EFFECTIVENESS OF A SELF-EFFICACY ENHANCING STROKE SELF-MANAGEMENT PROGRAM ON PROMOTING RECOVERY OF COMMUNITY-DWELLING STROKE SURVIVORS

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Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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Community dwelling, community health nursing, community health services, community integration, disease management, outcome expectation, quality of life, randomised controlled trial, rehabilitation, self-efficacy, self-management, stroke, stroke survivors, systematic review.
Abstract

Background

Stroke recovery is long-term and demanding. Stroke survivors need to be equipped with new knowledge and skills for better adaptation to their post-stroke challenges and reintegration into the community. Self-management programs have been widely applied to people with chronic conditions over the past decades, and have been associated with significant improvement in health outcomes. However, the application of self-management to stroke survivors increased only in the past few years. Examination of the best approach to deliver stroke self-management programs for promoting rehabilitation among community-dwelling stroke survivors is essential.

Objectives

Phase One of the research project was aimed at assessing the current research evidence on the effectiveness of theory-based stroke self-management programs for community-dwelling stroke survivors.

Phase Two was aimed at developing and evaluating the effectiveness of a new 4-week nurse-led self-efficacy enhancing stroke self-management program (SSMP) on promoting recovery of Chinese community-dwelling stroke survivors.

Methods

In Phase One, a systematic review was conducted. All randomised controlled trials in English or Chinese which examined the effectiveness of stroke self-management programs underpinned by a theoretical framework for community-dwelling stroke survivors were included. Two reviewers independently assessed study eligibility and methodological quality, and extracted the data. A narrative summary of the effectiveness of the stroke self-management programs was presented. The results of the systematic review informed the development, implementation and evaluation of the SSMP in Phase Two.
In Phase Two, a new nurse-led SSMP for Chinese community-dwelling stroke survivors was developed. The program was underpinned by Bandura’s constructs of self-efficacy and outcome expectation. It consisted of one individual home visit, two community-based group sessions, and three follow-up phone calls. A total of 15 videos of experience sharing by volunteer stroke survivors who had managed stroke successfully and a program workbook were developed. A two-arm randomised controlled trial was conducted to evaluate the effectiveness of the SSMP. All adult patients with a first or recurrent ischaemic or haemorrhagic stroke were recruited from three acute stroke units in Hong Kong. Eligible participants were randomised to receive either usual care or the new SSMP plus usual care. All participants were assessed at baseline and at eight weeks after randomisation on self-efficacy, outcome expectation and satisfaction with performance in stroke self-management behaviours, health-related quality of life, depressive symptoms, and community reintegration. The participants in the intervention group were also phoned immediately after program completion to collect their feedback on usefulness of the SSMP. Generalised estimating equations were performed to evaluate the differential changes in outcomes across time between the intervention and the control groups.

**Results**

In Phase One, three randomised controlled trials in English, involving 306 community-dwelling stroke survivors were included in the systematic review. Preliminary evidence showed potential benefits of theory-based stroke self-management programs on stroke participants’ health-related quality of life and self-efficacy.

In Phase Two, the Stroke Self-Efficacy Questionnaire and the Stroke Specific Quality of Life Scale were translated into Chinese and tested among 135 Chinese community-dwelling stroke survivors. The results showed high internal consistency (Cronbach’s alpha 0.92 and 0.93 respectively) and satisfactory convergent validity of these two tools. Two measuring instruments which assessed outcome expectation and satisfaction with performance in stroke self-management behaviours were developed in English and translated into Chinese. Testing among 83 Chinese community-dwelling stroke survivors showed high internal consistency of these two tools (Cronbach’s alpha 0.94 and 0.93 respectively).
A total of 128 patients (mean age 67.46 years, SD 11.95) were recruited (response rate: 70.33%) into the randomised controlled trial. Analysed using the intention-to-treat principles, the results showed that the participants in the intervention group, compared with the control group, had significant improvements in self-efficacy in and outcome expectation for stroke self-management, satisfaction with their performance in stroke self-management behaviours, health-related quality of life, and community reintegration, at 8-weeks follow-up assessment relative to baseline. However, the participants in the intervention group, compared with the control group, did not have a significant decrease in depressive symptoms at 8-weeks follow-up assessment relative to baseline. Overall, the participants were satisfied with the SSMP, particularly the videos of experience sharing and the individual home visit.

**Conclusion and Implications**

The results of the study indicated that the SSMP, applying Bandura’s constructs of self-efficacy and outcome expectation, was effective in promoting recovery of Chinese stroke survivors after discharge from hospital to home. The SSMP which features setting goals of recovery and action plans, providing vicarious experiences by group sessions and videos about stroke survivors’ experience sharing of managing stroke, providing verbal persuasion, assisting with reinterpretation of physiological and emotional states, and reinforcing positive outcomes after performing stroke self-management behaviours was found helpful in enhancing the participants’ confidence in managing their post-stroke challenges. Further examination of effective strategies to enhance the participants’ capabilities in self-managing their psychological needs, and integration of the SSMP into current stroke care practice is needed. More evidence on effectiveness of the SSMP on long-term outcomes would be worthwhile.
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<td>AE</td>
<td>Activities and exercise engagement</td>
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<td>ANOVA</td>
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<td>AR-1</td>
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<td>CI</td>
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<td>CONSORT</td>
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<td>Digital versatile disc</td>
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<td>Population, Intervention, Comparison, Outcomes</td>
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<td>PS</td>
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<td>r</td>
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Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors
Statement of Original Authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

QUT Verified Signature

Signature:

Date: 12-9-2016
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Chapter 1: Introduction

1.1 BACKGROUND

Stroke is a debilitating neurological disorder, which causes multiple physical and psychosocial challenges to people surviving a stroke. The trajectory of recovery after stroke is complicated in that it involves several interrelated aspects. It is often a long-term and demanding experience for stroke survivors. As soon as the stroke survivors are discharged from hospital, they are expected to learn to manage their physical and functional disabilities, and emotional disturbance consequential to the stroke. They are also expected to adapt to the limitations after stroke and reintegrate into the community to resume their pre-stroke roles and lives, or to assume new family and/or social roles. The complexities of adapting to post-stroke challenges and reintegrating into the community cannot be underestimated. Some challenges are only realised when the stroke survivors have returned home, when the immediate support from healthcare professionals is no longer available. Family members and carers also need to resume their normal lives. Stroke survivors need to be equipped with new knowledge and skills for better adaptation and reintegration. More importantly, they need to be confident in their own capabilities in managing their health conditions. Development and provision of effective interventions to enhance stroke survivors’ confidence and skills in managing stroke is important for promoting their rehabilitation. Self-management programs have been widely applied to people with chronic conditions over the past decades and have been associated with significant improvement in health outcomes. However, the application of self-management to stroke survivors increased only in the past few years. Examination of the best approach to deliver stroke self-management programs for promoting rehabilitation among community-dwelling stroke survivors is essential.

1.1.1 Stroke prevalence and mortality

Stroke is a broad term, which includes ischaemic stroke, stroke caused by intracerebral or subarachnoid haemorrhage, or cerebral venous thrombosis, and stroke of an unspecified type (Sacco et al., 2013). Stroke is a significant public health problem with high prevalence and mortality. According to the latest report by the American Heart Association, an estimated 33 million people globally were living with stroke in
2010 (Mozaffarian et al., 2015). The prevalence of stroke is expected to increase with the expanding ageing population (Mozaffarian et al., 2015).

Stroke was the second leading cause of global death after ischaemic heart disease between 2000 and 2012. It accounted for 6.7 million (11.9%) global deaths in 2012 (World Health Organisation (WHO), 2016a). The highest death rate, 126 per 100,000 population, was found in upper-middle-income countries; followed by high, lower-middle and low-income countries causing 95, 78 and 52 deaths per 100,000 population respectively (WHO, 2016b). With advancements in evidence-based interventions for stroke risk reduction, particularly improved control of hypertension, there has been a gradual decline in stroke mortality of approximately 0.5% per year over the past decade (Lackland et al., 2014). However, the death toll attributable to stroke remains high and it is estimated that it will increase to 7.8 million deaths worldwide by 2030 (Mukherjee & Patil, 2011).

In Hong Kong, similar patterns in both the prevalence and mortality rate of stroke are observed. Statistics showed that the prevalence of stroke was 0.04 million stroke survivors in Hong Kong in 2012 (Centre for Health Protection, 2013). The number of those living with the effects of stroke in the Hong Kong community in 2036 is estimated to increase to 0.11 million people aged 65 and above (Yu et al., 2012). Stroke has been the fourth leading cause of death after cancer, pneumonia and heart disease for the past decade. Statistics showed that the age-standardised death rate for stroke decreased from 34.4 in 2001 to 21.1 in 2014. However, stroke still accounts for 3,000 to 3,300 deaths annually (7.2% to 9.5% of total deaths) (Centre for Health Protection, 2015). In view of the huge number of stroke survivors and the high mortality rate of stroke, it is important to develop and provide effective interventions to address the health needs of those who live with stroke at home in the absence of immediate and continuous support by healthcare professionals.

