estimate the extent of activity and participation of stroke survivors six months post stroke and their influence on quality of life. Four hundred and thirty four survivors of first-ever stroke (either ischaemic or haemorrhagic) were interviewed by telephone at 6-month post stroke. Thirty nine percent reported a limitation in functional activities, 54% reported limitations with higher-level ADLs, such as housework and shopping, and 65% reported restrictions on reintegration into community activities. Almost 50% of stroke survivors needed some form of home help. A large proportion also reported lack of meaningful activity, indicating a need
for organized support groups for people with stroke that include activities to overcome boredom. This is because boredom may lead to depression, and deterioration of function, health status and quality of life. This study provided evidence that consideration of the components of ICF could enable health providers to identify existing or potential problems that could compromise an individual obtaining benefit from rehabilitation and which could negatively affect the stroke survivors’ outcomes and quality of life. Similarly, in a phenomenological study, Bendz (2003) revealed differences in priorities between stroke survivors and health care professionals. Fifteen stroke survivors were interviewed and transcripts of conversations with professional were reviewed. Stroke survivors focused on loss of control, fatigue and a fear of relapse which they perceived influenced their ability to participate in the rehabilitation process. Conversely, the health care professionals ignored these aspects and were more concerned with the patients’ loss of function and need for training. This divergence of priorities between patients and health care professionals may be lessened by using the ICF framework to guide assessment and priority setting, and to broaden the focus of rehabilitation by including the social as well as physical needs (Kearney & Pryor, 2004).

Kearney and Pryor (2004) and Buchbinder, Jolly and Wyatt (2001) suggest that nurses apply ICF in their practice as the framework will enable better understanding of the issues surrounding disability. Additionally, ICF directs nurses to work more effectively and collaboratively with disabled people and broaden their understanding of the issues surrounding disability. In addition, Kearney and Pryor (2004, p.167) also recommend that nurses should aim to “maintain the integrity and function of body structures, restore the integrity and function of body structures, prevent and
minimize activity limitations, enable participation, and prevent or minimize participation restrictions”.

2.3.3 Community based rehabilitation

Returning to the community can be difficult for persons with physical and/or psychological impairment. This is especially the case when people lack information about their condition and its management, complications and comorbidities, and have limited access to services (Jullamate et al., 2006; Kalra et al., 2004).

Community based rehabilitation (CBR) is a form of community action that is supported by the World Health Organisation (WHO). It is a strategy to relieve the socio-economic burden imposed by poor health care and inadequate services in under developed countries (World Health Organization, 2004a). Community based rehabilitation, described by WHO as a human right (World Health Organization, 2004a), is based on the premise that if an individual who is disabled is provided with education and access to rehabilitation, the person is more likely to achieve some level of functionality, which in turn may reduce poverty by enabling the person to earn an income (World Health Organization, 2004a).

Guidelines to assist the development and implementation of CBR programs have been developed by the WHO (World Health Organization, 2004a). In addition, the WHO and other United Nations organizations hosted an international consultation in 1994 (the Helsinki Mandate) to set future directions for CBR.
This approach to rehabilitation aims for inclusion, participation, sustainability, empowerment and self-advocacy (World Health Organization, 2004a). In addition to these principles, CBR programs must take into account local resources and conditions. Successful CBR program will be influenced by the needs of the specific target group, for example, a political, religious or cultural group that is encouraged to be a long-term stakeholder and beneficiary of the program.

According to the WHO (World Health Organization, 2004a), several factors strengthen CBR programs. Firstly, the raising of community awareness must be done in a manner appropriate to the targeted group. Secondly, appropriate and successful role models in other communities where CBR programs have been conducted can help to motivate communities new to CBR (World Health Organization, 2003). Thirdly, the community and the people with disabilities should be involved in identifying and prioritising needs. This will increase community empowerment and ownership as well as enable decision making (World Health Organization, 2003). Fourthly, people with disabilities need to be encouraged to decide about the use of the available funding, and women and children should be included in CBR programs.

Finally, multi-sectoral collaboration is strengthens the CBR programs. It is important that the reduction of disability be part of national goals within all sectors and that governments allocate budgets for specified CBR related activities. Different sectors and stakeholders should be encouraged to exchange information with one another to ensure co-ordination of activities (World Health Organization, 2003).
Most importantly, disability issues need to be considered in poverty reduction programs and CBR be seen as important strategy for poverty reduction.

In order to sustain CBR, it is important that governments provide support to the community to enable the needs of people with disabilities to be addressed along with the needs of all vulnerable groups in the society. It should be inclusive of all persons with disabilities and include people without disabilities.

2.3.4 The Nursing Role in Rehabilitation

Nursing’s role in rehabilitation begins with the first assessment after admission of the patient and continues along the continuum from stabilization of acute symptoms until the patient has achieved his/her maximal level of functioning and has adapted successfully to this level. Nurses work with other members of the team to motivate the patient and their family and friends to participate in the rehabilitation process, providing education, including a focus on adaptation to limitations, and development of strategies to restore self-care (Pryor & Smith, 2000). Brillhard (2001) described nurses as educators, consultants, supporter persons, co-workers and researchers in rehabilitation. Additionally, nurses work with other team to evaluate and intervene as appropriate, by assessing the level of function and disability and contextual factors, and then provide therapeutic intervention according to a client’s needs (Brillhart, 2001). Similarly, a study of nursing interventions in stroke units (O'Connor, 2000), emphasized the fine balance between nurses offering direct help and encouraging independence. Nurses in this study also understood the importance of involving stroke patients and their caregivers in the rehabilitation process.
The role of the nurse within the multi-professional rehabilitation team was investigated in a two year qualitative study in the United Kingdom (Long, Kneafsey, Ryan & Berry, 2002). Forty nine clients were recruited and data were collected by observing the event that could theoretically or potentially be rehabilitative (for example, the nurse was observed interacting with clients and carers or with other members of the rehabilitation team in providing rehabilitation), and interactions between nurses. Clients, carers and staff were also interviewed. Six related roles for nurses were identified: assessment; co-ordination and communication; technical and physical care therapy; therapy integration and therapy carry on; emotional support and involving the family. A single interaction usually involves a combination of roles that reflect a client’s needs.

Although these studies (Brillhart, 2001; Long et al., 2002; O'Connor, 2000; Pryor & Smith, 2000) were conducted in different countries and various settings, the role of the nurse in rehabilitation is similar and while nurses do provide rehabilitation in every day practice, they generally underestimate their rehabilitation role.

Based on the literature, the nursing role in rehabilitation can be summarised as follows. The nurse is:

- an assessor, coordinator and team member, who assesses the extent to which the client could live independently, and works usually with a multi professional team to deliver the best therapy for the client;

- a supporter and motivator, who assists the client and family to return to the community and provides support to the family caregivers; and
• an educator, who provides education to assist the client and family to regain self-care, and adjust to the situation; and

• a facilitator, who assists clients and their families to develop strategies for restoring maximal self-care and adaptation to limitations, so they can live as independently as possible.

The nursing role in rehabilitation is significant, however, it is largely unrealized (Nolan & Nolan, 1999). Although the role of the rehabilitation nurse is developing, nurses generally do not see rehabilitation as specialty practice. They interpret the rehabilitation role as a component of holistic care and rehabilitation is integrated as part of their nursing broad role (Stryker, 2002). As a consequence, deficits in rehabilitation practice have been identified (see Table 2.5) (Nolan & Nolan, 1999).

The specialist role of rehabilitation nursing is also under-recognised by other groups of nurses; this may be because there is insufficient educational preparation for rehabilitation nursing (Low, 2003; Nolan & Nolan, 1999). This contributes to a lack of clarity of the role and limited experience and training for the majority of nurses (Low, 2003; Nolan & Nolan, 1999; Smith, 1999; Snape, 2002). Therefore, nurses do not see the importance of rehabilitation as they lack an understanding of rehabilitation practice and how they might contribute to its achievement, particularly at a time of high workload and staff shortage (Hill & Johnson, 1999).

Therefore, it is essential that nurses understand the principles of rehabilitation to enable them to fulfil their full potential role (Long et al., 2002; Low, 2003; Nolan & Nolan, 1999). It is also important that the nurse’s role in rehabilitation be valued and
recognized by nurses themselves as well as other team members (Long et al., 2002). Rehabilitative knowledge and skills should be included in all nursing curricula (Nolan & Nolan, 1999). Additionally, to advance nursing practice in rehabilitation, a clear set of competencies should be specified and combined with appropriate education and training program (Stokes, 2000).

Table 2.5: Areas of deficit in rehabilitation nursing practice

<table>
<thead>
<tr>
<th>Area of deficits in nursing rehabilitation practice</th>
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</thead>
<tbody>
<tr>
<td>• Imbalance between professional perspectives and those of disabled people, particularly the emphasis professionals place on the physical outcomes of rehabilitation to the neglect of existential, temporal and biographical perspectives important to disabled/chronically ill people and their carers. Rehabilitation is therefore seen as a time-limited intervention rather than addressing on-going needs</td>
</tr>
<tr>
<td>• A failure to individualize rehabilitation programs</td>
</tr>
<tr>
<td>• Insufficient information/advice/education</td>
</tr>
<tr>
<td>• Insufficient attention to emotional needs</td>
</tr>
<tr>
<td>• Insufficient attention to psychological needs</td>
</tr>
<tr>
<td>• Insufficient attention to work, vocational aspects of care</td>
</tr>
<tr>
<td>• Insufficient attention to specific area of concern such as sexuality</td>
</tr>
<tr>
<td>• A failure to address the temporal aspects of rehabilitation, such as transitions through the health care system, lack of coordination and fragmented services, insufficient/absent long-term follow up</td>
</tr>
<tr>
<td>• Neglect of the needs of family carers</td>
</tr>
<tr>
<td>• Insufficient attention to the attitudinal and environmental barriers to the full integration of disabled and chronically ill persons into society. Rehabilitation focuses primarily on impairment, less so on disability and only minimally on handicap</td>
</tr>
</tbody>
</table>

Source: (Nolan & Nolan, 1999, p.965)
2.3.5 Rehabilitation nursing competence

Around the world there are a number of rehabilitation nursing groups (for example, Association of Rehabilitation Nurses, USA, Australasian Rehabilitation Nurses’ Association [ARNA], Rehabilitation and Intermediate Care Forum, UK) that have published competency standards for rehabilitation nursing practice. Seven domains of rehabilitation nursing competence have been described by ARNA (2003): the rehabilitative approach; the teaching and coaching role; observation, assessment and interpretation; administering and monitoring therapeutic interventions; management of rapidly changing situations; management, advocacy and co-ordination role; monitoring and ensuring the quality of health care practices. These domains were identified by Pryor and Smith (2000) in a systematic investigation of the registered nurse role in rehabilitation in Australia.

The effectiveness of rehabilitation nursing competence has been demonstrated by Burton and Gibbon (2005) who conducted a randomized controlled trial to test the impact of an expanded specialist role for nurses by providing outreach education and support to stroke survivors and their family caregivers in north-west England. Patients with a diagnosis of stroke, who were randomized to the intervention (n=87), received continued support from a stroke nurse and follow-up after discharge from hospital compared to no follow-up for the control group (n=89). At the 12 month follow-up, the intervention had improved the stroke survivors’ perceptions of general health, and had reduced negative emotional reactions and perceived social isolation significantly. In addition, the intervention reduced carer strain at three months and at 12 months, patients had a higher level of independence. This study provides evidence that continued outreach education and support provided by stroke nurses
after discharge from hospital has significant benefits for stroke survivors and their family caregivers. This research supports a role for specialist rehabilitation nurses in the education of family caregivers in relation to providing ongoing rehabilitation and care for people, who have suffered a stroke.

Like the intervention studied by Burton and Gibbon (2005), the program reported in this thesis centres on a specialist rehabilitation nursing role. In this instance, the intervention was underpinned by the work of Pryor and Smith (2000) because the domains they identified guide nurses to support the rehabilitation of individuals according to their physical, mental and social needs.
2.4 Conceptual Framework

2.4.1 Conceptual Framework

Orem’s theory of self-care (Orem, 1991) and adult learning theory (Knowles, 1984) were used to develop the conceptual framework for this study.

Orem’s self-care theory (Orem, 1995) has been widely used to guide the development of nursing interventions. According to Orem (1995), nurses use three systems. Firstly, the wholly compensatory system in which the nurse provides total care to the patient; secondly, the partly compensatory system in which the nurse and the patient share responsibility for care, and, thirdly, the educative supportive system in which the patient has primary responsibility for personal health, with the nurse acting as a consultant or providing information and education. The intervention developed for this study focused on the educative supportive nursing system and was designed to guide caregivers and enable them to feel more confident. When people understand information and have confidence, their ability to perform an activity increases (Exall & Johnston, 1999).

The educative supportive nursing intervention in this study is informed by the role of the nurse in rehabilitation as educator, which is developing in Thailand. In this role nurses focus on improving outcomes for stroke survivors and their caregivers. (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002) highlight how nurses are uniquely positioned to support the family caregivers and identify the caregivers’ most relevant needs and adapt interventions appropriately. Moreover, a critical review by Visser-Meily et al. (2005) has also drawn a firm conclusion about the
positive outcomes of providing a counselling program which focuses on the
problems of the family caregivers of stroke survivors.

The implementation of the SELF intervention was underpinned by adult learning
theory (Knowles, 1984). When providing education to adult learners, there are four
main factors to be considered; firstly, adults learn from their experience which
means that they should be able to share their opinion and bring in their past
experiences. Secondly, the learning process should be self-directing which means
individuals should be able to decide what they want to learn. Thirdly, they are
willing to learn and, finally, the knowledge provided or education should be relevant
to their real life situations (Knowles, 1984). In addition, the learning process needs
be active and learners have opportunities to practise (Knowles, 1970, 1984).

These four factors (experience, self-directing, relevant and active learning) were
used in this study to inform the delivery of SELF program. The intervention was
designed to include common problems identified by family caregivers (Jatupornpat,
2000; Jullamate et al., 2006). During the education sessions, family care givers were
encouraged to share their caring experience and discuss their experience of
providing care. Attendance at the education sessions by family caregivers was
critical to the effective implementation of the SELF program. The family caregivers
attended the education sessions and participated in the demonstration and practice.
This active learning process equipped family caregivers with skills and confidence
to assume their new role. Providing education and training to family caregivers was
intended to promote good outcomes for stroke survivors and their family caregivers.
The conceptual framework of this study is presented in Figure 2.2.
Stroke is a significant cause of mortality and morbidity around the world. Stroke survivors usually experience some degree of functional and/or cognitive deficit ranging from mild disability that has little influence on the person’s day to day functioning to total dependence on others for all activities. Caring for family members with severe disabilities interrupts established work and family responsibilities and causes stress in the family, particularly to those who assume the care giving role. It is important to prepare caregivers to fulfil their role effectively while at the same time minimising carer burden and strain. Nurses provide much of
the ongoing care during hospitalisation, therefore they are well placed to prepare family for their caregiving role following discharge.

The literature review has supported the role of nursing in stroke rehabilitation and identified the lack of research in this area in Thailand. In the following chapter, the issues related to the methodology of the research will be discussed.
Chapter Three

Method

3.1. Introduction

This chapter describes the research approach and methods of the study. A rationale for the research design is given and the study population and sample selection presented. Development of the data collection tools is described, including validity and reliability of the instruments. The intervention used in this study will be described. Finally, the data analysis and ethical considerations will be presented.

3.2. Study design

A comparative study with concurrent controls, using a two-group pre-test and post-test design was used for this research. This study was conducted in two hospitals in different cities in Thailand. Although the randomised control trial is considered the “gold standard” for an experimental study, approaches to care and staff to patient ratios in Thai hospitals prevent compliance with protocols to control bias and to prevent contamination of the groups.

3.3. Population and sample

The target population was patients admitted to the study hospitals with a diagnosis of acute stroke and their family caregivers who met the inclusion criteria described below (see 3.4).
Apart from the intervention that was implemented in one study site, both hospitals are similar. These two hospitals are provincial hospitals with 800-1000 beds administered by the Government’s Ministry of Public Health, Thailand. The patient demographics are similar as are the type of services provided and the protocols and procedures for patient care. There are no factors at either facility (apart from the intervention at one hospital) that could be anticipated to influence results. The intervention hospital was determined by the toss of a coin. To preserve anonymity of the study sites, the hospitals will be described as site A (intervention) and site B (control). All participants from site A were assigned to the intervention group, while all the patients and their caregivers in site B were assigned to the control group.

Two hospitals in different cities were selected for the study to prevent the contamination of the control group by staff also providing care to patients assigned to the intervention group. Participation of two study sites also ensured recruitment of an adequate sample in the limited time of the study.

A power analysis demonstrated that, based on the calculation of T-test, to have 80% chance of detecting effect size of 0.5 SD, a minimum of 64 patients per group was required. Effect size was calculated on readmission for management of complications. Retrospective observations indicated that there were approximately 184 new stroke patients in the intervention hospital (site A) and 200 new stroke patients in the control hospital (site B) registered as in-patients during 2003, which indicated that an adequate sample would be recruited when the exclusion criteria were taken into account. The process for recruitment and intervention, including follow-up, is summarized in the flow chart (Figure 3.1).
Figure 3.1 Study design

Patients admitted to control and intervention hospitals and their family caregivers who met inclusion criteria

Meet inclusion criteria
- YES – consent obtained
- NO – excluded

Intervention group N=70
Patients and caregivers in site A

Control group N=70
Patients and caregivers in site B

Baseline measures
- Demographic data for patients and family caregivers
- BI for patients

Family carers’ training program (SELF)

Conventional care

Outcome at discharge
- Patient: GHQ-28, BI, Rankin Scale
- Caregivers: GHQ-28, CSI

Telephone follow-up for intervention group (1*3 month)

Outcome assessment at three months
1 Primary outcome:
- BI and CSI
2 Secondary outcomes
- GHQ-28 (patients and caregivers)
- Modified Rankin Scale (mRS)
- Readmission rate
- Complications and mortality rate

Training program for the control group
3.4. Inclusion and exclusion criteria

3.4.1 Inclusion criteria for patients

Patients were eligible to participate in the study if they:

1. Had suffered a first stroke.
2. Scored $\geq 20$ for Mini Mental State Exam (MMSE).
3. Spoke Thai Language.
4. Were to be discharged to their homes.
5. Had a family caregiver at home.
6. Had access to a telephone.
7. Gave informed consent to participate.

Patients with a family caregiver who did not meet the following inclusion criteria were not included in the study.

3.4.2 Inclusion criteria for caregivers

Family caregivers of patients who were eligible to participate were also invited to participate if they:

1. Spoke and read Thai Language.
2. Were the primary family caregivers living in the same house with the patient.
3. Were not involved in any other study.
4. Were willing to provide support to the stroke patient after discharge.
5. Gave informed consent to participate in the study.
3.4.3 Exclusion criteria for patients

Patients were excluded if they:

1. Did not speak Thai.
2. Scored < 20 for MMSE.
3. Were to receive follow-up care in another region of Thailand.

3.4.4 Exclusion criteria for caregivers

Family caregivers were excluded if they:

1. Had a notable disability or history of any serious illness that would impede their ability to implement skills learned in the education program.
2. Scored < 20 for MMSE.
3. Did not read or speak Thai Language.

3.5 Recruitment

The nurse in-charge of the shift for each of the study wards notified the researcher when a patient with a diagnosis of acute stroke was admitted. Additionally, the nurse researcher also phoned the ward every Monday, Wednesday and Friday evening to confirm stroke admissions to each site.

After the acute phase (24-48 hours) following admission, the nurse researcher or the research assistant informed the patient and the family caregiver of the study. The Information Sheets (Appendix 1 & 2) were given to both the patients and their family caregivers to read. Each patient was then assessed for cognitive impairment by administering the MMSE (Folstein, Folstein & McHugh, 1975). In order to see the effect of the intervention, the participants who obtained a score of 20 or higher...
on the MMSE were invited to participate. This is because cognitive impairment adversely influences the stroke survivor’s functional outcomes after stroke and the caregiver’s ability to understand and implement the training (Zwecker, Levenkrohn, Fleisig, Zeilig, Ohry & Adunsky, 2002).

When a potential participant was identified, the family caregiver was also informed of the study and if they agreed to participate, they were also assessed. If both patient and caregiver met the inclusion criteria, they were recruited into the study.

The participant consent forms for patients and their family caregivers (Appendixes 3 and 4) were then given to the potential participants to read. The patients and the caregivers were assured that they had the right to refuse to participate in the study and refusal would not affect the care they received.

In Thailand, consent is normally obtained verbally, not in writing. This is because in the Thai culture, signing a document is associated with the potential for future repercussions including unwanted responsibilities. Requiring a signed consent form may be interpreted as coercion by some potential participants. To overcome the cultural situation, the nurse researcher offered the option to give consent verbally or in writing. Participation by the carer in the education was interpreted as implied consent and participation in the assessment and provision of post discharge contact detail was interpreted as implied consent by those in the control group. The additional procedures of ethical approval were applied prior to commencing the study as detailed in Section 3.9.
3.6. The SELF program

The Supportive Educatve Learning program for Family caregivers (SELF) is a training program that comprises didactic education sessions, hands on training for family caregivers, a booklet for family caregivers describing stroke care and three follow-up phone calls. The program was developed by the researcher, based on the theory and evidence from the literature reviewed and advise from experts in stroke rehabilitation (Boonkerd, 1997; Carrozzella & Jauch, 2002; Chuangsawadsak, 1998; Jullamate et al., 2006; Komjakrathan, 2000; McCullagh et al., 2005; Pajaree, 2004; Poungvarin, 2001b; Poungvarin et al., 2000; Sze et al., 2000; Tosayanon, 2001).

Group education sessions were chosen as the main teaching method as it was believed that group education is an effective way to provide knowledge and information regarding stroke (Johnson & Pearson, 2000; Warner, 2000). Additionally, the sessions provided an opportunity to family caregivers to share their opinions and support each other (Johnson & Pearson, 2000; Rodgers et al., 1999; Warner, 2000). Furthermore, Knowles (1984), the founder of adult learning theory, believed that group learning is more motivational and offers a chance to learn new skills. Moreover, a supportive environment promotes positive behaviours, interaction and each individual can share their experience with one another. In particular, group learning also provides an opportunity to the group members to receive reinforcement from one another which could help them to improve their practice (Knowles, 1984). The components of the SELF program were developed based on the theory as follows (Table 3.1)
Table 3.1: Theory underpinning the intervention

<table>
<thead>
<tr>
<th>Learning Method</th>
<th>Theory</th>
<th>Content</th>
<th>How delivered</th>
</tr>
</thead>
</table>
| Group learning and experience          | Adult learning theory (Knowles, 1984) and theory of self-care (Orem, 1991) | • What is stroke?  
• Complications due to stroke  
• Prevention of complications  
• Prevention of subsequent stroke  
• Maintaining adequate hydration and nutrition  
• Identification of swallowing difficulties/safe swallowing  
• Positioning, mobility and transfer  
• Management of catheter/NG tube/PEG tube  
• Bladder and bowel training  
• Role of family caregivers/looking after themselves | Three education sessions maximum of six in each group during the lecture sessions.  
Participants were encouraged to discuss their caring experience, with their researchers and within the groups |
| 2 Active learning /self-care           | Adult learning theory (Knowles, 1984) and theory of self-care (Orem, 1991) | • Practise positioning  
• Practise feeding  
• Practise catheter care  
• Practise assisting with mobility  
• Incontinence exercise | Demonstration and practice or hands on training maximum of two in each group to enable the participant to practise thoroughly |

The booklet contained a summary of the content of the education program. The SELF booklet provided to the participants in the intervention group was in the Thai language (the booklet is included as Appendix 5 in English for ease of examination). The features of the booklet were diagrams that were used wherever possible to replace text. This approach was used to support comprehension of the principles of stroke rehabilitation regardless of literacy level (Appendix 5).
In addition, a telephone follow-up service was used to provide consistent reinforcement, support and counseling to family caregivers. This was necessary because family caregivers take on the role of caring and they might feel stressed or have an unpleasant situation about which it might be hard for them to make a decision. Therefore, support and motivation were provided in order to keep up the positive outcomes (Orem, 1995). This action is supported by the results of a randomized control trial (Wilson, Hareendran, Grant, Baird, Schulz, Muir & Bone, 2002) that provided telephone support intervention regarding social problem solving to 74 family caregivers of stroke survivors after rehabilitation. The study found that the participants had better problem solving skills, felt less depressed, and had significant improvement regarding vitality, social functioning and mental health. Additionally, they were well prepared for their role when compared to the control groups. Therefore, an integration of these studies and theories helped to identify the best way to provide help to stroke patients and their families.

