Abstract of thesis entitled

“An evidence-based guideline of pre-discharge education program to informal caregiver of stroke survivors to reduce caregiver burden”

Submitted by

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In Hong Kong, cerebrovascular disease is the fourth cause of death according to Department of Health in 2015. There were over 3000 people diagnosed with stroke, not as specific as haemorrhage or infraction.

Most of the stroke survivors are taken care of by informal caregivers in the community after discharge. Caregivers always express their worries about the discharge issue and caring issue. Many of the informal caregivers experienced heavy caregiver burden. Some studies showed that chronic stress e.g. caregiver stress may put caregivers at risk of developing depressive symptoms and anxiety. Caregiver burnout is always a result of excessive long-term stress.

However, there are not many interventions to cope with the caregiver burden or caregiver stress of stroke survivors in Hong Kong currently.

This dissertation describes a translational nursing research on a pre-discharge education
program to informal caregivers of stroke survivors which results in reducing caregiver burden.

The aims of this dissertation are assessing the effect of education program to informal caregiver of stroke survivors in reducing caregiver stress; developing an evidence-based guideline of pre-discharge education program; assessing the implementation potential of the proposed education program to informal caregivers of stroke survivors in hospitals in Hong Kong; and setting up an implementation plan and an evaluation plan for the evidence-based education program for informal caregivers of stroke survivors. Systematic search was done from 20 Nov 2015 to 13 Dec 2015 by using two electronic databases, PubMed and ProQuest. Quality and risk of bias of five selected literatures were evaluated using the appraisal system developed by Scottish Intercollegiate Guideline Network. The transferability of the reviewed papers was high as the implementation potential was assessed based on the similarity of target setting and proposed environment.

An evidence-based guideline was developed in this dissertation. An implementation plan with communication plan and pilot study was developed. Besides, evaluation plans on patients, frontline staff and system outcome were established. The estimated time required for planning, preparation, pilot study and evaluation of this guideline was about twelve months.

In summary, the proposed program can lower the caregiver stress and reduce the re-admission rate of stroke survivors.
An evidence-based guideline of pre-discharge education program to informal caregiver
of stroke survivors to reduce caregiver burden

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A thesis submitted in partial fulfilment of the requirements for
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Declaration

I declare that this thesis represents my own work, except where due acknowledgement is made, and that it has not been previously included in a thesis, dissertation or report submitted to this University or to any other institution for a degree, diploma or other qualifications.

Signed:

__________________________________________

Lee Chui Ting
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CHAPTER 1

INTRODUCTION

1.1 Background

Stroke, cerebrovascular accidents, is the major cause of disability and health burden globally (DH, 2015; "Heart disease and stroke statistics-2013 update," 2013). It means the interruption of blood supply to brain which causes damage to brain tissue due to reduction of oxygen and nutrients supply to brain according to World Health Organization (WHO). Weakness of limbs, difficulty in speaking or receiving speech are the common symptoms of stroke. The levels of disability depend on the parts of brain affected and severity of damage. The consequences of stroke can cause short-term physical effects as well as a lifelong and psychological effects to both stroke survivors and their informal caregivers.

Caregiver, who can be formal or informal, is the one who offers assistance to stroke survivors (AHA, 2015a). Informal caregivers are usually spouse, family members or even friends of the stroke survivors. It is often a challenge which gives stress to both parties, informal caregivers and stroke survivors, due to the change of roles. A growing number of studies shows that there are different factors contributing to caregiver burden after stroke. This increase recognized as a significant health problem (H. Rigby, G. Gubitz, & Phillips, 2009). The contributing factors of caregiver burden would be untrained care-giving skills, sleep disturbances and troubles in managing their own family life (Ain, Dar, Ahmad, Munzar, &

As a caregiver of stroke survivors, their responsibilities vary from different individuals. There is no job description for all caregivers (AHA, 2015a). In general, they have to provide assistance in activities of daily life and transportation. Also, they have to manage financial, legal and business affairs. Likewise, safety issues, monitoring of health status, sustaining acquired rehabilitation skills are the common duties of caregivers. Apart from taking care of stroke survivors, caregivers are usually the care providers of a household. They are responsible for housework and providing meals for other family members and stroke victims as well (AHA, 2015a).

1.2 Affirming Needs

Cerebrovascular disease is the 4th cause of death in Hong Kong according to Department of Health in 2015. Hence, stroke is a major cause of disability and health burden in globe as well as in Hong Kong. From the statistics of Hospital Authority in 2014-2015, there was a total of 3507 people diagnosed with stroke, not specified as haemorrhage or infraction. Around one third of them were admitted to acute medical wards of a public hospital in Hong Kong (Hospital A) in 2014.
According to statistics of Hospital A, stroke survivors were usually transferred to stroke rehabilitation units in Hospital A on day 4 after onset of stroke. Following the protocol of stroke management, series of training will be provided in stroke rehabilitation wards. Early engagement of therapeutic exercise would minimize the disabilities caused by stroke (Duncan et al., 2005). Therefore, multidisciplinary management, including doctors, nurses, physiotherapists, occupational therapists, and speech therapists, etc., is adapted for the rehabilitation training of stroke victims.

In current setting, stroke rehabilitation wards of Hospital A, stroke victims are the focus of stroke rehabilitation program. The therapeutic exercise is usually done to stroke survivors only whereas their informal caregivers are not involved. Approximately 90% of the stroke survivors were discharged to home from stroke rehabilitation wards of Hospital A, and were cared by their family members, the informal caregivers, in the community. Training of caregivers was not provided to all of them before discharge. Only a minority of caregivers were given a hand-on skills training from physiotherapists and occupational therapists. And, some of them attended the interfacing program, which is held by ward nurses and about fall prevention at home.

Caregivers always express their worries about the discharge issue of stroke survivors during interviews at bedside. Caregivers do not know how to assist stroke survivors in their daily living. They are not trained for the transfer and lifting technique. Thus, they are fear of injuring
the stroke victims due to accidental falls and improper transferring techniques. The caregivers are hopeless as they do not have enough knowledge about stroke and they do not have the insight. Besides, financial issue is another concern because most of the stroke survivors are the breadwinner of the family. They cannot work owing to the disability after stroke. Some caregivers show a depressive mood on their face or even burst into tears while they are discussing the discharge plan of stroke survivors with nurses. Since the stroke survivors are their beloved one, family members would like to take care of stroke victims at home and hope the survivors can enjoy their life with families.

Currently, there are not many interventions which deal with the caregiver burden or caregiver stress of stroke survivors. Counselling of relatives are mainly done by nurses when they see relatives in ward showing low mood. In present practice of stroke rehabilitation wards of Hospital A, there is a stroke interfacing program for stroke survivors and caregivers which is held by nurses in ward once every two weeks. Stroke survivors and caregivers are invited to join according to their availability. It is not a compulsory event and relatives are invited by a memo only. Besides, printed materials about stroke i.e. booklet, are available in stroke rehabilitation wards. Relatives can take them if they wish. However, not many people would take the booklet away or have a glance at it. Furthermore, caregivers’ training is only provided upon request of relatives or order of medical officers. Otherwise, no training is provided to informal caregivers of stroke survivors.
In total, the rehabilitation program is patient-centered rather than family-centered currently. Nonetheless, the disability of stroke survivors is affecting not only patient himself but also the family members, the informal caregivers. Hence, caregivers should be taken into consideration of a comprehensive rehabilitation program. A pre-discharge education program to informal caregivers of stroke survivors may be beneficial to both stroke survivors and caregivers. Also, systematic review of this topic will be performed due to a lack of systematic review being done.

1.3 Objectives and Significance

1.3.1 Objectives

1. To evaluate the current evidence on education program to informal caregiver of stroke survivors.

2. To assess the implementation potential of the proposed education program to informal caregivers of stroke survivors

3. To develop an evidence-based education program for informal caregivers of stroke survivors.

4. To set up an implementation plan and evaluation plan for the evidence-based education program for informal caregivers of stroke survivors.
1.3.2 Significance

Taking care of stroke survivors at home could be stressful. Studies showed negative health impacts, such as depressive symptoms, were found in stroke caregivers ("Caregiver stress fact sheet," 2013). Caregivers with higher stress levels may prone to a higher risk of elder abuse. The burden of caregiver is a source of stress and burnout (AHA, 2015b; Shim, Barroso, & Davis, 2012). Also, depression is one of the common psychological disorders among caregivers (FCA, 2010).

Mental health of informal caregivers of stroke victims is as important as health status of stroke survivors. Thus, rehabilitation training of stroke survivors should be family-centered. Pre-discharge education of caregivers can enhance the preparedness of discharge of stroke survivors. A local study identified that stroke caregivers would like to receive education and training about skills of caring for stroke survivors especially at the beginning of discharge (C. Chow. & A. Tiwari, 2014). It is believed that the program can reduce their worries about the discharge and caring issue of stroke survivors. Relatives are willing to have prior discussions about discharge plan and have early discharge. Hence, it is important to carry out an education program to caregivers of stroke survivors in Hong Kong, as part of a comprehensive stroke rehabilitation program.
CHAPTER 2

CRITICAL APPRAISAL

2.1 Search and Appraisal Strategies

2.1.1 Identification of study

A systematic search was done from 20 Nov 2015 to 13 Dec 2015 by using two electronic databases, PubMed and ProQuest. The relevant studies were identified from these databases with regard to effects of education program to informal caregivers of stroke survivors on caregiver burden. The keywords used were as follows, ‘stroke’, ‘cerebrovascular accident’, ‘caregivers’, ‘carers’, ‘education’ and ‘programs’.

The inclusion criteria are:

- The intervention is related to education or pre-discharge preparation for caregiver of stroke survivors
- The target group was informal caregivers of in-patients with stroke
- Stroke survivors were cared by informal caregivers in the community after discharge
- The outcome measures were psychological aspects of informal caregivers of stroke survivors
- The study design was controlled trial
The exclusion criteria are:

- Caregivers of chronic stroke survivors
- Stroke survivors who were discharged

2.1.2 Data Extraction

The search was performed within the mentioned period. Title and abstracts of the resulting citations were screened. Thus, full text of papers and the reference lists were reviewed if the articles matched the selection criteria.

Information about design of study, characteristics of participants, intervention, length of follow up, outcome measures and effect size were summed up and presented in a table of evidence following the guideline by SIGN (SIGN, 2014).