1.1.2 Impact of stroke

Stroke is associated with profound negative impacts on survivors’ physical, psychological and social functioning (Carod-Artal & Egido, 2009; Lee, Tang, Tsoi, Fong, & Yu, 2009). Some of the most prominent impacts are limitations in physical mobility, activities and functions, and loss of independence. Stroke is a significant cause of disability. The extent of physical disabilities, commonly one-sided weakness or hemiplegia, and shoulder pain experienced by survivors varies. Challenges also arise in
that long periods of repetitive rehabilitation training and hard work are required for improvement or adaptation to the limitations (Feigin et al., 2014). Furthermore, fatigue is one of the most frequent complaints of stroke survivors. Studies consistently reported that fatigue was a significant barrier to survivors’ motivation for and participation in exercise, and hence slowed their rates of recovery (Duncan, Kutlubaev, Dennis, Greig, & Mead, 2012). Other common physical impacts of stroke which often pose challenges to survivors’ recovery include aphasia or dysphasia (Sinanović, Mrkonjić, Zukić, Vidović, & Imamović, 2011), visual impairment (Sand et al., 2013), and cognitive impairment such as memory loss or decreased attention (Sun, Tan, & Yu, 2014).

In addition to post-stroke depression, several studies have reported that stroke survivors had a higher risk of developing psychological distress, anxiety or lowered levels of self-esteem (Campbell Burton et al., 2011; Chau, Thompson, Twinn, Chang, & Woo, 2009; Robinson & Spalletta, 2010). This may be due to their loss of independence or uncertainties about their recovery and prognosis of the condition, or to the pathological changes in the brain (White, Barrientos, & Dunn, 2014). Moreover, stroke survivors found difficulties in participating in their pre-stroke social roles, work or leisure activities. Stroke causes restrictions to survivors’ social participation, which in turn impairs their sense of freedom and autonomy (Chau et al., 2009; Woodman, Riazi, Pereira, & Jones, 2014). Higher levels of disability, poorer emotional well-being and decreased participation are consistently reported as significant factors compromising stroke survivors’ health-related quality of life (HRQoL) (Cerniauskaite et al., 2012; Katona, Schmidt, Schupp, & Graessel, 2015; Kwok, Pan, Lo, & Song, 2011). Indeed stroke was the leading cause of global lost disability-adjusted life years (DALYs) among adults aged 45 to 69 years. For all ages, it was also ranked as the seventh leading cause of lost DALYs globally (Mukherjee & Patil, 2011).

1.1.3 Support for community-dwelling stroke survivors

The trajectory of stroke can be divided into four phases, namely hyper-acute phase, acute phase, rehabilitation and recovery (Stein, Harvey, Macko, Winston, & Zorowitz, 2009). International guidelines on management of stroke recommend that stroke survivors receive organised multidisciplinary stroke care at acute stroke units in the hyper-acute and acute phases, and continue to receive inpatient or outpatient rehabilitation care depending on their recovery progress (Royal College of Physicians, 2012; Scottish Intercollegiate Guidelines Network (SIGN), 2010). The recovery phase
is the last and longest phase during which stroke survivors continue to rehabilitate in residential care or home settings. More importantly, they learn and practise new skills to reintegrate themselves into their post-stroke lives and roles (Vanhook, 2009).

In Hong Kong, all public hospitals with accident and emergency departments are equipped with acute stroke units which provide comprehensive acute inpatient care for stroke patients according to a well-established hospital-wide stroke care pathway. Patients surviving stroke, after having their acute medical condition stabilised, are either transferred to rehabilitation hospitals to continue with rehabilitation, or discharged directly to their homes, old aged homes or other residential care settings depending on their progress. To support stroke patients’ transition from hospital to home, early discharge support services are arranged when required. Arrangement is also made for discharged stroke patients to undertake a course of rehabilitation training at day care centres, and attend medical follow-up consultations, or other outpatient therapies provided by nurses, and other allied healthcare professionals such as physiotherapists, occupational therapists and speech therapists. Information about or referrals to community-based stroke support groups, such as the Hong Kong Society for Rehabilitation, are also provided (Hospital Authority Head Office, 2012).

However, the level of complexity in adaptation is particularly intensified when stroke survivors return home. Some post-stroke challenges may become obvious only after patients return home (Woo, Chan, Sum, Wong, & Chui, 2008). Initially, stroke survivors discharged home have to adjust to less support from healthcare professionals and carers, as the day-rehabilitation training or outpatient therapy sessions are less intensive compared with those received as inpatients. These training or therapeutic programs may cease when stroke survivors are considered physically independent. However, support for stroke survivors, albeit reduced, extends well beyond the period of hospitalisation to longer-term recovery in the community (Woo et al., 2008).

Community support for stroke survivors in Hong Kong often revolves around stroke support groups, private physiotherapy or occupational therapy, and social services offered by non-government organisations such as vocational training. However, the focus and type of support programs for community-dwelling stroke survivors should not only be on physical or functional rehabilitation, but also on psychological and social aspects. New knowledge and skills are required for better reintegration into the community and assumption of post-stroke life roles. While there
is abundant evidence supporting the provision of self-management support for people with chronic conditions such as diabetes, this has only more recently been recognised as essential by international guidelines for enhancing post-stroke recovery (Royal College of Physicians, 2012; SIGN, 2010).

Nurses have a unique role in initiating and providing appropriate interventions for community-dwelling stroke survivors during their rehabilitation. Accordingly, it is worthwhile to examine the effectiveness of a stroke self-management support intervention delivered by nurses on promoting recovery of community-dwelling stroke survivors.

1.2 PURPOSES OF THE RESEARCH PROJECT

1.2.1 Research questions

This research project was undertaken in two phases to answer the following two research questions:
1. “What is the current research evidence regarding the effectiveness of theory-based self-management programs on promoting recovery among community-dwelling stroke survivors?”
2. “What is the effectiveness of a new nurse-led community-based self-efficacy enhancing stroke self-management program implemented after discharge from hospital, compared with usual care, on promoting recovery among Chinese community-dwelling stroke survivors?”

1.2.2 Aim and objectives

The aim of Phase One of this research project was to determine the current research evidence on effectiveness of theory-based self-management programs for community-dwelling stroke survivors. A systematic review was conducted.

Specific objectives of the systematic review were to determine the effectiveness of theory-based self-management programs on community-dwelling stroke survivors’:
1. Self-efficacy in managing stroke;
2. Health-related quality of life (HRQoL);
3. Physical outcomes;
4. Psychological outcomes; and
5. Social outcomes.
The aim of Phase Two of this research project was to develop and evaluate in a randomised controlled trial (RCT) the effectiveness of a new nurse-led community-based self-efficacy enhancing stroke self-management program on recovery of Chinese community-dwelling stroke survivors.

Specific objectives of the RCT were to evaluate the effectiveness of a new stroke self-management program implemented after discharge from hospital, compared with usual care at 8-weeks follow-up, on Chinese community-dwelling stroke survivors:

1. Self-efficacy in stroke self-management as measured by the Stroke Self-Efficacy Questionnaire;
2. Outcome expectation for stroke self-management as measured by the Stroke Self-management Outcome Expectation Scale;
3. Satisfaction with performance in stroke self-management behaviours as measured by the Stroke Self-management Behaviours Performance Scale;
4. HRQoL as measured by the Stroke Specific Quality of Life Scale;
5. Depressive symptoms as measured by the Geriatric Depression Scale; and
6. Community reintegration as measured by the Reintegration to Normal Living Index.

1.2.3 Hypotheses

It is hypothesised in the RCT that Chinese community-dwelling stroke survivors who received the new nurse-led community-based self-efficacy enhancing stroke self-management program implemented after discharge from hospital, when compared with usual care at 8-weeks follow-up, will have a significant:

1. Increase in self-efficacy in stroke self-management;
2. Improvement in outcome expectation for stroke self-management;
3. Increase in satisfaction with performance in stroke self-management behaviours;
4. Improvement in HRQoL;
5. Reduction in depressive symptoms; and
6. Increase in the level of community reintegration.

1.3 SIGNIFICANCE OF THE RESEARCH PROJECT

This research project, involving a two-phase study, is to develop and evaluate the effectiveness of a new nurse-led theory-based stroke self-management program, based on the best available research evidence, for community-dwelling stroke survivors.
survivors. It is anticipated that Chinese community-dwelling stroke survivors would benefit from receiving such a program because it aims to increase survivors’ self-efficacy in and outcome expectation for stroke self-management, increase their level of satisfaction with performance in stroke self-management behaviours, enhance HRQoL, reduce depressive symptoms, and improve their level of community reintegration. The findings from the research project would provide evidence to inform clinicians’ and stakeholders’ decision-making in integrating the new program into current community support services for stroke survivors.

Despite increasing numbers of studies examining stroke self-management interventions, there has been no systematic review which determines the effectiveness of theory-based self-management interventions for community-dwelling stroke survivors. Given the importance of underpinning complex interventions with a theoretical framework in their design, implementation and evaluation (Craig et al., 2008), a systematic review was conducted in Phase One of this research project. This systematic review aimed to determine the evidence for using a theoretical framework to underpin the design and evaluation of community-based stroke self-management interventions. Furthermore, the best approach for delivering the interventions as informed by the theoretical framework could be identified to address more systematically the possible influencing factors. Additionally the systematic review could provide valuable information to inform the evaluation plans, in terms of design, outcome measures and measurement times, as well as to facilitate the assessment of causal relationships between stroke survivors’ changes in outcomes with the interventions received.

