# Effect of a community based rehabilitation program
# on outcomes for stroke survivors in Thailand

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## บทคัดย่อ

โรคหลอดเลือดสมองหรือที่นิยมเรียกกันว่า "Stroke" ในทางการแพทย์มักจะเรียกกันว่า CVD "Cerebrovascular disease" นั้น เป็นหนึ่งในสาเหตุหลักที่ทำให้ผู้ป่วยเสียชีวิตทั่วโลกประมาณ 20 ล้านคนต่อปี (องค์การอนามัยโลก, 2542; เมนดิส และ คณะ, 2547) ผู้ป่วยโรคหลอดเลือดสมองหากรอดชีวิตมักมีความพิการหลงเหลือ ส่งผลกระทบต่อร่างกาย จิตใจ และสังคมของผู้ป่วย ทั้งนี้ เนื่องจากการกลับไปใช้ชีวิตที่บ้าน ผู้ป่วยจำเป็นต้องได้รับการดูแลจากผู้อื่นอย่างต่อเนื่อง เนื่องจากความสามารถในการปฏิบัติกิจวัตรประจำวันที่จำกัด ส่งผลให้ผู้ป่วยเกิดปัญหาด้านจิตใจ ดังนั้น จึงมีความจำเป็นที่ญาติผู้ให้การดูแลผู้ป่วยที่บ้านมีความรู้และทักษะในการดูแลผู้ป่วย เพื่อที่จะสามารถให้การดูแลผู้ป่วยได้อย่างถูกต้อง ป้องกันการเกิดภาวะแทรกซ้อน

การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อสร้างและทดลองการใช้โปรแกรมการพยาบาลระบบสนับสนุนสำหรับญาติ หรือผู้ให้การดูแลผู้ป่วยโรคหลอดเลือดสมองที่บ้าน (SELF) ประเมินผลประสิทธิภาพของโปรแกรมการพยาบาลระบบสนับสนุนสำหรับญาติ หรือผู้ให้การดูแลผู้ป่วยในการฟื้นฟูสภาพร่างกายผู้ป่วยที่บ้าน และลดภาวะแทรกซ้อนในผู้ป่วย การศึกษาครั้งนี้เป็นการศึกษาแบบทดลองเปรียบเทียบผู้ป่วย 2 กลุ่ม จากโรงพยาบาล 2 แห่ง เก็บข้อมูลก่อนและหลังการใช้โปรแกรมการทดลองโดยเปรียบเทียบระหว่างกลุ่มควบคุมและกลุ่มทดลอง กลุ่มทดลองได้เข้าโปรแกรมพัฒนาความรู้ ฝึกทักษะในการดูแลผู้ป่วย และให้คำแนะนำทางโทรศัพท์หลังจำหน่ายทุก 1 เดือน เป็นระยะเวลา 3 เดือน

ผลการศึกษาพบว่า หลังจากจำหน่ายกลับบ้านครบ 3 เดือน ผู้ป่วยโรคหลอดเลือดสมองในกลุ่มทดลองมีประสิทธิภาพการทำงานของร่างกายดีกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ (BI $t$ = 2.43, $p$ = 0.017; mRS Z = 3.176, $p$ = .001) และมีการกลับเข้ารับการรักษาเนื่องจากภาวะแทรกซ้อนน้อยกว่ากลุ่มควบคุม (กลุ่มทดลอง $n$ =10 [14.3%]; กลุ่มควบคุม $n$ = 34 [48.6%]) จากผลการศึกษาครั้งนี้ทำให้กล่าวได้ว่าการให้การฟื้นฟูสภาพร่างกายแก่ผู้ป่วยโรคหลอดเลือดสมองอย่างมีแบบแผนโดยการใช้โปรแกรมการพยาบาลระบบสนับสนุนสำหรับญาติโดยให้ความรู้และฝึกทักษะ มีผลอย่างมีนัยสำคัญทางสถิติในการฟื้นฟูสภาพร่างกายผู้ป่วย และป้องกันภาวะแทรกซ้อน

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## ABSTRACT

Stroke is the leading cause of death worldwide (WHO Guidelines Subcommitte, 1999) attributing to the death of around 20 million people a year (Mendis et al., 2004). Stroke survivors usually have some degree of disability which makes the condition a particularly costly disorder for individuals, the health system and society.

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Returning home or to the community can be a traumatic experience for stroke survivors. It is vitally important that family caregivers have sufficient knowledge and skills to provide appropriate care to assist the stroke survivors to avoid complications and to overcome their functional deficits. This study aims to (i) develop and implement a nurse led supportive educative learning programme for family caregivers (SELF) of stroke survivors in Thailand, (ii) evaluate the effect of the SELF programme on functional ability of stroke survivors and (iii) reduce the incidence of complications among stroke survivors in Thailand. This study was a comparative study with concurrent controls, using a two-group pre-test and post-test design and was conducted in two hospitals in different cities in Thailand. The intervention groups received training program (SELF) that comprises didactic education sessions, hands on training for family caregivers, a booklets and three follow-up phone calls. The findings demonstrated that stroke survivors in the intervention group scored better for functional outcome at three months follow-up (BI $t$ = 2.43, $p$ = 0.017; mRS Z = 3.176, $p$ = .001), and had fewer readmissions for the management of stroke related complications (intervention $n$ =10 [14.3%]; control $n$ = 34 [48.6%]). Consequently, this research has demonstrated that a structured rehabilitation skills education programme for family caregiver of stroke survivors can significantly improve the functional status of stroke survivors and prevent development of the common complications.