2.1.3 Appraisal Strategies

The qualities of studies were appraised critically and divided into different grading by using a methodology checklist developed by SIGN (SIGN, 2014). The SIGN checklist is used to assess to methodological quality of the studies. Quality of studies will be assessed concerning the following aspects:

1. Appropriate and clearly focused question is addressed in study
2. Allocation method of subjects
3. Method of concealment
4. Blinding of parties involved in studies
5. Baseline similarity of between intervention group and control group

6. Contamination of intervention

7. Validity and reliability of outcome measurement

8. Drop-out rate

9. Intention-to-treat analysis

10. Comparability of results from different sites

The chosen studies will be rated in terms of level of evidence by means of SIGN grading system after the critical appraisal done as above (SIGN, 2014). According to the categorizing system of SIGN(2014b), number 1 to 4 are used to categorize the level of evidence of the reviewed papers. Besides, signs of + and – are used to segregate the level of evidence of the paper. The sign ++ indicates has fewest or no bias, while + indicates the paper has few bias. For the sign -, it indicates the paper is prone to have bias. A table showing the categorizing system of level of evidence is shown in Appendix 1.

2.2 Results

2.2.1 Search Results

By using the keywords listed former, 366 to 8824 results were generated from the two databases. Then, study type was limited to controlled trial, 69 studies were found in PubMed and 1119 studies from ProQuest. After screening for duplication, 1174 studies were screened manually based on the titles, abstracts, and full text by which inclusion and exclusion criteria
were considered. After abandoning the unrelated studies, five studies remained. Thus, these studies were selected for appraisal in this dissertation. The history of search was concluded in PRISMA Flow Diagram in Appendix 2.

2.2.2 Study Characteristics

All related information and data were extracted from the selected studies and were presented in a table of evidence (Appendix 3).

The selected studies were published from 1998 to 2010. Four studies are randomized control trials (RCTs) (L. Kalra et al., 2004; Mant, Carter, Wade, & Winner, 1998; Perrin et al., 2010; Rodgers et al., 1999) and one is non-randomized controlled trial (Oupra, Griffiths, Pryor, & Mott, 2010). Four studies were conducted in western countries i.e. the United Kingdom (L. Kalra et al., 2004; Mant et al., 1998; Rodgers et al., 1999) and the United States (Perrin et al., 2010), while one of them were conducted in Thailand (Oupra et al., 2010). All selected studies were carried out in hospitals or stroke rehabilitation units.

All selected studies included educational sessions which were held by multidisciplinary team as part of the interventions. Three of them included hand-on skills training to caregiver as education program (L. Kalra et al., 2004; Oupra et al., 2010; Perrin et al., 2010) and two of them provided information leaflet as part of the interventions (Mant et al., 1998; Oupra et al., 2010). For the control group, subjects of five studies received usual care or standard treatment.
For the effectiveness measurement, three studies measured the caregiver strain by Caregiver Strain Index (Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010) and one study used the Caregiver Burden Scale (Kalra et al., 2004). The quality of life of caregivers, two studies used General Health Questionnaire (Oupra et al., 2010; Rodgers et al., 1999) and one study used EuroQol Visual analogue (Kalra et al., 2004). Two out of five studies measured the carers’ perceived health status by Short Form 36 health survey questionnaire (Rodgers et al., 1999; Mant et al., 1998).

2.2.3 Subject Characteristics

In five selected studies, all were in-patients of stroke rehabilitation wards or acute wards in hospitals. All caregivers recruited for the studies were informal caregivers who were mainly the family members of the stroke survivors. All stroke survivors would be cared by informal caregivers in the community after discharge.

2.2.4 Methodological Issues

The assessment of methodological quality of selected studies was performed by SIGN checklist (SIGN, 2014). The results of assessment of each study were shown in appendix 4.

First of all, all the studies stated the research question clearly. They are correlated to the objective of this dissertation.

Randomization was done in four studies (L. Kalra et al., 2004; Mant et al., 1998; Perrin et al., 2010; Rodgers et al., 1999). Randomization method used were block randomization (Rodgers
et al., 1999), computer generated random numbers (Kalra et al., 2004; Mant et al., 1998) and table of randomized number (Perrin et al., 2010). Most of the methods were reliable. One study (Oupra et al., 2010) was non-randomized controlled trial; so, no randomization was done. Among the RCTs, there were three studies used adequate concealment, where sealed envelopes were used (Mant et al., 1998), allocation code which was remoted in central office was used (Kalra et al., 2004), and central telephone (Rodgers et al., 1999). Concealment method was not mentioned in Perrin et al.’s study (2010).

Since the interventions of the RCTs was education program for caregivers, it was hard to keep caregivers blinded about the intervention due to its nature. Four RCTs (Kalra et al., 2004; Oupra et al., 2010; Mant et al., 1998; Rodgers et al., 1999) could keep assessors blinded as to reduce the bias.

Four RCTs (Kalra et al., 2004; Oupra et al., 2010; Mant et al., 1998; Rodgers et al., 1999) reported subjects in both intervention group and control group were having similar demographic data and thus the data was comparable. One study (Perrin et al., 2010) only compared the demographic data of subjects between two sites. Besides, for study done in 1998, age difference of two groups of subjects may contribute to insignificant outcome. However, most of the demographic data were comparable in two arms of this study (Mant at el., 1998). The selected studies have used validated and reliable tools for measuring quality of life, caregiver strain and their perceived health especially in psychological aspect. Though the tools
used were not the same, they are similar in nature and commonly used.

Drop-out rate in 3 of the RCTs were less than 20% which was an acceptance level according to SIGN guideline (Kalra et al., 2004; Oupra et al., 2010; Perrin et al., 2010). Factors contributing to the drop-out rate of these studies were similar. The factors were unavailability of caregiver, failure in contacting caregivers, withdrawal or death of stroke survivors. One RCT had a drop-out rate of 40% in intervention group because subjects could not fulfill the attendance rate of education program (Rodgers et al., 1999). Drop-out rate of another RCT was 23% to 24% in intervention and control group. It was due to the death of subject or withdrawal of subject (Mant et al., 1998).

Two RCTs could applied intention-to-treat analysis as to reduce the bias (Kalra et al., 2004; Mant et al., 1998). Study of Oupra et al., (2010) and Rodgers et al., (1999) did not mention the details about the application of intention-to-treat. Only one study did not apply any analysis of intention to treat Perrin et al., (2010).

All RCTs could keep the only difference of treatment group was due to the investigation. Three studies conducted in multi-sites, where two of them could be comparable (Oupra et al, 2010; Perrin et al., 2010). The remaining one did not provide specific data for each sites (Mant et al., 1998). Two RCTs were conducted in one site (Kalra et al., 2004, Rodgers et al., 1999).

After the quality assessment performed, one studies (Kalra et al., 2004) could be rate as 1++ level of evidence as it meets majority of criteria of the SIGN checklist for RCT. Two RCTs
were rate as 1+ (Perrin et al., 2010; Mant et al., 1998). These studies met most of the criteria with low risk of bias presented. Another RCT was rated as 1- (Rodgers et al., 1999). It is exposed to high risk of bias, because inconsistence in randomization method, uneven distribution of control and intervention groups, and the high drop-out rate. The non-randomized controlled trial was rated 2++ level of evidence as it met most of the criteria in the checklist with low risk of bias presented (Oupra et al., 2010).

2.3 Summary and Synthesis

2.3.1 Summary

The selected studies included four RCTs and one non-randomized controlled trial. They were published between 1998 and 2010 and written in English (Kalra et al., 2004; Oupra et al, 2010; Perrin et al., 2010; Mant et al., 1998; Rodgers et al., 1999).

Five studies measured about psychological aspects of caregivers which were focused on caregiver burden, quality of life, perceived health status and depression. Four of the five studies were rated with acceptable or high quality in minimizing bias and showed positive effect on caregivers in their intervention groups after caregiver education program.

The education program of three studies were similar which involved more than one component in the intervention (Kalra et al., 2004; Oupra et al, 2010; Perrin et al., 2010). The components were information packs of stroke, education sessions, hand-on skills training sessions and supportive follow up after discharge. Significant effects were reported in these three studies
with the mixed components. In study of Rodger et al., (1999), the components of interventions were group education sessions and group discussion sessions. In study of Mant et al., (1998), the component of interventions was only distributing leaflets to caregivers which did not cause significant change.

The length of follow up varies from 3 months to 12 months. Only one study (Kalra et al., 2004) follow up participant after 12 months. The comparison of effects of follow up after 3 and 12 months were similar which suggested that time might not cause a significant change in the effects.

### 2.3.2 Synthesis of Data

Firstly, three studies reported that caregiver burden was significantly reduced after the intervention provided when compared with control group in post treatment three months (Kalra et al., 2004; Oupra et al, 2010; Perrin et al., 2010). In Kalra et al. (2004), Caregiver Burden Scale was used to measure caregiver strain. A significant reduction in score of Caregiver Burden Scale was noticed after treatment three months and twelve months, where the score was eight and nine units lower than the control group respectively. In Oupra et al. (2010) and Perrin et al. (2010), Caregiver Strain Index was used as the outcome measurement of caregiver strain. A significant reduction in caregiver strain was noted in both studies after three months of intervention, which was -4.3 and -2.61 respectively, as compared to the control group. The significance decrease in caregiver burden in these three studies may due to the hand-on training
of techniques in the education program to caregivers, where three studies included hand-on skills training sessions as development of transferring or lifting skills (Kalra et al., 2004; Oupra et al., 2010; Perrin et al., 2010).

Secondly, quality of life was reported as better after three months of intervention in two studies (Kalra et al., 2004; Oupra et al, 2010). In Kalra et al. (2010), EuroQol Visual analogue score was significantly increased while comparing to control group after three months and twelve months of implementation of intervention. Besides, quality of life measured by General Health Questionnaire in Oupra et al. (2010) was improved when it was compared with control group at three-month post treatment. These two studies showed significantly better in quality of life of caregiver of stroke survivors when compared to control group three months after interventions.

In two studies, interactive education sessions, hand-on skills training and information packs were the common interventions used. These might contribute to the significant effect on improving quality of life. One study showed a worsening of quality of life of caregivers (Rodger et al., 1999). However, the result was not statistically significant which might be due to the poor quality of study.

The perceived health status was reported significantly increased in Mental Health of Short Form 36 health survey questionnaire as compared to the control group in study of Mant et al. (1998). Nonetheless, study of Rodger et al. (1999) reported a decrease in carers’ social functioning of Short Form 36 health survey questionnaire, comparing to the control group. The
intervention of Mant et al. (1998) was only providing leaflet of stroke while Rodger et al. (1999) had an education session during in-patients stay and after discharge with information leaflet provided. The education sessions after discharge might hinder caregivers’ life and thus the score of social function decreased.