The RCT conducted in Phase Two of this research project is to evaluate the effectiveness of a new nurse-led theory-based stroke self-management program for Chinese community-dwelling stroke survivors. It is expected that the rigorously designed RCT will add reliable and valid evidence regarding the program effectiveness. Furthermore, the project is pioneering in the adoption of Bandura’s constructs of both self-efficacy and outcome expectation as the underlying premises of the new stroke self-management program. Bandura’s construct of self-efficacy has been widely applied in stroke rehabilitation research. However, the evidence on applicability of the construct of outcome expectation has been limited. Acknowledging the role of outcome expectation in influencing behaviours, it could be worthwhile to examine the effectiveness of stroke self-management programs underpinned by both constructs. Moreover, the current evidence is largely based on Western studies. The project will
add evidence related to applicability of the constructs in enhancing the self-management capabilities of Chinese stroke survivors, whose cultural differences may affect program delivery and effectiveness.

The best approach and strategies for enhancing stroke survivors’ self-efficacy in and outcome expectation for stroke self-management were tested in this research project. This included setting goals of recovery and action plans with participants, providing individualised assessment during home visits, facilitating group discussions and reflection during community-based group sessions, offering videos of experience sharing by stroke survivors who had successfully managed stroke, and providing a program workbook and follow-up phone calls. Furthermore, the facilitators of and barriers to implementing the new stroke self-management program in a Chinese community setting were explored. The results of the RCT would lay the groundwork for standardising the components, delivery format, and approach of the program that would work best for Chinese community-dwelling stroke survivors.

Recruiting and retaining stroke participants to participate in a community-based research study that involve recruiting participants from acute hospitals and conducting the intervention and baseline and follow-up assessments in the community or at home after discharge from hospital pose numerous challenges. It requires much detailed planning and collaboration with clinical partners (Hadidi, Buckwalter, Lindquist, & Rangen, 2012). It is expected that the experience derived from this study would inform future studies about the facilitators of and barriers to recruiting stroke participants from acute inpatient settings, and keeping the participants in the study after they have been discharged from hospital. The flow of participants in this community-based study will provide a clearer picture of recruitment and attrition rates. It is essential for a better estimation of the study duration, costs, human and administrative resources, as well as the time required, when the results of the study could be available (Roberts, Waddy, & Kaufmann, 2012).

Furthermore, analyses of outcome variables of this study were performed based on the principles of intention-to-treat (ITT), as well as per-protocol and the dose of the program received. These analyses were important for demonstrating the effectiveness of the program in real settings, as well as the effectiveness of the program for those who fully adhered to the program, and the dose of the program that would result in significant changes in the outcome variables.
This research project involved the translation into Chinese and test of equivalence of two stroke-specific measuring instruments, namely the Stroke Self-Efficacy Questionnaire (SSEQ) and the Stroke Specific Quality of Life Scale (SSQOL). It is expected that the availability of the translated instruments will facilitate future measurement of outcomes in Chinese stroke survivors. Moreover, this research project developed two new instruments, namely the Stroke Self-management Behaviours Performance Scale (SSBPS) and the Stroke Self-management Outcome Expectation Scale (SSOES). Both of the instruments were developed in English and translated into Chinese, as there was none available for measuring satisfaction with performance in stroke self-management behaviours and the associated expectations. The development of these two new instruments will enable a more comprehensive evaluation of changes in stroke survivors’ behaviours and beliefs towards self-management after receiving the program.

The new stroke self-management program examined in this research project was led by the Doctor of Philosophy (Ph.D.) candidate who is a registered nurse with experience in stroke rehabilitation care and self-management. When delivering the program, the nurse was autonomous in making decisions on appropriate interventions for the participating stroke survivors in consultation with supervisors. Collaboration between the nurse and survivors was realised through discussions and compromises regarding the establishment of realistic recovery goals and action plans. It strengthened the rapport between the two parties. It is believed that the results of this research project are significant in highlighting nurses’ roles and contribution to stroke survivors’ recovery after discharge from hospital.

1.4 THESIS OUTLINE

The thesis consists of eight chapters. Chapter One introduces the background and scope of the problem examined in this research project. The research questions, aim and objectives, hypotheses, and significance of the research project are presented. Chapter Two is the literature review for the research project. It provides an in-depth discussion of the current literature on characteristics of stroke recovery, the physical, psychological and social challenges encountered by community-dwelling stroke survivors and their health needs. Then, the literature on the concept of self-management and its importance to stroke survivors, the empirical evidence on effectiveness of self-management interventions, common health behaviour theories and their relevance to self-
management, and issues related to developing theory-based complex interventions are reviewed. Finally, the preliminary evidence on the effectiveness of self-management interventions for stroke survivors and gaps in the literature is presented.

Chapter Three reports the methods for and conduct of a systematic review in Phase One of the research project. The systematic review was aimed at determining the evidence on effectiveness of theory-based self-management programs on promoting recovery among community-dwelling stroke survivors. Results of the systematic review informed the development and evaluation of a new nurse-led stroke self-management program for Chinese community-dwelling stroke survivors conducted in Phase Two.

Chapters Four to Six discuss the methods and results of Phase Two of the research project. Chapter Four reports the methods of the RCT, which was aimed at testing the effectiveness of a new nurse-led self-efficacy enhancing stroke self-management program on recovery among Chinese community-dwelling stroke survivors. It includes a detailed description of the research questions, aim and objectives, hypotheses, research design and instruments of the RCT. A detailed discussion of the development of the new stroke self-management program including the application of the underpinning theoretical framework and the components, contents, and delivery of the program is provided. The methods of evaluation of the new program, including the translation into Chinese and test of equivalence of two stroke-specific measures of self-efficacy and HRQoL respectively are also reported.

Chapter Five reports the development of two new measuring instruments for assessing stroke survivors’ outcome expectation and satisfaction with performance in stroke self-management behaviours.

Chapter Six reports the results of the RCT. It includes a description of the stroke participants’ demographic and clinical characteristics, baseline and follow-up mean scores of primary and secondary outcomes, and the differential changes in the outcome variables after receiving the new stroke self-management program, analysed using generalised estimating equation (GEE) models. Analyses of the ITT and per-protocol populations, and populations who received all and some sessions of the program are also reported. Furthermore, the stroke participants’ feedback on usefulness of the program is presented.

Chapter Seven discusses the comparability of the participants of the current RCT with previous studies, and the effectiveness of the new stroke self-management
program. Issues related to the applicability of Bandura’s constructs of self-efficacy and outcome expectation, and the effective strategies to enhance Chinese stroke survivors’ self-efficacy in and outcome expectation for stroke self-management are discussed. Furthermore, the challenges in recruiting stroke participants from acute settings to community-based studies and implementing the new program among Chinese stroke survivors, and the solutions to address the challenges are discussed. Discussion will take into account the results of previous studies on stroke self-management programs and stroke recovery to compare the similarities and differences in the findings.

Chapter Eight is the conclusion of the research project. The limitations of the RCT, and the implications and recommendations for future policy, practice, education and research related to care of community-dwelling stroke survivors are discussed.
Chapter 2: Literature Review

2.1 INTRODUCTION

This chapter reviews and discusses the literature related to the main concepts of the research project. The chapter starts by discussing current evidence on the characteristics of the stroke recovery journey; common physical and psychosocial challenges, and health needs of community-dwelling stroke survivors. Second, the definitions and key concepts of self-management, and their importance for stroke survivors are discussed. Next, the common approaches to providing self-management support for people with chronic conditions including stroke are reviewed. The fourth part reviews common health behaviour theories and their applications to underpinning self-management interventions, and evidence on the significance of self-efficacy and outcome expectation in stroke recovery. Issues related to developing theory-based complex interventions are discussed. Then, the current research evidence pertaining to the effectiveness of self-management interventions for stroke survivors, and factors influencing the effectiveness of the interventions are examined. This chapter is concluded by a summary of identified gaps in the literature.

2.2 RECOVERY AFTER STROKE

Recovery after stroke is complicated and involves multiple interrelated aspects. Vanhook (2009) developed a synopsis of the literature suggesting that stroke rehabilitation consists of three major domains, namely physical, psychological and social. Within each domain, there are two categories. The two categories in the physical domain are cognition and function; health perception and self-concept are the categories in the psychological domain; and role change and relationships are the categories in the social domain. Vanhook’s (2009) elaboration of the complexity of the recovery process is based on the three domains and six categories, which were multifaceted and interrelated, that survivors need to manage after stroke.

The difficulties encountered in the recovery process are exacerbated by the absence of continuous and immediate support by healthcare providers when survivors return home from hospital. Family members or carers may resume their usual roles and are no longer able to provide close support. While it is desirable that stroke
survivors are able to solve the post-stroke challenges themselves (Nicholson et al., 2013; Olofsson, Andersson, & Carlberg, 2005), even people with minor strokes encounter challenges in re-evaluating their life priorities and plans after stroke. Management of the stroke recovery is further complicated by the need to manage changes associated with the normal ageing process (Green & King, 2010).