**The aims of the intervention were to:**

1. Assist family caregivers to develop skills in providing rehabilitation to their relatives after discharge to:
   - assist patients to achieve their optimal level of function; and
   - reduce the incidence of stroke-related complications, for example urinary tract infections, pressure sores, chest infections and contractures.

2. To reduce the stroke survivor’s family caregiver’s stress.
The training sessions and booklet

The family caregivers in the intervention group received additional education and training to prepare them to provide rehabilitation to the patients after discharge. A research nurse who explained the training program visited the participating patients and family caregivers. An appointment was made with family caregivers in the intervention group to attend three training sessions, which were held in the medical surgical ward meeting room. At the time of recruitment, family caregivers were asked to nominate whether morning or afternoon sessions were most convenient; afternoon was nominated by the majority. After attending each session, the appointment was made for the next session.

The training program consisted of three interactive education sessions with a maximum of six caregiver/patient pairs in each session to enable the researcher and research assistants to spend time with each patient and carer team during the practise component of the sessions.

The first session focused on the causes and risk factors of stroke, the associated complications and methods to prevent or reduce the severity of complications; for example, management of pressure areas, prevention of decubitus ulcers and assistance with ADLs. The second session, provided the family caregivers with knowledge and skills regarding swallowing difficulties and feeding, and maintaining adequate hydration and nutrition. The final session included urinary catheter care, preventing urinary tract infections, techniques for bladder and bowel training, positioning, mobility and transfer, the role of the family carer and caring for themselves. Family caregivers were supervised practising with the stroke survivors.
activities such as adjusting the patient’s position to prevent pressure ulcers, feeding, catheter care, lifting and handling technique, and mobility and transfer.

Each session was approximately 120 to 150 minutes’ duration including time for group discussion. During the hands on training, the participants were separated into three groups (2 in each). The participants practiced with their relatives under the supervision of the nurse researcher and two research assistants who were registered nurses (RNs), had worked in the medical wards in Thailand, had experience in caring for stroke patients and were nurse lecturers in a nursing college, Ministry of Public Health Thailand. Each family caregiver was given written information on the education provided (Appendix 5). The topics and brief contents in each session are listed in Table 3.2.

Table 3.2: Training sessions

<table>
<thead>
<tr>
<th>Day and Session</th>
<th>Topics</th>
<th>Activity</th>
</tr>
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</table>
| Tuesday: Session One (2 hours) | • What is a stroke?  
• Complications due to stroke.  
• Prevention of complications associated with stroke (pressure sore, shoulder pain, chest infection and contractures).  
• Prevention of subsequent stroke. | • Lecture (45 minutes)  
• Group discussion (15 minutes)  
• Information sheet given (Thai version)  
• Hands on training |
| Wednesday: Session Two (2.5 hours) | • Maintaining adequate hydration and nutrition.  
• Identification of swallowing difficulties.  
• Safe swallowing, nasogastric (NG) tube and gastrostomy (PEG) tube feeding and care of the tube. | • Lecture (60 minutes)  
• Group discussion (20 minutes)  
• Demonstration  
• Hands on training with their relative. The participants were divided into three groups, 2 in each group. Each participant practised with their own relative  
• Information sheet given |
| Thursday: Session Three (2.5 hours) | • Bladder and bowel function, catheter care, bladder and bowel training.  
• Positioning, mobility and transfers.  
• Role of family carer.  
• Caring for yourself. | • Lecture (50 minutes)  
• Group discussion (10 minutes)  
• Demonstration  
• Hands on training with their relative. The participants were divided into three groups. |
The content of the training program was based on interventions described in the literature review. It is also informed by retrospective studies describing frequent readmission by stroke patients to hospitals in Thailand, for management of stroke related complications and stress in family caregivers (Chantawatchai, 1999; Natechang, 2002; Niyomthai, 2002; Perkdetch, 2002; Sangboon, 2002; Taneerat, 2002; Thipsamniag, 2000). The content of the training program was reviewed for content validity by a panel of experts in stroke rehabilitation and rehabilitation nursing from Thailand and Australia. The readability of the information booklet was written to be lower than level four (4 years of primary education or 10 years old) so that all caregivers could easily read and understand it. It was then pilot tested with people of various educational levels and backgrounds (10 lay people) to check the readability of the English version. The few technical terms used were found to be a minor problem and these were amended to lay terms for ease of reading.

Besides the main factors mentioned above, a key issue is that the study was located in Thailand. Therefore, the education materials were translated into the Thai language by the researcher and another Thai academic from the Faculty of Nursing, Department of Medical and Surgical Nursing Chiang-Mai University. Then, another bilingual English language teacher from the Faculty of Humanities and Social Sciences, Rajabhat Institute Chiang-Rai, Chiang-Rai, Thailand retranslated the Thai version of the instrument into English in order to verify the Thai material. This was done in order to keep the equivalence of the instrument and to reduce any language alteration (Chang, Chau & Holroyd, 1999).
Additionally, all materials designed for the family caregivers in Thailand (Thai Language) were pilot tested with 20 stroke family caregivers, who had similar characteristics as the sample (i.e. those who met the inclusion and exclusion criteria as mentioned in section 3.4) but who were not included in the study sample (Polit & Hungler, 1999). This was done during 25 April to 20 May, 2005 before commencing the actual study. The family caregivers were recruited from the intervention hospital (Site A) and the control hospital (site B), 10 from each hospital. The education materials were given to each of the participants to read and they were asked to circle the words or pages that they could not understand. Each of the participants was given one week to read the material; this process was done to check the literacy and the content of the document to ensure its suitability for family caregivers. After one week, the participants returned the document with their comments. The majority of them could read and understand the document and only minor changes were needed. For example some of the terms used were technical terms like NG tube or naso-gastric tube was written in Thai exactly the same as in the English language so it was changed to a more detailed description of the words like tube that was inserted into the stomach via the nose. Additionally the picture labels were made larger. The documents were revised according to the findings of the pilot test and suggestions by testers to enhance the resource. The literacy level was revised to clarify some of the terms or the meaning of the sentences. After all the corrections were made, six family caregivers were invited to attend the training sessions. The process of the teaching sessions was pilot tested with the family caregivers. Six families from the intervention site (site A), attended the teaching sessions for three consecutive afternoons and practiced the skills with their relatives (stroke survivors). The comment made by the majority of family caregivers was that
they needed more time to practise. However, they did not have any problems understanding the lecture except some of them could not see the writing on the screen. The process of the teaching and the content were adjusted according to comments and feedback from the pilot sessions and suggestions from the family caregivers.

**Telephone support**

Prior to discharge, a research assistant made an appointment with the family caregivers for the follow up telephone support. The appointment date and time were written on the daily planner. The research assistant phoned the family caregivers on the date and time written on the planner. These calls took place during the third week of each month, for three months. This contact enabled the research assistant to discuss problems, provide suggestions for care and provide support to the caregiver. The duration of the interview was between 30-45 minutes depending on the family caregiver and the stroke survivor’s situation. The schedule of general questions around which the telephone interview was structured is provided in Appendix 6.

When the family caregivers were contacted for the second time, problems and discussions from the previous telephone support follow-up were reviewed prior to the research assistant proceeding with the structured questions.

The patients and their family caregivers in the control group received the usual care provided from the hospital and the health care service. Additionally, at the conclusion of the data collection stage of this study, they received all the education
materials that were provided to the intervention group, but did not receive training sessions.

3.7 Data collection

Data were collected at three stages (Table 3.3): stage one - during the hospital stay; stage two - immediately prior to discharge; stage three - three months after discharge. At the third stage, research assistants, who were blind to study group allocation, assessed the patients and the family caregivers using the study instruments described below (see 3.8).

The period of three months was chosen in this study because the first three months following stroke are seen to be the most critical period when greatest recovery is thought to occur. This is supported by a study conducted by Jorgensen et al. (1995) which investigated the outcomes and time course of recovery in stroke patients. They found that patients achieved their optimal neurological outcome around 11 weeks from the time of stroke onset and optimal basic self-care and mobility skills had been achieved at 12-13 weeks post-stroke.

The demographic data were obtained from the patients in both groups, together with the personal health status questionnaire. The Barthel Index (BI) was administered to the stroke patients in both groups immediately following recruitment. The patients’ family caregivers also completed a survey.

Prior to discharge from the hospital, patients completed the General Health Questionnaire (GHQ-28), Modified Rankin Scale (mRS) and BI. Additionally, the
Caregiver Strain Index (CSI) and GHQ-28 were administered to the family caregivers.

Follow-up data were collected three months following discharge, by research assistants who were blind to the study group allocation to assess the patients (BI, mRS, GHQ-28) and family caregivers (GHQ-28, CSI) in both groups. Additionally, the readmission rate and the reason for readmission to hospital of patients in both groups were recorded.

**Table 3.3: Summary of the data collection in each stage**

<table>
<thead>
<tr>
<th>Measurements</th>
<th>Baseline and at entry of the study</th>
<th>Discharge</th>
<th>Three month follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic data for patients</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographic data for caregivers</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMSE (used for screening test ) in patients and caregivers</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Modified Rankin Scale (mRS) for patients</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Barthel Index (BI) (for patients)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General Health Questionnaire (GHQ-28) for patients</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>General Health Questionnaire (GHQ-28) for caregivers</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Strain Index (CSI)</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Readmission rate and complications</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Mortality rate</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
</tbody>
</table>
3.8 Validity and reliability of the study instruments

Bowling (2002) defined validity as the extent to which the instrument measures what it is intended to measure. Validity is reflected in the instrument’s ability to obtain the data required, identify items that need to be included, and examine what it is assumed to test (Polit & Hungler, 1999). In addition, Burns and Grove (2001) stated that the content validity also involves the relevant items to the research questions and should involve the questions relevant to the research topic. Reliability is defined as the extent or degree to which an instrument obtains consistent results when reused or repeated over time (Bowling, 2002). In this study, the majority of instruments used for data collection had been validated in previous studies for use in the Thai population. They are well accepted with their validity and reliability established in the study population.

As stated previously in this thesis, the aim of the study was to develop and implement a nurse led supportive educative learning program for family caregivers (SELF) of stroke survivors, evaluate the ability of the intervention to maintain or promote the functional ability and quality of life of the stroke survivors, to evaluate the family caregivers’ stress and quality of life following participation in the program, and to reduce the incidence of complications and mortality among stroke survivors. In order to measure the effect of the intervention, MMSE, BI, mRS, GHQ-28 and CSI were used to answer the questions and evaluate the aims of the study (table 3.4). These instruments were critically reviewed and selected for each aim mentioned. Details for each instrument follow.
Table 3.4. Aims of the study and instrument used

<table>
<thead>
<tr>
<th>Question</th>
<th>Aims of the study</th>
<th>Mode of Measurement</th>
<th>Instrument used</th>
</tr>
</thead>
</table>
| What is the effect of a nurse-led supportive, educative learning program on outcomes for stroke survivors and their family caregivers in rural Thailand? | To evaluate the effect of the SELF program on the functional ability and quality of life of stroke survivors | • Functional ability or physical ability  
• Stroke survivors’ quality of life | • BI and mRS (FIM and FAI was considered but not used as detailed in topic 3.8.2 section ii)  
• GHQ-28 |
| To evaluate the effect of the SELF program on family caregivers’ strain and quality of life | • Family caregivers’ quality of life. (Somatic symptoms, anxiety and insomnia, social dysfunction & severe depression)  
• Family caregivers’ strain(employment, financial, physical, social and time) | | • GHQ-28  
• CSI |
| To reduce the incidence of complications among stroke survivors | • Readmission | | • Record stroke survivors’ hospital readmission rates and deaths in each group. |
3.8.1 Pre-consent screening

(i) **Mini-Mental State Exam (MMSE)** The Mini-Mental State Exam (Appendix 7) (Folstein et al., 1975) is a short instrument for assessing the cognitive status of older adults and take 5-10 minutes to administer (Folstein et al., 1975). The MMSE is also recommended by the American Heart Association to use for assessing the cognitive status of stroke patients (Kelly-Hayes, Robertson & Broderick, 1998). It comprises 11 questions that measure orientation, registration, attention, calculation, recall, and language. The maximum score is 30 and the reliability calculated by using a Pearson coefficient was 0.089 (Folstein et al., 1975).

The Thai version of MMSE that is used by the Department of Mental Health, Ministry of Public Health, Thailand (Taemeeyapradit, Tanchaiswad, Hangsprueg & Phunsiri, 1990) was used in this study to assessed the participants. The Thai version of MMSE has been validated in 44 elderly and 36 neurological patients in Thailand. The sensitivity and specificity in detecting cognitive impairments by using the MMSE at cut off points \( \geq 20 \) were 91.67\% and 95.45\% respectively (Taemeeyapradit et al., 1990). Additionally, the Thai version of the MMSE has also been validated in 100 Thai elderly people and the internal consistency was 0.79, while the test retest reliability was 0.69 p<0.000 (Kangsaranak & Kotchabhakdi, 1991). In the study reported here the optimal cut off score of 20 was used to separate possible cognitive impairment cases from non-cases, and the participants who scored MMSE \( \geq 20 \) were recruited.
3.8.2 Data collection instruments

(i) Demographics and personal health status questionnaire  All patient participants in both groups completed a survey form developed by the researcher to collect data on the demographic characteristics of age, gender, marital status, religion, educational level, occupation, income and primary caregiver, together with their personal health status. The personal health status questions collected data about the type of cerebrovascular disease or stroke, personal illness, side of weakness, the time from onset of symptoms to treatment, rehabilitation after onset, and other resources or treatment (Appendix 8).

The patients’ family caregivers also completed a survey developed by the researcher (Appendix 9). The following data were collected: age, gender, duration of care giving, time spent in care giving per day, family income, adequacy of income, care giving experience, care giving assistance, relationship to patient, caregivers’ health problem status, and other persons for whom they have a caring responsibility.

The questionnaires were developed in English and then translated into Thai by the research nurse and back translated from Thai to English by another academic person from Borommarajonani School of Nursing Chiang-Mai, Thailand and a bilingual English language academic from the Faculty of Humanities and Social Sciences, Rajaphat Institute Chaing-Rai.

The questionnaires were pilot tested with 20 stroke patients and 20 family caregivers. After minor corrections were made, they were used for data collection in the study.
(ii) **The Barthel Index (BI)** The Barthel Index (Appendix 10) (Collin, Wade, Davies & Horne, 1987; Mahoney & Barthel, 1965) measures functional status and rates of self-care abilities in the areas of personal hygiene, bathing, feeding, toilet use, mobility, transferring, walking up and down stairs, dressing, and bowel and bladder control. For each item, the patient is scored based on their ability to perform the tasks independently or with help (Collin et al., 1987; Jitapunkul, 1998). The BI evaluates the state of independence before treatment, the progress while under treatment and the patients’ status when they reach the maximum benefits (Yamamoto & Magalong, 2003).

There are various types of instruments that have been used to measure ADLs, for example the Functional Independence Measurement (FIM) and the Frenchy Activity Index (FAI). In this study, the BI was considered to be the most effective tool to measure functional status because it is widely used to assess stroke patients and has excellent validity and reliability (Kelly-Hayes, 2004). It is an empirically derived scale with proven inter-observer and test retest reliability and validity and has been widely tested for validity and reliability in patients with physical disabilities (Al-khawaja, Wade & Turner, 1997). In addition, in the study by Van der Putten, Hobart, Freeman and Thompson (1999), the responsiveness of the BI and the FIM was compared in 201 multiple sclerosis patients and 82 stroke patients. The admission score and discharge score were generated for the BI and three scales of the FIM. The results indicate that the BI and FIM total and FIM motor scale had similar responsiveness suggesting that both the FIM total and FIM motor scales have no advantages over the BI in evaluating changes. Unlike the FIM, training is not
required to administer the BI and it can be completed in 5-10 minutes, compared to 30-45 minutes for the FIM.

A further significant factor in the decision to use the BI in the study was because a Thai version had already been used and accepted in Thailand (Jitapunkul, 1998). The internal consistency of the translated instrument tested by using Cronbach’s coefficient alpha of the translated instrument was 0.93 (Jitapunkul, 1998; Suwanno, 1997; Yamvong, 1996).

The maximum score of the BI is 20 with higher scores denoting greater independence. The score from 0-4 indicates very severe disability, 5-9 indicates severe disability, 10-14 indicates moderate disability, 15-19 indicates mild disability and 20 indicates independence with ADLs (Wade, 1988).

The reliability of the BI has been demonstrated against observations by carers, nurses and patients (Collin et al., 1987), which found a highly significant coefficient of concordance between the following four rating methods. The first method: an observer asked the patient or relative about the patient’s ability. The second method was for the same observer to ask the nurse who had worked with the patient for at least one shift for the opinion on the patient’s ability. The third method required a trained nurse to ask the patient, and with the fourth method the occupational therapist tested the patient within 72 hours of admission. The reliability and validity testing demonstrated a Kendall’s coefficient of concordance to be $W=0.93$, $p<0.001$ and the Cronbach’s coefficient alpha of internal consistency of the Barthel Index to be 0.87 (Shah, Vanclay & Cooper, 1989).
(iii) **The Caregiver Strain Index (CSI)** The Caregiver Strain Index (Appendix 11) (Robinson, 1983) is the scale most commonly used to identify stressors on the caregivers. It is a brief scale which is easy to administer (Robinson, 1983). The CSI represents the major domains cited in the caregiver burden literature: employment, financial, physical, social, and time. Burden is a multi-dimensional concept, hence different domains must be measured (Visser-Meily, Marcel, Riphagen & Lindeman, 2004). Additionally, the CSI has been used to assess the effect of care giving for stroke survivors in many studies (Anderson et al., 2000; Bugge et al., 1999; Mant et al., 2000; Rudd, Wolfe, Tilling & Beech, 1997; Van den Heuvel, de witte, Schure, Sanderman & Meyboom-de Jong, 2001).

The CSI comprises 13 statements covering physical and psychological situations thought to act as stressors. Scores range from 0-13, obtained by summing “Yes” responses. A high score denotes a high level of stress. It has a high internal consistency at 0.86, which was measured by Cronbach’s alpha (Robinson, 1983).

In this study, the CSI was translated into the Thai language and verified by the researcher with another Thai academic from the Nursing College Phayao Province, Thailand.

As recommended by Chang et al., (1999), to keep the equivalence of the instrument and reduce the language alteration, the translated instrument was verified by another academic from the School of Nursing Chaing-Mai University, a bilingual English language academic from the Faculty of Humanities and Social Sciences, Rajaphat Institute Chaing-Rai Thailand and two experienced clinical nurses.
The CSI Thai version was then pilot tested with 20 caregivers who had the same characteristics as the sample and who would not be included in the main study (Polit & Hungler, 1999). The internal consistency of the translated instrument as tested by using Cronbach’s coefficient alpha was 0.87.

(iv) Modified Rankin Scale (mRS) The Modified Rankin Scale (Appendix 12) (Rankin, 1957; Van Swieten, Koudstaal, Visser, Schouten & Van Gijn, 1988) was used to classify the stroke patients based on severity of disability. The mRS has proved to be valid and reliable for defining outcomes in stroke patients (D'Olhaberriague, Litvan, Mitsias & Mansbach, 1996; Van Swieten et al., 1988). Additionally, it is the most popular tool in use for the assessment of global outcomes in stroke (Van Swieten et al., 1988). The mRS is widely used as a functional outcome measure in stroke especially for measuring independence rather than performance of specific task (Duncan, Jorgensen & Wade, 2000; Van Swieten et al., 1988). The particular strength of mRS is the ability to assess the full range of activity limitations and participation restrictions after stroke (Van Swieten et al., 1988). The mRS is categorised into six grades of disability and is reported as rank 5, 4, 3, 2, 1 and 0. Patients with rank 5 are considered to be totally dependent and bedridden, while patients with rank 0 are totally independent. The inter rater reliability of the mRS was measured by using structured interviews and the overall agreement between raters was 78% (Wilson et al., 2002).

In this study, the mRS was translated into the Thai language and verified by the researcher with another Thai academic, from the Boromarajonani College of
Nursing, Phayao, Thailand. Then, for verification, it was given to another academic from the School of Nursing Chiang-Mai University, and a bilingual English language academic from the Faculty of Humanities and Social Sciences, Rajaphat Institute Chiang-Rai Thailand and two experienced clinical nurses (Chang et al., 1999).

The Thai version was pilot tested with 20 stroke patients, who were not included in the study to test the inter-rater reliability (Polit & Hungler, 1999) between the researcher and another Thai academic from the Boromarajonani College of Nursing, Chiang-Mai, Thailand. The inter-rater reliability was tested in order to assess the consistency of the rating or to assess the degree to which different raters/observers gave consistent estimates of the same phenomenon. The overall agreement between raters of the translated instruments was 90%.

(v) General Health Questionnaire (GHQ-28) The General Health Questionnaire (Appendix 13) (Goldberg & Hiller, 1979) was designed to examine two main areas: the ability of an individual to carry out usual healthy activities; and subjective symptoms of psychological distress (Goldberg & Williams, 1988). The GHQ-28 has been used widely for measuring psychiatric morbidity after stroke (Goldberg, 1972). It is a four-subscale tool, which assesses somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. (Werneke, Goldberg, Yalcin & Ustun, 2000). Each subscale has seven items scored zero to three (Likert scale scored 0, 1, 2, 3) with zero being least distressed. The maximum score is 84. To separate cases of stress from non-cases, Bridges and Goldberg (1986), suggested a cut off score of 23/24. Higher scores denote worse psychological health (Goldberg & Hiller, 1979).
The GHQ-28 has been validated in many studies, the internal consistency measured by using Cronbach’s alpha is 0.91-0.94 (Krol, Sanderman, Moum, Suurmeijer, Doeglas, Krijnen, Robinson, Briancon, Bjelle & Heuvel van den, 1994).