A significant decrease of depression score was reported in Kalra et al. (2004) after twelve months when compared to control group. Meanwhile, a suggestive decrease of depressive mood was showed in study of Perrin et al. (2010) after three months of the intervention. The suggestive effect caused by the intervention over time might due to the enhanced caregiving skills and lowered disability levels of stroke survivors after course of training.

Information of stroke which was printed on a booklet or leaflet were included in three studies showing significant effects (Kalra et al., 2004; Oupra et al, 2010; Perrin et al., 2010). It was suggested that the information packs should be written in dialect where caregivers can understand easily (Oupra et al., 2010).

Small group of teaching, a maximum number of six pairs of patients and their informal caregivers, were adapted in education sessions (Oupra et al, 2010). Small group of teaching enhanced the interaction between caregivers and educators and along caregivers. This might allow discussion and provide social support within groups. Number of education sessions varied from three to five sessions and last for thirty to one hundred and fifty minutes for each session according to studies (Kalra et al., 2004; Oupra et al., 2010).
Hand-on skills training should be included in the education program as development of transferring or lifting skills (Kalra et al., 2004; Oupra et al, 2010; Perrin et al., 2010). Also, follow-through sessions should be done at home as to assess the adaptation of skills and revision the skills learnt (Kalra et al., 2004). Videophone technology could be embraced as a support measures for discharged stroke survivors and their informal caregivers (Perrin et al., 2010).

All in all, education program to informal caregiver of stroke survivors was suggested to be effective in lowering caregiver burden and enhancing better quality of life of caregivers by the reviewed studies. Thus, implementing an education program to informal caregiver of stroke survivors might be effective in improving quality of life and reducing burden of care providers of stroke survivors in stoke rehabilitation unit in Hospital A in Hong Kong. The education program may be provided before discharge, in a small group of four pairs of stroke victims and their informal caregivers. Education sessions with discussion sessions, followed by and a hand-on skills training session, should be proposed in the suggested pre-discharge education program. Skills of transferring and lifting can be included in the hand-on skills training sessions. Besides, printed materials regarding to the topics covered in education sessions can be a quick reference and revision for informal caregivers.
Chapter 3

Implementation Potential and Clinical Guideline

3.1 Target Setting and Audience

The target setting is stroke rehabilitation wards in Hospital A. In 2014-15, 1881 of the 3507 peoples diagnosed stroke in Hong Kong were admitted to Hospital A, according to statistical report of Hospital Authority. Among these stroke survivors, about 700 of them were admitted to stroke rehabilitation wards for courses of rehabilitation training. There were about 420 stroke patients being discharged to home and taken care by their relatives, i.e. informal caregivers, in community.

Stroke survivors are transferred to stroke rehabilitation wards in Hospital A on day four of post-stroke according to statistics of Hospital A. Following the protocol of stroke management, early engagement of therapeutic exercise would minimize the disabilities caused by stroke (Duncan et al., 2005). A multidisciplinary management is therefore adapted in the stroke rehabilitation wards in Hospital A. Training includes limbs exercises, training of activities of daily life and speech acquiring exercises. These trainings vary as plans are tailor-made for each of the stroke survivors. Stroke survivors will stay in stroke rehabilitation wards in hospital A for three weeks in average so as to participate in patient-centered rehabilitation program.

The suggested evidence-based pre-discharge education program for informal caregivers is proposed to be implemented in stroke rehabilitation wards in Hospital A. Informal caregivers
of stroke survivors in stroke rehabilitation wards in Hospital A will be targeted in the protocol. The suggested pre-discharge education program will be conducted in a multidisciplinary approach. Hands-on skills sessions, educational talks and sharing sessions will be provided to informal caregivers of in-patients of stroke rehabilitation wards. Yet, a complementary evidence-based pre-discharge education program has not been implemented in stroke rehabilitation wards in Hospital A. Besides, many caregivers voiced out that they would like to have a well-organized education program on caring skills before discharge in order to lower their caring stress and to equip themselves for the discharge of stroke survivors.

3.2 Transferability of Findings

Transferability means the research findings can be comparable and be applied to other situations referring to characteristics of target population, philosophy of care and target setting.

3.2.1 Nature of Setting and Audience

The reviewed studies were comparable to the target setting of proposed pre-discharge education program (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999). The informal caregivers of the studies were caregivers of stroke survivors who were also the targeted populations of the suggested program (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999). According to the selected studies, most of the informal caregivers were female (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999). In Hong Kong,
The majority of the caregivers are female and they are usually spouse or children of the sick people (Lee & Kin, 2005). Meanwhile, the informal caregivers in the chosen studies were also spouse or children of stroke survivors (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999).

The setting of the proposed program and characteristic of the targeted caregivers are comparable with those reviewed studies. Hence, the findings from studies are highly transferable.

### 3.2.2 Philosophy of care

The mission of rehabilitation service of Hospital A is to provide patient-centered rehabilitation service holistically, so as to optimize patient’s functional independence, to reintegrate them to the community and to maintain quality of life.

The aim of the proposed pre-discharged education program is to reduce caregiver stress of informal caregivers. The informal caregivers of stroke survivors play vital roles in reintegration of stroke survivors to the community and enhancement of their quality of life (Artal & Egido, 2009). Caregivers are very significant in stroke rehabilitation and activities of daily life of stroke survivors since they give both physical and mental support to stroke patients. Thus, the pre-discharge education program can help to maintain the quality of life of both caregivers and stroke patients in a way of holistic care before and after discharge. Also, the suggested program can help stroke survivors to engage in the community.
3.2.3 Number of Clients to be benefited

There were 700 stroke patients admitted to stroke rehabilitation units of Hospital A in 2014-2015. The patients will be discharged to home or to aged homes after serial trainings. Most of them, i.e. 516 stroke patients, were discharged home and were cared by the informal caregivers who were usually their spouses or children. Hence, it is expected that 80% of the informal caregivers in stroke rehabilitation wards of Hospital A will participate in the proposed pre-discharge education program if they are available and they can complete the whole program. It is estimated that around 410 stroke survivors’ informal caregivers will be benefited from this program annually.

3.2.4 Duration of implementation and Evaluation

The proposed pre-discharged education program to informal caregivers of stroke survivors, including implementation and evaluation, may last for twelve months. It will take three months to prepare the proposal, propose and communicate with other involved parties and get the approval of the management. It will take one month to prepare the education materials and internal training for nurses to be educators. Pilot study which will last for three months will be carried out and evaluated for the proposed program. The suggested program will be started after the pilot study. Five months will be allowed for carrying out the program and collecting data of the effects of pre-discharge education program. Most of the selected studies evaluated the effect in the third month after discharge (L. Kalra et al., 2004; Oupra et al., 2010; Perrin et
Therefore, the evaluation of this program will be carried out in the third month after discharge. Thus, twelve months will be needed in total for the implementation and evaluation of the suggested program. A chronological outline is available in appendix 5.

3.3 Feasibility

The feasibility of a program is governed by a few parts, which are organization climate, administrators’ support, supports for frontline staff and other stakeholders and also the availability of resources including equipment and training etc.

3.3.1 Organizational climate and administrative support

Generally, the climate of implementing an evidence based program is positive in the stroke rehabilitation wards of Hospital A. Medical staff, nursing staff as well as staff of allied health take care of the patients in a holistic way. Staff in stroke rehabilitation ward are working in a multidisciplinary approach and providing training to patients with the aim of facilitating stroke survivors to reintegrate to the community where quality of life of stroke patients and their informal caregivers can be maintained (Artal & Egido, 2009).

Besides, the evidence-based program will be welcomed in this ward as further training and continuous professional development are supported by the administrator of ward. Most of the registered nurses are studying or have completed their Master degree which is related to nursing or neurology. Besides, nearly half of the registered nurses completed their post-registration certificate course of rehabilitation or stroke. Due to the good academic
atmosphere, it was believed the administrative level and staff will agree with the implementation of the evidence-based program.

3.3.2 Support from Frontline staff

For the manpower, experienced registered nurses are eligible to be the educators of the program as they are familiar with the stroke rehabilitation program currently being provided to in-patient stroke survivors. There are totally twelve registered nurses, seven of them are having at least three years of experience in stroke rehabilitation nursing. They are suitable to be the educators of the program who will educate the informal caregivers of stroke survivors. Besides, assigned registered nurse will not be counted as manpower of the daily ward duties and routine. They are assigned to perform the education program to informal caregivers only. The nurse educators have to prepare for the educational talk and equipment on the day of conducting the program. Thus, they are free from ward duties and no extra duties are required for nurse educators. They will be assigned as “day-shift” on the program day. Therefore, sufficient manpower should be available to carry out this program. Also, those experienced nurses in stroke rehabilitation nursing are willing to perform such duties as job satisfaction can be redeemed. Physiotherapist and Occupational therapists will participate as educators in the one-hour hands-on skills session. Their workload should be added as they have to provide caregiver training individually to caregivers upon request currently. However, they are expected to be willing to join this suggested multidisciplinary program as it can reinforce their
importance in rehabilitation and position in health care system in Hong Kong.

3.3.3 Availability of resources

Resources are required to perform the suggested program containing hardware and the professional. First, hardware like conference rooms with computers and projectors are required. Information packs of stroke and some teaching materials are prepared for the educational talks and sharing sessions. These materials will be shown on the screen. Thus, a room with such facilities is needed for the talk and sharing sessions afterwards. Also, integrated activities rooms are required for hands-on skills sessions. The hands-on skills sessions require commode chairs, geriatric chairs, walking aids as to demonstrate transferring skills. Moreover, fall prevention education can be done as well. The mentioned rooms and equipment are available in Hospital A.

Secondly, educators from different disciplines are required. Paramedical staff like physiotherapists and occupational therapists are invited to join the program. Physiotherapists are the educator of fall prevention and usage of walking aids. Occupational therapists are educators of assistance of daily activities, usage of commode chair as well as transfer skills. Meanwhile, nursing educators are responsible for the topics of prevention of recurrent stroke, management and prevention of pressure sore, caring of urinary catheters, feeding skills of nasogastric tube and information of community resources.

After the educational parts of the program, evaluation is also an essential component in the
program. It can show the effectiveness of the program. Thus, we use Caregiver Strain Index as the evaluation tool of caregiver stress which is a commonly used outcome measure in the literatures (Thornton & Travis, 2003)(see appendix 6).