Indeed, a substantial number of studies reported that community-dwelling stroke survivors were left with different degrees of residual physical impairment, partial or marked dependence in activities of daily living (ADL), feelings of frustration or anxiety, reduced self-efficacy and self-esteem, and participation restriction in the longer term, despite evidence of some improvement or successful adaptation to the limitations (Chau et al., 2009; Lee et al., 2015; White et al., 2008). An earlier qualitative study of nine mild to moderately affected stroke survivors found that stroke survivors often needed to adjust physically and psychosocially during most of the first year after stroke. Effort was required to regain optimal functions, and more importantly continue with survivors’ pre-stroke roles and lives in the community while living with different degrees of resultant disabilities after stroke (Kirkevold, 2002). The following sections discuss common physical, psychological, and social challenges encountered by community-dwelling stroke survivors.

2.2.1 Physical challenges

Stroke survivors experienced different physical challenges in daily life after discharge from hospital. Common challenges reported included decreased range of motion and strength of limbs; difficulties in mobility and maintaining balance; sensory impairment in upper or lower limbs, impaired vision; eating or swallowing difficulties; and aphasia and/or dysphasia (Koenig-Bruhin, Kolonko, At, Annoni, & Hunziker, 2013). Furthermore, stroke survivors may have experienced limitations in ADL well before the stroke and decline in ADL independence at the time of stroke, and these may have continued for weeks or months afterwards (Capistrant, Wang, Liu, & Glymour, 2013).

The physical and functional challenges faced by stroke survivors cannot be underestimated. Studies have consistently reported that a higher level of disability and perceived worsened health state were associated with a decrease in stroke survivors’ HRQoL (Cerniauskaite et al., 2012; Dhamoon et al., 2010). Dhamoon et al. (2010) found a significant linear decline in stroke survivors’ HRQoL annually, up to five years after
stroke. Decreased functional and cognitive status were two of the significant factors associated with the decline. A large-scale survey of 6,698 stroke survivors in Korea also found that stroke survivors’ HRQoL was negatively associated with the number of persistent physical deficits. Specifically survivors with one-sided hemiplegia or paralysis had a significantly lower level of HRQoL than those with other deficits, including facial palsy, dysarthria, dysphagia or visual disturbance (Min & Min, 2015).

Hemiplegia or paralysis is common among stroke survivors and participation in regular exercise is one of the priorities in stroke rehabilitation and recovery (SIGN, 2010). White, Bartley, Janssen, Jordan, and Spratt (2015) stressed the importance of undertaking intense and frequent repetition of physical activities or exercises for maximal recovery. However, participation in physical activities or exercises required hard work. Stroke survivors need to overcome their limitations regarding mobility, pain and discomfort to enable them to engage in and sustain the exercise (Crowe et al., 2015; Min & Min, 2015; White et al., 2012). Adhering to the repeated practices often poses challenges to both stroke survivors and healthcare providers (Lee et al., 2015).

A systematic review of six qualitative studies found that the commonly reported barriers to stroke survivors’ participation in physical activity included inadequate motivation and knowledge, existing physical impairment, transportation problems or financial concerns in accessing the training facilities, fear about deterioration in health conditions after exercise or stroke recurrence, and negative emotions such as embarrassment (Nicholson et al., 2013). Some of the survivors in these six studies also doubted the usefulness of participating in physical activity for improving their health (Nicholson et al., 2013). Furthermore, Duncan et al. (2012) reported that fatigue was a significant barrier, resulting in stroke survivors’ decreased motivation and participation in exercise, and hence slowed their rates of recovery. Stroke survivors were found to have accelerated and persistent declines in cognition over the six years following stroke (Levine et al., 2015). Such decline in cognitive functions including memory loss and decreased attention may play a role in survivors’ difficulties in adhering to the exercise regimens (Sun et al., 2014).

Stroke survivors’ perceived self-efficacy in performing exercise or activity also played a role. A cross-sectional study of 50 community-dwelling stroke survivors at six to 358 months after stroke in the United States (US) found that balance and fall-related self-efficacy explained 27% to 55% of the variance in participation in
community walking (Robinson, Shumway-Cook, Ciol, & Kartin, 2011). Later a cross-sectional study in the US of 77 community-dwelling survivors with chronic stroke reported that balance self-efficacy was significantly associated with activity and participation (Schmid et al., 2012). Another cross-sectional study in Sweden of 195 community-dwelling stroke survivors consistently reported that fall-related self-efficacy was significantly associated with self-reported physical activity (Vahlberg, Cederholm, Lindmark, Zetterberg, & Hellström, 2013).

Provision of appropriate support to help stroke survivors to cope with these challenges in regaining optimal physical independence is of utmost importance (Kuluski, Dow, Locock, Lyons, & Lasserson, 2014). A review by Nicholson et al. (2013) found that the commonly reported motivators for stroke survivors’ participation in physical activity included the need to perform normal tasks, desire to be physically active, social interaction, and social or professional support. In addition to healthcare providers’ role in providing feedback and positive reinforcement, the results highlighted the importance of stroke survivors’ perceived need to be independent and their perceived self-efficacy for sustaining their efforts in physical activities or exercise.

White et al. (2015) reported preliminary evidence on the potential benefits of an enriched environment with enhanced motor, cognitive and sensory stimulation in motivating stroke survivors to participate in activities and in reducing their perceived sense of boredom. Consistent with the review results by Nicholson et al. (2013), integrating elements such as social interaction or various stimulations in the exercise regimen was helpful in enhancing stroke survivors’ interest and participation. However, in the community or home settings with limited resources, stroke survivors need to develop their own solutions to solve the problems of boredom and other barriers to sustain their efforts in the repeated exercise regimens.

Indeed, problem-solving skills are imperative. For example, while fatigue is a frequent complaint made by stroke survivors, there is insufficient evidence on the best strategies to prevent or treat post-stroke fatigue. Stroke survivors need to explore and test workable strategies to solve the negative impact of fatigue (Wu et al., 2015). Furthermore, the skills of goal-setting and action-planning enabled stroke survivors to pace their exercise schedule, and hence enhanced their autonomy and mastery over their health behaviours (Peoples, Satink, & Steultjens, 2011). Therefore, it is important to tailor-make interventions to enhance stroke survivors’ self-efficacy, reinforce their
expectations to achieve better ADL independence, and develop their capabilities in exercising skills such as problem-solving, goal-setting and action-planning to promote their recovery.

2.2.2 Psychological challenges

The experience of stroke causes different psychological impacts on survivors. A cross-sectional study of 81 stroke survivors in Italy found that one in every two survivors had a high level of anxiety one year after stroke (D’Aniello et al., 2014). A literature review estimated that the overall prevalence rates of major and minor depression among stroke survivors were 21.7% and 19.5% respectively (Robinson & Spalletta, 2010). Development of post-stroke depression was associated with greater physical and cognitive impairment and increased mortality (Robinson & Spalletta, 2010). Another descriptive study of 1,285 stroke survivors of 65 years or above in Taiwan found that depression was significantly associated with decreased HRQoL (Hsu, Tsao, Chen, & Chou, 2014).

While stroke survivors may have different psychological symptoms after stroke, a qualitative study of 23 community-dwelling stroke survivors in Australia found that survivors had four distinct psychological trajectories over the first year after stroke (White et al., 2012). In particular, the findings showed that majority of the survivors experienced sustained psychological improvements over the first year. Initially they were found to have low mood and fear related to the stroke incident and possible recurrence. Their fear lessened over time and their mood improved, as they became more able to adapt to the post-stroke challenges, reframe their expectations and find a new perspective on their lives. They tended to have higher self-efficacy and participation as they found the benefits of persisting with rehabilitation therapies after they returned home.

However, White et al. (2012) found that there were stroke survivors, of a lesser proportion, who experienced a trajectory of ongoing mood disturbance. They felt isolated and anxious, and were distressed by the residual post-stroke disabilities. They tended to have an external locus of control and avoided making their own health decisions. Their mood disturbance might improve as they resumed some of their pre-stroke roles. However, other personal life stressors often interrupted their rehabilitation. A small proportion of stroke survivors might develop depressive symptoms for several months after stroke when difficulties in their daily life emerged. Such depression often
occurred when they realised their incapability in coping with some daily tasks after returning home. Life stressors such as social issues, comorbidities, deteriorated health condition, and increased physical or psychosocial dependency also compounded the depressive symptoms (White et al., 2012).

Consistently, studies have found that stroke survivors’ physical impairment contributed largely to mood disturbance after stroke (Robinson & Spalletta, 2010). Stroke survivors were found to have mixed feelings of frustration, anger, sadness, loss, grief, or even depression particularly when they returned home. They realised that they needed to depend on others for tasks that they took for granted before stroke (Lutz, Young, Cox, Martz, & Creasy, 2011). Stroke survivors who had aphasia, dysphasia or difficulties in communication had lower confidence in participating in activities or social interactions with others (Koenig-Bruhin et al., 2013). Furthermore, an increasing number of studies found that considerable uncertainty and fear prevailed among survivors. Focus group interviews of 33 stroke survivors and their family caregivers in the US found that they were uncertain about future stroke events, signs and symptoms of stroke, and resources for managing post-stroke health and risk factors. These uncertainties not only influenced the survivors’ emotional adjustment to post-stroke challenges, but also their adherence to medical regimens and their recovery (White et al., 2014).