In this study, the Thai version of GHQ-28, which has been published by the Department of Mental Health, Ministry of Public Health, Thailand, was administered. The internal consistency of the Thai Version of GHQ-28 is 0.84-0.94 (Kuptniratsaikul, Smerasuta & Klomjaiyen, 2000; Nilchaikovit, Sukying & Silpakit, 1996). The GHQ-28 Thai version was used to measure the ability of the individual to carry out usual healthy activities; and subjective symptoms of psychological distress which may affect an individual’s quality of life. Hence this instrument is considered appropriate for measuring quality of life in Thailand. Additionally, the GHQ-28 has been used to measure quality of life widely by the Department of Mental Health, Ministry of Public Health, Thailand and has been well accepted (Nilchaikovit et al., 1996).

3.9. Ethical considerations

To conduct research, it is important that permission should be granted in order to protect the participant (Parahoo, 1997). Ethics approval to undertake this study was obtained from The University of Western Sydney (UWS) Human Ethics Committee, Australia (Appendix 14). When ethics approval was obtained from UWS, approval was sought from each of the study hospitals in Thailand (Human Ethics Committee from Chiang-Rai Regional Hospital, and Mae-Rim Province Hospital, Chiang-Mai). In addition, the ethics governing research stipulate that the participants should not be harmed and should give informed consent to participate (Bowling, 2002). Each
potential participant was provided with the Participant Information Sheet, the study was explained and their consent to be included in the study sought. However, as previously explained, participant consent in Thailand is frequently verbal and implied by participation in the study. The protection of human subjects included in the consent form was as follows:

- assuring the subjects that all information would be kept confidential;
- in the case of the stroke patients and/or their caregivers who did not desire to participate in this study, they were assured that their decision did not affect the medical or nursing treatment that the patients received;
- the subjects could terminate their cooperation before the end of the study. Additionally, all data would be reported as group data and no individual would be identified; and
- the Participant Information Sheet and consent form were translated into Thai language by the nurse researcher and another Thai academic.

3.10 Data Analysis

Data obtained from this study were coded and entered into SPSS (Statistical Package for the Social Sciences) for Windows Version 12 (SPSS Inc, 2003) and then analyzed on an intention to treat basis. Results are presented in Mean and standard deviation (SD) for continuous data and chi-square for ordinal data. Data were analysed as follows:

1. Demographic data were tested for differences between intervention and control groups.
2. The categorical data were analyzed using the chi–square test. For those variables that have expected frequencies less than five, the cells were grouped together to prevent inaccurate results (Dempsey & Dempsey, 1992; Hills, 2005).

3. Student parametric t-test or Mann–Whitney U non-parametric test was used for independent samples and continuous data.

4. The Mann–Whitney U test (non-parametric) was used to compare the differences in the median values of the functional scales whenever the variable was not normally distributed.

5. Repeated measures ANOVA were used to test the significance of differences for functional assessment scale from baseline to three month follow-up.

6. ANOVA of general factorial model using the baseline scores as covariates was used to examine the significance for the change of scores with the functional instruments.

3.11. Summary of the process of study design, data collection and trial procedure

After approval from each Ethics Committee was obtained, the data were collected according to the steps as follows:

1) The Directors of Chiang-Rai Prachanukro Hospital and Chiang-Mai Hospital were contacted for approval to conduct the study.

2) The head of the medical ward in each hospital was contacted, and the study explained and permission sought.

3) The research team was formed and informed about the study. Two research assistants and two independent assessors were employed.
4) A pilot test of 20 eligible caregiver/patient pairs completed to test the program, the data collection instruments were pilot tested. Following the pilot tests, the training program and data collection instruments were revised according to feedback and finalised for use in the study.

5) The study commenced by following the study procedures as detailed in sections 3.7 and 3.8.

6) Data were collated and analysed.

### 3.12 Summary

This chapter has described the research method used in this study and the process in recruiting the sample, study procedure, developing the training program and developing the data collection tools. The strategies aimed at maximizing validity and reliability were reported. Additionally, the process for data analysis was reported. The following chapter will present the results and findings obtained from this study.
Chapter Four

Results

4.1 Introduction

This chapter presents the results of the study. An overview of the study is provided and the sample described, followed by the results of data from the stroke survivors and the family caregivers. The chapter concludes with findings from the telephone interviews with the family caregivers allocated to the intervention group.

4.2 Section one: Overview of the sample

One hundred and six patients meeting the inclusion criteria were identified at the intervention hospital and 105 were identified at the control hospital during the study period. A total of 140 patients and 140 family caregivers were recruited; 70 patients and family caregivers in each group. Baseline data were obtained for each patient/carer pair. At the three month follow-up, data were obtained from 64 patients and 70 carers who received the intervention and 63 patients and 67 caregivers in the control group. Six patients (8.6%) died in the intervention group and four patients (5.7%) died in the control group. In the control group, three patients and their caregivers could not be contacted for the three month follow-up (Figure 4.1). Family caregivers of participants who died prior to follow–up were assessed at three months using the GHQ-28, however the CSI was not re-administered because this measurement is needed only when they have caring responsibilities.
Patients admitted with acute stroke (new cases)
During June 2005 –January 2006

Intervention Hospital
N = 106

* Transferred = 27
Death = 2
Refused to stay = 7

Control Hospital
N = 105

* Transferred = 22
Death = 3
Refused to stay = 6
Refused to participate = 4

Total Recruited
Patients = 70
Family Caregivers = 70

Follow-up at 3 months
Patients n = 64
• 6 deceased
Family Caregivers n = 70

Follow-up at 3 months
Patients n = 63
• 4 deceased
• 3 not contactable
Family Caregivers n = 67
• 3 not contactable

* Transferred to be cared for by another hospital.

Figure 4.1: Participant flow chart
4.3 Section two: Stroke survivors’ results

This section presents the results and findings from patients recruited to the study. The findings are presented in sequence as follows:

4.3.1 Pre-inclusion screening (MMSE)

4.3.2 Demographics data

4.3.3 Functional ability (BI)

4.3.4 Activity limitation (disability) (mRS)

4.3.5 Quality of life (GHQ-28)

4.3.1. Inclusion criteria

A MMSE score of at least 20 was necessary for inclusion in the study. Of the 164 stroke survivors who were identified as potential participants and screened, 24 did not meet the criterion and were excluded from the study. There was no significant difference between the mean MMSE score of the intervention group (23.91, SD = 3.42) and the control group (24.16, SD = 3.72).

4.3.2. Demographics data

The demographic data (Table 4.1) from both groups were comparable. There was no significant differences between the groups for age, gender, occupation, relationship to the carer or marital status, although stroke survivors in the intervention group were taller than the control group ($t = 3.23$, p = .002). The mean ages of the patients were 63.29 years in the control group, and 66.81 years in the intervention group. The majority of the patients in both groups were male (55.7% in control group and 50.7% in the intervention group). The majority of patients in both groups were not in the paid workforce prior to the stroke (control = 54.3%; intervention = 61.4%).
However, it was found that there was a statistically significant difference for level of education ($\chi^2 = 16.19$, d.f. = 4, $p = .000$) between the groups with those allocated to the intervention group having a higher level of education. Nineteen people in the control group and two in the intervention group had no formal education although they were literate, and 48 in the control group and 60 in the intervention group identified elementary school as their highest level of education. Prior to education reforms in Thailand, it was usual for children to receive instruction in basic literacy at the temple, rather than attend school which accounts for the low level of formal education.

There was no statistically significant difference regarding the side of the body affected by stroke or the number of participants with comorbidities. Eighty four percent of patients in the control group and 87% in the intervention group reported at least one comorbidity. The most frequently reported comorbidities in both groups were hypertension (HT), diabetes mellitus (DM), ischaemic heart disease (IHD), dyslipidemia, and alcoholism and cirrhosis. Chronic obstructive pulmonary disease, HIV positive, peptic ulcer and gout were also reported. A complete list of the comorbidities is presented in Table 4.1. The majority of people in each group were smokers, and one third of people in each group drank at least one glass of alcohol per day.

The subtypes of stroke were cerebral infarction ($n = 108$ [77.10%]), stroke unclassified ($n = 24$; [17.1%]) and intra-cerebral haemorrhage (ICH) ($n = 8$; [5.8%]). Although it would be more helpful to clarify the type of stroke this was not possible in either hospital because when the patients were admitted, the doctor in
charge was the only person who diagnosed and the diagnosis was given as cerebral infarction or intracerebral haemorrhage. Therefore the data that could be collected were as reported above. There was no difference between the groups for the type of stroke that were suffered. Figure 4.2 presents the classifications by group. There was a statistically significant difference between the groups for type of therapy received ($\chi^2 = 7.24$, d.f. = 2, p = .007), with participants in the intervention group attending physiotherapy sessions more than the control group. Sixty one (91%) participants in the intervention group and 51 (73%) of the control group received physiotherapy during hospitalization. This may be because of the advice and education provided to the family caregivers in the intervention group. Only one patient received neuro-psychological therapy and this patient was in the control group.

The majority of the participants were married, 51 (72.9%) in the control group and 52 (74.3%) in the intervention group. The majority of stroke survivors were cared for by one of their children (control = 57.1%; intervention = 55.7%).
Table 4.1: Stroke survivors’ demographic data in control and intervention groups

<table>
<thead>
<tr>
<th>Patients’ Information</th>
<th>Control n = 70 (%)</th>
<th>Intervention n = 70 (%)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (SD)</td>
<td>63.29 (11.70)</td>
<td>66.81 (11.86)</td>
<td>1.76*</td>
<td>.080</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>.35</td>
<td>.556</td>
</tr>
<tr>
<td>Male</td>
<td>39 (55.7)</td>
<td>35 (50.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>31 (44.3)</td>
<td>34 (49.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td>16.19</td>
<td>.000</td>
</tr>
<tr>
<td>No education</td>
<td>19 (27.1)</td>
<td>2 (2.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated</td>
<td>51 (72.9)</td>
<td>68 (97.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>48</td>
<td>61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle grade/professional</td>
<td>2</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/University</td>
<td>-</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td>1.63</td>
<td>.443</td>
</tr>
<tr>
<td>Unemployed</td>
<td>38 (54.3)</td>
<td>43 (61.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agriculturist</td>
<td>17 (24.3)</td>
<td>11 (15.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>15 (21.4)</td>
<td>16 (22.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government official</td>
<td>1</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employee</td>
<td>10</td>
<td>12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Business or self employed</td>
<td>4</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>**</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>69 (98.6)</td>
<td>69 (98.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>51</td>
<td>52</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>18</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>-</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care giver</td>
<td></td>
<td></td>
<td>3.12</td>
<td>.210</td>
</tr>
<tr>
<td>Spouse</td>
<td>26 (37.1)</td>
<td>21 (30.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>40 (57.1)</td>
<td>39 (55.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relative or others</td>
<td>4 (5.7)</td>
<td>10 (14.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House work</td>
<td>45 (64.3)</td>
<td>49 (70.0)</td>
<td>0.52</td>
<td>.472</td>
</tr>
<tr>
<td>TV, radio</td>
<td>66 (94.3)</td>
<td>63 (90.0)</td>
<td>0.89</td>
<td>.346</td>
</tr>
<tr>
<td>Reading</td>
<td>24 (34.3)</td>
<td>35 (50.0)</td>
<td>3.55</td>
<td>.060</td>
</tr>
<tr>
<td>Social activity</td>
<td>50 (71.4)</td>
<td>56 (80.0)</td>
<td>1.40</td>
<td>.237</td>
</tr>
<tr>
<td>Exercise</td>
<td>28 (40.0)</td>
<td>34 (48.6)</td>
<td>1.04</td>
<td>.307</td>
</tr>
<tr>
<td>Other activity at home</td>
<td>35 (50.0)</td>
<td>31 (44.3)</td>
<td>0.46</td>
<td>.498</td>
</tr>
<tr>
<td>Other activity outside home</td>
<td>22 (31.4)</td>
<td>33 (47.1)</td>
<td>3.62</td>
<td>.057</td>
</tr>
</tbody>
</table>
Table 4.1: Stroke survivors’ demographic data in control and intervention groups (cont’)

<table>
<thead>
<tr>
<th>Patients’ Information</th>
<th>Control</th>
<th>Intervention</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 70 (%)</td>
<td>n = 70 (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td>0.64</td>
<td>.726</td>
</tr>
<tr>
<td>No</td>
<td>32 (45.7)</td>
<td>29 (41.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, but quit more than 5 yrs</td>
<td>15 (21.4)</td>
<td>19 (27.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23 (32.9)</td>
<td>22 (31.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– less than 20 cig./day</td>
<td>21</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– more than 20 cig./day</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
<td>0.04</td>
<td>.848</td>
</tr>
<tr>
<td>No</td>
<td>51 (72.9)</td>
<td>52 (74.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-2 glass/day</td>
<td>14 (20.0)</td>
<td>16 (22.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 or more than 4 glass/day</td>
<td>5 (7.1)</td>
<td>2 (2.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type/Site of lesion</td>
<td></td>
<td></td>
<td>3.08</td>
<td>.214</td>
</tr>
<tr>
<td>Left</td>
<td>30 (43.5)</td>
<td>34 (48.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>32 (46.4)</td>
<td>34 (48.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>7 (10.0)</td>
<td>2 (2.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of therapies</td>
<td></td>
<td></td>
<td>7.24</td>
<td>.007</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>52² (74.3)</td>
<td>64 (91.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>18 (25.7)</td>
<td>6 (8.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidity</td>
<td></td>
<td></td>
<td>0.23</td>
<td>.629</td>
</tr>
<tr>
<td>Hypertension</td>
<td>35 (50.0)</td>
<td>34 (48.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension with DM</td>
<td>6 (8.6)</td>
<td>8 (11.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DM</td>
<td>5 (7.1)</td>
<td>6 (8.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension with IHD</td>
<td>3 (4.3)</td>
<td>4 (5.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcoholism &amp; cirrhosis&amp;</td>
<td>2 (2.9)</td>
<td>2 (2.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>dyslipidemia</td>
<td>5 (7.1)</td>
<td>18 (25.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>18 (25.7)</td>
<td>13 (18.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Height</td>
<td>158.28 (6.16)</td>
<td>161.75 (6.43)</td>
<td>3.23*</td>
<td>.002</td>
</tr>
<tr>
<td>Weight</td>
<td>55.41 (9.51)</td>
<td>54.82 (10.43)</td>
<td>0.34*</td>
<td>.733</td>
</tr>
</tbody>
</table>

* *-test: to compare the Mean score between 2 groups which the probability distribution of the data (in 2 group of data) are normally distributed
1 only one case in control group has both left and right
2 only one case of neuropsychological therapy
Chi-square were used to compare the proportion (or percentage) of the event between 2 groups
** Fisher Exact test were used for 2X2 tables that cannot group row together (when the cell has expected less than 5), so “Fisher Exacted Test” were used instead of using Chi-square.
4.3.3. Functional ability (Barthel Index)

The Barthel Index (BI) is a measure of functional ability. The score ranges from 0-20, with higher scores denoting greater independence. The BI was measured at three time points during the study; immediately following recruitment, prior to discharge and at the three month post-discharge follow-up. In this section, the mean score at each assessment for each group is compared and the major functional deficits for each group identified. Finally, the mean score at each stage will be compared between the control and intervention group.

From table 4.2, the total mean score in both groups indicated that they were severely disabled at recruitment (control 9.00 [SD = 5.16], intervention 8.57 [SD = 4.98]). At discharge, stroke survivors in both groups scored in the moderate disability range (control 10.06 [SD = 5.10], intervention 10.09 [SD = 4.99]).

At the three month follow-up, the stroke survivors in both groups scored significantly higher on the BI than at discharge. For stroke survivors in the
control group the mean score increased from 10.06 (SD = 5.10) to 14.10 (SD = 5.26) \( (F = 52.24, \ p = .000) \), which is classified as moderate disability and the intervention group increased from 10.09 (SD = 4.99) to 16.22 (SD = 4.56) \( (F = 168.96, \ p = .000) \) which is classified as mild disability.

The five functions ranked most impaired (from most to least) in the control group were bathing, climbing stairs, grooming, dressing and use of toilet, and in the intervention group they were bathing, grooming, climbing stairs, dressing and use of toilets consecutively.

However, when the BI score of the stroke survivors in the control group was compared with the score of the stroke survivors in the intervention group, it was found that at the three month follow-up, the stroke survivors in the intervention group scored significantly higher than the stroke survivors in the control group \( (t = 2.43, \ p = .017) \) (Table 4.3 & Figure 4.3).
### Table 4.2: Average scores of BI at baseline, at discharge and at the three month follow-up

<table>
<thead>
<tr>
<th>Barthel ADL Index</th>
<th>Group</th>
<th>Mean (SD)</th>
<th>F</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Baseline</td>
<td>At discharge</td>
<td>At three months</td>
</tr>
<tr>
<td>Feeding</td>
<td>Control</td>
<td>0.81 (0.73)</td>
<td>0.97 (0.72)</td>
<td>1.68 (0.53)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.77 (0.66)</td>
<td>1.03 (0.59)</td>
<td>1.78 (0.49)</td>
</tr>
<tr>
<td>Grooming</td>
<td>Control</td>
<td>0.47 (0.50)</td>
<td>0.51 (0.50)</td>
<td>0.84 (0.37)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.34 (0.48)</td>
<td>0.39 (0.49)</td>
<td>0.92 (0.27)</td>
</tr>
<tr>
<td>Transfer</td>
<td>Control</td>
<td>1.40 (0.86)</td>
<td>1.60 (0.82)</td>
<td>2.24 (0.86)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>1.41 (0.75)</td>
<td>1.70 (0.71)</td>
<td>2.56 (0.61)</td>
</tr>
<tr>
<td>Toilet use</td>
<td>Control</td>
<td>0.71 (0.68)</td>
<td>0.83 (0.72)</td>
<td>1.30 (0.73)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.73 (0.63)</td>
<td>0.87 (0.68)</td>
<td>1.54 (0.59)</td>
</tr>
<tr>
<td>Mobility</td>
<td>Control</td>
<td>1.20 (1.10)</td>
<td>1.33 (1.10)</td>
<td>2.06 (1.08)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>1.13 (1.10)</td>
<td>1.49 (1.15)</td>
<td>2.43 (0.98)</td>
</tr>
<tr>
<td>Dressing</td>
<td>Control</td>
<td>0.70 (0.60)</td>
<td>0.77 (0.66)</td>
<td>1.24 (0.59)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.69 (0.65)</td>
<td>0.81 (0.71)</td>
<td>1.41 (0.71)</td>
</tr>
<tr>
<td>Stairs</td>
<td>Control</td>
<td>0.39 (0.55)</td>
<td>0.43 (0.55)</td>
<td>0.70 (0.64)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.37 (0.57)</td>
<td>0.40 (0.60)</td>
<td>1.13 (0.83)</td>
</tr>
<tr>
<td>Bathing</td>
<td>Control</td>
<td>0.16 (0.37)</td>
<td>0.23 (0.42)</td>
<td>0.60 (0.49)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.17 (0.38)</td>
<td>0.21 (0.41)</td>
<td>0.65 (0.48)</td>
</tr>
<tr>
<td>Bowels</td>
<td>Control</td>
<td>1.73 (0.54)</td>
<td>1.86 (0.35)</td>
<td>1.84 (0.48)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>1.73 (0.51)</td>
<td>1.77 (0.49)</td>
<td>1.97 (0.18)</td>
</tr>
<tr>
<td>Bladder</td>
<td>Control</td>
<td>1.43 (0.83)</td>
<td>1.53 (0.76)</td>
<td>1.59 (0.69)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>1.23 (0.87)</td>
<td>1.41 (0.71)</td>
<td>1.84 (0.37)</td>
</tr>
<tr>
<td>Total</td>
<td>Control</td>
<td>9.00 (5.16)</td>
<td>10.06 (5.10)</td>
<td>14.10 (5.26)</td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>8.57 (4.98)</td>
<td>10.09 (4.99)</td>
<td>16.22 (4.56)</td>
</tr>
</tbody>
</table>

This statistical test was One-way Repeated ANOVA.
Reason for using: to compare means from more than 2 groups of data.
The data came from repeated measure in the same subject more than 2 times (baseline, at discharge, 3 months) and the distribution of data (in each group) were normal distribution.
Table 4.3: Comparison of average scores of Barthel Index at baseline, at discharge and after three months for stroke patients in control and intervention groups

<table>
<thead>
<tr>
<th>Barthel ADL Index</th>
<th>Group Mean (SD)</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (SD)</td>
<td>Intervention (SD)</td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>9.00 (5.16)</td>
<td>8.57 (4.98)</td>
<td>0.50</td>
</tr>
<tr>
<td>At discharge</td>
<td>10.06 (5.10)</td>
<td>10.09 (4.99)</td>
<td>0.03</td>
</tr>
<tr>
<td>At three months</td>
<td>14.10 (5.26)</td>
<td>16.22 (4.56)</td>
<td>2.43</td>
</tr>
</tbody>
</table>

Figure 4.3: Comparison between intervention and control groups of BI scores at each stage
4.3.4. Activity limitation (Modified Rankin Scale)

The mRS is a measure of the severity of stroke and functional outcome, serving as a measure of independence following stroke. The mRS is categorised into six grades (5, 4, 3, 2, 1, 0) of activity limitation (disability) after stroke. Patients with rank 5 are considered to be totally dependent and bedridden, while patients with rank 0 are totally independent.

The mRS rank at discharge was similar for both groups (Table 4.4), the control group rank was 3.89 (SD = 0.73) and intervention rank was 4.00 (SD = 0.68) indicating moderate to severe disability at discharge in both groups. At three months follow-up, there was a significant improvement in stroke survivors in both groups, the stroke survivors in the control group had a mRS rank 3.32 (S.D = 1.02) (Z = 4.23, p = .000) and the intervention group rank was 2.59 (S.D = 1.29) (Z = 6.413, p = .000), indicating reduced disability for stroke survivors in both groups.

However, when the mRS ranks at the three month follow-up were compared, the stroke survivors in the intervention group had improved significantly more than the stroke survivors in the control group (Z = 3.176, p = .001).
Table 4.4: Comparison of modified Rankin Scale scores of stroke survivors at discharge and follow-up

<table>
<thead>
<tr>
<th>Rankin scale</th>
<th>Mean score (SD)</th>
<th>Z (Wilcoxon signed rank)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>At discharge</td>
<td>After three months</td>
<td></td>
</tr>
<tr>
<td>Control n = 70</td>
<td>3.89 (0.73)</td>
<td>3.32 (1.02)</td>
<td>4.23</td>
</tr>
<tr>
<td>Intervention n = 70</td>
<td>4.00 (0.68)</td>
<td>2.59 (1.29)</td>
<td>6.413</td>
</tr>
</tbody>
</table>

Compare Rankin Scale between Control & Intervention

<table>
<thead>
<tr>
<th>Z (Mann-Whitney U)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.744</td>
<td>.457</td>
</tr>
<tr>
<td>3.176</td>
<td>.001</td>
</tr>
</tbody>
</table>

4.3.5 Quality of life (General Health Questionnaire-28)

The GHQ-28 is a measure of the ability of the individual to carry out usual healthy activities and subjective symptoms of psychological distress. The scores for the tool range from 0-84 with higher scores denoting worse psychological health. The GHQ-28 was completed for all stroke survivors at discharge and at the three month follow-up.

There was an improvement for all stroke survivors at the three month follow-up (Table 4.5) with both groups having statistically significant improvement in their quality of life (control $t = 3.39$, $p = .001$; intervention $t = 9.56$, $p = .000$).

However, the mean score of the GHQ-28 in the control group at three months was 24.97 (SD = 18.13) (cut off score 23/24) which indicates that stroke survivors in the control group reported higher levels of distress. The intervention
group scored 11.19 (SD = 11.01) indicating better quality of life and no distress.
In addition, there was a statistically significant improvement in quality of life reported by stroke survivors in the intervention group compared to the control group at the three month follow-up ($t = 5.17, p = .000$).