3.4 Cost- Benefit Ratio of the Program

Cost-effectiveness of a program is very important in terms of potential of implementation of a program. Potential risk and benefit, and the material and non-material cost are taken into account for the cost- effectiveness of a program.

3.4.1 Potential Risk and Feasibility

There is no reported potential risk of carrying out the planned program. Nonetheless, there are some potential barriers regarding to the program. Unwillingness of frontline staff, i.e. nurses and other disciplines, to be the educators may be the main obstacle. It may be due to the personality of the staff. They may not be outgoing and are not willing to give public speech. The program may increase their working stress. Their reluctance in being educators may result in low staff morale or even high turnover rate. This is one of the risks of the suggested program. Another barrier of program is the willingness of relatives to participate in the program. In Hong Kong, most of the caregivers are spouse or children. Children may need to work on weekdays and spouse may need to take care of young children at home. They may not be able to take part in the education program if they cannot take leave or find somebody to take their roles for a few hours. This factor may lower the feasibility of the suggested program
3.4.2 Potential benefit of program

In current practice, there is no education program provided to informal caregivers of stroke survivors during in-patient stay. The informal caregivers always complain about being stressed and they do not know the proper way of caring stroke survivors. Many studies showed negative health impacts, for example, depressive symptoms, were found in stroke caregivers ("Caregiver stress fact sheet," 2013).

There are benefits which can be potentially gained from the proposed program. First of all, stress of caregivers of stroke survivors can be lowered as the results of the selected studies found (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999). Pre-discharge education of caregiver can enhance their preparedness of discharge of stroke survivors. A local study identified that stroke caregiver would like to receive education and training on caring for stroke survivor especially in the beginning stage (C. Chow. & A. Tiwari, 2014). Besides, the quality of life of both stroke survivors and caregivers can be maintained or even increased (Meily, vanHeugten, Post, Schepers, & Lindeman, 2005).

Apart from patients and their informal caregivers, staff can get the job satisfaction from the education program. As the topics included in the pre-discharged education program are closely related to nursing care, relatives and informal caregivers may appreciate the effort spared by nurses to take care of a stroke patient. Job satisfaction will be gained by then. Besides, nurses can realize their roles are absolutely important in rehabilitation progress of stroke survivors.
Simultaneously, communication skills and presentation skills will be cultivated. It is because there are increased chances of giving a speech to public audience. Also, with the discussion serious held after educational sessions, rapport will be built between informal caregivers, patients and nurses.

3.4.3 Material and Non-Material Cost

Cost of the program includes set-up cost and operational cost. Manpower contributes to the majority of the set-up cost. One medical officer, one advanced practice nurse, two registered nurses, one physiotherapist, one occupational therapist and one clerical staff are included in the preparation meetings, and preparations of the program which lasts for eight hours in total. There will be four preparation meetings where the duration of each meeting is two hours. Preparation of materials of education program and briefing session of educators are also included in preparation phase. Seven experienced registered nurses, two physiotherapists and two occupational therapists are also invited to be educators of educational talk and hands-on skills training sessions. They are required to attend a briefing session before providing education to caregivers. The one-hour briefing session will be guided by one Medical Officers, one Advanced Practice Nurse, two Registered Nurses, one Physiotherapist and one Occupational therapist. The hourly rates of different discipline are as follows: medical officer rated HKD 390, Advanced Practiced Nurse rated HKD 259, Registered Nurse rated HKD 163, Physiotherapist and Occupational therapist rated HKD 248 respectively and clerical staff rated...
HKD 50. Totally, HKD 35,788 are required for the set-up cost as shown in appendix 7.

The pre-discharge education program consists of two sessions, a two-hour educational session led by registered nurses and one-hour hands-on skills session led by allied health team. The two-hour educational session includes a one-hour educational talk followed by a one-hour sharing session. Printed materials will be prepared for caregivers as a reminder of learnt information and skills. By calculation, HKD 85,281 are needed for the operational cost in one year which is shown in appendix 8. In the first year, total cost to run this program will be HKD121,069.

The operational cost can be saved by the proposed program because of the reduction in the re-admission to hospital (Joubert et al., 2009). Since stroke patients re-admitted to hospital may stay for 5 days in average according to statistical report of Hospital Authority (2015). The reduction of re-admission by one episode could reduce the cost of hospital care for 5 days. As Hong Kong SAR Government estimated the average operational cost of serving one patient in general ward as HKD 4190 per day (Bureau, 2015). In a conservative assumption, only 80% of the stroke survivors, i.e. 328 of the stroke survivors, would not be re-admitted. By calculation, HKD 6,871,600 (HKD 4190 x 5 days x 328 stroke patients) is saved by carrying out the proposed program. Hence, there will be HKD 6,750,531 saved in one year.

3.5 Evidence-Based Guideline

A guideline of evidence based on a pre-discharge education program for informal caregivers of
stroke survivors was established since systematic review had been undergone in previous chapter. Recommendations were graded regarding to the grading system developed by Scottish Intercollegiate Guidelines Network where grade A evidence is the most credible and grade D evidence should be treated judiciously (SIGN, 2014).

This evidence-based guideline is targeted to nurses, physiotherapists and occupational therapists in stroke rehabilitation wards of Hospital A. After reviewing the studies, six recommendations were generated and graded by the grading system developed by Scottish Intercollegiate Guidelines Network. The proposed guidelines and recommendations were shown in Appendix 9.
Chapter 4

Implementation Plan

Formerly, we have discussed the transferability of evidence into practice and the implementation potential of evidence-based guidelines. An evidence-based guideline for the innovative program is developed and putting it into practice will be the next step. With the aim of operating the proposed guidelines, a communication plan, pilot testing and evaluation plan should be established. A schedule of implementation and evaluation of proposed program is shown in Appendix 5.

4.1. Identification of the Major Stakeholders

It is vital to identify stakeholders in effective communication which can help to establish a good rapport between different parties and gaining the support (Podnar & Janic, 2006). The major stakeholders are categorized into three levels, i.e. administrative level, management level and frontline users of guidelines.

4.1.1 Administrative level

Administrative level includes hospital Chief Executive Officer (CEO) and General Manager of Nursing (GM(N)). They are responsible for the policy and operation of a hospital. Therefore, it is a must to inform them and get their approval for implementation of any new protocol. Also, the newly implemented protocol can be added to the annual plan which may help in applying for funding for the hospital.
4.1.2 Management level

Management level of the department includes Chief of Service (COS), Assistant Consultant (AC), Department Operation Manager (DOM) of medical and geriatrics (rehabilitation service), Ward Manager (WM), one Nursing Officers (NO), three Advanced Practiced Nurses (APN), one senior Physiotherapist and one senior Occupational therapist. They are responsible for planning and operating the clinical services whereas implementing the newly proposed protocols. Thus, the support and approval from this group of people is indispensable. With their supports, smooth operation of new guidelines can be ensured and accomplishment can be provided to frontline staff.

4.1.3 Frontline users

Frontline users of guidelines are seven Registered Nurses (RN), two Physiotherapists (PT), and two Occupational therapists (OT). They are responsible for educating the informal caregivers of stroke survivors in stroke rehabilitation wards in Hospital A. Full understanding of guidelines and clear explanation to informal caregivers is crucial in safeguarding the smooth operation of the proposed program.

Besides, caregivers of stroke survivors and stroke survivors are the users of the suggested program as well. They are being introduced to and benefited from the suggested program. Also, good communication with all parties can enhance the feasibility of the program as informal caregivers and stroke survivors would be willing to join the program with a full and clear
elaboration by program educators.

4.2 Communication Plan

A communication plan will be set up in order to facilitate effective communication with different stakeholders. Thus, the program can be carried out smoothly. There are three phases in the communication plan which includes initiation phase, facilitating phase and sustaining phase.

4.2.1 Initiation phase

The initial phase is to identify the concerns of staff towards the proposed guidelines of pre-discharge education program. A casual discussion will be held in wards as to collect comments from frontline staff and gain their support for the program which will last for one month. During the casual discussion, benefits of the program and the evidence-based guideline will be discussed so as to get the support from frontline staff. Their concerns will be addressed and reassurance will be given by the proposer. After gathering the comments from frontline staff, the proposer of proposal will work on the proposal and a budget plan. This innovative idea will be presented to WM, NO, and APN as to seek their support. WM may help in sharing this proposal to COS, AC and DOM during departmental meeting in order to get the approval from the management level. During the presentation of proposal, content of guidelines, budget, manpower and duration of the pilot study will be presented.

Forming a committee will be the following step. In this committee, WM will be the leader who
facilitates the communication with all parties, gives comments on guidelines and provides support to frontline staff. Meanwhile, one APN will be the supervisor who directs the proposed guideline and monitor the progress of it. There are two RNs, one PT and one OT in the committee who prepares for the training materials and other handy works. Correspondingly, they will be the trainers of the educators of pre-discharge education program of informal caregivers of stroke survivors. There will be seven RNs, two PTs and two OTs to act as educators to informal caregivers of stroke survivors. There will be two-month time needed in this phase.

Then, WM will announce the proposed guideline to frontline staff. Frontline staff will be explained about the content of guideline with evidence, budget and timeframe of implementation. Also, the additional role as well as the workload will be addressed by WM and proposer to frontline users of guidelines. A forum is allowed for all frontline staff to express their concern, and to raise questions and suggestions.

4.2.2 Facilitating phase

A one-hour-briefing session will be prepared by the committee. The Associate Consultant, one advanced practice nurse, two registered nurses, one physiotherapist and one occupational therapist in the committee will held a training session to other five registered nurses, two physiotherapists and two occupational therapists, who will be the educators to informal caregivers of stroke survivors. The theoretical knowledge, understanding of guidelines and
skills practice will be enhanced after this briefing session. Public speaking skills will be reinforced such that the educators will be confident to lead the sessions. Besides, soft copies of training materials and a flow chat of the guideline will be sent through intranet E-mail to all frontline users of guidelines. In order to facilitate the communication and understanding of the guideline, any update of progress and review of guidelines will be sent to frontline staff, management level and administrative level through intranet E-mail. The briefing session and the announcement will use about one month.

4.2.3 Sustaining phase

In this phase, the acceptance of frontline staff with the proposed guideline and the feasibility of carrying out the guidelines will be monitored. A pilot study will be performed and the outcome will be evaluated accordingly.