## Background

In Thailand, the incidence of stroke is increasing and currently one new stroke is diagnosed every four minutes (Ministry of Public Health Thailand, 2004).

Stroke is the third leading cause of death in Thailand (Ministry of Public Health Thailand, 2004). For the six years 1999 to 2004 the number of people who died due to stroke increased dramatically with men having a higher incidence than women. The study claims 12,636 men and 9,120 women died from stroke in 2004 (National Statistical Office Thailand, 2004). Stroke carries a high rate of morbidity (Asian Acute Stroke Advisory Panel, 2000), and is ranked in the top 20 causes with 150,000 people becoming disabled each year in Thailand (Ministry of Public Health Thailand, 1999). 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 et al., 2000).

In some countries, community care programmes, 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 in developed countries is 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 programmes 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 et al., 2006).

## Aims of the study

This study sought to develop and implement a nurse led supportive educative learning programme for family caregivers (SELF) of stroke survivors in Thailand, evaluate the effect of the SELF programme on functional ability and quality of life of stroke survivors and to reduce the incidence of complications among stroke survivors in Thailand.

## Methods

This two group comparative study with concurrent controls was conducted in two hospitals in different cities in Thailand. While the Randomised Control Trial is the preferred design for trials of effectiveness, a comparative study with each group located in different hospitals was considered to be the most effective way to prevent contamination of the control group by staff also providing care to patients assigned to the intervention group. This paper reports data from stroke survivors. Data describing family caregivers' outcome will be reported elsewhere.

## Recruitment

The target population was the stroke survivors admitted to the study hospitals with a diagnosis of acute stroke. Stroke survivors who met the inclusion criteria were recruited 24-48 hours following admission. The stroke survivors were recruited if they : a) had suffered a first stroke; b) scored $\geq 20$ for Mini Mental State Exam (MMSE); c) spoke Thai language; d) were to be discharge to their homes; e) had a family caregiver at home; f) had access to a telephone and g) gave informed consent to participate. The stroke survivors were excluded if they meet the inclusion criteria but were to receive follow-up care at another region of Thailand. Patients were also excluded if their family caregiver had a

notable disability or history of any serious illness that would impede ability to implement skills learned in the education program. A power analysis demonstrated that, based on the calculation of t-test, to have 80% chance of detecting effect size of 0.5 S.D., a minimum of 64 patients per group was required.

## The Intervention

The Supportive Educative Learning programme for Family caregivers (SELF) is a training programme that comprises didactic education sessions and hands on training for family caregivers, a booklet for family caregivers describing stroke care and a follow-up phone call each month for three months following discharge. Carers assigned to the intervention group received education in group sessions which provided an opportunity for them to share their opinions and support each other. (Johnson & Pearson, 2000; Rodgers et al., 1999; Warner, 2000) The three interactive education sessions of approximately 90 to 150 minutes' duration, included time for group discussion. The content included risk factors for stroke, management of complications, nutrition and hydration, bladder and bowel care, positioning and transferring stroke survivors, and caregiver self-care strategies. A maximum of six family caregivers participated in each session.

## Data collection tools

Data collection tools used in this study comprised the following previously validated scales

1. The Barthel Index (BI) (Collin et al., 1987; Jitapunkul, 1998; Mahoney & Barthel, 1965) is a measure of functional ability. The score ranges from 0-20, with higher scores denoting greater independence

2. The modified Rankin scale (mRS) (Rankin, 1957; Van Swieten et al., 1988) is a measure of the severity of stroke and functional outcome, and serves as a measure of independence following stroke

### Data collection

Data were collected at three stages:

Stage one: Immediately following recruitment demographic data were obtained from the patients in both groups, together with the BI.

Stage two: prior to discharge from the hospital, the mRS, and the BI were administered to patients in both groups.

Stage three: The Barthel Index (BI) and mRS were collected at three months following discharge. Additionally, the reasons for readmission to hospital of patients in both groups were recorded. Data were collected by research assistants who were blind to the study group allocation.

### 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 will be presented in Mean and standard deviation (S.D.). Student parametric t-test or Mann–Whitney U non-parametric test was used for independent samples and continuous data. 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)

### Results

A total of 140 patients and their 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 whose carers received the intervention and 63 patients 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 could not be contacted for the three months follow-up

#### (I) Demographics data

The demographic data from both groups of patients were comparable. There were no significant differences between the groups for age, gender, occupation, relationship to the carer or marital status. There was a statistically significant difference in education between the groups with patients in the intervention group having a higher level of education than those in the control group ($\chi^2$ = 16.19, $df$ = 4, $p$ = .000). The most frequently reported comorbidities in both groups were hypertension, diabetes mellitus, ischaemic hearth disease, dyslipidemia, and alcoholism and cirrhosis. Chronic obstructive pulmonary disease, Human immunodeficiency virus, peptic ulcer and gout were also reported.