**Table 4.5:** Comparison of the Thai GHQ-28 average score of stroke survivors in control and intervention groups at discharge and after three months

<table>
<thead>
<tr>
<th>GHQ-28</th>
<th>Group Mean (SD)</th>
<th>$t$-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (SD)</td>
<td>Intervention (SD)</td>
<td></td>
</tr>
<tr>
<td>At discharge</td>
<td>34.67 (16.04)</td>
<td>31.37 (14.34)</td>
<td>1.28</td>
</tr>
<tr>
<td>At three months</td>
<td>24.97 (18.13)</td>
<td>11.19 (11.01)</td>
<td>5.17</td>
</tr>
<tr>
<td>$t$-test</td>
<td>3.39</td>
<td>9.56</td>
<td></td>
</tr>
<tr>
<td>p-value</td>
<td>.001</td>
<td>.000</td>
<td></td>
</tr>
</tbody>
</table>
4.4 Family caregivers’ results

This section presents the results from the family caregivers of stroke survivors assigned to both groups. The data collection was at three points: at entry to the study, at discharge of the patient and at the three month follow-up. The findings are presented in sequence as follows:

4.4.1 Pre-inclusion screening (MMSE)

4.4.2 Demographics data

4.4.3 Quality of life (GHQ-28)

4.4.4 Care giver strain (CSI)

4.4.1 Inclusion criterion or MMSE

A MMSE score of at least 20 was necessary for inclusion of the family caregivers in the study. There was no statistically significant difference between the intervention group (23.91, SD = 3.41) and the control group (24.16, SD = 3.71).

4.4.2 Demographic results of the family caregivers

Demographic data for the family caregivers included in the study were collected at the entry to the study and are presented in Table 4.6.

One hundred and forty family caregivers were included in this study (70 in each group). Comparison of data demonstrated that the family caregivers in both groups had similar characteristics. The mean age of the family caregivers in both groups was 44.29-44.17 years (SD = 10.07), and the majority were female
The majority of family caregivers in each group was the child of the stroke survivor (control n = 38 [54.3%]; intervention n = 38 [54.3%]), followed by their spouse (control n = 26 [37.1%]; intervention = 21 [30%]) (Figure 4.4).

The majority of family caregivers were employed (control n = 68 [97.1%]; intervention n = 62 [89.9%]). There was a statistically significant difference regarding occupation ($\chi^2 = 17.20$, d.f. = 4, $p = .000$), this may be because there were three family caregivers in the control group who worked for the government, but none of the family caregivers in the intervention group worked for the government. In addition, there were more agriculturists in the control group. The majority of caregivers in both groups were married (control n = 51 [72.9%]; intervention n = 57 [83.3%]) and mostly educated until elementary level (control n = 52 [74.3%]; intervention n = 40 [58.0%]). There was only one (1.4%) family caregiver in each group who was not educated directly at school.

The leisure activities of both groups were similar with most identifying doing house work, watching TV and listening to the radio. However, it was found that the family caregivers in the intervention group exercised more than the control group (control n = 36, [51.4%]; intervention n = 48 [68.6%]; $\chi^2 = 4.29$, d.f. = 1, $p = .038$).

Thirty percent of family caregivers in the control group and 18.6% in the intervention group had previous caring experience for example dementia patients, diabetes, old age, paralyses and HIV-AIDS. Additionally, some family caregivers
in both groups were also caring for another person (control n = 15 [21.4%]; intervention n = 7 [10.0%]). Although the carers had responsibility for more than one person, it was found that the majority of them had at least one other person to assist them to provide care to the stroke survivors (control n = 52 [74.53%]; intervention n = 59 [84.53%]).

In regard to their economic status, the family caregivers in both groups reported having adequate family income, however, the majority of them did not have sufficient income to enable them to save (control n = 29 [41.4%]; intervention n = 38 [55.9%]). The average family income for the control group at 5677.61 baht or $206.45 AUD (SD = 7187.25) per month was higher than the intervention group whose mean income was 5373.85 baht or $195.41 AUD (SD=2941.90) per month, indicating that the family caregivers in the control group had a higher income (Z = 2.44, p = .015).

There were significant differences in the health status of family caregivers between the groups ($\chi^2 = 4.20$, d.f. = 1, p = .040), family caregiver of stroke survivors in the control group reported more health problems (n = 36 [51.4%]) than the intervention groups (n = 21 [34.3%]). The main health problems reported by family caregivers in the control group were hypertension (n = 8), pain in joints (n = 4), gastric ulcer (n = 3), allergy (n = 2), diabetes mellitus (n = 2), and miscellaneous (n = 21). In the intervention group, the main health problems reported were back pain (n = 5), hypertension (n = 4), hypotension (n = 2), allergy (n = 2), cholelithiasis (n = 2), and miscellaneous (n = 8).
Table 4.6 Caregivers’ demographic data in control and intervention groups

<table>
<thead>
<tr>
<th>Caregivers’ Information</th>
<th>Control n = 70 (%)</th>
<th>Intervention n = 70 (%)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>mean Age (SD)</td>
<td>44.29 (10.07)</td>
<td>44.17 (10.07)</td>
<td>0.06*</td>
<td>.951</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>0.27</td>
<td>.600</td>
</tr>
<tr>
<td>Male</td>
<td>20 (28.6)</td>
<td>17 (24.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>50 (71.4)</td>
<td>52 (75.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family income</td>
<td>5677.61 (7187.25)</td>
<td>5373.85 (2941.90)</td>
<td>2.44**</td>
<td>.015</td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>26 (37.1)</td>
<td>21 (30.0)</td>
<td>2.00</td>
<td>.367</td>
</tr>
<tr>
<td>Child</td>
<td>38 (54.3)</td>
<td>38 (54.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents / Relative / Others</td>
<td>6 (8.6)</td>
<td>11 (15.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
<td></td>
<td>17.20</td>
<td>.000</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (2.9)</td>
<td>7 (10.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Agriculturist</td>
<td>32 (45.7)</td>
<td>10 (14.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>36 (51.4)</td>
<td>52 (75.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government official</td>
<td>3</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employee</td>
<td>25</td>
<td>39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Business or self employed</td>
<td>8</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td>***</td>
<td>1.000</td>
</tr>
<tr>
<td>No education</td>
<td>1 (1.4)</td>
<td>1 (1.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educated</td>
<td>69 (98.6)</td>
<td>69 (98.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school</td>
<td>52</td>
<td>41</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middle grade/professional</td>
<td>9</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>6</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/University</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td>0.60</td>
<td>.438</td>
</tr>
<tr>
<td>Single</td>
<td>10 (14.3)</td>
<td>7 (10.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>60 (85.7)</td>
<td>63 (89.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>51</td>
<td>57</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>5</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>House work</td>
<td>62 (88.6)</td>
<td>61 (87.1)</td>
<td>0.07</td>
<td>.796</td>
</tr>
<tr>
<td>TV, radio</td>
<td>63 (90.0)</td>
<td>64 (91.4)</td>
<td>0.09</td>
<td>.771</td>
</tr>
<tr>
<td>Reading</td>
<td>43 (61.4)</td>
<td>53 (75.7)</td>
<td>3.31</td>
<td>.069</td>
</tr>
<tr>
<td>Social activity</td>
<td>48 (68.6)</td>
<td>54 (77.1)</td>
<td>1.30</td>
<td>.254</td>
</tr>
<tr>
<td>Exercise</td>
<td>36 (51.4)</td>
<td>48 (68.6)</td>
<td>4.29</td>
<td>.038</td>
</tr>
<tr>
<td>Other activity at home</td>
<td>39 (55.7)</td>
<td>40 (57.1)</td>
<td>0.03</td>
<td>.865</td>
</tr>
<tr>
<td>Other activity outside home</td>
<td>28 (40.0)</td>
<td>26 (37.1)</td>
<td>0.12</td>
<td>.728</td>
</tr>
</tbody>
</table>
Table 4.6 Caregivers’ demographic data in control and intervention groups (cont’)

<table>
<thead>
<tr>
<th>Caregivers’ Information</th>
<th>Control n = 70 (%)</th>
<th>Intervention n = 70 (%)</th>
<th>Chi-square</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous caring experience</td>
<td>21 (30.0)</td>
<td>13 (18.6)</td>
<td>2.49</td>
<td>.115</td>
</tr>
<tr>
<td>Other person caring responsibilities</td>
<td>15 (21.4)</td>
<td>7 (10.0)</td>
<td>3.45</td>
<td>.063</td>
</tr>
<tr>
<td>Other people at home to assist with care</td>
<td>52 (74.3)</td>
<td>59 (84.3)</td>
<td>2.13</td>
<td>.144</td>
</tr>
<tr>
<td>Adequacy of income</td>
<td>5.52</td>
<td>.063</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequate</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>no money saved</td>
<td>29 (41.4)</td>
<td>38 (55.9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>had money saved</td>
<td>14 (20.0)</td>
<td>5 (7.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inadequate</td>
<td>27 (38.6)</td>
<td>25 (36.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health problem</td>
<td>36 (51.4)</td>
<td>24 (34.3)</td>
<td>4.20</td>
<td>.040</td>
</tr>
</tbody>
</table>

* t-test
** Mann-Whitney U test (Z)
*** Fisher Exact test
*Italic text* Items were grouped together to solve the limitation of Chi–square which were the total number of cells which have the expected frequencies less than five.

Figure 4.4 Family caregiver characteristics
4.4.3 Quality of life (GHQ-28)

The quality of life of the family caregivers was measured prior to discharge and at the three month follow-up by the GHQ-28. The results were compared within each group and between the two groups at both time points. The scores range from 0-84 with higher scores denoting worse psychological health.

As presented in Table 4.7, there was a statistically significant lower GHQ-28 score within each group, from time of discharge to follow up. Both groups had improved quality of life at the three month follow-up (control $t = 3.80$, $p = .000$; intervention $t = 7.67$, $p = .000$).

However, when the control and the intervention groups were compared at discharge and at the three month follow-up, the mean score in the intervention group at both times was significantly less than the control group. (at discharge $t = 2.82$, $p = .006$; at the three month follow-up $t = 6.80$, $p = .000$), indicating the intervention group had better quality of life and less distress.
Table 4.7 Family caregivers’ GHQ-28 average score at the time of discharge and after three months

<table>
<thead>
<tr>
<th>GHQ-28</th>
<th>Group Mean (SD)</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (SD)</td>
<td>Intervention (SD)</td>
<td></td>
</tr>
<tr>
<td>At discharge</td>
<td>22.60 (12.46)</td>
<td>17.20 (10.07)</td>
<td>2.82</td>
</tr>
<tr>
<td>At three months</td>
<td>16.39 (9.05)</td>
<td>7.96 (4.70)</td>
<td>6.80</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.80</td>
<td>.000</td>
</tr>
<tr>
<td>7.67</td>
<td>.000</td>
</tr>
</tbody>
</table>

4.4.4 Caregiver Strain (CSI)

The CSI was administered twice, prior to discharge of the patient and at the three month follow-up. The results were compared within the group and between the two groups at both stages. Scores range from 0-13, obtained by summing “Yes” responses. A high score denotes a high level of stress.

As illustrated in Table 4.8, the most common causes of stress for family caregivers in the control group were changes to their personal plan (0.81 [SD = 0.39]), demand on their time (0.76 [SD = 0.43]) and family adjustments (0.74 [SD = 0.44]). For the family caregivers in the intervention group the main reasons for being stressed were family adjustments (0.63 [SD = 0.49]), demand on their time (0.49 [SD = 0.50]) and financial strain (0.49 [SD = 0.50]).

There was a statistically significant decline in CSI scores for the family caregivers in both groups at three month follow up, which demonstrates a
decrease in stress (control \( t = 4.72, \ p = .000 \); intervention \( t = 8.77, \ p = .000 \))(Table 4.9). However, the family caregivers in the control group reported higher levels of stress than the intervention group at both time intervals, (at discharge control = 8.56[SD = 3.01], intervention = 5.07[SD = 3.07]; at the three month follow-up control 5.85[SD = 4.03], intervention= 1.52 [SD = 1.90]). In addition, there was a statistically significant difference between the control and intervention groups at discharge and at the three month follow-up (at discharge \( t = 6.73, \ p = .000 \); at three month follow up \( t = 7.67, \ p = .000 \)). This indicates that the family caregivers in the control group were experiencing higher levels of stress.

Table 4.8 Caregiver Strain Index scores at discharge and after three months.

<table>
<thead>
<tr>
<th>CSI</th>
<th>Group</th>
<th>Mean (SD)</th>
<th>At discharge</th>
<th>At three months</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sleep is disturbed (e.g. Because… is in and out of bed and wanders around at night)</td>
<td>Control</td>
<td>0.73(0.45)</td>
<td>0.40(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.30(0.46)</td>
<td>0.02(0.13)</td>
<td></td>
</tr>
<tr>
<td>2. It is inconvenient (e.g. because helping takes so much time or it is a long drive over to help)</td>
<td>Control</td>
<td>0.53(0.50)</td>
<td>0.15(0.36)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.34(0.48)</td>
<td>0.13(0.33)</td>
<td></td>
</tr>
<tr>
<td>3. It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)</td>
<td>Control</td>
<td>0.54(0.50)</td>
<td>0.50(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.41(0.50)</td>
<td>0.23(0.43)</td>
<td></td>
</tr>
<tr>
<td>5 There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)</td>
<td>Control</td>
<td>0.74(0.44)</td>
<td>0.61(0.49)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.63(0.49)</td>
<td>0.33(0.47)</td>
<td></td>
</tr>
<tr>
<td>6 There have been changes in personal plans (e.g. had to turn down a job; could not go on a vacation/holiday)</td>
<td>Control</td>
<td>0.81(0.39)</td>
<td>0.56(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.43(0.50)</td>
<td>0.05(0.21)</td>
<td></td>
</tr>
<tr>
<td>CSI</td>
<td>Group</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>At discharge</strong></td>
<td><strong>At three months</strong></td>
<td></td>
</tr>
<tr>
<td>7 There have been other demands on my time (e.g. from other family members)</td>
<td>Control</td>
<td>0.76(0.43)</td>
<td>0.52(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.49(0.50)</td>
<td>0.19(0.39)</td>
<td></td>
</tr>
<tr>
<td>8 There have been emotional adjustment (e.g. because of severe argument)</td>
<td>Control</td>
<td>0.59(0.50)</td>
<td>0.35(0.48)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.33(0.47)</td>
<td>0.17(0.38)</td>
<td></td>
</tr>
<tr>
<td>9 Some behaviour is upsetting (e.g. because of incontinence;…has trouble remembering things, or accuses people of taking things)</td>
<td>Control</td>
<td>0.56(0.50)</td>
<td>0.26(0.44)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.40(0.49)</td>
<td>0.05(0.21)</td>
<td></td>
</tr>
<tr>
<td>10 It is upsetting to find …has changed so much from his/her former self (e.g. he/she is a different person from how he/she used to be)</td>
<td>Control</td>
<td>0.73(0.45)</td>
<td>0.32(0.47)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.40(0.49)</td>
<td>0.03(0.18)</td>
<td></td>
</tr>
<tr>
<td>11 There have been work adjustments (e.g. because of having to take time off)</td>
<td>Control</td>
<td>0.61(0.49)</td>
<td>0.47(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.29(0.46)</td>
<td>0.02(0.13)</td>
<td></td>
</tr>
<tr>
<td>12 It is a financial strain</td>
<td>Control</td>
<td>0.70(0.46)</td>
<td>0.66(0.48)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.49(0.50)</td>
<td>0.22(0.42)</td>
<td></td>
</tr>
<tr>
<td>13 Feeling completely overwhelmed (e.g. because of worry about…; concerns about how you will manage)</td>
<td>Control</td>
<td>0.56(0.50)</td>
<td>0.47(0.50)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>0.27(0.45)</td>
<td>0.05(0.21)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>Control</td>
<td>8.56(3.01)</td>
<td>5.85 (4.03)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intervention</td>
<td>5.07(3.07)</td>
<td>1.52(1.90)</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.8 Caregiver Strain Index scores at discharge and after three months (cont’)
Table 4.9: Comparison of Caregiver Strain Index scores at discharge and after three months

<table>
<thead>
<tr>
<th></th>
<th>Group Mean (SD)</th>
<th>t-test</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Control (SD)</td>
<td>Intervention (SD)</td>
<td></td>
</tr>
<tr>
<td>At Discharge</td>
<td>8.56(3.01)</td>
<td>5.07(3.07)</td>
<td>6.73</td>
</tr>
<tr>
<td>At three months</td>
<td>5.85(4.03)</td>
<td>1.52 (1.90)</td>
<td>7.67</td>
</tr>
<tr>
<td>t-test</td>
<td>4.72</td>
<td>8.77</td>
<td></td>
</tr>
<tr>
<td>p-value</td>
<td>.000</td>
<td>.000</td>
<td></td>
</tr>
</tbody>
</table>

4.5 The incidence of complications and readmission to hospital among stroke survivors

In this study, the stroke survivors in the intervention group had fewer unplanned, stroke-related readmissions during the three month follow-up period than the control group (n = 10 [14.3%] vs 34 [48.6%]). Six patients (8.6%) allocated to the intervention group and 4 (5.7%) patients allocated to the control group died during the study (Figure 4.5).

In the main, the reasons for unplanned readmissions differed between the groups, with the control group requiring admission more frequently for management of complications associated with immobilization. In the control group (Figure 4.6) there were readmissions to hospital during the study period (within three months following discharge). The main reasons for readmission were pressure ulcers (n = 11), pneumonia (n = 7), urinary tract infections (UTI) (n = 5), recurrent stroke.
(n = 3), incontinence (n = 2), upper gastrointestinal haemorrhage (UGIH) (n = 2), falls (n = 1), weakness (n = 1), epileptic seizure (n = 3) and limb and joint pain (n = 1). Reasons for unplanned readmissions for the intervention group (Figure 4.6) within the first month after discharge were due to recurrent stroke (n = 4), weakness (n = 2), epileptic seizures (n = 3) and limb and joint pain (n = 1).

**Figure 4.5:** Hospital readmission and death in stroke survivors

**Figure 4.6:** Stroke survivors’ complications
4.6 Telephone support interviews

The intervention included telephone support once per month for three months to enable family caregivers of stroke survivors assigned to the intervention group to discuss problems with a health professional and for the health professional to give suggestions and provide support to the caregiver. The most common inquiries from family caregivers related to positioning, feeding via naso gastric tube and types of food recommended for stroke survivors with swallowing difficulties, problems related to incontinence, exercise, looking after patients with a Foley catheter and using a walking stick. The telephone support intervention provided the opportunity to encourage the family caregivers that they were doing the right thing and to provide and reinforce the information. However, there were three family caregivers who experienced stress due to time adjustment, feeling guilty and financial status. These problems were mainly found in the first two months. In addition, those patients who had major problems, such as swollen hands and/or lower legs and feet, or swallowing difficulties were advised to attend the hospital for possible readmission and further investigation. In addition, advice was also provided about positioning as many stroke survivors were positioned incorrectly on the affected side.
4.7 Summary

From the results, it is clear that the stroke survivors and their family caregivers admitted to the intervention hospital demonstrated improved outcomes for all measures when compared with the control group at the three month follow-up. This study provided sufficient evidence to support the hypotheses of the study as follows

- Hypothesis one: Participation by family carers of stroke survivors in the SELF program will improve the functional level of stroke survivors compared to those whose family caregivers have not participated in the program. This is demonstrated by the results of the study as the stroke survivors in the intervention group reported better functional outcomes (BI $t = 2.43, p = 0.017$; Rankin scale $Z = 3.176, p = .001$) when compared to the control group.

- Hypothesis two: Participation by family carers of stroke survivors in the SELF program will improve the quality of life of stroke survivors compared to those whose family caregivers have not participated in the program. This is demonstrated by the results of the study as the stroke survivors in the intervention group reported better quality of life (GHQ-28 $t = 5.17, p = .000$) when compared to the control group.

- Hypothesis three: Family carers of stroke survivors who participate in the SELF program will have lower levels of strain compared to family carers who have not participated in the program. This is demonstrated by the results of the study that the family caregivers in the intervention group
reported less strain (CSI $t = 7.17$, $p = .000$) when compared to the control group.

- **Hypothesis four:** Family carers of stroke survivors who participate in the SELF program will have a higher quality of life compared to family carers who have not participated in the program. This is demonstrated by the results of the study that the family caregivers in the intervention group reported better quality of life (GHQ-28 $t = 6.80$, $p = .000$) when compared to the control group.

- **Hypothesis five:** Stroke survivors whose family carers have participated in the SELF program will have fewer readmissions to hospital for management of stroke related complications compared to stroke survivors whose carers have not participated in the program. This is demonstrated by the results of the study that the intervention group reported fewer readmissions due to complications (intervention n = 10 [14.3%]; control n = 34 [48.6%]) when compared to the control group.

Moreover, the study demonstrated that the family caregivers’ quality of life and strain have an effect on patients’ functional outcomes which means that family caregivers with better quality of life could provide better care or rehabilitation to the stroke survivors. In the following chapter, discussion of the findings will be presented.
Chapter Five
Discussion

5.1 Introduction

Western health systems have recognised that ongoing rehabilitation, support from community based health services and provision of appropriate devices will assist survivors of stroke to return to their maximum level of function. Effective and ongoing rehabilitation of stroke survivors following the acute phase will also support carers who participate in the ongoing care required following stroke. In developing countries, the focus of health care has been to establish a system of hospitals and clinics to provide acute services. In Thailand access to care is improving for the population and the focus is now moving to include ongoing care for people with chronic disorders. This research was undertaken to develop, implement and evaluate a nurse led supportive educative learning program for family caregivers (SELF) of stroke survivors in Thailand. The aims of this program were to: improve quality of life and function for survivors of acute stroke; improve quality of life and reduce family caregiver strain; and reduce the incidence of complications among stroke survivors.

This study, which was supported by the Royal Thai Government through a postgraduate scholarship, is the first formalised initiative to involve carers of people with a chronic disorder as “therapists” providing care in Thailand. The idea of teaching carers how to assist stroke survivors through the long period of rehabilitation has the potential to prolong life and reduce complications such as
pneumonia and decubitus ulcers. Teaching carers to identify problems early and respond in appropriate ways, can minimise conditions that cause unnecessary suffering and contribute to early death.

This study demonstrated that a structured education program for family caregivers of stroke survivors can significantly improve the functional status of stroke survivors and prevent development of the common complications, as well as improve the quality of life of family caregivers. Stroke survivors and their family caregivers, who received the intervention, scored significantly higher results compared to those who did not, in all the measures.

The study sends a clear message to government and providers of care to people with chronic conditions in developing countries, that well designed educational programs and ongoing support in the community can achieve positive outcomes. Community education initiatives that emphasise the importance of early diagnosis and adherence to treatment should be a priority to build health care capacity, particularly in developing countries.

In this chapter, the main findings of the study are discussed in the context of the wider literature and compared with findings of other studies relevant to the topic. The strengths and limitations of this study will be discussed, and finally, implications for practice and further research to provide support to stroke survivors and their family caregivers will be presented.
5.2 Characteristics of the stroke survivors

This study provided an opportunity to profile stroke patients presenting at two hospitals in Thailand. The information will assist these facilities to identify the needs of this group of patients and their carers and to develop appropriate services. Stroke is more likely to occur in older people, who, as shown in this and other studies (Pajaree, 2004; Poungvarin, 2001b) commonly have comorbidities, such as hypertension, diabetes mellitus and ischaemic heart disease. These conditions also complicate management following stroke.