4.3 Pilot study

A pilot study is a small-scale implementation of study before proposed guidelines which takes two months to carry out. The pilot study can help in testing the feasibility and evaluate the logistics of the proposed program. It can help in improving and implementing the full-scale program after evaluation the pilot study.

4.3.1 Participants and setting

The pilot test will be implemented in stroke rehabilitation wards of Hospital A. The target participants will be the informal caregivers of in-patient stroke survivors who are mainly the
family members. All stroke survivors will be cared by informal caregivers in the community after discharge.

4.3.2 Target Sample Size and Duration of Pilot Test

The sample size in pilot study will be based on the number of groups which can attend the group education sessions. There are seven nurse educators available for the program. In order to let each of the educators experience the intervention, twenty-eight informal caregivers are required, i.e. seven groups of participants are required. There are four participants included in each group, i.e. two caregivers and two stroke survivors. Thus, twenty-eight of the informal caregivers are required in the pilot study. In this way, all nurse educators will have a chance to hold the education session. Besides, two physiotherapists and two occupational therapists will have chance to be involved in the intervention i.e. hands-on skill training sessions.

In order to gather enough samples, one month will be needed to recruit suitable participants. There will be around thirty-five patients to be discharged home and cared by informal caregivers in the community in one month.

Participants of the pilot study will be recruited and asked for consent. Eligible participants will be provided with a two-hour group education session and discussion session which is held by RN and one-hour hands-on skills workshop which is held by PT and OT. Education pamphlet, PowerPoint and equipment required will be prepared by the committee. It may take one month to get the preparation work ready for the pilot study. Two months are suggested to review and
collect the feedback on the logistics of the pilot study by interviewing the frontline staff. The result of pilot testing is used to refine the proposed guidelines.

4.4 Evaluation Plan

After pilot testing, the program is refined and implemented fully in stroke rehabilitation wards of Hospital A. This evaluation plan is expected to determine the effectiveness of pre-discharge education program to informal caregivers of stroke survivors in stroke rehabilitation wards of Hospital A in reducing caregiver stress.

4.4.1 Patient Outcomes

Patient outcome is focused on the emotional outcome of informal caregivers of stroke survivors. The primary outcome of the program is the emotional outcome which is assessed by Caregiver Strain Index (CSI) (Appendix 6) (Robinson, 1983) which is ranged from 0 to 13. A Chinese version of Caregiver Strain Index is also available to be used in Hong Kong (Chan, Chan, & Suen, 2013) (Appendix 10). The lower score means the better emotional outcome i.e. lower caregiver stress. In the review studies, Caregiver Strain Index was also used as a measuring tool of outcome (Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010).

4.4.2 Health Care Provider Outcomes

Frontline staff involved in the innovated program is invited to respond to a structured self-reported questionnaire which includes questions about satisfaction and acceptance of the program (Appendix 11). Those questions are on a 5-point Likert scale. A mean score between 4
and 5 means satisfactory, while means score between 3 and 3.9 means neutral. For the mean score between 1 and 2.9 means dissatisfaction. Thus, the higher score indicated a higher level of satisfaction.

4.4.3 System outcome

Cost and benefit will be measured as a system outcome. Expenditures like set up cost and manpower and savings from reduced re-admission will be calculated.

4.4.4 Sample Size and Recruitment Duration

The proposed program will be implemented in stroke rehabilitation wards in Hospital A. The target participants will be the informal caregivers of stroke survivors of in-patients in Hospital A while stroke survivors will be cared by the informal caregivers.

Sample size calculation is based on the primary outcome which is Caregiver Strain Index. Assuming a clinically meaningful difference in Caregiver Strain Index after the implementation of the innovation is 2 units, and from the reviewed studies, the standard deviation is 4.0 (Oupra et al., 2010). The sample size is 27 for a one-tailed t-test which ensured a power of 80% and significance level of 0.05. Assuming there will be 15% of attrition rate, the sample size required for the program will be 32.

4.4.5 Data Collection

In order to recruit nineteen informal caregivers of stroke survivors in Hospital A, three weeks are allowed. The score of caregiver strain index of informal caregivers of stroke survivors will
be collected after discharge and three months after training. For the health care providers, the
structured self-reported questionnaire will be collected at the end of evaluation period. Besides,
the cost and saving i.e. the system outcome will be worked out at the end of the evaluation
period.

4.4.6 Data Analysis

The collected data will be processed and analyzed by using SPSS version 22. Demographic
data and characteristics of informal caregivers will be summarized as descriptive statistics.
For patient outcomes, mean values of Caregiver Strain Index will be calculated. The mean
values of caregiver strain index after training and three months after discharge will be
compared with that under the current setting. The lower mean values indicated the caregiver
strain is lowered after the program which means the program is effective. Thus, a one-tailed
paired t-test will be performed to test if the caregiver strain index is at least 2 units less than that
under the current setting at 0.05 significance level.
For healthcare providers’ outcome, the mean score of the structure self-report question on 5-
point Likert scale will be computed whereas the mean score indicated the satisfaction of
frontline staff. The proportion of frontline staff with mean score between 4 and 5 will be
counted. A one-tail z test will be used to test to see if there are more than 70% of frontline staff
who are satisfied, at 0.05 significance level.
For the system outcome, a financial report showing all expenditures and saving will be done.
This report may help in monitoring the cost and profit of this program.

4.5 Basis for adopting the guideline

A formal written report will be done after evaluation of the program. It will be presented to administers of hospital and cluster in an attempt to justify a long-term implementation of this proposed program.

The basis is determined by the following conditions. The mean score of Caregiver Strain Index is lowered by 2 at third month after discharged to home when compared to the mean score immediately after discharge. The decrease in mean score indicates a lowering of caregiver strain which is the aim of the program. Thus, it should be justified to be implemented as a long-term program.

Moreover, the positive satisfaction of frontline staff should be at least 70%. This can remain the willingness of staff to run this program in long-term. Furthermore, there should be net gain in calculating the balance of expenditure and saving.
Chapter 5: Conclusion

In view of the prevalence of caregiver stress of informal caregivers of stroke survivors, there is no pre-discharge education program available for informal caregivers of stroke survivors currently. Caregiver burden may lead to depression and increase risk of elder abuse. Also, re-admission due to recurrent stroke maybe one of the adverse consequence as caregivers do not have knowledge of preventing recurrent stroke. Thus, systematic review of literature was done which showed a significant decrease in caregiver burden if a pre-discharge education program is carried out to informal caregivers of stroke survivors. A translational nursing research was done in order to develop an evidence-based guideline of pre-discharge education program to informal caregivers of stroke survivors to reduce caregiver burden. The proposed guideline aimed in providing a framework for nurses and paramedical staff to provide pre-discharge education program and standardization. The potential benefit and costs of carrying out the suggested program were assessed and discussed. Also, implementation plan and evaluation plan were designed in order to assess the feasibility and to refine the proposed guideline. This innovative program can lower the caregiver stress and reinforced the importance of multidisciplinary approach in rehabilitation of stroke.
Appendix 1: SIGN Grading System of Level of Evidence and key to evidence statements (SIGN, 2014)

Table showing the Level of Evidence

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1++</td>
<td>High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias</td>
</tr>
<tr>
<td>1+</td>
<td>Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias</td>
</tr>
<tr>
<td>1-</td>
<td>Meta-analyses, systematic reviews, or RCTs with a high risk of bias</td>
</tr>
<tr>
<td>2++</td>
<td>High quality systematic reviews of case control or cohort or studies</td>
</tr>
<tr>
<td></td>
<td>High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal</td>
</tr>
<tr>
<td>2+</td>
<td>Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal</td>
</tr>
<tr>
<td>2-</td>
<td>Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal</td>
</tr>
<tr>
<td>3</td>
<td>Non-analytic studies, e.g. case reports, case series</td>
</tr>
<tr>
<td>4</td>
<td>Expert opinion</td>
</tr>
</tbody>
</table>

Table showing Grades of Recommendation

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results</td>
</tr>
<tr>
<td>B</td>
<td>A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+</td>
</tr>
<tr>
<td>C</td>
<td>A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 2++</td>
</tr>
<tr>
<td>D</td>
<td>Evidence level3or4; or Extrapolated evidence from studies rated as 2+</td>
</tr>
</tbody>
</table>
Appendix 2: Flow Diagram of Systematic Search

Records identified through database searching (PubMed and ProQuest)

Additional records identified through other sources

Records after duplicates removed (n = 1174)

Records screened (n = 1174)

Records excluded (n = 1144)

Full-text articles excluded, with reasons (n = 25)
- Target group is focused on community stroke survivors or chronic stroke survivors (n=18)
- Interventions are not focused on education program to carer (n=3)
- Outcome measures were not related to psychosocial aspect of carer (n=4)

Full-text articles assessed for eligibility (n = 30)

Studies included in qualitative synthesis (n = 5)
## Appendix 3: Table of Evidence

<table>
<thead>
<tr>
<th>Citation/ Design (Study Quality)</th>
<th>Sample Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome (Assessment Time)</th>
<th>Effect Size (intervention – control)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Kalra et al., 2004/ RCT (1++)</strong></td>
<td>1. In-patients of stroke rehabilitation unit 2. Caregiver of stroke survivors 3. UK</td>
<td>Care Giver Training (n=151) 1. Conventional support and; 2. Instruction by appropriate professionals (stroke related problems, prevention and management of bed sores etc.) ; 3. Hand- on training in lifting and handling techniques; 4. 3-5 sessions depends on needs; 5. 30-45 minutes per session; 6. follow-through session at home to adapt learnt skills</td>
<td>Conventional care (n=149) 1. Information on stroke; 2. Goal setting and discharge planning 3. Encouragement to attend nursing and therapy activities 4. Advice on community services</td>
<td>(At 3 and 12 months) Emotional Health: 1. Caregiver Burden Scale (¹Range: 22–88) 2. Median Hospital Anxiety and Depression Score (at 12 months) (¹Range: 0–21) Quality of life: 3. EuroQol Visual Analogue Score (²Range: 0–100)</td>
<td>1. At 3M: -8  At 12M: -9  (p=0.0001)  2. At 3M: N/A  At 12M: Anxiety: -1  Depression: -1  (p=0.0001)  3. At 3M: 10  At 12M: 10  (p=0.0001)</td>
</tr>
<tr>
<td>Oupra et al., 2010/ Non-randomized Controlled trial (2++)</td>
<td>SELF (n=70)</td>
<td>Control (n=70)</td>
<td>(At discharge and 3 months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
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<td>----------------</td>
<td>----------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. In-patients with acute stroke</td>
<td>1. Didactic group education sessions</td>
<td>1. Usual care</td>
<td>Caregiver Strain:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Caregiver of stroke survivors</td>
<td>2. Hands- on training (techniques of lifting, transfer; catheter care etc)</td>
<td>2. Teaching materials of intervention group will be given at conclusion of data collection stage</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Thailand</td>
<td>(2 pairs in a group)</td>
<td></td>
<td>1. CSI</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Group discussion (6 pairs in each session)</td>
<td></td>
<td>(¹Range 0&lt;13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Booklet of information about stroke (written in Thai)</td>
<td></td>
<td>Quality of life:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Three follow up calls</td>
<td></td>
<td>2. GHQ-28</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Three sessions in total (120-150 minutes each)</td>
<td></td>
<td>(¹range 0&lt;84)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Caregiver Strain:  