Maintaining stroke survivors’ psychological well-being is important. An earlier literature review suggested that a realistic expectation of stroke was a pre-requisite for successful adjustment in recovery (Kirkevold, 2002). Support to assist stroke survivors to accept changes in their levels of functioning and life roles, and to re-evaluate their goals in life is necessary (Graven, Sansonetti, Moloczij, Cadilhac, & Joubert, 2013). Moreover, acknowledging the survivors’ uncertainties and unresolved rehabilitation needs, it is essential to motivate them to use coping strategies such as self-talk, maintaining hope, expressing anger, appreciation of being fortunate, or seeking support from family or friends to adapt to the changes (Taule & Raheim, 2014; Williams & Murray, 2013).

However, living with uncertainties can be difficult (Lorig et al., 2012). The findings by White et al. (2012) indicated that continuous assessment of community-dwelling stroke survivors’ changes in psychological well-being as well as prompt support to enhance their self-efficacy, physical independence, and capabilities to solve
their life stressors are important for minimising mood disturbance after stroke. More importantly, continuous and effective interventions to help stroke survivors to amend their personal values and continue to learn to adapt to their abilities and limitations are warranted. Such interventions promoted survivors’ satisfaction with life and facilitated their development of new self-identities after stroke (Pallesen, 2014; Western, 2007).

2.2.3 Social challenges

Studies found that stroke survivors encountered various challenges in reintegrating into their social roles and lives after stroke. Common challenges included returning to work, reintegrating into the community, participating in leisure or valued activities, and maintaining relationships with their families, friends and healthcare professionals (Kuluski et al., 2014; Wang, Kapellusch, & Garg, 2014). A qualitative study of 15 survivors who had a first-ever stroke in the previous five years found that the survivors described a huge change in their life patterns. They lived more home-centred lives with minimal participation in their neighbourhood. Compared with life before stroke, they had fewer social and workplace contacts, and fewer interactions with friends. They avoided inviting their friends for daily events such as chatting and shopping. Consequently, they felt isolated, frustrated and worthless (Pallesen, 2014).

Another qualitative study of 17 community-dwelling stroke survivors in the United Kingdom found that all respondents described a change in sense of self after stroke. Some indicated that they experienced a loss of self-identity and valued activities, as well as family disruption (Kuluski et al., 2014).

Returning to work is one of the significant indicators of stroke survivors’ level of community reintegration. A comprehensive literature review found that the most consistently reported factor that negatively predicted return to work was stroke severity such as weakness, or other neurological deficits or impairments. Psychological and environment factors including depression, nature of the occupation, and number of remaining working years until retirement also influenced the likelihood of returning to work (Wang et al., 2014). Even stroke survivors with minimal obvious physical disability experienced workplace challenges. A critical review of 29 articles found that embarrassment, misunderstanding and negative attitudes of employers or colleagues towards the stroke survivors might cause them to feel being ignored or discriminated against. This impaired the relationships with their colleagues or even forced the survivors to retire early (Wolfenden & Grace, 2009).
A meta-synthesis of 11 articles indicated that factors associated with stroke survivors’ social participation were multifaceted. The influencing factors included survivors’ perceptions about stroke and the consequential disruptions, self-confidence and perceived magnitude of barriers, as well as their thoughts about the future and associated personal meanings (Woodman et al., 2014). Indeed the stroke survivors’ physical, psychological and social status were interrelated. A longitudinal study of 188 stroke survivors in Hong Kong found that functional ability was the most significant predictor of community participation restriction. Psychosocial factors including depressive symptoms, low state self-esteem, and living in residential care facilities, female and older age, explained 71% of variance in participation restriction at 12 months after discharge from hospital (Chau et al., 2009). The importance of physical and psychosocial factors in influencing participation is also supported in a study, which examined the trajectories of 102 stroke survivors over the first year post-stroke, where those with excellent walking capacities, better mood and good social support demonstrated excellent participation (Mayo, Bronstein, Scott, Finch, & Miller, 2014).

Similar to the physical and psychological challenges, appropriate interventions to enable stroke survivors to accept the changes after stroke, and enhance their physical independence and self-efficacy are important. Additionally support to help stroke survivors to resume or develop new leisure or valued activities is needed to develop their sense of life satisfaction. Relationships with their families and healthcare professionals are also changed. Stroke survivors need to develop the skills to assume responsibility and control over their health decisions and behaviours with support from their families, as well as skills to collaborate with healthcare professionals in planning their care regimen (Arntzen, Borg, & Hamran, 2015; Peoples et al., 2011).

2.2.4 Rate of stroke recovery

Stein et al. (2009) proposes that the lack of clear-cut end-points to stroke survivors’ recovery journey or criteria for the expected level of stroke recovery adds to the difficulties in coping with various physical and psychosocial post-stroke challenges. The duration of recovery is different and unique among individual stroke survivors. It may continue for years or even a lifetime (Kirkevold, 2002). However, most studies reported that the extent of physical recovery, ranging from 48% to 91%, was the most significant in the first three months after stroke (Lee et al., 2015; Verheyden et al., 2008). For periods beyond six months after stroke, a longitudinal
study of 204 stroke survivors in Sweden found that the impact of stroke on physical strength and emotion was significantly lower at 12 months after stroke than at three months. The perceived recovery in physical strength and emotion at 12 months after stroke was significantly higher than that at three months irrespective of stroke severity, age and gender (Guidetti, Ytterberg, Ekstam, Johansson, & Eriksson, 2014).

The rate of physical recovery also differs by type and severity of stroke, and the body parts involved. Survivors with haemorrhagic stroke were found to have a higher risk of physical impairment and medical complications, and to require a longer period of time to recover, compared with those with ischaemic stroke (Lipson et al., 2005). Furthermore, survivors with recurrent ischaemic stroke and moderate disability post-stroke were seven times more likely to recover than those with very severe disability (Hankey, Spiesser, Hakimi, Carita, & Gabriel, 2007). Recovery of the affected lower leg and trunk control was more significant over the first six months after stroke compared with recovery of the affected upper arm (Lee et al., 2015).

Despite the varying rate of recovery after stroke, it cannot be denied that recovery occurs even one year after stroke. Furthermore, adaptation and readjustment to post-stroke challenges require time and experience to achieve. White et al. (2012) in their study highlighted the importance of follow-up therapy over the first few months, or which may take at least one year after stroke, by providing assistance and encouragement in coping with emotional needs for better recovery after stroke. With regard to diverse health needs, it is essential for stroke survivors to have adequate knowledge and skills for better self-management of their health condition. Effective interventions for community-dwelling stroke survivors to support their long-term recovery is essential.

2.3 SELF-MANAGEMENT

Self-management that first appeared in the 1960s is a common term used in health education and health promotion (Lorig & Holman, 2003). The effectiveness of self-management interventions across chronic conditions including diabetes, asthma, chronic obstructive pulmonary disease (COPD), and arthritis has been examined extensively (Fu et al., 2003; Lorig et al., 2001). International evidence-based practice guidelines recommend that the provision of self-management training to people with chronic conditions is integral for improved health outcomes and more efficient
utilisation of healthcare services (Haas et al., 2014; National Institute for Health and Care Excellence, 2011).

Up until now, there has been no universal definition of self-management. Some of the common definitions included that self-management referred to the daily tasks that one performs to manage the daily activities, cope with the psychosocial problems associated with the condition, and minimise the impact of the condition on one’s health status. The individual collaborates with healthcare professionals to perform the health-related tasks. Nakagawa-Kogan, Garber, Jarrett, Egan, and Hendershot (1988) defined self-management as an intervention or treatment that combined the biological, psychological and social aspects for maximal functioning. Alderson, Starr, Gow, and Moreland (1999) further elaborated that self-management was an interdisciplinary group education underpinned by the principles of adult learning and case management theory. However these definitions were limited in recognising the individual’s role in managing own health.

The definition by Barlow, Wright, Sheasby, Turner, and Hainsworth (2002) has been more commonly adopted by in the literature, who defined self-management as “an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (p.178). The importance of “self” in managing one’s own health condition is highlighted in the following description by Barlow et al. (2002):

“... efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life … a dynamic and continuous process of self-regulation is established.” (p.178).

2.3.1 Key concepts of self-management

Self-management consists of three major aspects, namely medical, emotional and role management (Lorig et al., 2001). Medical management is the organisation by the people with chronic conditions of all activities that are important for improved health and well-being, for dealing with the medical consequences of the chronic conditions. Emotional management is the management of the negative emotional consequences, such as frustrations, fear or depression, associated with the conditions. Role management is concerned with the resumption or continuation of pre-morbid lives or roles, or the assumption of new life roles, for reintegration into the community.
(Lorig et al., 2012). Individuals often need to learn new skills to manage the associated physical and psychosocial challenges in order to live well with the chronic condition (Lorig et al., 2012). The concept of self-management assumes that people with chronic conditions need to perform certain health behaviours that are critical for their medical, emotional, and role management. Some behaviours that are common for all those with different chronic conditions are called self-management behaviours. Examples include regular exercise, healthy diet, adequate rest, medication adherence, symptom management, maintenance of social activities, relaxation and managing psychological states (Lorig et al., 2012).