Although the study was conducted in two city hospitals, the majority of patients lived in rural areas and had an elementary level of education; factors that should be taken into account in the design and implementation of community based patient education and the preparation of the written materials that accompany education programs. Health promotion and disease prevention is not a focus of health care in Thailand, therefore it is not surprising that most participants in this study did not realise that chronic disease is a risk factor for stroke, and in fact did not follow-up with their doctor after being diagnosed with hypertension or take the prescribed medications. In this way, these findings are similar to many studies in Thailand (Chantawatchai, 1999; Moonkrtkklang, 1999; Nakara, 1999; Niyomthai, 2002; Poungvarin, 2001a) and other countries (Arboix, Garcia-Eroles, Massons, Olivers & Targa, 2000; Williams et al., 1999).

Promoting healthy living for older people and providing education about risk factors and stroke prevention are important primary health initiatives for rural-dwelling people in Thailand. This education should include awareness of common chronic
disorders that affect the population and be presented using a population approach to influence people who may not have developed a chronic condition in addition to those who have.

It is also important to educate family members who will help to raise community awareness of stroke. Additionally, in Thailand most of the population is Buddhist, therefore monks are an untapped health promotion resource. The majority of elderly people, especially those living in rural areas, regularly attend their temples and are influenced by the monks.

5.3 Family caregivers: a hidden resource

The majority of caregivers in this study were daughters of stroke survivors, reflecting the Thai culture, whereby females take up the role of caring for family members. In addition, it is an expectation that daughters will show gratitude to their parents in this way, while the role of sons is to take over the financial responsibilities for the family.

In Buddhism, care is the symbol of positive growth not only in this life but also in the next life (Kespichayawattana, 1999; Panyanunthaphikhu, 2000). Most caregivers expressed the feeling of happiness they felt when they saw their family member’s condition improving day by day. They expressed feelings of fulfilment as a consequence of their ability to fulfil their care giving responsibility. Their satisfaction is based on their sense of being able to provide quality care. They felt warm, accomplished and fortunate to have their parents with them.
(Kespichayawattana, 1999). This concept is very important in the Thai culture and is known to be an underlying social value.

It is very important to provide education about care giving roles and to emphasize the importance of ongoing care and monitoring of family members with chronic conditions. As women are the main family caregivers, it is very important to have community awareness campaigns which target women, informing them of risk factors of various conditions, as well as identifying the action they can take in their family context to modify risk factors. In this way, women, who are a valuable resource in the community, will be supported and empowered to enhance the health of their families and in the community.

Feedback from participants in the intervention group demonstrates that the telephone support service provided in this study is an effective and low cost approach to reaching people in the community, including rural areas. Community health care personnel could provide such a service in Thailand. Alternatively, volunteers from the same community could be trained by health care personnel to provide this support. Each Thai village does have a health care centre, which could be developed as a drop in centre for the village where women can attend to obtain information and support. In this way, community based rehabilitation will be sustained as the people in the community are aware of the risk of chronic conditions, and are willing to take on the role of carer.

The majority of family caregivers in this study had other people to assist them with care at home. This may be because large families are common in Thailand and
generations of one family commonly live in the same house or within the same area and provide support to each other. The Thai family structure enables health care personnel to educate key family members, who will then encourage other family members to modify their lifestyle and adhere to treatments prescribed for chronic conditions, such as hypertension and diabetes mellitus, which are risk factors for stroke. This community participation, if well designed and appropriately resourced, could be a cost effective means of providing rehabilitation and management for survivors of stroke and people with other chronic conditions, where currently no services exist.

Although there is no stroke rehabilitation provided in the community by the health care personnel, the family can be trained to provide effective basic care as shown in this study. Therefore, a most important resource in the community within this context are family members of stroke survivors. They are the people involved in the problem and are aware of the situation when a family member is ill. Therefore, providing education and training for them to develop the skills required is an effective strategy to begin to address the lack of health services.

5.4 Community based rehabilitation in action

Community based rehabilitation (CBR) draws on local strengths and resources by promoting community participation, empowering the community and encouraging self advocacy. The CBR approach has been particularly effective in organizing people or resources in the community to be ready to support the needs of people with impairments, activity limitations and participation restrictions. For example the Jin
Hua Street CBR program was established in a densely populated urban centre of Canton City, China (Zhuo & Kun, 1999). This program has improved the physical function of up to 90% of participants with physical disabilities.

The intervention used in this study is noteworthy because it was one of the first stroke CBR programs in Thailand. Like the Canton program, this study demonstrated a statistically significant improvement among stroke survivors who received rehabilitation from their family caregivers. Quality of life was better for both stroke survivors and family caregivers following participation in the program.

As a result of the SELF study, hospital readmissions due to complications were reduced resulting in savings for families, communities and government. The SELF intervention could be implemented by provincial and district hospitals across Thailand at minimal cost. The CBR approach, which uses family caregivers to provide care, is also an effective way to compensate for health service limitations. Family caregivers proved to be willing to provide rehabilitation and demonstrated that, with training, they could learn the necessary skills to provide a range of appropriate care to stroke survivors.

It has been hypothesised that quality of life and depression are factors that influence a person’s achievement of functional status after stroke (Herrmann, Black, Lawrence, Szekely & Szalai, 1998). Depression decreases motivation which results in lower scores on functional and neurological scores (Herrmann et al., 1998). The results from this study demonstrated that, through education, family members, can provide timely and appropriate stroke rehabilitation to achieve better outcomes for
stroke survivors. Stroke survivors in the intervention group had significantly better outcomes in relation to functional ability and improved quality of life when compared to the control group. Persons assigned to the intervention group also demonstrated less depression than the control group. The association between depression and functional outcomes following stroke requires further research.

Although it could be seen that the functional ability of stroke survivors in both groups had improved in each stage, when results from the groups were compared, the intervention group had superior outcomes. The findings of this study were consistent with other research demonstrating that the functional and neurological recovery is best achieved within the first three months following the onset of stroke (Jorgensen et al., 1995; Zhou et al., 2005). Hence, it is very important that stroke rehabilitation commence as soon as possible after the acute phase of stroke, and within the first three months after the onset of symptoms.

This finding is related to a similar study by Kalra et al. (2004), who evaluated the effectiveness of training caregivers in reducing burden of stroke in stroke survivors and their family caregivers in England. The intervention had benefits for both stroke survivors and family caregivers. The family caregivers had less caregiving burden, anxiety and depression as well as better quality of life. Stroke survivors whose family caregivers participated in the intervention reported less anxiety and depression and a higher quality of life, and achieved independence at an earlier stage when compared with the control group. Unlike the study reported in this thesis, the study by Kalra et al. (2004) did not find any statistically significant differences in patient mortality, readmission or disability. One possible explanation may be that
the National Health Service in England has established stroke rehabilitation services in community and hospital settings, which may have influenced the findings of their study.

Prior to this study, there was no stroke rehabilitation provided in the community in Thailand and no formal programs that provide family caregivers with skills and knowledge that enables them to feel more confident and well supported to provide care to stroke survivors at home. The SELF program included follow-up telephone support as well as skill development. The benefits of maintaining links between health providers and family caregivers has been shown in other studies to reduce hospital readmission (Andersen et al., 2000; Grant et al., 2002). For that reason, ongoing telephone contact with family caregivers following discharge of stroke survivors was included in this study, and is recommended as a component of future CBR in Thailand.

The effectiveness of the SELF program is further evidenced in relation to reduced complications following stroke. The main complications in the intervention group were subsequent stroke, epileptic seizures, weakness, and limb and joint pain. However, in the control group the most common complications were pressure ulcer, aspiration pneumonia, urinary tract infection and subsequent stroke. These complications may significantly compromise stroke recovery (Kelly et al., 2002) and may be minimised by appropriate preventative measures or early intervention as shown in this study, where no stroke survivors in the intervention group had preventable complications such as pressure ulcers, urinary tract infections, pneumonia.
In this study, family caregivers in the intervention group had better outcomes than the control group. Although it was shown from the study that the quality of life improved and strain was reduced in both groups, at the three month follow-up, family caregivers in the intervention group had better quality of life and reported less strain when compared with the control group. This is because education and skill development have been identified as key supports required to prepare a person for their new role (Hammer & Collinson, 2000). The results of this study show that outcomes for stroke survivors can be significantly improved when their family caregivers receive education and support.

The results of this study are supported by an earlier randomized controlled trial regarding family support for stroke survivors (Mant et al., 2000). They found that support was associated with significantly improved quality of life for family caregivers. However, they did not find any significant improvement in outcomes for stroke survivors, unlike the study reported in this thesis, which found significant functional improvement for stroke survivors. A possible explanation may be that, unlike the SELF program, the study by Mant, et al. (2000) did not include hands-on training. Participation of family caregivers in face-to-face education has been shown to be more effective than providing information alone (Forster et al., 2004).

There are a number of stroke rehabilitation programs that could have been replicated in this study; however health programs need to take into account a number of variables if they are to be successful. Of paramount importance to the design and implementation of a CBR program is the social and cultural context of the area. The SELF program, which drew on published evidence, was enhanced by being
embedded in Thai culture. Community Based Rehabilitation was chosen as the preferred model of care rather than establishing a stroke rehabilitation unit in the hospital, because in Thailand the elderly are cared for in the family home rather than entering an aged care facility. Establishing a home based rehabilitation program enables younger family members to fulfil their obligation to care for the elderly. Training of the family commenced while the patients were in hospital for two main reasons. Firstly, in Thailand the family accompanies the patient during hospitalization, and secondly, stroke survivors are discharged directly home rather than transferred inpatient rehabilitation.

This study has demonstrated that a CBR initiative, that takes account of the needs of the community and focuses on patient centred care, is an appropriate model for the management of stroke, and potentially other chronic conditions in Thailand.

5.5 Development of a nursing role in stroke rehabilitation

Rehabilitation is developing as a nursing specialty in western countries, and the knowledge gained to date should be taken into account when developing a rehabilitation role for Thai nurses. This study has contributed to the development of the nursing profession in Thailand by defining a specialist role for the nurse in stroke rehabilitation. The SELF program was a nurse designed and implemented initiative, informed by the principles of CBR (World Health Organization, 2004b), adult learning theory (Knowles, 1984) and Orem’s theory of self care (Orem, 1995), which exemplifies the effective and efficient use of nursing expertise to improve the health
of the community. Application of each of these theories to the design and content of the intervention undertaken is detailed in table 3.1 chapter three.

The results of this study clearly demonstrate the effectiveness of nurses as rehabilitation teachers and coaches in line with the ARNA Competency Standards for Registered Nurses (Australasian Rehabilitation Nurses' Association, 2003). Furthermore, development of the role of nursing needs to take into account the principles of The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) as suggested by Kearney and Pryor (2004), to enable nurses to look beyond traditional nursing functions to be more effective rehabilitators. By taking the specific context of rural-dwelling Thai stroke survivors into consideration in the design and implementation of the SELF program, this study has highlighted the importance of environmental and personal factors (both central elements of ICF) in the design and conduct of effective rehabilitation programs.

The nurse–led stroke rehabilitation initiative described in this study has demonstrated how nursing can have positive outcomes for patients, their families, and for the government. The SELF program provides a model for advanced nursing practice in community health and the management of chronic conditions that could also be applied, for example, to diabetes mellitus, asthma, palliative care and cardiac rehabilitation.
5.6 Using evidence to enhance health outcomes

Research is carried out to evaluate the most effective ways to improve the quality of care. In recent years, the most well known approach to improving quality care is the move towards evidence based practice (EBP) (Hammer & Collinson, 2000). The benefits of applying evidence to practice include high quality care (Shirey, 2006), increasing uniformity in the workplace (Bennett, Daly, Kirkwood, McKain & Swope, 2006), initiating changes in the workplace (MacGuire, 2006), and closing the gap between knowledge, research and practice (Hertel, 2005).

In order to use evidence to enhance health outcomes, it is very important that the evidence should be suitable for the target group as well as the social and cultural aspects. Consequently, the design and implementation of a project to promote the use of evidence in practice needs to consider the best available evidence, the cultural perspectives, the available health resources and the needs of the population (Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Spiegelhalter & Tyrer, 2000).

Evidence based practice is not only a medical approach but is the combination of research, clinical expertise and patient choice. Therefore the quality of evidence is the issue in practice (Kitson, Harvey & McCormack, 1998). It is very important that an intervention designed to improve health care be based on the problem of the population, identify the risk, understand what is the pathways by which the problem is caused, explore whether those pathway are amendable to change and finally, quantify the potential improvement (Campbell, Murray, Darbyshire, Emery, Farmer, Griffiths, Guthrie, Lester, Wilson & Kinmonth, 2007). Clinicians also need
particular skills and knowledge to enable them to locate evidence and then to successfully navigate the myriad issues that arise if they are to achieve the cultural and organisational changes that determine whether initiatives to introduce practice change in a health facility will be successful (Johnson & Griffiths, 2001)

5.6.1 Using the SELF program to enhance health outcomes

Many nurses in Thailand are used to traditional ways of providing care and may resist changes in practice or new services (Srisuphan, 2002). In order to implement evidence into practice it is essential to study the factors which may inhibit the change process (Bozak, 2003). Recognising this resistance and planning strategies to work through these barriers may be the key to implementing the SELF program in healthcare organizations in Thailand.

The process of successful change management in an organisation requires a systematic and planned approach to address the resistance and issues that will invariably surface. Education, training and communication are essential components of change management that will assist to overcome some of the hurdles.

There are many theories that can assist during various stages of planning, implementing and evaluating an intervention (Nicols, 2000). To illustrate, a successful implementation of leg ulcer care (by using high compression bandaging) undertaken in the community in United Kingdom (Moffatt & Franks, 2004) improved the healing rate from 9%-24% pre-implementation to 19%-39% post implementation. In addition, the intervention led to major improvement in health–related quality of life (measured using the Nottingham Health Profile) with
significant improvements for energy, pain, sleep and mobility ($p< 0.01$). The researcher in the study used the change theory by Lewin (1951) to provide guidelines, creating a model for implementation. The authors of the study (Moffatt & Franks, 2004) first explored the barriers to change and driving forces to change as it is an essential part of the implementation process. After all the barriers were identified, they conducted a meeting with relevant health care personnel and formed a steering committee which was responsible for overseeing the process of implementation with day to day management delegated to the clinical nurse specialist, a change agent was also appointed. Nurses in the community were provided with skills and knowledge to deliver leg ulcer care and resources which included specialist support both in the community and in the acute service were established. After the nurses were prepared, new services were implemented. The results of this study show that a formal implementation strategy may provide improved patient outcomes with a service wide approach to care, as well as the importance of adopting a systems approach (Moffatt & Franks, 2004) The results demonstrated that post implementation overall healing rate of the participants improved significantly ($p< 0.001$) from 71 of 518 (14%) to 160 of 437 (37%) and the frequency of treatment visits reduced from a mean of 24.0 over 12 weeks to 13.5 ($p< 0.001$). Therefore, in order to implement any change, education and training are essential. In addition, barriers to change should be identified in order to overcome the restraining forces. This could be done by using a relevant change theory or strategy to implement the evidence.

Redfern and Christian (2003) evaluated a practice development project consisting of nine projects implemented in nine community health centres. The projects were leg
The aims of STEP were to establish and assess evidence–based practice in nursing and other health care areas, to identify and assess outcomes from the process of change (intermediate outcomes) and to investigate the association between the intermediate outcome and patient outcomes. The outcomes were measured before and after the changes were introduced. Data collection methods included interviews with the change agents and other stakeholders, and a questionnaire to staff in each centre. Patient outcome data were collected from each centre. The nine projects were operated independently. Six project leaders were nurses and the others were a midwife, a dietician, and a social worker. All of the project leaders attended a two week training program based on a theory of change. The training also included a seminar every three months. The content of the training program included reviewing the literature on evidence based practice, managing change, auditing practice, developing evidence based guidelines, research methods, data analysis, ethical issues and research presentation skills.

The project leader implemented changes to practice in their local centres using clinical guidelines, a staff training program and active support in the practice setting. The findings revealed dissemination of information to staff and adherence by staff to
new practice guidelines to be important to intermediate outcomes in the process of change. The need emerged for a supportive organizational culture and commitment, recognition of the importance of change and a believable change agent. In addition, several key factors emerged from interviews with the project leaders as important to achieving successful change which were: target staff should be familiar and understand what is expected of them; staff should receive appropriate training; necessary resources are in place; staff are motivated to participate in the change and should be provided with support in order to sustain the changes (Redfern & Christian, 2003).

It can be seen that the studies mentioned above (Moffatt & Franks, 2004; Redfern & Christian, 2003), demonstrate successful implementation of projects. Both studies were conducted in the United Kingdom and the key strategies in implementing the programs were that they educated the staff involved as well as the community. The former study (Moffatt & Franks, 2004) used theory of change by Lewin (Lewin, 1951), to guide the process of implementation. The latter study (Redfern & Christian, 2003) mentioned adopting a theory of change to implement the programs but did not specify exactly which change theory was used. Therefore it can be ascertained that using theory of change was effective in implementing evidence to enhance outcomes in health care. This may be because as change becomes an increasingly common occurrence in the health care environment, change theory offers one way of understanding the dynamic interaction between individuals and the complex social systems in health care facilities. (Kubsch, Shaughnessy, Carrick, Willihnganz, Henricks-Soderberg & Sloan, 2007).
Likewise, evidence from community based rehabilitation projects implemented in several countries in Asia, for example Vietnam (Hai & Chuong, 1999), Republic of China (Baolin & Huang, 1999), South Korea (Kim & Jo, 1999), Lao (Stuelz, 1999) and Hong Kong (Ka-Sing, 1999) utilize similar strategies which appear to be effective. The strategies, which included involving relevant people from the community, were based on the concept of CBR (World Health Organization, 2004b).

For example, a community-based rehabilitation program for people with disability in the People’s Republic of China (Zhuo & Kun, 1999) improved the quality of life of the participants and was successful in training the family caregivers. They first formed a supervisory committee which was responsible for making decision and writing up policy for CBR. The committee comprised a representative from rehabilitation professionals from the University, several representatives from local health care worker, civil worker and a person with disability. The supervisory committee appointed an intermediate-level supervisor (ILS) who was a physician in the local area and was familiar with the skills and knowledge essential to implement CBR. The ILS was the key person in the CBR network, who had the role of manager, organizer and instructor for CBR. Thirty-three local supervisors (LSs) selected from each residential area of the community were appointed to work under supervision of the ILS. The majority of LSs were middle aged females who were active in community work. The LSs worked with the people with disability and were responsible for training the family caregivers. The LSs were trained in the area of community rehabilitation by the ILS, therapists and physiatrists from the University. They were also provided with a simplified manual which was developed and amended to meet local requirements and produced in Chinese characters along with detailed teaching materials and a work-book. After the implementation, the ILS
and LSs were provided with training periodically to sustain the change. The project was then implemented in other communities throughout the country.

This study demonstrates that, to achieve successful implementation and to sustain the change, it is important that the project is beneficial to and involves the community. Moreover, they (Zhuo & Kun, 1999) integrated the traditional Chinese medical culture in the care and rehabilitation of people with disability and this was supported by the traditional Chinese doctor in the community, which represents a successful integration of cultural beliefs in implementing change.

From all the studies mentioned above, it can be concluded that in order to implement any change to enhance health outcomes, one of the main strategies is to involve the relevant people and provide them with education and support. The stakeholders should be involved in making decisions during the change process; this is especially important when change is implemented in the community. Moreover, the evidence used should be suitable to the culture. In addition, it would be beneficial to guide the implementation using a relevant change framework.

Implementing the SELF program across Thailand requires a plan to manage the process that will be required to change health care personnel behaviour, influence them to accept the SELF program, and identify barriers to implementation. Therefore, the researcher recommends Lewin's theory of change (Lewin, 1951) and the concepts of CBR to guide the planning, implementation and evaluation of the SELF program. The CBR approach focuses on community level, which is also the focus for the SELF program, with community development involving mobilization.
of local resources such as families and opportunities for education and training (Mitchell, 1999). Community development is one strategy to encourage the support from the community that is required by the families who carry out rehabilitation at home to ensure optimal outcomes for stroke survivors and their caregivers (Mitchell, 1999).

Lewin's theory of change (Lewin, 1951) states that change occurs in three stages: unfreezing, moving and refreezing (Table 5.1). This theory provides the guidance needed to analyse the process of change and to assist in identifying forces that either drive the change forward or create barriers that inhibit the change (Lancaster, 1999). Many studies (Bozak, 2003; Chung & Nguyen, 2007; Gurum & Gibson, 2005; Kubsch et al., 2007; Moffatt & Franks, 2004) using Lewin’s theory of change as a framework to guide the process of implementation in health care organisations have been successful in introducing change to health services. Therefore, the integration of Lewin’s theory of change and CBR (World Health Organization, 2004b) is considered an appropriate structure for implementing the SELF program. The process by which that could be achieved in Thailand is detailed in the action plan (Table 5.1). Additionally in order to sustain the SELF program, a formal evaluation will be a necessary component of a strategy to implement the SELF program.
### Table 5.1: Implementation of the SELF program

<table>
<thead>
<tr>
<th>Stage of Implementation (Lewin, 1951)</th>
<th>Action Plan</th>
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<tr>
<td><strong>Stage I: Unfreezing:</strong></td>
<td>During the implementation process, an appropriate experienced individual will be taking the role of the change manager or implementation leader. Aim: The change manager will motivate clinicians to be engaged in the process of change and to recognise the advantages of implementing the SELF program.</td>
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<tr>
<td>Aware that a problem exists. At this stage there are driving forces (those that move people towards change) and restraining forces (those that hamper the change process) to be explored. Additionally, at this stage the participants recognise the problems and try to seek new ways to solve problems.</td>
<td>(i) Notify the problems to the Ministry of Public Health (MOPH) and identify problems as follows</td>
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<tr>
<td></td>
<td>• Many stroke survivors readmitted due to complications which could be prevented</td>
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<td></td>
<td>• No stroke rehabilitation service in the community</td>
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<tr>
<td></td>
<td>• Stroke survivors living in rural areas of Thailand</td>
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<tr>
<td></td>
<td>• Family caregivers lack the information and skills to provide care</td>
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<td></td>
<td>• Stroke survivors do not get proper rehabilitation due to shortage of beds in hospital, short lengths of stay, no rehabilitation service provided in the community</td>
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<td><strong>Stage of Implementation</strong> (Lewin, 1951)</td>
<td><strong>Action Plan</strong></td>
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<tr>
<td>(ii) <strong>Provide evidence that the SELF program could reduce the problems by:</strong></td>
<td></td>
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<tr>
<td>• Encouraging family caregivers and stroke patients to provide self-care</td>
<td></td>
</tr>
<tr>
<td>• Providing sufficient knowledge and skills regarding stroke to family caregivers to improve stroke survivors’ functional ability, restore function, reduce family caregivers’ strain and improve stroke survivors’ and their family caregivers’ quality of life</td>
<td></td>
</tr>
<tr>
<td>• Reducing readmission due to complications</td>
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<tr>
<td>• Providing telephone follow-up to support to family caregivers</td>
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<tr>
<td>(iii) <strong>Analyse barriers to change in order to promote driving forces and overcome restraining forces</strong></td>
<td></td>
</tr>
<tr>
<td>• <strong>Driving forces:</strong> MOPH, stroke patients, their family caregivers, researcher’s colleagues, reduced readmission rate, improved patient and family caregiver outcomes</td>
<td></td>
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<tr>
<td>• <strong>Restraining forces:</strong> staff fear of increased workload, fear of role being undermined for example physiotherapist.</td>
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<tr>
<td><strong>Strategy:</strong> This can be overcome by explaining the benefit and reason for implementing the SELF.</td>
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<tr>
<td><strong>Stage of Implementation</strong> (Lewin, 1951)</td>
<td><strong>Action Plan</strong></td>
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<tr>
<td><strong>Stage II: Move to a new level:</strong></td>
<td>Aim: Clinicians will support implementation of the SELF program and commence implementation in their facilities.</td>
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</table>
| Gather information, diagnose problems, examine options and begin to move from status quo to implementing the change. At this phase participants realise the existing problems and begin to predict or diagnose the problems. They will try to seek options to solve problems by gathering information so they can examine the options. Many organisations go through this stage because it is the stage that the changes occur. | • Allocate financial support  
• Develop nurse-led stroke team, conduct meetings with related health care organisations and establish supervisory committee (SC) responsible for all the policies and protocols  
• Develop Intermediate Level Supervisory team (ILS) (home health care nurses and nurses at primary care unit)  
• Develop local supervisors team (LS) (health care workers working in the community health care centre in each village, working under supervision of ILS and LS will follow-up family caregivers in the villages.  
• Train ILS to be able to carry out assessment of stroke patients and provide support to family caregivers and how to conduct the SELF program while stroke patients are in hospital |
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<tr>
<th><strong>Stage of Implementation</strong> (Lewin, 1951)</th>
<th><strong>Action Plan</strong></th>
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|                                          | • Train LSs in the village health centres to provide support and follow-up after discharge. The LS will be provided with the protocol and manual, as well as support from the ILS  
• Implement the project and evaluate the project after six months |

**Stage III: Refreezing:**
Incorporate the new behaviour into action. At this stage, it is important to maintain the change. The best method is reinforcement (Lewin, 1951).