- At D/C: -3.5  
- At 3M: -4.3  
- P<0.001

2. Quality of life:  

- At D/C: -5.4  
- At 3M: -8.4  
- P<0.05
| Perrin et al., 2010/ RCT (1+) | 1. In-patients who diagnosed stroke | Transition Assistance Program (TAP) (n=27)  
1. Standard treatment and;  
2. Face-to-face meeting before discharge  
(Skill Development and Education)  
3. Supportive Problem Solving videophone calls (once a week at wk 1& 2 post discharge) | Standard Treatment (n=37)  
1. Caregiver guide book including, basics of stroke and overview of recovery experience | (At 3 months)  
Caregiver Strain:  
1. Change in CSI  
(¹Range 0–13)  
Caregiver depression:  
2. change in CESD-10  
(²Range 0→30) | 1. -2.61 (p=0.01)  
2. Treatment effect over time: -1.32 (p= 0.07) |
<table>
<thead>
<tr>
<th>Rodger et al., 1999/ RCT (1-)</th>
<th><strong>1. In-patients with acute stroke</strong></th>
<th><strong>Stroke Education Program (SEP) (n=107)</strong></th>
<th><strong>Control Group (n=69)</strong></th>
<th><strong>At 6 months</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Caregivers of stroke survivors</td>
<td>1. Group education sessions (1 session during in-patient and 6 sessions after discharge) (about stroke, social services)</td>
<td>1. Routine communication with nurses, doctors, and therapy staff during hospitalization</td>
<td>Carers’ Perceived health status:</td>
<td>1. Carers’ social functioning subscale score: -37.5 (p=0.04) (other subscales are insignificant)</td>
</tr>
<tr>
<td>3. UK</td>
<td>2. Led by members of multidisciplinary team</td>
<td>2. Information leaflet</td>
<td>Carer Emotional Outcome</td>
<td>2. 16 (p=0.29)</td>
</tr>
<tr>
<td></td>
<td>3. Group discussion sessions</td>
<td></td>
<td>2. GHQ-30 (²range 0→84)</td>
<td></td>
</tr>
<tr>
<td>Mant et al., 1998/RCT (1+)</td>
<td>1. In-patients with acute stroke</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Caregivers of stroke victims</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. UK</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Information Packs</strong> (n=48)</td>
<td>1. Leaflets published by Stroke Association were delivered to home address a week after randomization</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Control</strong> (n=45)</td>
<td>1. Received nothing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(6 months)</td>
<td>1. -1 (NS)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver Strain:</strong></td>
<td>1. CSI (¹Range 0→13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Health status:</strong></td>
<td>2. SF-36 (²Range 0→100)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Mental Health: 12 (p=0.04)</td>
<td>(other subscales are not significant)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Footnote:**
- SELF: nurse-led Supportive Educative Learning program for family caregivers;
- CSI: Caregiver Strain Index;
- SF-36: Short Form 36 healthy survey questionnaire;
- GHQ-30: General Health Questionnaire 30;
- GHQ-28: General Health Questionnaire 28;
- CESD-10: 10-item version of Center for Epidemiologic Studies Depression;
- CBS Caregiving Burden Scale;
- NS Not significant

**Remarks:**
- “→” denoted from worse score to best score;
- ¹Lower value means better results
- ²Higher value means better results
Appendix 4: Quality Assessment

Methodology Checklist 2: Controlled Trials (No.1)

<table>
<thead>
<tr>
<th>SIGN</th>
<th>Study identification (Include author, title, year of publication, journal title, pages)</th>
</tr>
</thead>
</table>

Guideline topic: An evidence-based education program targeting informal caregivers of stroke survivors to reduce caregiver burden

<table>
<thead>
<tr>
<th>Key Question No: 1</th>
<th>Reviewer: C.T. Lee</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Before** completing this checklist, consider:

1. Is the paper a randomised controlled trial or a controlled clinical trial? If in doubt, check the study design algorithm available from SIGN and make sure you have the correct checklist. If it is a controlled clinical trial questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be rated higher than 1+

2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

Reason for rejection: 1. Paper not relevant to key question □ 2. Other reason □ (please specify):

**SECTION 1: INTERNAL VALIDITY**

**In a well conducted RCT study…**

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes ✔</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes ✔</strong> Block randomization with computer generated random numbers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes ✔</strong> Allocation codes: Remote in central office</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes ✔</strong> Assessor Blinded</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes ✔</strong></td>
</tr>
</tbody>
</table>
1.6 | The only difference between groups is the treatment under investigation. | Yes ✔
---|---|---
1.7 | All relevant outcomes are measured in a standard, valid and reliable way. | Yes ✔
---|---|---
1.8 | What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed? | Dead: 11%  
Missing data: Percentage of total dropped out is not available  
Reasons: lack of time etc.
---|---|---
1.9 | All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis). | Yes ✔
---|---|---
1.10 | Where the study is carried out at more than one site, results are comparable for all sites. | Not applicable ✔  
Stroke rehabilitation unit
---|---|---

**SECTION 2: OVERALL ASSESSMENT OF THE STUDY**

2.1 | How well was the study done to minimise bias?  
*Code as follows:* | High quality (++)✔  
Acceptable (+)☐  
Low quality (-)☐  
Unacceptable – reject 0 ☐
---|---|---
2.2 | Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention? | Good randomization, adequate concealment methods and blinded examiner were applied in the study.  
This avoided the chance of unfair treatment and biased assessments. Also, drop-out rate is acceptable.  
Thus, it is quite certain that the overall effect is due to the study intervention.
---|---|---
2.3 | Are the results of this study directly applicable to the patient group targeted by this guideline? | Yes, because the participants of this study are the same as my target group, i.e. caregivers of stroke survivors
---|---|---
2.4 | **Notes.** Summarise the authors’ conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above. | This study did match the topic of interest. Good methodological method was used to minimize bias and thus the significant improvement in clients’ stroke care was certain that it was due to the intervention of the staff oral health care education program.
The dropped out rate expressed did not clearly stated. It is not certain that if there is any duplication in missing data of different questionnaires. The drop-out rate in the study is low.

Overall, the study can answer question in terms of types of participant, interventions and outcome.
# Methodology Checklist 2: Controlled Trials (No.2)

**SIGN**

<table>
<thead>
<tr>
<th>Study identification (Include author, title, year of publication, journal title, pages)</th>
</tr>
</thead>
</table>

Guideline topic: An evidence-based education program targeting informal caregivers of stroke survivors to reduce caregiver burden  

<table>
<thead>
<tr>
<th>Key Question No: 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reviewer: C.T. Lee</td>
</tr>
</tbody>
</table>

Before completing this checklist, consider:

1. Is the paper a **randomised controlled trial** or a **controlled clinical trial**? If in doubt, check the study design algorithm available from SIGN and make sure you have the correct checklist. If it is a **controlled clinical trial** questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be rated higher than 1+

2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

### SECTION 1: INTERNAL VALIDITY

**In a well conducted RCT study…**

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.1</strong> The study addresses an appropriate and clearly focused question.</td>
</tr>
<tr>
<td>Yes ☑</td>
</tr>
</tbody>
</table>

| **1.2** The assignment of subjects to treatment groups is randomised. |
| N/A |

| **1.3** An adequate concealment method is used. |
| N/A |

| **1.4** The design keeps subjects and investigators ‘blind’ about treatment allocation. |
| N/A |

Data collected by researchers who are blinded to study group allocation
1.5 The treatment and control groups are similar at the start of the trial.  Yes ✓

1.6 The only difference between groups is the treatment under investigation.  Yes ✓

1.7 All relevant outcomes are measured in a standard, valid and reliable way.  Yes ✓

1.8 What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed?  

<table>
<thead>
<tr>
<th></th>
<th>patients</th>
<th>carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>Control</td>
<td>10%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Dropped out rate

Intervention group: 9% died
Control group: 6% died, 4% cannot contact

1.9 All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis).  Can’t say ✓

Analysis mentioned but details was not discussed

1.10 Where the study is carried out at more than one site, results are comparable for all sites.  Yes ✓

Similar provincial hospitals

SECTION 2: OVERALL ASSESSMENT OF THE STUDY

2.1 How well was the study done to minimise bias?  

*Code as follows:*

- High quality (++): ✓
- Acceptable (+): □
- Low quality (-): □
- Unacceptable – reject 0: □

2.2 Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention?  