The notion underpinning self-management is that the person with a chronic condition is an active self-manager who is competent and responsible for making own health decisions (Lorig et al., 2001). To attain effective self-management, people with chronic conditions need to be equipped with five core self-management skills. They include problem-solving, decision-making, goal-setting and action-planning, resources utilisation, and skills in communicating with healthcare professionals (Lorig & Holman, 2003). People with chronic conditions are expected to be able to identify and solve their own health problems amid uncertainties about their future health. They identify and prioritise the possible solutions, weigh the advantages and disadvantages of the solutions, and decide on the appropriate choices, given their own contexts. The capability of putting ideas into action is integral to self-management. People need to learn how to set goals and action plans, implement the action plans and evaluate the results. A successful plan is one that addresses the problem, is achievable and action-specific, and is one that the person is confident to carry out (Lorig et al., 2012).

Furthermore, it is necessary to identify the resources needed to help with self-management. The resources can range from friends, family or neighbours, to health organisations, the Internet, libraries, television, radio, newspapers and magazines. People with chronic conditions collaborate with healthcare professionals to manage their health. The role of those with chronic conditions shifts from being a passive recipient of information to a collaborator with healthcare professionals, who become facilitators to support the person’s self-management. Hence, effective communication with healthcare professionals is necessary (Lorig et al., 2012).

The core self-management skills may be difficult for some people. However, these skills can be learnt and practised in their daily lives. In addition, the importance of self-
management relates not only to the type or amount of self-management behaviours that one has achieved, but also to a sense of confidence and control achieved from successfully performing the self-management behaviours (Lorig et al., 2012).

2.3.2 Importance to stroke survivors

Effective self-management by stroke survivors is important. As discussed in the earlier sections, stroke survivors encounter multiple physical, psychological and social challenges consequential to stroke. To cope with these challenges, stroke survivors commonly need to perform physical and functional training, which often require repetitive practices and hard work. Other aspects of post-stroke rehabilitation and care encompass various self-monitoring practices and health-promoting behaviours such as blood pressure monitoring and control, smoking cessation, healthy diet, and monitoring for signs and symptoms of recurrent stroke (Jauch et al., 2013; National Stroke Foundation, 2011). Management of their psychological and social challenges requires reorientation of stroke survivors’ own perceptions of post-stroke changes, and increased self-efficacy and determination to learn to resume pre-stroke roles or assume new roles after stroke (White et al., 2012). All these emphasise the integral role of stroke survivors themselves in self-managing their health.

Furthermore, stroke survivors’ health needs are not limited to information about stroke and professional medical advice regarding post-stroke management. Knowledge and skills to solve daily health problems and make health decisions, and capabilities to locate resources and assimilate health information to promote stroke recovery are also of top priority (Peoples et al., 2011). For example, they need to problem-solve the barriers to participating in activities and exercise; and to set goals related to their exercise regimens for pacing themselves during the recovery period. Capability in managing these aspects enhanced stroke survivors’ autonomy and mastery over their health behaviours (Peoples et al., 2011). An integrative review of 11 articles found that the ability to accept problems associated with stroke, and adapt their behaviours and attitudes using self-management skills such as problem-solving or decision-making were important factors for reintegrating into the community after stroke (Woodman et al., 2014). Obviously, the core self-management skills posited in the concepts of self-management are essential in long-term management of stroke, particularly when stroke survivors have to depend on themselves after they have returned home from hospital.
In view of their diverse health needs throughout the long-term post-stroke recovery period, it is important to equip stroke survivors with the necessary knowledge as well as the skills and confidence related to self-management, for developing their own ways and regimens to self-manage their health conditions effectively.

2.4 MODELS TO PROVIDE SELF-MANAGEMENT SUPPORT

There have been different models examined in the literature to provide self-management support for people with chronic conditions including stroke to enhance their recovery. These models were often in the form of structured self-management educational programs (Barlow et al., 2002). Self-management education is different from traditional didactic patient education or skill training. In addition to instillation of knowledge or information, self-management education adopts activities which are aimed at boosting participants’ confidence and improving their capabilities and active participation in making informed decisions for managing the challenges associated with the chronic conditions (Barlow et al., 2002).

The Stanford Chronic Disease Self-management Program (CDSMP), with a history of over 30 years, developed by Dr. Kate Lorig and her colleagues in the US, is one of the most widely adopted models (Lorig et al., 2001). It is a generic, community-based self-management education program. It consists of six 2-hour sessions held once a week for six consecutive weeks. It is group-based, with 10 to 15 participants in each sub-group, to provide opportunities for participants to share and learn from others’ experiences. Each group is facilitated by trained lay leaders (Lorig et al., 2001). The delivery modalities include educational sessions, group sharing, goal-setting and action-planning, psychological support, counselling and feedback (Lorig et al., 1999; Lorig et al., 2001). The program is characterised by the underlying premise of enhancing the participants’ self-efficacy in performing self-management behaviours in order to enhance their health outcomes. Different strategies are adopted to enhance the participants’ self-efficacy, such as having the CDSMP led by trained laypersons with similar chronic conditions, to enable participants to observe and learn from each other (Lorig et al., 2001). The CDSMP has been extensively applied to people with different chronic conditions such as diabetes, arthritis, stroke, chronic pain, cancers, acquired immune deficiency syndrome, and hypertension (Fu et al., 2003; Lorig & Holman, 2003). Some studies adapted the model of CDSMP to address stroke survivors’ health needs (Cadilhac et al., 2011; Kendall et al., 2007). The CDSMP has been consistently reported
in the literature as associated with significant improvements in health outcomes, such as
duration of exercise, self-reported health, self-efficacy, and social and role activities
participation (Lorig et al., 1999; Lorig et al., 2001). However, these studies did not
specifically report stroke survivors’ changes in outcomes.

Nevertheless, there are studies which adopted the concepts of self-management
in developing and evaluating interventions aimed at enhancing stroke survivors’
capabilities in coping with post-stroke challenges. Although these studies did not label
the interventions as self-management interventions or programs, favourable results
among stroke survivors were reported (Egan, Kessler, Laporte, Metcalfe, & Carter,
2007; Green, Haley, Eliaasz, & Hoyte, 2007; Markle-Reid et al., 2011).

Green et al. (2007) and Rimmer et al. (2000), with a program underpinned by
the Transtheoretical Model, asked stroke participants to set goals appropriate for their
stage of change related to adoption of health-promoting behaviours. Another two
studies utilised the Social Cognitive Theory to inform the development of a home-
based leisure educational program. However, a similar approach to that by Green et al.
(2007) and Rimmer et al. (2000) was adopted, with participants required to reflect on
and solve the problems encountered in engaging in their leisure activities until they
participated successfully in the activities that they aimed to do (Desrosiers et al., 2007;
Nour, Desrosiers, Gauthier, & Carbonneau, 2002). The studies by Glass et al. (2004)
and Markle-Reid et al. (2011) likewise developed participants’ goal-setting, problem-
solving and decision-making skills to enhance their recovery and community
reintegration. Participants were guided to reflect on and devise strategies to solve the
problems encountered in accomplishing their goals, and to make decisions regarding
their behaviours. Additional strategies were provided to support these processes
including interactive and facilitated group discussions (Desrosiers et al., 2007; Egan
et al., 2007; Green et al., 2007; Nour et al., 2002; Rimmer et al., 2000), motivational
interviewing (Green et al., 2007), client-centred counselling (Markle-Reid et al., 2011),
and facilitation of social support systems (Glass et al., 2004).

2.5 APPLICATION OF HEALTH BEHAVIOUR THEORIES

In reviewing the models commonly adopted to provide self-management support,
it is obvious that self-management interventions are characterised by the adoption of
multiple activities to enhance the capabilities of people with chronic conditions to self-
manage their conditions. Self-management interventions are regarded as behavioural change interventions involving multiple activities designed to change a specific behaviour (Michie, van Stralen, & West, 2011). Such interventions are typically complex consisting of multiple components, of varying strengths, doses or contents, all of which interact in the process of behavioural change (Craig et al., 2008). Accordingly, it is important to design effective complex self-management interventions using a systematic approach to address all relevant factors influencing the behaviours within the particular context. According to the latest Medical Research Council guidance on developing and evaluating complex interventions (Craig et al., 2008), one integral initial step in designing complex interventions is to develop a theoretical understanding of the process of change to be expected within the context examined.

Theory is defined as “a set of interrelated concepts, definitions and propositions that present a systematic view of events or situations by specifying relations among variables, in order to explain or predict the events or situations” (Glanz & Rimer, 2005, p. 4). Health behaviour theories are extremely important both for understanding health behaviours and providing a basis from which interventions aimed at changing health behaviours can be developed. A scoping review of 276 articles published between 1977 and 2012 identified 82 theories of behaviour and behaviour change of individuals, and which were potentially applicable for developing and evaluating public health interventions (Davis, Campbell, Hildon, Hobbs, & Michie, 2015). Four of the theories, Social Cognitive Theory, Transtheoretical Model of Change, Theory of Planned Behaviour, and Information-Motivation-Behavioural-Skills Model, accounted for 174 (63%) of the included articles. The Health Belief Model and three other theories were adopted in 32 (12%) of the articles (Davis et al., 2015).