#### (II) Functional ability

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. The mean control and intervention group scores were compared at each stage. All patients were severely disabled at recruitment (control 9.00 [S.D. = 5.16], intervention 8.57 [S.D. = 4.98]), and at discharge stroke survivors in the both groups scored in the moderate disability range (control 10.06 [S.D. = 5.10], intervention 10.09 [S.D. = 4.99]. At three months follow-up, there was a significant improvement in the stroke survivors in both groups compared to discharge. However, when the BI score of the stroke survivor in the control group was compared with the score of the stroke survivors in the intervention group, it was found people in the intervention group scored significantly higher than

people in the control group ($t$ = 2.43, $p$ = .017). For stroke survivors in the control group the mean score has increased from 10.06 (S.D. = 5.10) to 14.10 (S.D. = 5.26) ($F$ = 52.24, $p$ = .000), which classified as moderate disability and the intervention group increase from 10.09 (S.D. = 4.99) to 16.22 (S.D. = 4.56) ($F$ = 168.96, $p$ = .000) which is classified as mild disability.

### (III) Activity limitation

The mRS is categorized into six grades (5, 4, 3, 2, 1, 0) of activity limitation (disability) after stroke. Patients who score 5 are considered to be totally dependent and bedridden, while patients who score 0 are totally independent. The mRS at discharge was similar for both groups (control group 3.89 [S.D. = 0.73]; intervention group 4.00 [S.D. = 0.68]) which indicates moderate to severe disability at discharge for both groups. At three months follow-up, there was a significant improvement in stroke survivors in both groups (control group mRS 3.32 [S.D. = 1.02] [$Z$ = 4.23, $p$ = .000]; intervention group mRS 2.59 [S.D. = 1.29] [$Z$ = 6.413, $p$ = .000]) indicating reduced disability for stroke survivors in both group. However, when the mRS at three months follow-up were compared, the stroke survivors in the intervention group had improved significantly compared to those in the control group ($Z$ = 3.176, $p$ = .001).

### (IV) 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 three months follow-up period than the control group ($n$ = 10[14.3%] vs 34[48.6%]).

### Discussion

This study demonstrated a statistically significant improvement among stroke survivors who received rehabilitation from their family caregivers. Stroke survivors in the intervention group also reported fewer complications and readmissions to hospitals resulting in cost savings for families and the government.

The results from this study have demonstrated that by empowering family members, they can provide timely and appropriate stroke rehabilitation to achieve improved outcomes and quality of life for stroke survivors. Stroke survivors in the intervention group had significantly better outcomes in relation to functional ability when compared to the control group. 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.

This finding is related to a similar study by Kalra, Evan, Perez, Melbourn, Patel and Donalson (2004), who attempted to evaluate 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 the stroke survivors and their family caregivers. Stroke survivors whose family caregivers participated in the training provided as the intervention, reported less anxiety and depression and a higher quality of life, and achieved independence at an earlier stage when compare to the control group.

The effectiveness of the SELF programme designed for this study is further evidenced in relation to complications following stroke. The main complications in the intervention group were recurrent stroke, epileptic seizure, weakness and limb and joint pain. However, in the control group the most common complications were pressure ulcer, aspirate pneumonia, urinary tract infection, and recurrent stroke. These are preventable complications that may have

resolved if family caregivers or the stroke survivor has regular contact with a health professional, who could provide appropriate and timely support, knowledge and skills. These complications may significantly compromise stroke recovery (Kelly et al., 2002) and contrast to complications seen in the intervention group where none of the stroke survivors had preventable complications such as pressure ulcer, urinary tract infection or pneumonia.

Prior to this study, there was no stroke rehabilitation provided in the community in Thailand. Therefore stroke survivors and their family caregivers had an opportunity to obtain skills and knowledge to provide therapy at home to enable them to feel more confident and well supported. The SELF programme 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 readmission (Andersen et al., 2000; Grant et al., 2002).

This study which was supported by the Royal Thai government through a postgraduate scholarship is the first formalized 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 family caregivers to identify problems early and respond in appropriate ways can minimize conditions that cause unnecessary suffering and contribute to early death. This study has demonstrated that taking account of the needs of the community and focusing on patient centered care is an appropriate model for the management of chronic conditions and disability in Thailand.

## Conclusion

This study has demonstrated that when there is no stroke rehabilitation provided in the community by the health care personnel, effective and ongoing rehabilitation of stroke survivors following the acute phase of healthcare can be provided by family caregivers who complete a training program. 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 study sends a clear message to government and providers of care to people with chronic disorders in developing countries, that well designed programmes that provide skills and knowledge, and support ongoing care in the community do demonstrate 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.

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