It was a non-randomized controlled trial. Concealment and blinding were not applied. Blinding the assessor could lower the bias. The drop-out rate is low. Thus, overall effect was like due to the study intervention.
| 2.3 | Are the results of this study directly applicable to the patient group targeted by this guideline? | Yes, the participants in study is caregiver of stroke. |
| 2.4 | **Notes.** Summarise the authors’ conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above. |
|     | Most criteria for a good quality controlled trial were met. |
|     | Thus, the probability that the relationship between the intervention and result was high and it provided good evidence that education program for formal caregivers could reduce caregiver burden |
Methodology Checklist 2: Controlled Trials (No.3)

S I G N

Study identification (Include author, title, year of publication, journal title, pages)


Guideline topic: An evidence-based education program targeting informal caregivers of stroke survivors to reduce caregiver burden

Key Question No: 1

Reviewer: C.T. Lee

Before completing this checklist, consider:

1. Is the paper a **randomised controlled trial** or a **controlled clinical trial**? If in doubt, check the study design algorithm available from SIGN and make sure you have the correct checklist. If it is a **controlled clinical trial** questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be rated higher than 1+

2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

Reason for rejection: 1. Paper not relevant to key question □ 2. Other reason □ (please specify):

SECTION 1: INTERNAL VALIDITY

In a well conducted RCT study…

<table>
<thead>
<tr>
<th></th>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>The study addresses an appropriate and clearly focused question.</td>
</tr>
<tr>
<td>1.2</td>
<td>The assignment of subjects to treatment groups is randomised.</td>
</tr>
<tr>
<td>1.3</td>
<td>An adequate concealment method is used.</td>
</tr>
<tr>
<td>1.4</td>
<td>The design keeps subjects and investigators ‘blind’ about treatment allocation.</td>
</tr>
<tr>
<td>1.5</td>
<td>The treatment and control groups are similar at the start of the trial.</td>
</tr>
</tbody>
</table>
1.6 The only difference between groups is the treatment under investigation. | Can’t say ☑
Only demographic information of two sites is compared

1.7 All relevant outcomes are measured in a standard, valid and reliable way. | Yes ☑

1.8 What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed? | 12%
(deconditioning 3, self-care 1, nursing home 2, fail to meet TAP appointment 1, moved away 2, death 1, personal reason 1)

1.9 All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis). | No ☑
Only included all of the follow-up data which can be able to amass

1.10 Where the study is carried out at more than one site, results are comparable for all sites. | Yes ☑

### SECTION 2: OVERALL ASSESSMENT OF THE STUDY

2.1 How well was the study done to minimise bias? *Code as follows:* | High quality (++) ☐
Acceptable (+) ☑
Low quality (-) ☐
Unacceptable – reject 0 ☐

2.2 Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention? | This was a pilot study where the sample size is satisfactory. Good Randomization was applied. The drop-out rate is acceptable. However, the concealment and blinding method were not mentioned.

2.3 Are the results of this study directly applicable to the patient group targeted by this guideline? | Yes, the target group is caregiver of stroke survivors
<table>
<thead>
<tr>
<th>2.4</th>
<th><strong>Notes.</strong> Summarize the authors’ conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. It is not certain about the similarity of demographic information of intervention group and control group.</td>
</tr>
<tr>
<td></td>
<td>2. Method of concealment is not mentioned.</td>
</tr>
<tr>
<td></td>
<td>3. Blinding method and party to be blinded is not mentioned.</td>
</tr>
<tr>
<td></td>
<td>4. Apart from the follow-up data which cannot be amassed is neglected; the any method to deal with the participants who dropped out is not mentioned. Any method of intention to treat is not certain.</td>
</tr>
<tr>
<td></td>
<td>5. Since it was a pilot study, the sample size was satisfactory.</td>
</tr>
</tbody>
</table>
**Methodology Checklist 2: Controlled Trials (No.4)**

**SIGN**

**Study identification** *(Include author, title, year of publication, journal title, pages)*


**Guideline topic:** An evidence-based education program targeting informal caregivers of stroke survivors to reduce caregiver burden

**Key Question No:** 1

**Reviewer:** C.T. LEE

**Before** completing this checklist, consider:

1. Is the paper a **randomised controlled trial** or a **controlled clinical trial**? If in doubt, check the study design algorithm available from SIGN and make sure you have the correct checklist. If it is a **controlled clinical trial** questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be rated higher than 1+

2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

**Reason for rejection:** 1. Paper not relevant to key question ☐ 2. Other reason ☐ (please specify):

**SECTION 1: INTERNAL VALIDITY**

**In a well conducted RCT study...**

<table>
<thead>
<tr>
<th></th>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>The study addresses an appropriate and clearly focused question.</td>
</tr>
<tr>
<td>1.2</td>
<td>The assignment of subjects to treatment groups is randomised.</td>
</tr>
</tbody>
</table>

Randomization in block of 8 and were stratified by continence of urine at 24 hours after stroke as a proxy marker for stroke severity. Randomization method changed at 7 month of study. Randomization ratio of 2 SEP to 1 conventional care.
| 1.3 | An adequate concealment method is used. | Yes ☑ | Central telephone service used to invite subject to attend SEP or control group |
| 1.4 | The design keeps subjects and investigators ‘blind’ about treatment allocation. | Yes ☑ | Assessor Blinded |
| 1.5 | The treatment and control groups are similar at the start of the trial. | Yes ☑ | |
| 1.6 | The only difference between groups is the treatment under investigation. | Yes ☑ | |
| 1.7 | All relevant outcomes are measured in a standard, valid and reliable way. | Yes ☑ | |
| 1.8 | What percentage of the individuals or clusters recruited into each treatment arm of the study dropped out before the study was completed? | Intervention: 40% Control: 40% Both group are fail to attend more than 3 SEP session |
| 1.9 | All the subjects are analysed in the groups to which they were randomly allocated (often referred to as intention to treat analysis). | Not sure ☑ | |
| 1.10 | Where the study is carried out at more than one site, results are comparable for all sites. | Does not apply ☑ | One site only |

**SECTION 2: OVERALL ASSESSMENT OF THE STUDY**

<p>| 2.1 | How well was the study done to minimise bias? <em>Code as follows:</em> | High quality (++): ☑ Acceptable (+): ☑ Low quality (-): ☒ Unacceptable – reject 0 ☐ |
| 2.2 | Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention? | a drop-out rate was high in the study. The drop-out rate for both treatment groups were the same and it might be due the frequent number of SEP sessions to be attended. Randomization method was not a consistence. Also, the number of treatment group and control group is not equally distributed. |
| 2.3 | Are the results of this study directly applicable | Yes, the target group are also caregiver of stroke |</p>
<table>
<thead>
<tr>
<th></th>
<th>to the patient group targeted by this guideline?</th>
<th>survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4</td>
<td><strong>Notes.</strong> Summarise the authors’ conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some data were not statistically significant, it may due to the high drop-out rate and inconsistence of randomization. Although nearly all points are met in internal validity, the inconsistence of randomization may lead to errors. Thus, this study is rated as low quality.</td>
<td></td>
</tr>
</tbody>
</table>
Methodology Checklist 2: Controlled Trials (No.5)

Study identification  
(Include author, title, year of publication, journal title, pages)


Guideline topic: An evidence-based education program targeting informal caregivers of stroke survivors to reduce caregiver burden

<table>
<thead>
<tr>
<th>Key Question No: 1</th>
<th>Reviewer: C.T. Lee</th>
</tr>
</thead>
</table>
| Study identification | (

**Before** completing this checklist, consider:

1. Is the paper a randomised controlled trial or a controlled clinical trial? If in doubt, check the study design algorithm available from SIGN and make sure you have the correct checklist. If it is a controlled clinical trial questions 1.2, 1.3, and 1.4 are not relevant, and the study cannot be rated higher than 1+

2. Is the paper relevant to key question? Analyse using PICO (Patient or Population Intervention Comparison Outcome). IF NO REJECT (give reason below). IF YES complete the checklist.

Reason for rejection: 1. Paper not relevant to key question ☐ 2. Other reason ☐ (please specify):

**SECTION 1: INTERNAL VALIDITY**

In a well conducted RCT study…

<table>
<thead>
<tr>
<th>Does this study do it?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.1</strong> The study addresses an appropriate and clearly focused question.</td>
</tr>
<tr>
<td><strong>1.2</strong> The assignment of subjects to treatment groups is randomised.</td>
</tr>
<tr>
<td><strong>1.3</strong> An adequate concealment method is used.</td>
</tr>
<tr>
<td></td>
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<tr>
<td>1.4</td>
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<tr>
<td></td>
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<tr>
<td>1.5</td>
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<td>1.6</td>
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<tr>
<td>1.7</td>
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<tr>
<td>1.8</td>
</tr>
<tr>
<td>1.9</td>
</tr>
<tr>
<td>1.10</td>
</tr>
</tbody>
</table>

**SECTION 2: OVERALL ASSESSMENT OF THE STUDY**

|   | How well was the study done to minimise bias?  
*Code as follows:* |
|---|-------------------------------------------------------------------------------------------------|
|2.1| High quality (++)
Acceptable (+)
Low quality (-)
Unacceptable – reject |

| 2.2 | Taking into account clinical considerations, your evaluation of the methodology used, and the statistical power of the study, are you certain that the overall effect is due to the study intervention? | Only for the Mental health is reliable as it was statistically significant. Randomization method was good. Concealment methods used was enough. Also examiner was kept blind during the assessment. This avoided the chance of unfair treatment and biased assessments. |
| 2.3 | Are the results of this study directly applicable to the patient group targeted by this guideline? | Yes, both are carer of stroke survivors |
| 2.4 | **Notes.** Summarise the authors’ conclusions. Add any comments on your own assessment of the study, and the extent to which it answers your question and mention any areas of uncertainty raised above. | 1. No characteristics of different hospitals are mentioned.  
2. Sample size is small which may lead to type II error.  
3. drop-out rate is a bit higher than the acceptable range.  
4. Age of 2 groups of carers may causes difference of result. But other demographical data is comparable.  
5. Bias is minimized by methodological method. Significant improvement of mental health of health status of caregiver is due to the intervention of education program. |
Appendix 5: Timeline of implementation of pre-discharge education program to
informal caregivers of stroke survivors in stroke rehabilitation ward in Hospital A

<table>
<thead>
<tr>
<th>Event/ Month</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casual discussion</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>➢ Preparation of proposal</td>
<td></td>
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<td></td>
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<tr>
<td>➢ Seeking approval from</td>
<td></td>
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<tr>
<td>DOM, WM and administers</td>
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<tr>
<td>➢ Announcement to staff</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>➢ briefing session</td>
<td></td>
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<tr>
<td>Pilot testing</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>➢ Analysis data</td>
<td></td>
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</tr>
<tr>
<td>➢ Review of guidelines</td>
<td></td>
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<tr>
<td>Implementation</td>
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<td></td>
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</tr>
<tr>
<td>Evaluation</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>
Appendix 6: Questionnaire of Caregiver Strain Index

Caregiver Strain Index (CSI)

I am going to read a list of things that other people have found to be difficult. **Would you tell me whether any of these apply to you? (GIVE EXAMPLES)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes = 1</th>
<th>No = 0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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>It is confining (e.g., helping restricts free time or cannot go visiting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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>There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been emotional adjustments (e.g., because of severe arguments)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>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>It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been work adjustments (e.g., because of having to take time off)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a financial strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling completely overwhelmed (e.g., because of worry about . . .; concerns about how you will manage)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Total Score** (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)

---


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Appendix 7: Table showing set-up cost (Manpower) of evidence-based pre-discharge education program