The explicit use of theories is advantageous at identifying the key constructs that are causally associated with the behaviours concerned and the causal determinants of change to inform the systematic selection of intervention techniques. Furthermore, it informs the choice of outcome variables, enables understanding of the mechanism of change or causal chain between components of interventions and outcomes, and predicts change in behaviours (Craig et al., 2008). Theories also facilitate more efficient refinement of the interventions (Michie & Prestwich, 2010). Health interventions, which are driven by theories are regarded as superior to studies which are non-theory-driven. It is because the former is considered as more able to address the possible factors
reported in previous studies of various populations and contexts as relevant to the behaviour concerned, and hence results in better outcomes (Craig et al., 2008).

In the following section, the main concepts of common health behaviour theories, and their relevance to stroke recovery and applicability to designing and evaluating self-management interventions for people with stroke are discussed.

2.5.1 Common health behaviour theories

2.5.1.1 Social cognitive theory

Social Cognitive Theory (SCT), which originated from Social Learning Theory, was developed by Professor Albert Bandura in the 1970s (Bandura, 1997). The SCT postulates that human behaviours interact with another two factors forming a triadic reciprocal causation, specifically the dynamic bi-directional relationships among the behaviour, the personal factors including cognitive, affective and biological events, and the environment (Figure 2.1). These three factors of reciprocal determinism are affected by different constructs including self-efficacy, observation learning (modelling), expectations, expectancies, emotional arousal, behavioural capability, reinforcement and locus of control (Bandura, 1997).

A number of studies cited the use of SCT in designing self-management interventions for people with chronic conditions (Inouye et al., 2011; Smith, Rublein, Marcus, Brock, & Chesney, 2003). However, a closer inspection of the literature found that majority of the studies solely utilised the construct of self-efficacy within the theory (Coleman et al., 2012; Creer, 2008; Tougas, Hayden, McGrath, Huguet, & Rozario, 2015). The partial utility of SCT may be due to the fact that the theory was far too comprehensive, making it difficult to operationalise and to specify how the components interact in practice and research (Jang & Yoo, 2012).

![Figure 2.1 The relationships between the three major classes of determinants in the triadic reciprocal causation postulated in the social cognitive theory](image_url)

(Adapted from Bandura, 1997, p.6)
Self-efficacy is regarded as the central construct of SCT in that it exerts the most determining effect on behaviours (Bandura, 1997). Self-efficacy refers to a person’s perception of her/his own capability to perform a behaviour required to produce a certain goal. People with a strong sense of self-efficacy are more likely to initiate and adhere to a behaviour, even in the face of difficulties or adverse events. They see these as challenges and are able to increase and sustain their efforts and perseverance to persist with a behaviour. In contrast, people with a low level of self-efficacy interpret the challenges encountered as threats. They doubt their capabilities and tend to avoid the behaviours that they believe exceed their coping ability (Bandura, 1997).

Self-efficacy is situation-specific. The level of self-efficacy differs in terms of the difficulties (magnitude) and types (generality) of the behaviours, and how strong the behaviour is (strength) (Bandura, 1997). Expectation of self-efficacy in performing a behaviour stems from four principal sources of information namely performance accomplishment, vicarious experience, verbal persuasion, and physiological or emotional states (Figure 2.2). Mastery experience is the most influential in strengthening one’s judgement of self-efficacy, as it related to a person’s experiences of repeated successes. Vicarious experiences are observations of successes or failures of others or models. The greater the perceived similarity of a person to the model, the more the person’s self-efficacy is influenced by the model’s behaviours. Having others verbally persuade a person regarding her or his capability to master a behaviour increases one’s beliefs in himself or herself. Furthermore, assisting a person with recognition and reinterpretation of physical or emotional arousal helps minimise the negative effects of these arousals on a person’s self-efficacy (Bandura, 1977, 1997).

![Diagram of efficacy expectations](image-url)
The construct of self-efficacy has been commonly utilised to underpin the design and implementation of self-management interventions. The CDSMP and other stroke self-management programs are examples (Jones, Mandy, & Partridge, 2009; Kendall et al., 2007; Lorig et al., 2001). In these programs, different strategies are used to enhance stroke survivors’ self-efficacy in stroke self-management. Examples of the strategies include breaking a complicated task into several simpler steps, offering sessions for interactions and sharing among the participants with similar experiences, and providing verbal positive reinforcement. It is expected that the changes in behaviours would improve health outcomes (Damush et al., 2011; Franek, 2013).

Construct of outcome expectation

Outcome expectation is another key construct of SCT. It refers to a person’s judgement of the outcomes that will likely occur after performing a particular behaviour. Outcome expectation can be positive or negative and it can take three major forms. The first form is the physical effect that occurs after performing the behaviour, such as pleasant sensory experiences or discomfort. The second is the social effect that accompanies the behaviour, such as increased opportunities for social reactions and attaining social approval. The third form is the self-evaluative reaction to the behaviour such as self-satisfaction and self-criticism (Bandura, 1977). Outcome expectation is affected by cultural, social, economic and sexual factors, and racial differences. Expectations of individuals and the types of expectations may also change over time. Bandura (1997) suggested that human behaviours would be best explained by the combined influence of efficacy beliefs and outcome expectations. The relationship between these two constructs is depicted in Figure 2.3. However, there have been no studies which examined the effectiveness of stroke self-management interventions underpinned by both the constructs of self-efficacy and outcome expectation.

![Figure 2.3 The relationships between efficacy beliefs and outcome expectancies postulated in the social cognitive theory](Adapted from Bandura, 1977, p.193)
2.5.1.2 Health belief model

The Health Belief Model (HBM) developed by Hochbaum and Rosenstock in the 1950s explains people’s participation in preventive health behaviours (Rosenstock, 1960, 1974). The HBM posits that an individual’s motivation to perform a health behaviour is determined by personal beliefs or perceived threat of the disease and the effectiveness of the health behaviour in decreasing the risk of the disease. It consists of four main constructs, namely perceived seriousness of and perceived susceptibility to a disease, and perceived benefits for and perceived barriers against engaging in a health behaviour (Figure 2.4). The HBM explains that individuals are more likely to take actions to avoid the threat of a disease if they have a high perceived threat consequential to high perceived susceptibility to having the disease, coupled with high perceived seriousness or severity of the consequences of the disease. Furthermore, the individuals need to perceive that the benefits of performing the health behaviour outweigh the perceived barriers to doing it, before they take actions (Rosenstock, 1974). Studies found that perceived barriers and benefits were strongly correlated with performances of preventive behaviours (Tanner-Smith & Brown, 2010).

The four constructs are modified by demographic, socio-psychological and structural factors such as a person’s age, gender, ethnicity, educational level, past experiences, knowledge and skill; and cues to action such as media information, and advice from friends and family members (Rosenstock, 1974). In 1988, self-efficacy was introduced to the HBM as an independent influencing factor to account more fully for health behaviours (Rosenstock, Strecher, & Becker, 1988). It indicated the importance of having confidence in one’s capability in performing a health behaviour for effecting long-term change in behaviours (Noar, 2005). There have been several extensions of the HBM, with increased predictive and explanatory power of variance in performance of preventive health behaviours. The variables included self-identity, perceived importance, perceived consequences in future, and concerns about appearance (Orji, Vassileva, & Mandryk, 2012); or locus of control, self-efficacy, health value, and social support (Gillibrand & Stevenson, 2006).
The Health Belief Model (HBM) has been widely applied in designing and developing self-management programs for various health conditions, such as asthma, diabetes, and COPD (Al-Durra, Torio, & Cafazzo, 2015; Jalilian, Mtlagh, Solhi, & Gharibnavaz, 2014), as well as in combination with other health behavior theories (Vonck en-Brewster et al., 2015). Significant improvements in participants’ beliefs in severity, susceptibility, benefit, barrier, self-efficacy, and self-management were reported after receiving the HBM-based self-management programs (Jalilian et al., 2014). However, there has been no study that adopted the HBM in designing self-management programs for stroke survivors.

2.5.1.3 Transtheoretical model

The Transtheoretical Model of Health Behaviour Change (TTM) was first developed by Prochaska and DiClemente in 1979 (Prochaska & Velicer, 1997). The TTM explains that human behaviors take place in discrete stages. People move from one stage to the next depending on their consciousness about the need for and readiness to change. The TTM consists of five stages. The first stage is known as pre-contemplation, during which a person is unaware of the need to change and has no intention of changing. The second stage is contemplation, during which one acknowledges the need to change. The third stage is the preparation phase, in which one has decided to change and enacted a plan to change. The fourth stage is action, in
which the person puts the plan into action. The last phase is maintenance where the person sustains the change in behaviours over time without relapsing. The move through stages is dynamic and cyclical (Noar, 2005). In addition to stages of change, the TTM consists of the processes of change and self-efficacy to explain how people move through the stages (Table 2.1).