Aims: a) SELF program is implemented across Thailand and provided with ongoing funding to sustain the program as mainstream healthcare. b) Funding will be allocated to enable an robust evaluation with an adequate sample size to provide conclusive evidence of the effectiveness of the SELF program.

(i) **Reinforcement**
• Provide monthly supervision from the district hospital and community hospital to ILS and LS  
• Provide training program and workshop periodically to meet the need of staff

(ii) **Evaluation:** the outcome of the SELF implementation will be evaluated by using questionnaire and interview as follows
• The stroke patients and their family caregivers will be asked to give their views as to the satisfaction of the service
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<th><strong>Stage of Implementation</strong> (Lewin, 1951)</th>
<th><strong>Action Plan</strong></th>
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<tr>
<td>• ILS and LS will be asked to reflect on their knowledge and problems before, during and after the implementation of the SELF program.</td>
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<tr>
<td>• Readmission due to complications before and after the implementation will be analysed</td>
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<tr>
<td>• The results will be reported to the MOPH</td>
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(iii) **Announce the policy** (if MOPH grants permission) for all health care sectors in the northern area of Thailand to implement the SELF program. Disseminate the program to other regions if is successfully implemented in the northern area.
From this study, it can be seen that a nurse-led stroke rehabilitation support service is clearly very important. The results demonstrate that by providing appropriate education and skills training, family caregivers can provide CBR that effectively reduces complications, thereby reducing health care costs. Further, the SELF program provides a model that could be adapted for other chronic conditions that require patients and/or their family to actively manage the disorder on a day-to-day basis. This research project and the SELF program provide evidence that development of community rehabilitation practices for stroke survivors can improve their functional ability, reduce family caregiver stress, improve both stroke survivors’ and their family caregivers’ quality of life, reduce hospital readmission and introduce a new role to community health care personnel in Thailand. The model is sustainable and could be implemented with minimum cost, particularly when the potential social and cost benefits are considered.

5.7 Strengths and limitations of the study

5.7.1 Strengths

- A strength of this study is the quantitative design that used tools validated for the Thai population. This validated the data measuring the extent of family caregivers’ role strain and quality of life, as well as stroke survivors’ quality of life and functional outcomes.

- The design included adequate statistical power to enable the results to be confidently considered as representative of the stroke population. This is in contrast to a small sample size, which can limit validity of a study and result in misinterpretation of results or Type II error (Hills, 2005; Kidpredaborisuth, 2002).
• There was a 98% follow-up which is a major strength of the study, because it ensured the results at follow-up were representative of the study population. Therefore, the results from this research might be inferred or applied to all cases of the stroke population and their family caregivers in the northern region of Thailand.

5.7.2 Limitations

There were also some limitations of the study.

• Although the RCT is the gold standard design for studies of effectiveness, a comparative design was used. It was not possible to blind patients, family caregivers and staff to groups. Recruiting stroke survivors and their family caregivers from different sites was considered the best solution to prevent contamination between groups.

• Due to time constraints and distance (the nurse researcher was studying in Australia and the sample was in Thailand), the sample group was selected from two provinces in Thailand, that were the most convenient to the researcher, to ensure an adequate sample size was recruited within the timeframe for the intervention. However, this is an inevitable limitation of this study.

• Finally, funding was not available to provide basic equipment for stroke survivors, such as wheelchairs, commodes and walking frames. To compensate for this, family caregivers were provided with the names of providers of such equipment.
5.8 Recommendations

Based on the results of this study, the following recommendations are made.

5.8.1 Health service delivery in Thailand

5.8.1.1 The SELF program would be enhanced by the inclusion of allied health expertise to broaden its rehabilitative effect.

5.8.1.2 The enhanced SELF program for family caregivers of stroke survivors should be implemented in all acute care hospitals.

5.8.1.3 Nurses currently working in acute settings need to adopt a rehabilitative approach commencing on admission for all patients whose functional limitations are expected to continue beyond discharge.

5.8.1.4 Nurses currently working in acute settings should be upskilled to provide rehabilitative care to patients and to provide education and support to families.

5.8.1.5 At the under-graduate level, rehabilitation education should be included for all health care professionals to ensure optimal patient and family outcomes.

5.8.1.6 A formal referral process to community health services should be established to ensure stroke survivors and their family caregivers have access to appropriate services.

5.8.1.7 Health care workers in the community should be upskilled to provide ongoing education and support to stroke survivors and family caregivers in the community as part of the SELF program.
5.8.1.8 The SELF program should be used as a model to improve health outcomes for people with chronic conditions other than stroke.

5.8.1.9 The implementation of the enhanced SELF program across Thailand should be supported by government and hospital administrators to ensure adequate resourcing and sustainability.

5.8.2 Implications for research

5.8.2.1 An evaluation of the enhanced SELF program should be undertaken.

5.8.2.2 This study should be reproduced in other developing countries to determine effectiveness of the enhanced SELF program across cultures.

5.8.2.3 An in-depth qualitative project should be undertaken to explore the phenomenon of family caregiving to stroke survivors in Thailand.

5.8.2.4 A study should be undertaken to determine the current rehabilitation knowledge and skill set of nurses in Thailand.

5.9 Summary

The findings of this study have given a broad view and understanding of stroke survivors and their family caregivers in Thailand. The results of this study indicate that providing a nurse-led supportive educative learning program can improve outcomes for both stroke survivors and their family caregivers. Family caregivers in the intervention group experienced less carer strain and had better quality of life than those in the control group. At the same time, stroke survivors in the intervention group had better functional outcomes and quality of life. Hospital readmissions were lower in the intervention group. Hence, it is important that all stroke survivors’
family caregivers should be trained during the acute phase so they can confidently and effectively support stroke rehabilitation following discharge.

In order to improve the quality of care for stroke survivors and to reduce family caregiver burden, it is essential to provide education and training to those who will be providing care following discharge. This includes professional training and development for community nursing staff as well as hospital nursing staff so that they can provide training and proper education to meet the needs of family caregivers and stroke survivors. Knowledge and skills are essential in order to advance nursing practice (Rolfe & Fulbrook, 1998). It would be beneficial for government officials to consider the results of this study when developing policies and guidelines for the management of acute stroke and rehabilitation in Thailand.

The primary role of the PhD candidate who completed this study is to teach nursing students. It will be important for her to include relevant content regarding rehabilitation, both theoretically and practically. Nursing students need to develop competence in general as well as specific knowledge and attitude about the management of chronic conditions, in particular stroke. Recommendations of this thesis will be drawn to the attention of the Ministry of Public Health in Thailand, so that the Thai community can benefit from the positive outcomes of this study.
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Appendix 1

University of Western Sydney
School of Nursing, Family and Community Health
Participant Information Statement for Control Hospital

My name is Roshinee Oupra, I am a PhD student at the School of Nursing, Family and Community Health, The University of Western Sydney, Australia. I am conducting a research study that aims to reduce the caregivers’ stress, maintaining functional level of the stroke patients, prevent complications and improve quality of life in patients and caregivers.

This Participant Information Sheet provides people recovering from a stroke and their carer with information about the project. Please read this explanation before deciding whether you agree to be included in the study.

(I) People recovering from stroke.

While you are in hospital you will be asked to complete a survey that will take about 30 minutes to complete. You can complete it by yourself, or a research nurse will be available to help you.

At your routine visit to the hospital 3 months following discharge, the survey will be repeated to obtain information about your level of activity and functioning.
(II) Family caregivers of people recovering from stroke

While you are looking after the patient in the hospital, you will be encouraged to observe what is being done for the patient and learn as much as you can. You are encouraged to assist nurses’ care for the patient and to ask anything you feel that you are not sure of regarding the patient’s condition or disease or procedure.

Prior to leaving the hospital you will be asked to complete some assessment by yourself, if you could not do it by yourself, the researcher will read it out for you and ask you to answer.

When the patient comes to the hospital for the routine 3 months follow up, we would like you to complete another survey. You will be assisted by a research assistant if you prefer assistance to complete the survey. This will take approximately 15-20 minutes.

There are no risks to you (the caregiver) or the patients from participation in this study. Your participation will, however help the researcher to improve care and service for stroke patients in the future.

It is up to you to decide whether or not to take part in the study. Please take time to read the information carefully and discuss it with others if you wish. Please feel free to ask us if there is anything that is not clear or if you would like more information. If you decide to take part, you will be asked to sign the consent form or you can give the consent to participate verbally, if you prefer. If you decide to take part, you are free to withdraw at any time and without giving a reason. A decision to withdraw at
anytime or a decision to take part will not affect the standard of care that you (the patient) or your relative (the caregivers) receive.

All information gained during the study will be kept confidential, no one who participates in the study will be identified in the final report, and all information will be kept securely for five years then destroyed.

If you have any questions, please feel free to contact either the Director of Nursing or myself. The contact numbers are as follows:

Director of Nursing: (Phone number)
My contact number: (Phone number)

Thank you for reading this

Roshinee Oupra

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Office (Phone + 61 2 4570 1136) or e-mail K.BUCKLEY@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 2

University of Western Sydney
School of Nursing, Family and Community Health

Participant Information Statement for
Intervention Hospital

My name is Roshinee Oupra, I am a PhD student at the School of Nursing, Family and Community Health, The University of Western Sydney, Australia. I am conducting a research study that aims to reduce the caregivers’ stress, maintaining functional level of the stroke patients, prevent complications and improve quality of life in patients and caregivers.

This Participant Information Sheet provides people recovering from a stroke and their carer with information about the project. Please read this explanation before deciding whether you agree to be included in the study.

(I) People recovering from stroke.

While you are in hospital you will be asked to complete a survey that will take about 30 minutes to complete. You can complete it by yourself, or a research nurse will be available to help you.

At your routine visit to the hospital 3 months following discharge, the survey will be repeated to obtain information about your level of activity and functioning.
(II) Family caregivers of people recovering from stroke

While you are looking after the patient in the hospital, you will be encouraged to observe what is being done for the patient and learn as much as you can. You are encouraged to assist nurses care for the patient and to ask anything you feel that you are not sure of regarding the patient’s condition or disease or procedure. Additionally, you are invited to attend three education and training sessions. Each session is one–week apart. The sessions are 1, 2.5 and 1.5 hours long respectively. In each session, you will be taught about how to care for stroke patients. Hands on training will be provided and you will be given a handout from each session.

Prior to leaving the hospital you will be asked to complete some assessment by yourself, if you could not do it by yourself, the researcher will read it out for you and ask you to answer. While at home, You will be followed up by a telephone interview once a month up to three months to discuss any problems. The timing of the appointments will be arranged with you at your convenience.

When the patient comes to the hospital for the routine 3 months follow up, we would like you to complete another survey. You will be assisted by a research assistant if you prefer assistance to complete the survey. This will take approximately 15-20 minutes.

There are no risks to you (the caregiver) or the patients from participation in this study. Your participation will, however help the researcher to improve care and service for stroke patients in the future.

It is up to you to decide whether or not to take part in the study. Please take time to read the information carefully and discuss it with others if you wish. Please feel free to ask us if there is anything that is not clear or if you would like more information.
If you decide to take part, you will be asked to sign the consent form or you can give the consent to participate verbally, if you prefer. If you decide to take part, you are free to withdraw at any time and without giving a reason. A decision to withdraw at anytime or a decision to take part will not affect the standard of care that you (the patient) or your relative (the caregivers) receive.

All information gained during the study will be kept confidential, no one who participates in the study will be identified in the final report, and all information will be kept securely for five years then destroyed.

If you have any questions, please feel free to contact either the Director of Nursing or myself. The contact numbers are as follows:

Director of Nursing in Chiang-Mai hospital: (Phone number)
My contact number: (Phone number)

Thank you for reading this

Roshinee Oupra

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Office (Phone + 61 2 4570 1136) or e-mail K.BUCKLEY@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 3

University of Western Sydney
School of Nursing, Family and Community Health

Consent form for patients

**Research Title:** The Effect of an Educative Supportive Nursing Intervention for the Stroke Caregivers on Providing Care to Stroke Patients

I have been given information about the project in which I am to take part, which is to investigate the effect of a supportive educative nursing intervention for stroke caregivers on providing care to stroke patients.

YES/NO (circle as appropriate)

I have been informed that I can withdraw from the study at any time without affecting the care that I receive.

YES/NO (circle as appropriate)

Details of the study have been fully explained to me by Miss Roshinee Oupra and I agree to take part in the study while I am in hospital and for three months after discharge from hospital.

YES/NO (circle as appropriate)

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Office (tel + 61 2 4570 1136) or e-mail K.BUCKLEY@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

**SIGNATURE OF PARTICIPANT**…………………………..**DATE**………………
**NAME**…………………………………………………………………………………

**SIGNATURE OF RESEARCH NURSE**……………………**DATE**………
**NAME**…………………………………………………………………………………
Appendix 4

University of Western Sydney
School of Nursing, Family and Community Health

Consent form for Family caregivers

**Research Title:** The Effect of an Educatively Supportive Nursing Intervention for the Stroke Caregivers on Providing Care to Stroke Patients

I have been given information about the project in which I am to take part, which is to investigate the effect of a supportive educative nursing intervention for stroke caregivers on providing care to stroke patients.

YES/NO (circle as appropriate)

I have been informed that I can withdraw from the study at any time without affecting the care that my relative will receive.

YES/NO (circle as appropriate)

Details of the study have been fully explained to me by Miss Roshinee Oupra and I agree to take part in the study while my relative is in hospital and for three months after discharge from hospital.

YES/NO (circle as appropriate)

This study has been approved by the University of Western Sydney Human Research Ethics Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Research Office (tel + 61 2 4570 1136) or e-mail K.BUCKLEY@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

**SIGNATURE OF PARTICIPANT…………………………DATE………………
NAME………………………………………………………………………………

**SIGNATURE OF RESEARCH NURSE………………………..DATE………
NAME………………………………………………………………………………
Stroke

Handout for family caregivers of stroke survivors

This booklet is provided as a handout for family caregivers of stroke survivors’ during training sessions. Please do not use without permission.
Session One: Tuesday

Time: 1.30 pm - 2.30 pm

Duration: One hour

Topics:

- What is a stroke?
- Complications due to stroke
- Prevention of complications associated with stroke
- Prevention of subsequent stroke

Learning Objectives:

At the end of this session, family carers of stroke survivors will be able to:

- Understand the meaning and describe what a stroke is.
- List complications that are associated with stroke
- Describe how to prevent the complications after stroke.
- Describe strategies for preventing subsequent stroke.
Teaching methods and activity: Lecture and group discussion include

- Introduce myself and the team
- Invitation for family carers to share their experience of caring for a person and ask what they know about stroke
- Practice Range of Motion exercises (demonstrations, see video recording and hands on training)

Teaching materials

- Overhead projector or flip chart
- Video recording about Range of Motion exercises
- Handout

Evaluation

- By discussion and asking questions. For example, the caregiver should be able to explain briefly how to prevent complications from stroke
- Able to perform Range of Motion exercises
What is a stroke?

- A stroke is a sudden loss of brain function caused by either a blood clot in a brain blood vessel, or bleeding into the brain.

- Stroke is always sudden occurring over minutes. Nine out of ten strokes are due to unexpected blockage of a brain blood vessel.

- Stroke may cause different types of symptoms depending upon which part of the brain is affected.

What happens when someone has stroke?

During a stroke a person might have the following signs which may appear within minutes or take up to hours to show up.

- Sudden weakness (or paralysis) on one side of the body.

- Numbness (no feeling) in the face, arm or legs, especially on one side of the body.

- Difficulties in talking and/or understanding or unable to speak clearly.
• Difficulties in seeing with one eye or both. Vision may be blurred.

• Difficulties in balancing or co-ordination.

• Difficulties in swallowing.

• Sudden severe headache.
Potential complications after stroke and prevention

Chest infection (aspiration pneumonia):

What is chest infection?

- Chest infection happens when food or liquid is breathed into the lungs.

- A common chest infection for stroke survivors is breathing in (aspirating) acid or vomit from the stomach. Having food or drink go into the lungs can damage the lungs or cause a blockage. This damage or blockage may cause swelling and fluid in the lungs. It can also cause an infection in the lungs.

- A person who has trouble swallowing or coughing is at risk of getting aspiration pneumonia or chest infection.

What are the signs of chest infection?

The signs of chest infection may depend on what the person breathed in and if the person has a chest infection, you should be able to notice the following signs.

- Frequent coughing. The person may cough and bring up bad smelling mucous from the lungs. The secretions from lungs may contain pus or streaks of blood.

- Shortness of breath and noisy breathing.
• Fever or chills and sweating.
• Having chest pain when coughing or taking deep breaths.
• Trouble swallowing or have a feeling that something is stuck in the throat.
• Feeling dizzy or confused.
• Feeling that not enough air is getting into the lungs.
• Skin, lips or fingernails are pale (or white/blue tinge).

It is very important that you take the person to hospital immediately or ring the ambulance to take the person to hospital. A doctor should see the person. If they have aspiration pneumonia it is important that the person stays in hospital. They might need oxygen and to start antibiotics.

However, remember that aspiration pneumonia can be prevented if the person is able to swallow safely.
How to prevent chest infection?

- Make sure that food is not breathed in if the person has difficulties in swallowing.

- If the person has trouble swallowing, the doctor might order tube feeding. (explain next session)

- It is better to feed a person in the sitting position and remain sitting 1 to 2 hours after feeding

- Make sure that the person has good mouth care by making sure that there is no food left in the mouth after eating. (explain next session)
Stiff joints (contractures):

What are stiff joints?

A human body is made up of bone and junctions that are called joints. Joints are the places where bones meet, for example in the arms and legs. Each joint is surrounded by muscles, tendons, ligaments and a joint capsule. Shortening of a muscle, tendon, or ligament is called a contracture. Stiff joints results in less movement in joints such as the wrist, elbow, shoulder, or ankle.

How to prevent stiff joints?

We can prevent stiff joints by moving through the range of motion or help the person to perform range of motion exercises at least twice a day.

What are Range of Motion Exercises?

These exercises are done in order to protect flexibility and movement of joints. These exercises reduce stiffness and will prevent or slow down the freezing of the person’s joints. Each joint has its own amount of movement. Every joint in the body has a normal range of motion. Joints maintain their normal range of motion by being moved. It is therefore important to move all joints every day. You may help the person to perform the exercises if they are not able to do it by themselves. At other times, splints and other position tools may be used to hold the person’s limbs in the correct position. However, using a splint and other tools should be advised by health care professionals.
How can I help the persons to do Range of Motion Exercises?

- **Fingers**: open the person’s hands, with fingers straight (use your hand to support the person’s hand), then curl all the fingers tightly to touch the top of the palm. Repeat.

  ![Fingers Exercise](image)

- **Thumb**: Open the person’s hands, straighten the person’s fingers, and reach the person’s thumb across the palm until it touches the base of the little finger. Stretch the person’s thumb out and repeat.

  ![Thumb Exercise](image)
• **Shoulder:** Lay the person on their back. Use one of your hands to support the person’s elbow and use the other hand to hold the person’s wrist. Raise the person’s one arm over the person’s head, keeping the elbow straight and the arm close to their ear, then return the arm down slowly to the side. Repeat with the other arm.

![Shoulder Diagram](image)

• **Elbow:** Use one of your hands to hold the person’s upper arm and use the other hand to hold on to the forearm. Bend the person’s arm at the elbow so that the hand touches the shoulder. Then straighten the person’s arm all the way.

![Elbow Diagram](image)
• **Hip and knee:** Lay the person on their back, with one knee bent and the other as straight as possible. Use one of your hands to support under the person’s knee while the other hands on the person’s heel. Bend the knee of the straight leg and bring it towards the chest. The kneecap should be pointed toward the ceiling.

![Diagram of Hip and Knee Move](image)

• **Hip Rotation:**

Place one of your hands on the person’s thigh and the other hand below the knee (as pointed by arrows in the picture). Bend the person’s knee half way to the chest so that there is a 90 degree angle at the hip and knee pull the person’s foot towards you then push it away.

![Diagram of Hip Rotation](image)
• **Hip abduction**: Place one of your hands under the person’s knee and the other hand under the person’s heel. Keep the person’s knee straight and then move the person’s leg toward you and away from the other leg.

• **Hamstring Stretch**: Support the person’s knee and heel with your hands and use the other hand to raise the person’s leg up slowly. Keep the person’s knee straight. Return to the starting position.
- **Toe flexion (bent) and extension (straighten):** Lie the person on the bed with their knee straight. Use one of your hands to stabilise the foot below the person’s toes. With the other hand gently move each or all of the person’s toes forward and backward.

![Image of toe movement](image1)

- **Ankle Rotation:**

  Lie the person on the bed with their knee straight. Use one of your hands to hold the person’s ankle and place another hand around the person’s foot. Now move the person’s foot inward and then outward.

![Image of ankle rotation](image2)
How frequently do I need to do this?

- These exercises should be done at least twice a day.
- Repeat each exercise at least 5 times.
- The exercise should be performed as smoothly and gently as possible.
- There should be no pain.
- Always support the joints further down the arm or leg than the one being moved.
Pressure sores

What are pressure sores?

- Pressure sores are also called bedsores. They are caused by the pressure of the body resting on a hard surface. When this pressure cuts off blood flow, skin breaks down and pressure sores form. This causes damage to skin, tissue and bone.