<table>
<thead>
<tr>
<th></th>
<th>MO</th>
<th>APN</th>
<th>RN</th>
<th>PT</th>
<th>OT</th>
<th>Clerical Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hourly Salary</td>
<td>390</td>
<td>259</td>
<td>163</td>
<td>248</td>
<td>248</td>
<td>50</td>
</tr>
<tr>
<td>(HKD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Hour used

<table>
<thead>
<tr>
<th></th>
<th>MO</th>
<th>APN</th>
<th>RN</th>
<th>PT</th>
<th>OT</th>
<th>Clerical Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meeting Preparation</td>
<td>8</td>
<td>8</td>
<td>16 (8x2)</td>
<td>8</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Preparation of Material</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PowerPoint</td>
<td>1</td>
<td>2</td>
<td>24 (12x2)</td>
<td>/</td>
<td>/</td>
<td>2</td>
</tr>
<tr>
<td>Printed Materials</td>
<td>1</td>
<td>2</td>
<td>24 (12x2)</td>
<td>8</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Hand-on sessions</td>
<td>/</td>
<td>/</td>
<td>/</td>
<td>2</td>
<td>2</td>
<td>/</td>
</tr>
<tr>
<td>Briefing on Educators</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Briefing</td>
<td>1</td>
<td>1</td>
<td>2 (1x2)</td>
<td>1</td>
<td>1</td>
<td>/</td>
</tr>
<tr>
<td>Attendant</td>
<td>/</td>
<td>/</td>
<td>5 (1x5)</td>
<td>2(1x2)</td>
<td>2(1x2)</td>
<td>/</td>
</tr>
</tbody>
</table>

### Subtotal Salary (HKD)

<table>
<thead>
<tr>
<th></th>
<th>MO</th>
<th>APN</th>
<th>RN</th>
<th>PT</th>
<th>OT</th>
<th>Clerical Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5,070</td>
<td>8,029</td>
<td>11573</td>
<td>5,208</td>
<td>5,208</td>
<td>700</td>
</tr>
</tbody>
</table>

### Total Salary(HKD)

<table>
<thead>
<tr>
<th></th>
<th>35788</th>
</tr>
</thead>
</table>

Footnotes: MO: Medical Officer  
APN: Advanced Practiced Nurse  
RN: Registered Nurse  
PT: Physiotherapist  
OT: Occupational Therapist
## Appendix 8: Table showing operational cost of the evidence-based pre-discharge education program in a year

<table>
<thead>
<tr>
<th></th>
<th>Unit rate</th>
<th>Units used (sessions x hours)</th>
<th>Total Price (HKD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RN</td>
<td>163/hour</td>
<td>103x 2</td>
<td>33,578</td>
</tr>
<tr>
<td>PT</td>
<td>248/hour</td>
<td>103x 1</td>
<td>25,544</td>
</tr>
<tr>
<td>OT</td>
<td>248/hour</td>
<td>103x 1</td>
<td>25,544</td>
</tr>
<tr>
<td>Pamphlet</td>
<td>1.5/head</td>
<td>410</td>
<td>615</td>
</tr>
<tr>
<td><strong>Total (HKD):</strong></td>
<td></td>
<td></td>
<td><strong>85,281</strong></td>
</tr>
</tbody>
</table>

**Footnotes:**

MO: Medical Officer  
APN: Advanced Practiced Nurse  
RN: Registered Nurse  
PT: Physiotherapist  
OT: Occupational Therapist

**Duration of program:**

- Education sessions with discussion sessions: 2 hours  
- Hand-on skills session by PT and OT: 1 hours  
  (Group A: PT 0.5 hours then OT 0.5 hours)  
  (Group B: OT 0.5 hours then PT 0.5 hours)  
- Four pairs of caregivers separated into Group A and B
Appendix 9: Evidence Based Guideline

An evidence-based guideline of pre-discharge education program to informal caregivers of stroke survivors (Version 1, March 2016)

Aim:

To provide a structured framework for nurses and paramedical staff in stroke rehabilitation wards of Hospital A to implement a comprehensive evidence-based pre-discharge education program to reduce caregiver burden of informal caregivers of stroke survivors.

Objectives:

1. To develop a standardized evidence-based pre-discharge education program for informal caregivers of stroke survivor.

2. To give a framework for nurses and allied health staff to implement the pre-discharge education program based on evidence.

User of Guideline: Nurses, Physiotherapist, Occupational Therapists and other paramedical team in stroke rehabilitation wards of Hospital A

Target Population Informal caregivers of in-patient stroke survivors in stroke rehabilitation wards of Hospital A

of Guideline:
The grade of recommendation used in this guideline are graded according to grading system developed by Scottish Intercollegiate Guidelines Network. There are four grading in the grading system, which are A, B, C, D. Grade A evidence is the most credible, whereas Grade D evidence should be treated carefully (SIGN, 2014). (Appendix 4)

Recommendations:

1. **Two-hour group education sessions with discussion provided by registered nurse to informal caregivers of stroke survivors (GRADE A)**

   Group education sessions by nurses are suggested by four reviewed studies (L. Kalra et al., 2004; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999) (1++, 2++, 1+, 1-). Study recommended whole education session should last for two hours (Oupra et al., 2010)(2++). It was suggested to separate it into two parts, so two one-hour group education sessions and one-hour discussion session were proposed.

2. **Different topics, such as prevention and management of pressure sore, information and problems related to stroke, and community resources, can be covered in nurse-led education sessions (GRADE A)**

   Some topics are recommended in study such as prevention and management of pressure sore, information and prevention of recurrent stroke which can be covered in the education sessions (L. Kalra et al., 2004)(1++). Community resources is also suggested to be discussed in the education session (L. Kalra et al., 2004; Rodgers et
3. **Group discussion sessions is suggested for registered nurse to answer enquires (GRADE B)**

Group discussion session is recommend in studies as parts of education program for informal caregivers (Oupra et al., 2010; Rodgers et al., 1999)(2++,1-). Face-to-face meeting before discharge was suggested in another study (Perrin et al., 2010)(1+). It will be integrated with education session.

4. **A 1-hour hand-on training session provided by physiotherapists and occupational therapists to informal caregivers (GRADE A)**

Three reviewed studies showed that a hand-on training session can help to reduce caregiver stress (L. Kalra et al., 2004; Oupra et al., 2010; Perrin et al., 2010)(1++,2++,1+). L. Kalra et al. (2004) suggested a 30-45 minutes’ session would be enough for a hand-on session (1++). PT and OT will share the one-hour session by separating 4 pairs of patients into two groups. Thus, group one patients will receive 30 minutes PT session and then followed by 30 minutes OT session, then group two patients will be having the OT session first and followed by PT session where each part lasts for 30 minutes. Thus, a total 1-hour session was suggested is included in the training session.
5. **Ratio of nurses and therapists to informal caregivers should be one to four and one to two respectively (Grade B)**

Study suggested nurses to caregivers can be 1 to 6 (Oupra et al., 2010). Thus, four caregivers are suggested to be educated by nurses in education session. Meanwhile, the study also suggested two pairs of patients and caregivers to one therapist, OT or PT (Oupra et al., 2010) (2++). Hence, four pairs of caregivers can be separated into two groups in order to maximize the number of participants.

6. **Information leaflets or booklets as a summary and reminder of post-stroke care (GRADE A)**

All reviewed studies suggested to provide information booklets or leaflets to informal caregivers (L. Kalra et al., 2004; Mant et al., 1998; Oupra et al., 2010; Perrin et al., 2010; Rodgers et al., 1999) (1++, 2++,1+1-,1+). Booklets should be written in dialect (Oupra et al., 2010). Therefore, the information packs of the suggested program should be written in Chinese as caregivers in Hospital A are mainly Chinese.
References


## Appendix 10: Questionnaire of Caregiver Strain Index (Chinese Version)

<table>
<thead>
<tr>
<th>問題</th>
<th>經常</th>
<th>有時</th>
<th>完全無</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 感到困身（例如：因自由時間減少了或不能外出）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. 感到不方便（例如：因為需要花很多時間或長途跋涉去協助病者）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. 感到身體疲累（例如：需專注看護病者或費力去幫助病者坐立）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. 睡眠被打擾（例如：需在夜間照顧經常要上落床或無法安頓下來的病者）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. 起居生活習慣有變動（例如：因為往常的家居工作被打擾，私人時間少了）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. 個人計劃的改動（例如：要放棄轉工的念頭，或者不能放假）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. 要花時間應付其他人的需求（例如：來自其他家庭成員的要求）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. 情緒上要適應（例如：因為出現激烈的爭吵）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. 病者某些行為令人煩厭（例如：失禁、他記憶事情有困難或他怪責別人取了他的東西）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. 發現病者改變很大而令你不安（例如：他跟以往完全不同）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. 要改動工作安排（例如：因為要特別放假照顧病者）</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. 財政負荷</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. 感到心靈疲累（例如：因為擔心或顧慮該如何處理病者）</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 11: Self-reported survey of Frontline staff towards pre-discharge education program to informal caregivers in stroke rehabilitation ward in Hospital A

| Staff Survey on pre-discharge education program to informal caregivers in stroke rehabilitation ward in Hospital A |
|---|---|---|---|---|---|
| 5 | 4 | 3 | 2 | 1 |
| (5=Totally Agree; 1=Totally Disagree) |

**Part A: Staff satisfaction on pre-discharge education program to informal caregivers in stroke rehabilitation ward in Hospital A**

1. The aim, reducing caregiver stress, of the pre-discharge education program is achieved.
2. I am confident being an educator.
3. The duration of training session is suitable.
4. The extra workload of being educator is affordable.
5. I am proud of being an educator.

**Part B: Acceptance of EBP guideline in stroke rehabilitation wards of hospital A**

1. The EBP guideline for pre-discharge education program is user friendly and easy to follow.
2. The skills and knowledge from the guideline are easily understood after briefing session.
3. I have confidence in using the EBP guideline
4. Pre-discharge education program to informal caregivers of stroke survivors should be promoted in other stroke rehabilitation wards in Hong Kong.
References:


Chan, W., Chan, C., & Suen, M. (2013). Validation of the Chinese version of the Modified Caregivers Strain Index among Hong Kong caregivers: an initiative of medical social


Oupra, R., Griffiths, R., Pryor, J., & Mott, S. (2010). Effectiveness of Supportive Educativ
Learning program on level of strain experienced by caregivers of stroke patients in Thailand. *Health and Social Care in Community, 18*(1), 10-20.