- Pressure sores can develop in 1-2 hours.

- People who cannot easily move themselves and have to stay in bed or a chair most of the time are most likely to get pressure sores.

- The most common places where pressure sores develop are over a bony or firm area such as sacrum, shoulders, hip, heel, elbows, back of head, knees, feet, ear and ankle.

- The first sign is pale or white skin or a red area. The person may complain of pain or burning.
Picture of common sites for pressure areas

Picture of common sites for pressure areas


How to prevent pressure sores?

- Check the person’s skin several times a day for pale or white skin or a red area.
- Keep skin clean and dry. Moisture from sweating, wound drainage, or urine can increase the risk of skin damage.
- Protect dry skin (elbow, legs, ankle and heels) with moisturiser.
- Skin or areas that touch bed or sensitive to get pressure sore should be supported by pillow and foams to reduce contact between the skin and support surface (see the picture)
- Clean when incontinent (wetting or soiling in the bed) as soon as possible
- Keep the bed sheet free of wrinkles.
- A person must be lifted not dragged across the bed. Positioning and turning should be done by two people.
- Increase circulation by exercise of limbs, Range of Motion exercises.
- If the person is not able to move by himself or herself, help them to change the position every two hours. You might need to keep a record of position changes.
- Do not rub the skin over bony areas.
- Do not use alcohol or other drying agent on the skin.
Supporting pressure area

**Prone Bridging**

One pad

One to two pads or pillows

**Semi-prone position**

Pillow

Lengthwise folded pillow

**Side Lying position**

Supporting pressure area for person weak at one side (Hemiplegia)

**Side Lying person with hemiplegia, weak side down.**

**Side-lying person with hemiplegia, weak side up**

**Supine bridging person with hemiplegia**

**Position to prevent foot drop**

(place a small pad under the ankle to lift the heel from bed)

Constipation:

What is constipation?

Constipation is when a bowel movement is hard and dry, or when a person goes a longer time than usual without having a bowel movement. For some people it is normal to have a bowel movement every day, for others it may be every three to five days. It may be painful and hard to push out the bowel movement. A person may also feel that they need to have a bowel movement, but cannot. Constipation is a problem for many stroke survivors.

How to prevent constipation?

- The person should drink at least six to eight cups of water each day (unless there is some restriction, check with the doctor).

- The person should eat a high fiber diet. Fibre is the part of fruit, vegetables and grains that is not broken down by your body. A high fibre diet will add bulk and softness to the bowel movement. The diet should include fresh fruit and vegetables.

- If possible, try to help the stroke survivor to move or exercise.

- Avoid spicy food and dairy food.

- If constipated eat prunes, drink pear juice, you may contact the doctor or seek advice from health care personnel.
Shoulder pain

What is shoulder pain?
Shoulder pain is a common problem after stroke. It can cause the person to suffer and be less active. Shoulder pain is often caused by pulling on the weak arm. A person who needs help to move is more likely to develop shoulder pain. Handling, positioning and transferring on a day-to-day basis can cause great stress to the weak shoulder.

How to prevent shoulder pain?

• Take care not to pull the weak arm when moving a person with stroke.
• The weak or paralysed arm should be supported by pillows when in bed.
• While sitting, standing or walking support the weak arm with the non-paralysed arm or wear a supportive sling.
Can Stroke happen again?

Yes - a person who has had a stroke can have another stroke.

How to prevent another stroke?

- **Control high blood pressure:**

  This is the most important risk factor for stroke. The person should have their blood pressure checked regularly. High blood pressure (140/90 mm Hg or higher) is the most important risk of stroke. Make sure that blood pressure medication is taken exactly as arranged by doctor.

- **Reduce risk factors:**

  For example, smoking cigarettes, eating food high in salt or saturated fat, drinking a lot of alcohol, or being overweight.

- **Don’t smoke.**
• **Eat healthy food**: for example food low in salt. Avoid saturated fat (fats which are solid at room temperature) and have five portions of fresh fruit or vegetables each day.

• **Exercise regularly**: physical activity can reduce high blood pressure and help lose excess weight. Also, exercise can help reduce depression and anxiety, which are very common after stroke. However, before starting any exercise program, remember to talk to a doctor.

• **Limit the amount of alcohol**: Have no more than two small drinks a day.

• **Control body weight**: Maintain weight appropriate for height and age
Session Two: Wednesday

Time: 1.00 pm - 3.30 pm

Duration: 2.5 hours

Topics

• Maintaining adequate hydration and nutrition
• Identification of swallowing difficulties
• Safe swallowing, nasogastric (NG) tube and gastrostomy (PEG) tube feeding and care of the tube

Learning objectives

At the end of this session, the family carer of a stroke survivor will be able to:

• Describe how stroke can affect eating and nutrition.
• Describe how to recognise swallowing difficulties
• Describe how to feed the stroke survivor, and explain how to take care of a NG tube and PEG tube
• Demonstrate feeding the stroke survivor
Teaching methods and activity:

Lecture, video recording, group discussion, demonstration and hands on training. This includes:

- Inviting the family carer to share their experience or knowledge about maintaining adequate hydration and nutrition.
- Inviting the family carer to share experience in feeding (if they have had the experience). Introduce them to NG tube and PEG tube feeding by using overhead projector (or flip chart), play video recording about NG and PEG tube feeding and care of the tube. Give handout about blenderized diet and preparation.
- Demonstration
- Hands on training (divided in to three groups) and practice about feeding.

Teaching materials

- Overhead projector for lecture or flip chart.
- Video recording about NG and PEG tube feeding and care of the tube.
- NG and PEG tubes.
- Hand out for family carers.
Evaluation

By discussion and asking family carers questions as for example

- Explain how you would maintain adequate hydration and nutrition for the stroke survivor.
- Explain how you would help the stroke survivor to swallow safely.
- Demonstrate how you would feed the stroke survivor correctly and care for their feeding tube.
How can stroke affect eating or nutrition?

- After stroke the ability to eat may be affected by difficulty in feeding oneself due to a paralysed side, a general feeling of weakness and lack of appetite.

- Stroke can also weaken a person’s ability to swallow if it affects the muscles of the mouth, tongue and throat. As a result, a person may have trouble swallowing.

- Swallowing problems may result from weakening of the tongue or loss of co-ordination of tongue movement. Therefore food can become pocketed between the cheek and teeth, and drooling may occur because the person is not able to seal the lips.
What are the results of swallowing difficulties?

Swallowing difficulties can cause complication as follows

- Dehydration (deficiency of water which means that the person’s body does not have much water and fluids as it should) and malnutrition (deficiency of food or vitamins)
- Chest infection (aspirate pneumonia)

Maintaining sufficient fluid and food

Swallowing difficulties can cause food or fluid deficiency in stroke survivors. It is important to

- Make sure that the person gets enough food and fluids (25-35 ml/kg/day), in order to prevent fluid and food deficiency.
- Encourage and offer food that a person likes.
- If the person has a dry mouth, give fluids before meals to help to produce saliva and keep the person well hydrated.
- Food for a person with swallowing problem should be prepared separately or modified.
- Change the texture of food and fluid thickness, this helps the person to swallow the food easily and prevent breathing in food.
- Give nutrition supplement (consult with doctor).
• Make fluid handy by keeping near the person’s head on unaffected side. Provide fluid that the person prefers.

• Mouth care (keep the person’s mouth clean by rinsing their mouth before and after each meal) as this will help to produce saliva flow and clean up the taste buds.

• Watch for loss of body weight and possible signs of dehydration which are dry or sticky mouth, low or no urine, the urine appears dark yellow, deep-set eyes and dry skin. Consult with doctor if these appear.
How to find out if the person has swallowing difficulties?

Here are some signs to look for during and between meals to see if a person has swallowing difficulties. (Adapted from Pardoe 1993; American Dietetics Associations, 1996)

- Difficulty managing secretions or drooling excessive secretions
- Change in voice tone (hoarseness / moist sounding)
- Frequent throat clearing during and after meals
- Food or fluids come up into the nose or spitting out pieces of food
- Take several time to swallow when there are food in the mouth
- Facial weakness or paralysis of lips and tongue
- Pocketing of food in cheek or under tongue.
- Coughing or choking while eating
- Complaining of food stuck in the throat
- Taking long time to eat and chew or swallow
- Do not want to eat particular food consistencies or do not want to eat at all.
- Weight loss and/or sign of dehydration
- Frequent chest infection.
What should I do if a person has swallowing difficulties?

Here are some ideas to help if the person who has difficulty in swallowing:

- When eating, ask the person to sit upright, feet flat to the floor with the head tilted towards the chest.
- If the person is in bed, raise the head high with head and neck supported and neck slightly flexed.
- If you are feeding the person, you should sit at or below the person’s eye level.
- Place food on the unaffected side of the tongue, allow the person to feel where is the food.
- Ask the person to chew on the stronger side of his or her mouth.
- If you are helping to feed the person, try to place the spoon or fork inside the mouth on to the person’s tongue and get the person to take the food off with their mouth and lip while you are taking the spoon out.
- At each time give ½ to 1 tablespoon of solid food and 10 ml of liquid.
- Ask the person to clear his or her throat and mouth after each bite.
- Ask the person to remove food trapped in his or her cheek with their finger, you might help them by using a small mirror to show them where the food is trapped.
• Making food softer or smoother is easier to eat for example soft solid foods, such as porridge is easier to swallow. You can also help the person by chopping food or making it smaller or grinding food in a blender.

• You might also try to make liquids thicker, for example with a commercial thickener or cornstarch. Thickened liquids and semisolids foods are better than thin liquids, which can cause a person to aspirate. Avoid mucous forming food such as milk.

• Provide an environment that encourages the person to eat. Limit distraction and allow enough time for the person to eat; do not rush the person.

• If possible, ask the person to sit at the table and turn off the television and radio. Avoid talking with the person while eating. Quiet music may help create a pleasant environment.

• Make sure that the person with swallowing problems has another person nearby when eating.

• After eating, keep the person sitting up approximately for 30-60 minutes.

• Help or ask the person to brush their teeth and rinse after each meal.

• Seek help from health care personnel in the hospital (doctor will advise you).
Important things to remember when feeding a person

**Do**
- For safe eating or drinking, make sure that the person is sitting straight, if in bed, the legs can also be bent at the knees.

  ![Feeding in bed](image1)

  ![Feeding in chair](image2)

- If the person is sitting on the chair, the person’s feet should be flat on the ground.

- Face the person while feeding.

![Feeding face to face](image3)
Don’t

- Don’t stand above the person while feeding them, as this would make them look up.

- When in bed check that the person is not leaning back too far.

(Picture taken from www.hunter.health.nsw.gov.au accessed on 25/02/05)
What happens if a person cannot swallow or eat through their mouth at all?

If a person is not able to eat and drink or swallow or swallowing is considered not safe, it is important to make sure that he or she receives enough food and fluids by other means. This is important in order to keep the person with enough strength to perform daily activities and continue rehabilitation. In this case a doctor will order tube feeding in order to

- Supply a balanced diet to the person who is unable to eat and drink through the mouth.
- Give fluid and medication at an ordered rate.
- Maintain the person’s comfort.
- Prevent chest infection (aspirate pneumonia).
Types of feeding tube

- There are 2 types of tube that are used for feeding

1. **NG tube (Nasogastric tube)**: this is a tube that is inserted through the nose into the stomach.

2. **PEG tube**: PEG tube is the artificial feeding tube opening into the stomach through the front of abdominal wall. This is used when the person needs longer term feeding.

How do I feed a person with tube?

1. **Feeding a person with a NG tube (tube that is inserted through the nose into the stomach)**.

The person who has trouble swallowing and cannot eat through their mouth will be ordered tube feeding by the doctor. A nurse will insert the tube for the person. A NG tube is used for short term feeding usually not more than 30 days. You will be taught how to prepare the diet for feeding by the hospital dieticians. The amount of diet for feeding in each person will be decided by the dietitian and doctor. The feeding tube will need to be changed by the nurse. The PVC tube needs to be changed weekly and the polyurethane or silicone tube is to be changed every 1-3 months. However, recheck with your doctor and nurse.
What do I need in order to feed a person with NG tube?

1. 50 ml syringe
2. 50 ml water at room temperature
3. Food (or special fluid diet for feeding)
4. Clamp or stopper
5. Container to hold diet for feeding

How to feed a person with a NG Tube?

1. Wash hands before preparing special diet for feeding.
2. Prepare diet for feeding as advised by dietician. All feeding diet should be at room temperature.
3. Wash and dry hands before feeding the person.
4. Position the person to sit upright, feet flat on the floor
5. If the person is in bed, raise the head high with head and neck supported and neck slightly flexed.
6. Mouth care before feeding.

7. Check for feeding tube position by:
   • Checking that the mark on the tube is in line with the end of the person’s nose.
   • Checking that the tube is not coiled at the back of the person’s mouth by checking in the person’s mouth.
   • Using a syringe, gently pull out the content from the stomach to confirm the tube is in the person’s stomach. You should see some gastric juices, which is normally yellow–green colour.
   • If the fluid that you pull out is more than 150 cc, do not feed the person. Push the stomach contents back into the tube then flush with water. Wait a few hours then check again. Consult the doctor if this happens frequently.

8. Using the barrel of a syringe gravity–feed the food slowly (do not force the food).

9. Rinse the tube with water after feeding (check if the person has any fluid restrictions), or feed water every 4–8 hours.

10. Clamp or plug feeding tube.

11. After feeding, the person should remain sitting up approximately 30–60 minutes.

12. If diarrhoea occurs with tube feeding, talk to a doctor.
How to take care of NG tube and the person’s mouth?

- Brush the teeth at least twice daily.
- Mouth care after each meals
- Clean the area where the NG tube goes into the person’s nose every day by using a cotton tip applicator moistened with warm water.
- Change the tape on the nose every other day or when it is loose.
- Make sure that the tape on the nose is secure at all times.
- If the feeding tube falls out, see the doctor.
- Always rinse the feeding tube with water (50 -100 ml) each time after feeding or medication in order to prevent the feeding tube being clogged.
2. Feeding a person with a gastrostomy tube (tube inserted in the stomach from the front abdominal wall)

For a person who needs longer term feeding, a doctor will order PEG tube feeding. You will be taught how to prepare the diet for feeding by the hospital dietitian. A PEG tube is a thin tube that allows you to feed the person directly into their stomach. A doctor will insert the tube. A small hole is made in the skin, in the upper part of the belly, for the tube to come out forming a channel. On the inside of the stomach, a small spongy balloon on the end of the tube prevents it from falling out. After two weeks, the person can shower. The tube is designed to stay in place a long time. It can be in place up to 2 years before it needs to be changed. If the tube is no longer needed, the doctor will remove it.
What do I need to feed the person with gastrostomy tube?

1. Special fluid diet for feeding at room temperature
2. Container to hold diet for feeding
3. 50 ml syringe with a catheter tip
4. Water at room temperature
5. Stopper or clamp

How to feed the person with gastrostomy tube?

1. Wash hands before preparing special diet for feeding.
2. Prepare diet for feeding as advised by dietician. All feeding diet should be at room temperature.
3. Wash and dry your hands before feeding the person.
4. Position the person to sit upright, feet flat on the floor
5. If the person is in bed, raise the head high with head and neck supported and neck slightly flexed.
6. Check for the position of the tube by gently pulling the tube to make sure that the balloon placement is at the stomach wall.
7. Test patency of the tube by running 50 ml of water through the tube.
8. Clamp the gastrostomy tube, remove spigot and attach the syringe for gravity feeding.
9. Ensure air does not enter the stomach.
10. If delivering diet by gravity feeding, allow food to flow into the stomach from a distance above the gastrostomy. Do not force food into the tube.

11. If the person complains of a feeling of fullness, diarrhoea or constipation, stop giving the food. If necessary, get medical advice.

12. Rinse tube with water.

13. After food is given, encourage the person to stay in the same position for approximately 30-60 minutes.

14. If the tube is clogged or blocked:
   - Rinse the tube with 30-50 ml of warm water.
   - Remove the clogged with a 50-ml catheter tip syringe
   - Always avoid too much pressure on the tube.

15. Ask the person to rinse their mouth every 2-4 hours and do daily brushing of their teeth gums and tongue.
How to care for the gastrostomy site?

1. The person is allowed to shower (2 weeks after the tube is inserted). There is no need to cover the PEG tube site during the shower. If the PEG tube is inserted for less than 2 weeks do not shower and the tube site should be covered by sterile gauze.

2. After two weeks, a gauze dressing is not necessary if the site is clean and dry. However, if there is discharge, a dressing might be needed.

3. Check that the tube site is clean and dry. Clean around the site at-least twice daily with soapy water, dry thoroughly.

4. Do not apply powder to the gastrostomy site.

5. Check the insertion site for rubbing and friction. The tube may need to be secured to the abdomen for the person’s comfort.

6. Each day check the mark on the tube which indicates that the tube is properly in place.

7. Check the area around the tube (incision area) everyday for redness, pain, bad smell and swelling. If the condition appears seeks advice from the doctor.
How to give medication to a person with a feeding tube?

1. Try to use liquid medicine if possible.

2. If liquid medication is not available, crush tablets into fine powder and mix it in water.

3. If the medicine comes in a capsule, do not put any capsule or its particles down the feeding tube.

4. Fit the syringe to the feeding tube, before unclamping the tube fill the syringe partly with water then mix crushed medication in syringe, gently stir up the mixture quickly, unclamp the tube.(if there is liquid medications, give it first and follow them with water)

5. Rinse the tube with a syringe full of water (50 ml) which is attached directly to the tube.

6. Clamp or plug the tube.

7. Do not mix medication with tube feeding formulas.
See doctor if:

- you cannot unclog the feeding tube.
- the feeding tube (NG) falls out or you are not sure that the end of the tube is in the stomach.
- the gastrostomy tube becomes dislocated or not working properly.
- there is more drainage around the tube than usual or the drainage is coffer ground color, bloody color or has a foul smell.

See doctor immediately if:

- the person chokes or has difficulty breathing during a feeding, stop feeding and call emergency (191)
- The gastrostomy tube falls out.
- The following signs persist: diarrhea, constipation, sickness or dehydration.
- The skin around the tube is red, swelling, and leakage is present.
- The stomach is distended or tender.
Session Three: Thursday

Time: 1.30 pm - 3.00 pm

Duration: 1.5 hours

Topics

• Bladder and Bowel function (continence) after stroke, catheter care, bladder and bowel training.

• Positioning, mobility and transfer.

• Role of family carer.

• Caring for yourself.

Learning objectives:

At the end of this session, the family carer of a stroke survivor will be able to

• Perform urinary catheter care.

• Prevent urinary tract infection.

• Describe how to perform bladder retraining.

• Describe how to perform bowel training.

• Help to position, move and transfer the stroke survivor.

• Care for themselves.


**Teaching methods and activity:**

Lecture, video recording, group discussion and demonstration practice.

This includes:

- Invitation for the family carer to share their experience or knowledge about incontinence and catheter care. Lecture by using overhead projector or flip chart with video recording. The example of a catheter and catheter bag will be shown.

- Invite the family carer to share their experience or knowledge about mobility, positioning and transfer. Lecture about how to position the stroke patient in bed especially right and left hemiplegic patients, how to adjust the position (turn on the video recording).

- Practice positioning, moving and transfer.

- Invite the family carer to share their experience in solving the problems.
Teaching materials

- Overhead projector for lecture or flip chart.
- Video recording about catheter care.
- Video recording about positioning, moving and transfer.
- Urine drainage bag and Foley catheter and syringe.
- Handout for family carers.

Evaluation: by discussion and asking questions as for example the family carer should be able to

- explain about bladder retraining.
- explain how to perform catheter care.
- explain how to prevent urinary tract infection.
- help to position, move and transfer the stroke survivor.
- care for themselves.
What happens to bladder and bowel function after stroke?

After stroke, many stroke survivors are not able to control their bladder and bowels.

**Here are some common problems with the bladder after stroke**

- Not being able to control their urine.
- Not being able to get to the toilet in time and wetting themselves.
- Passing out urine without knowing that they have done so.
- Not able to empty the bladder.

**Here are some common problems with the bowels after stroke**

- Constipation
- Diarrhoea
- Not able to control the passage of their faeces.

**IN OTHER WORDS NORMALLY**

- A person has **urinary incontinence** when they have difficulty controlling when they pass urine.
- A person has **faecal incontinence** when they have difficulty with bowel control.
What should I do when a person has urinary incontinence?

- Advise the person to go to the toilet regularly (every two hours during the day if possible) although they may not feel as if they need to go.

- Use continence aids for example keep urinals near to men, or absorbent pads for both male and female stroke survivors by wearing them in their underwear.

- Males may use a condom attached to a urine bag.

- Do not cut down the person’s fluid intake as this can cause another problem like urinary tract infection or dehydration.

- Change pad, clothes and bedding as soon as the person is wet in order to avoid skin problems.

- If the urine is smelly or there is pain or burning when passing it, there may be an infection. See the doctor.

- **bladder re training** can help to control the passage of urine.

- If the person is having difficulty emptying the bladder, sometimes it may be necessary to **use a catheter**.
Is there anything that can be done to improve urinary incontinence?

**Yes.** Bladder and bowel training can help.

**Bladder “Re-training” plan**

- Ask the person or help the person write down the time when the person usually passes urine or empties the bladder. It is recommended that this should be done for 3 days.
- Review the time to find out the shortest time between voids (emptying the bladder)
  - If the person usually goes for more than 1 hour between voids, the person’s voiding schedule would start at every 60 minutes during the day.
  - If it is less than one hour, start at every 30 minutes.
- Then set voiding times. For example, if the person’s schedule is every 60 minutes, then the person should empty their bladder every hour for example 8am, 9am, 10am, etc…
- When the desire to void develops before the time, use distraction technique to delay voiding for example concentrate on another bodily sensation like take slow deep breaths through their mouth until the desire to void lessens or goes away.
• Ask the person to try to increase each interval by 15 minutes at a time, until the point is reached when the person can wait to void until their next regularly scheduled time.

• After each week of success, increase the intervals between voiding by 30 minutes.

• The goal is to achieve a consistent period of 2-4 hours between voids during the daytime and 6 hours during nighttime and no accidents between voids.

**Bowel training**

Bowel training helps to recover normal bowel movements in persons who suffer from bowel incontinence. Bowel training helps to recover the bowels’ normal reflexes and this can be done by

• Setting up a routine time to toilet. The best time is in the morning after breakfast. This might also depends on the past habit of the person.

• Follow the schedule regularly. You might assist the person to toilet for 30 minute after meals.

• Provide plenty of fibre in the diet (for example oat bran, wheat bran, brown rice and green vegetables) and ask the person to drink plenty
of water to promote soft stool (2000-2400ml/day but remember to check if the person has any fluid restriction).

- When the person has the urge to empty the bowel, do respond right away to that urge. This is because the longer the stool is in the rectum, the more water the rectum will absorb from it and it will make it harder to pass the faeces.
- If the person needs a stool softener, consult with doctor.

How to care for a urinary catheter?

A urinary catheter is a soft, thin rubber tube with a balloon on the end. This tube is placed through the urethra into the bladder. It is used for draining urine from the bladder. The balloon at the end of the catheter helps to hold the catheter in place (see picture).

- The person should shower regularly, washing the urethral meatus with warm soapy water and dry well.
- If the person is not able to shower, help the person to carry out good personal hygiene around the meatal area.
• Tap water is sufficient for cleaning genitalia.

• Encourage the person to drink plenty of fluids if the person’s condition permits.

• Make sure that the person does not lie or sit on the tube.

• The urinary bag or drainage bag should be below bladder level.

• Tape the catheter tube to the leg.

• Empty the urine bag when it is nearly full.

• Wash your hand before and after emptying or changing the bag.

• Ensure that urine is flowing freely and prevent the tube blocking by milking the tube.

• Check the urine colour, it should be clear yellow.

• Observe for leakage around the tube, check to see if the balloon has deflated, and check if the catheter is blocked. Correct, if possible, replacement may be required if unsuccessful.

• The nurse should change the tube at least once a month or more if necessary (for example urine does not flow).

• Remember that the tube is a foreign object in the body, thus it should be considered as a risk of infection. Therefore, proper hygiene should be maintained at all the time. Do not allow stool to collect on or around the tube. Clean immediately after every bowel movement.

• Change the bag weekly.
How do I know if a person has a urinary tract infection?

A urinary tract infection is a common problem associated with the use of a urinary catheter. Therefore it is very important to know how to look after a person who has a urinary catheter inserted.

Look out for the following problems:

• Observe the colour and the smell of urine; if it seems to be smelly and the urine is unclear or cloudy.

• Fever and chill or the body temperature is raised.

• Complaining of pain or burning while passing urine.

• Feeling unwell.

• Blood or pus in urine.

• Feeling tired.

If all or some of the condition mentioned appear, contact doctor to find out if the patient has urinary tract infection and what needs to be done.
Positioning, moving and transfer

General things that you should remember when helping the person with positioning, moving and transferring are

- The goals are to maintain the person’s safety and comfort and help them to reach as high level of independence as possible.
- Move slowly and gently.
- Encourage the person to participate as much as possible.
- Never pull the person’s affected arm.
- When the person is sitting, support the affected arm with pillows, armrest etc.
- Do not pull the person.
- During a transfer, make sure that the wheelchair brakes are applied, armrest removed and footrest up and swung out of the way.
- Start transferring with appropriate position by bringing their buttocks closer to the edge of the surface one side forwards at a time.
- Position yourself as close to the person as possible without blocking the direction of movement.
- Seek advice from doctor, nurse, physiotherapist or health care personnel if you fee that you are not sure and need advice.
Positioning

**Positioning for a person that is weak on one side of the body** (adapted from the leaflet by the Stroke foundation of New Zealand)

1. Sitting:

   - Support the affected arm on adjustable table or chair. If the armrest is too low, you might use pillows. (if in bed support with pillows)
   - Back supported by chair (if in bed by pillows)
   - The feet flat on the floor (if in bed feet straight)
   - Equal weight through both sides of buttocks
2. Lying on the unaffected side

- Head and trunk straight
- Pillow behind the back
- Shoulders and pelvic girdle forward
- Affected arm and leg relaxed forward onto pillow

3. Lying on affected side

- Ease affected shoulder forward
- Affected arm resting on the bed, palm upwards
- Place unaffected leg flexed forward on one or two pillows
4. Lying in bed

- Pillow supported under the affected arm
- Protect heel from pressure (support with pillow)
Moving

Moving the person to the side of the bed

To prevent injury to yourself, remember to bend your knees and keep your back straight.

1. Slide both hands under the person upper back until your hands are under the person’s far shoulder, then slide the person’s shoulders towards you on your arms, using your arms as rollers between the person and the sheet.

2. Slide both of your hands as far as you can under the person’s hips and slide the person’s hips toward you.

3. Lift and move the person’s legs in the same way.
**Turning the person to one side**

1. Stand at the side of the bed that you want the person to turn to.
2. Cross the person’s far leg over the near one bending the knee.
3. Reach across the person’s body, place one hand behind the person’s shoulder, and then place your other hand behind the person’s hip.
4. Gently roll the person towards you.


**Moving the person from lying to sitting**

Ask the person to (you might advise the person to do this by themselves but if they can’t do it, you might have to help):

- Bend both the person’s knees up.
- Lift and turn his or her head to look in the direction that you want to roll the person.
- Roll completely over onto his or her side, without forgetting the affected arm.
- Bend his or her hips up (draw knees towards chest).
- Slip both feet over the edge of the bed.
- Push up with his or her arm.
- Sit up tall.
**Moving from sitting to standing**

It is very important to make sure that the person wears non-slip footwear or bare feet. The person should not wear socks or stocking onto the floor because it might be too slippery and dangerous.

**Ask the person to** (you might advise the person to do this by themselves but if they can’t do it, you might have to help)

- Slide his or her hips forward to the edge of the bed/chair.
- Sit up tall.
- Position his or her feet about shoulder width apart, with heels directly below the knees. Be sure that the heels of both feet are touching the floor.
- Bend forward at the hips and look forward. Keeps his or her back straight (trunk and neck should remain extended as hips flex). Bring his or her shoulders forward in line with the knees
- Push up with both legs. Keep his or her weight equally distributed over both legs.
- Stand up tall
- Stand for few seconds until the balance is stable. Then place the hands on the walker’ handgrips before start walking.
To start walking

Ask the person to

- Pick up the walker, place it about one foot ahead.
- Place his or her affected leg ahead, respecting weight limitations allowed by the doctor. It should be even with back legs of walker.
- Push down with his or her hands and move the unaffected leg forwards. It should be midway between front and back leg of the walker.
- Repeat sequence.

Stairs

Going up the stairs

1. Lead up with the good foot
2. Move the cane and the affected foot up to the step at the same time
3. Continue one step at a time

Going down the stairs

1. Bring cane and affected leg down one step
2. Bring good leg down to cane and affected leg
3. continue one step at time
Remember to climb up with the Good and down with the weak. Do not attempt to use a walking frame on the stairs.
Transfer

Helping the person to transfer from bed to chair

1. Roll the person on to his or her side, lower the feet and get into seated position by having him or her push up with the hands.

2. Get the person ready, change their clothes and put on the shoes if required.

3. Get the wheelchair ready, remove the arm-rest of the wheelchair that is closer to the bed, swing away both foot rests, position the wheelchair by the side of the bed and apply the brakes to lock the wheelchair.

4. Get yourself ready, by position one foot between the person’s feet (with both heels touching the ground), place your other foot in the direction of movement and place your hands on both sides of the person’s back.

5. Get ready for the move, tell the person that you are making the move, keep your back straight, lean back to lift the person’s weight off the bed and swing over to the wheelchair in a smooth and controlled movement.

6. Lean the person forwards, move his or her buttock well into the seat and sit the person upright

7. Put back the arm rests and foot rests, place the person’s feet onto the foot rests in a comfortable position, straighten out the person’s clothes and unlock the wheelchair.
Role of family caregiver

As a family caregiver, you can help the person but you need to look after yourself as well. As a family caregiver, you need to:

1. Understand the stroke survivor: by observing the stroke survivor carefully you will gain insight and knowledge into the meaning of their survivor behaviors. This is because of your unique relationship with the person.

2. You can help in the recovery process by making sure you get as much information you can from the doctor, nurse or health care staff.

3. Be patient: a stroke survivor needs time to re-learn the life skills. This cannot be done overnight. You need to encourage the person by allowing time for the person to do for themselves. Remember that your aim is to help the person to be independent.

Caring for yourself

1. Organising care for the stroke person: you do not need to do everything on your own, if you can afford, you can ask for help from private health care professional and if you cannot, ask a family member to help.
2. Be aware of your limits: being a caregiver does not mean that you have to devote your entire life to the stroke survivor. You should know when to take time off.

3. Keep up social contact: do not isolate yourself or the survivor. Inviting friends and other family members to your home can help to create a supportive living environment.

4. Deal with your feelings by sharing with a close friend or another caregiver who can listen to you. Sharing experience has been shown to relieve stress.

5. Take time out for yourself regularly: this can include anything from taking a walk to reading a book or listening to music, going to temple etc.

6. Do not be afraid to ask your family members or friends to help when you need a break.

7. Do not worry that the survivor will fall apart without you, you should try to promote independence for them.

8. Consider counseling: some time you might feel that things are crushing, at this stage, you should seek for help from a health care professional. Professional advice may help you to deal with difficulties.

9. Don’t feel guilty for not doing everything.
Appendix 6

Interview Schedule for Telephone follow-up

To be completed by primary caregiver

1. Introduction

a) Introduce self (person interviewing) and remind family caregivers of education sessions that the family caregiver and the patients participated in during the hospitalisation.

2. Caregiver burden

a) How are you (name of family caregiver) managing?

b) Are there any problems or issues that effect you specifically as the main carer?

(prompt: asked about the detailed activities and support that the family caregivers provides to the stroke survivors; ability to make decision about care provide at home; the manner in which the family provides support to assist the stroke survivors perform his/her own care; factors that inhibit and facilitate self care)

c) Is there anything that would make it easier for you to provide care?

d) Is it difficult for you to reposition and move (name of stroke survivor)?
3 About the stroke survivor

a) How is (name of stroke survivor)?

(prompt: asked about the daily life of the stroke survivors; how life has change after stroke; the activity that the stroke survivors can do themselves and those needing help from others)

b) Has (name of stroke survivor) had any problem such as

- Urinary tract infection, bed sore or pressure ulcer, shoulder pain, contractures, chest infection, hypertension
- Did the stroke survivor have any problem with eating, swallowing or feeding?
- Did the stroke survivor have any incontinence problem (or any problem with the Foley catheter)

c) Has (name of stroke survivor) been to a hospital for treatment relating to complications of the stroke (give example such as urinary tract infection, chest infection, dehydration and etc)?

d) Anything else you (name of family caregiver) would like to discuss?

4 Follow-up

a) When is the best time to contact you (name of family caregiver) next month?
Appendix 7

Mini Mental State Examination (MMSE)

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Orientation</strong>: one point for each answer</td>
<td></td>
</tr>
<tr>
<td>• Ask: “What is the: year, season, date, month?”</td>
<td>__</td>
</tr>
<tr>
<td>• Ask: “Where are we: state, county, hospital, floors?”</td>
<td>__</td>
</tr>
<tr>
<td><strong>Registration</strong>: score 1, 2, 3, points according to how many are repeated</td>
<td>__</td>
</tr>
<tr>
<td>• Name three objects: Give the patients one second to say each</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patient to: repeat all three after you have said them</td>
<td>__</td>
</tr>
<tr>
<td>Repeat them until the patient says all three</td>
<td></td>
</tr>
<tr>
<td><strong>Attention and calculation</strong></td>
<td></td>
</tr>
<tr>
<td>Ask the patient to: begin from 100 and count backward by 7 stop after 5 answers. (93, 86, 79, 72, 65)</td>
<td>__</td>
</tr>
<tr>
<td><strong>Recall</strong>: one point for each correct answer</td>
<td></td>
</tr>
<tr>
<td>• Ask the patient to: name the three object from above</td>
<td>__</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
</tr>
<tr>
<td>• Ask the patient to: identify and name a pencil and a watch .(2 points )</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patients to: repeat the phrase “No ifs, and, or buts.”(1 point)</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patient to: “take a paper in your right hand, fold it in half, and put it on the floor” (1 point for each task completed properly)</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patient to: read and obey the following “close your eyes.” (1 points)</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patient to: write a sentence. (1 point )</td>
<td>__</td>
</tr>
<tr>
<td>• Ask the patient to: copy a complex diagram of two interlocking pentagons(1 point)</td>
<td>__</td>
</tr>
<tr>
<td><strong>TOTAL (0-30)</strong></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 8

Patients Survey

1. Date of Birth ..........................................................................................
2. Age..........................................
3. Address.................................................................
4. Phone number............................................................
5. Gender
   1=Male
   2=Female
6. Occupation
   1=Government official
   2=Employee (non government)
   3=Agriculturist
   4=Business or self employed
   5=Unemployed
7. Education
   0=No education
   1=Elementary school
   2=Middle grade/professional school
   3=High school
   4=College /University
8. Marital status
   1=Married
   2=Single
   3=Widowed
   4=Divorced
9. Care giver
   1=Spouse
   2=Child
   3=Parents
   4=Relatives
   5=Other (please indicate relationship)…………………

10. Leisure activity
   1=House work …… Yes…………No
   2=TV, Radio………. Yes………… No
   3=Reading ………..Yes……….. No
   4=Social activity…… Yes………… No
   5=Exercise ……… Yes………… No
   6=Other activity
      at home….. Yes……No (if yes please indicate the activity)………….
   7=Other activity
      outside home Yes……No (if yes please indicate the activity)………….

11. Smoking
   No………Yes (if yes please choose the answer below)
   1=Been smoking but already quit for…..years
   2=Been smoking for less than five years then quit
   3=Current smoker, less than 20/day
   4=Current smoker more than 20/day ago

12. Alcohol
   No………Yes (if yes please choose the answer below)
   1=0-2 standard drinks/per
   2=up to 4 drinks per day
   3=greater than 4 drinks /day in 2 or more days /week
   4=greater than 6 drinks/day in 4 or more days a week

13. Onset of stroke /date ………………………………

14. Diagnosis …………………………………………
15. Site of weakness
   1= Left side
   2=Right side
   3=Both side
   4=No weakness

16. Type of therapies in stroke rehabilitation/ number of sessions since onset of stroke
   1=Physiotherapy
   2=Speech therapy
   3=Occupational therapy
   4=Neurophychological therapy

17. Commodity
   1=No
   2=Yes (if yes please indicate disease/disorder)…………………………..

18. Height……………………

19. Weight ………………….

20. Blood Pressure…………..
Appendix 9

Family caregivers Survey

1. Age

2. Address

3. Phone number

4. Gender
   1= Male
   2= Female

5. Primary caregiver relationship to patient
   1= Spouse
   2= Child
   3= Parents
   4= Relatives
   5= Other (please indicate relationship)

6. Occupation
   1= Government official
   2= Employee
   3= Agriculturist
   4= Business
   5= Unemployed

7. Education
   0= No education
   1= Elementary school
   2= Middle grade/professional school
   3= High school
   4= College/ university
8. Marital status
   1=Married
   2=Single
   3=Widowed
   4=Divorced

9. Leisure activity
   1=House work ……  Yes………….. No
   2=TV, Radio……….. Yes………… No
   3=Reading …………. Yes………… No
   4=Social activity….. Yes………… No
   5=Exercise ……….. Yes………… No
   6=Other activity
      at home….. Yes… No (if yes please indicate the activity)…………
   7=Other activity
      outside home…. Yes No (if yes please indicate the activity)…………

10. Do you have any previous care giving experience?
    1=Yes please indicate (who, for what reason and for how long)…………
    2=No

11. Do you provide care for a person other than the patient in this study?
    1=Yes, please indicate
       • number of person you provide care for …………
       • disease …………. for how many years or how long ………
       • time spent in care giving per day …… (Hour/day)
    2=No

12. Do you have other people at home to assist with the care of the person in this study?
    1= Yes, please indicate how many at home who do assist ………………………
    2= No
13. Family income (Baht/month)…………………………

14. Adequacy of income
   1=Adequate and no money saved
   2=Adequate and had money saved
   3=Inadequate

15. Do you have any health problems?
   1. Yes, if yes please indicate your health problems………………
   2. No
# Appendix 10

**Barthel Index**

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Bowels</strong></td>
<td>0=Incontinent</td>
<td>1=Occasional accident</td>
</tr>
<tr>
<td></td>
<td>2=Continent</td>
<td></td>
</tr>
<tr>
<td><strong>2. Bladder</strong></td>
<td>0=Incontinent/catheterised</td>
<td>1=Occasional accident (max 1 per day)</td>
</tr>
<tr>
<td></td>
<td>2=Continent (for over 7 days)</td>
<td></td>
</tr>
<tr>
<td><strong>3. Grooming</strong></td>
<td>0=Needs help</td>
<td>1=Independent (face, hair, teeth, shaving)</td>
</tr>
<tr>
<td><strong>4. Toilet use</strong></td>
<td>0=Needs help</td>
<td>1=Needs some help but can do something</td>
</tr>
<tr>
<td></td>
<td>2=Independent (on and off, dressing/wiping)</td>
<td></td>
</tr>
<tr>
<td><strong>5. Feeding</strong></td>
<td>0=Unable</td>
<td>1=Need help, cutting, spreading butter</td>
</tr>
<tr>
<td></td>
<td>2=Independent</td>
<td></td>
</tr>
<tr>
<td><strong>6. Transfer</strong></td>
<td>0=Unable</td>
<td>1=Major help (1-2 people, physical)</td>
</tr>
<tr>
<td></td>
<td>2=Walk with help of one person</td>
<td>3=Independent</td>
</tr>
</tbody>
</table>

APPENDIX 10

Code.............
Date................
7. Mobility  
0=Immobile  
1=Wheelchair independent including corners  
2=Walk with help of one person (Verbal/physical)  
3=Independent (but may use any aid e.g. stick)  

8. Dressing  
0=Dependent  
1=Needs help but can do about half unaided  
2=Independent  

9. Stairs  
0=Unable  
1=Needs help (verbal and physical/carrying aid)  
2=Independent up and down  

10. Bathing  
0=dependent  
1=Independent  

Total (0-20)……………………
Appendix 11

Caregiver Strain Index (CSI)

‘I am going to read a list of things which other people have found to be difficult in helping with after someone comes from the hospital.’ (or)

‘I am going to read a list of things which other people have found to be difficult when helping someone who has an illness’.

‘Would you please tell me whether any of these apply to you?’ (give an example)

<table>
<thead>
<tr>
<th>Questions</th>
<th>Yes</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sleep is disturbed (e.g. Because… is in and out of bed and wanders around at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. It is inconvenient (e.g. because helping takes so much time or it is a long drive over to help)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. It is confining (e.g. helping restricts free time, or cannot go visiting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. There have been changes in personal plan (e.g. had to turn down a job; could not go on a vacation/holiday)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. There have been other demand on my time (e.g. from other family members)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. There have been emotional adjustment (e.g. because of severe argument)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Some behavior is upsetting (e.g. because of incontinence;…has trouble remembering things, or… accuses people of taking things)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. It is upsetting to find …has changed so much from his/her former self (e.g. he/she is a different person from he/she used to be)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. There have been work adjustments (e.g. because of having to take time off).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. It is a financial strain.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Feeling completely overwhelmed (e.g. because of worry about….; concerns about how you will manage).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Score ‘Yes’=1
‘No’=0
Appendix 12

Modified Rankin Scale (mRS)

<table>
<thead>
<tr>
<th>Grade description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. No symptoms at all</td>
</tr>
<tr>
<td>1. No significant disability, despite symptoms; able to carry out all usual duties and activities</td>
</tr>
<tr>
<td>2. Slight disability; unable to carry out all previous activities but able to look after own affairs without assistance</td>
</tr>
<tr>
<td>3. Moderate disability; requiring some help, but able to walk without assistance</td>
</tr>
<tr>
<td>4. Moderate severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance</td>
</tr>
<tr>
<td>5. Severe disability; bedridden, incontinent and requiring constant nursing care and attention</td>
</tr>
</tbody>
</table>
Appendix 13

General Health Questionnaire –28 (GHQ-28)

We would like to know if you have had any medical complaint and how your health has been over the past few weeks please answer all the questions on the following pages simply by marking the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not about those you have had in the past.

<table>
<thead>
<tr>
<th>Somatic symptoms</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Worse than usual</th>
<th>Much worse than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Been feeling perfectly well and in a good health</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Been feeling in a need of a good tonic</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>3. Been feeling run down and out of sorts?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>4. Felt that you are ill</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>5. Been getting any pains in your head</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>6. Been getting a feeling of tightness or pressure in your head ?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>7 Been having hot or cold spells?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Anxiety and insomnia</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Lost much sleep over worry?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>9. Had difficulty staying asleep once you were off?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>10. Felt constantly under strain?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>11. Been getting edgy and bad tempered?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td>12. Been getting scared or panicky for no good reason?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
<td>Much more than usual</td>
</tr>
<tr>
<td></td>
<td>13. Found everything getting on top of you</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td>---</td>
<td>------------------------------------------</td>
<td>------------</td>
<td>-------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td></td>
<td>14. Been feeling nervous and strung –up all the time</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td>Social dysfunction</td>
<td>Have you recently:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15. Been managing to keep yourself busy and occupied?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Rather less than usual</td>
</tr>
<tr>
<td></td>
<td>16. Been taking longer over things you do?</td>
<td>Quicker than usual</td>
<td>Same as usual</td>
<td>Longer than usual</td>
</tr>
<tr>
<td></td>
<td>17. Felt on the whole you were doing things well?</td>
<td>Better than usual</td>
<td>About the same</td>
<td>Less well than usual</td>
</tr>
<tr>
<td></td>
<td>18 Been satisfied with the way you have carried out your task?</td>
<td>More Satisfied</td>
<td>About same as usual</td>
<td>Less satisfied than usual</td>
</tr>
<tr>
<td></td>
<td>19 Felt you are playing a useful part in things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less useful than usual</td>
</tr>
<tr>
<td></td>
<td>20. Felt capable of making decisions about things?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
</tr>
<tr>
<td></td>
<td>21. Been able to enjoy your normal day-to-day activities?</td>
<td>More so than usual</td>
<td>Same as usual</td>
<td>Less so than usual</td>
</tr>
<tr>
<td>Severe depression</td>
<td>Have you recently:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22. Been thinking of yourself as worthless person?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td></td>
<td>23. Felt that life is entirely hopeless?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td></td>
<td>24. Felt that life isn’t worth living?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td></td>
<td>25. Thought of the possibility that you might make away with yourself?</td>
<td>Definitely not</td>
<td>I don’t think so</td>
<td>Has crossed my mind</td>
</tr>
<tr>
<td></td>
<td>26. Found at times you couldn’t do anything because your nerves were too bad</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td></td>
<td>27. Found yourself wishing you were dead and away from it all?</td>
<td>Not at all</td>
<td>No more than usual</td>
<td>Rather more than usual</td>
</tr>
<tr>
<td></td>
<td>28. Found that the idea of taking your own life kept coming into your mind?</td>
<td>Definitely not</td>
<td>I don’t think so</td>
<td>Has crossed my mind</td>
</tr>
</tbody>
</table>

Scoring from ‘0’ for the leftmost column to ‘3’ for rightmost column
Appendix 14

Human Research Ethics Approval

Miss Roshinee Oupra
Royal Rehabilitation Centre Sydney
Rehabilitation Nursing Research and Development Unit
PO Box 6
Ryde 1680

Dear Roshinee

Re: HREC 05/018 The effect of an educative supportive nursing intervention for the stroke caregivers on providing care to stroke patients

The Committee reviewed your application and has agreed to approve this project. It is suggested that you review the language question on page 17 of the questionnaire to read “ask the patients to: repeat the phrase no ands, if or buts”. Please also note a change in the telephone number for the Human Ethics Officer to 47 360 883, which should be revised in the Information letters and consent forms.

You are advised that the Committee should be notified of any further changes to the research methodology should there be any in the future. You will be required to provide a report on the ethical aspects of your project at the completion of this project. The form is located on the Research Services Web Page.

The Protocol Number HREC 05/018 should be quoted in all future correspondence about this project. Your approval will expire 30 December 2006. Please contact the Human Ethics Officer, Kay Buckley on tel: 02 47 360 883 if you require any further information.

The Committee wishes you well with your research.

Yours sincerely

Professor Elizabeth Deane
Chairperson
UWS Human Research Ethics Committee
Cc Professor Rhonda Griffiths