<table>
<thead>
<tr>
<th>Constructs</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages of change</td>
<td>Pre-contemplation, contemplation, preparation, action, maintenance</td>
</tr>
<tr>
<td>Decisional balance</td>
<td>Weighing the advantages and disadvantages of the change</td>
</tr>
<tr>
<td>Processes of change</td>
<td>Consciousness raising, dramatic relief, environmental reevaluation, self-liberation, self-reevaluation, stimulus control, helping relationship, counterconditioning, contingency management</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>One’s confidence in own ability to cope with high risk situations</td>
</tr>
</tbody>
</table>

(Adapted from Prochaska & Velicer, 1997, p.40, 43)

The TTM has been more commonly applied in understanding the behavioural stages than in designing self-management interventions (Ohlendorf, 2012). For example Al-Durra et al. (2015) applied the concepts of TTM in staging the asthma patients according to their readiness to change asthma-related self-management behaviours. Another study reported that the assessment of stages of change among people with diabetes facilitated the selection of individualised resources and support interventions for self-management, and adoption of diabetes self-management behaviours (Highstein, O’Toole, Shetty, Brownson, & Fisher, 2007). However, there has been no study reported which adopted TTM in designing stroke self-management programs.

### 2.5.1.4 The theory of reasoned action and the theory of planned behaviour

The Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB) were developed in the 1980s (Ajzen, 1991). It is one of the most frequently cited health behaviour theories. The TRA/TPB explains human behaviours in terms of people’s behavioural intentions, which in turn is influenced by three determinant constructs, namely attitudes, subjective norms and behavioural control (Figure 2.5). Attitudes are formed by the person’s behavioural beliefs about the possible consequences and values of the behaviour. Subjective norms and perceived social
pressure are determined by the person’s normative beliefs related to performance of the behaviour, and whether the person desires to comply with these norms. The TRA assumes that all behaviours are under the persons’ volitional control. The TPB, an extension of TRA, posits that behavioural control is the most important determinant of health behaviours. Perceived behavioural control represents the person’s control beliefs regarding the performance of the behaviours (Ajzen, 2002). The TRA/TPB suggests that an individual is more likely to perform a health behaviour if she or he has positive attitudes and norms related to the target behaviour, and perception of high behavioural control on the behaviour (Noar, 2005). Self-efficacy is often included to more fully understand the behavioural changes and outcomes (Muñoz-Silva, Sánchez-García, Nunes, & Martins, 2007; Tolma, Reininger, Evans, & Ureda, 2006).

Similar to TTM, however, systematic reviews have consistently shown that TRA/TPB were often applied to measure process and outcome variables and to predict health-promoting or preventive behaviours (Hackman & Knowlden, 2014; Hardeman et al., 2002; Riebl et al., 2015). There are few studies which applied TRA/TPB in designing self-management interventions. One identified study reported moderate support for the use of TPB and self-efficacy in predicting and explaining engagement in self-management behaviours among rheumatoid arthritis patients (Strating, van Schuur, & Suurmeijer, 2006). However, there have been no reports of studies adopting TRA/TPB in designing stroke self-management programs.

![Figure 2.5 The Theory of Reasoned Action and the Theory of Planned Behaviour](Adapted from Armitage & Conner, 2001, p.472)
2.5.2 Choosing a health behaviour theory

While there are multiple health behaviour theories, determining the best fitting theory to design and evaluate complex self-management interventions is not straightforward. The Medical Research Council guidance on designing and evaluating complex interventions does not provide explicit guidelines on selection of an appropriate theoretical framework (Craig et al., 2008). There has also been little consensus in the literature on a systematic basis for such identification, or suggestions for the most appropriate applicability of theories in designing, implementing and evaluating different health interventions in various contexts (French et al., 2012; Noar, 2005). Nevertheless, the selection of appropriate health behaviour theories to underpin a self-management intervention systematically is of utmost importance, as has been highlighted previously.

The literature is in general agreement on assessing the quality of the theories as the core first step (Davis et al., 2015). A review by Davis et al. (2015) identified nine defining features of a good theory. The features included clarity of key constructs in the theory and clarity of relationships between the constructs. Furthermore, it requires that the constructs can be explicitly measured and tested. Assessment is also made on the ability of the theory to explain different observations and mechanisms of change, generalisability across behaviours, populations and context, availability of the assumptions of the theory, and support by evidence. When it comes to determining the applicability of the theory in a given context, several considerations are required. Noar (2005) suggested that the theory needed to contain the components or variables that were shown to be important to the behaviour. Furthermore, it is necessary to clarify the health issue and the population affected, the possible reasons or causes for the problem, and the level of interaction, including intrapersonal, interpersonal and community interaction, of the causative factors.

The five health behaviour theories discussed in the previous sections are all individual-based theories with robust evidence to support the constructs (Noar, 2005). These five theories commonly posit the influence of personal attitudes, beliefs or intentions on a person’s engagement in a health behaviour (Ajzen, 1991; Bandura, 1997; Prochaska & Velicer, 1997; Rosenstock, 1960). The SCT additionally addresses the environmental influence on health behaviours (Bandura, 1997), while TTM focuses on discrete stages of change in behaviours (Rosenstock, 1960). The construct of self-
efficacy is regarded as intervention-based and directs the selection of appropriate strategies to address the principal sources of self-efficacy information (Noar, 2005).

While there has been wide application of these theories in health behaviour research, there have been criticisms of the theories. Key discussions indicate that the HBM considers the influences of a person’s own beliefs on behaviours only, without addressing social influences (Noar, 2005). The multifaceted stages of behaviours of a person make it difficult to categorise them into the five stages of change as postulated in the TTM. The SCT and the construct of self-efficacy do not consider a person’s actual capability of performing a behaviour. Furthermore, some researchers have suggested that TRA/TPB is obsolete due to its static nature and problems with predicting behavioural change (Hagger, 2015).

Furthermore, when assessing the five common health behaviour theories discussed in the previous section, it is not difficult to identify several overlapping constructs. Self-efficacy is a central construct of SCT (Bandura, 1997), while it is also an independent factor in the HBM (Rosenstock et al., 1988), and one of the processes of change in the TTM (Prochaska & Velicer, 1997). Self-efficacy plays an important role in enhancing the explanatory capacity of the extended HBM and TRA/TPB in relation to health behaviours (Gillibrand & Stevenson, 2006; Strating et al., 2006). Furthermore, the expectation of outcomes and values upon performance of a health behaviour is commonly referred to as the perceived benefits of a health behaviour in the HBM; as one of the key constructs of the SCT; as the weighing of advantages and disadvantages of the change in the TTM; and formulating personal behavioural beliefs and attitudes towards the behaviour in the TRA/TPB.

2.5.2.1 Self-efficacy and stroke recovery

Indeed self-efficacy has been examined extensively in stroke recovery research. Recent evidence-based clinical guidelines recommend that stroke survivors should be offered self-efficacy training to enhance post-stroke independence and emotional adjustment. Furthermore, survivors should be assessed for self-efficacy during the stage of rehabilitation (Royal College of Physicians, 2012; SIGN, 2010).

Self-efficacy plays a significant role in influencing stroke survivors’ engagement in self-management behaviours and outcomes (Jones & Riazi, 2011). Three systematic reviews consistently found that increased self-efficacy among stroke survivors was
associated with a significant improvement in HRQoL (Jones & Riazi, 2011; Korpershoek, van der Bijl, & Hafsteinsdóttir, 2011; van Mierlo et al., 2014). Two of the systematic reviews also reported that self-efficacy was positively associated with stroke survivors’ mobility and ADL, and negatively associated with depression (Jones & Riazi, 2011; Korpershoek et al., 2011). Nicholson et al. (2014) in a qualitative study of 13 ambulatory stroke survivors in the United Kingdom, at a median of about one year after stroke, consistently revealed that high self-efficacy was the most commonly reported motivators of physical activity. Another cross-sectional study of 96 ischaemic stroke inpatients at 6.5 weeks post-stroke found that high self-efficacy was one of the protective factors for depressive symptoms (Lewin, Jöbges, & Werheid, 2013).

Some studies examined the role of specific types of self-efficacy in stroke survivors’ recovery. Robinson-Smith, Johnston, and Allen (2000) examined the association of self-care self-efficacy among 63 survivors in the US in a longitudinal study. Self-care self-efficacy was the survivors’ self-efficacy in performing self-care activities. The results showed that self-care self-efficacy increased significantly after stroke. It was significantly and positively correlated with HRQoL, and significantly and negatively correlated with depression, both at an inpatient rehabilitation facility at one month after stroke, and at home at six months after stroke. A cross-sectional study of 50 community-dwelling stroke survivors at six to 358 months after stroke in the US consistently found that balance and fall-related self-efficacy explained 27% to 55% of variance in participation in community walking (Robinson et al., 2011). Two cross-sectional studies consistently reported that balance-related self-efficacy was significantly associated with activity and participation among 77 community-dwelling stroke survivors in the US (Schmid et al., 2012), and fall-related self-efficacy was significantly associated with self-reported physical activity among 195 community-dwelling stroke survivors in Sweden (Vahlberg et al., 2013). Self-efficacy was also associated with survivors’ psychosocial well-being. A cross-sectional study in Australia found that self-efficacy in psychosocial functioning was significantly and positively associated with life satisfaction, and with positive and negative affect among 80 community-dwelling stroke survivors (Maujean & Davis, 2013).

The predictive power and influencing factors of self-efficacy have been examined. An earlier study in Hong Kong found that fall-related self-efficacy was a significant influencing factor of falls in the preceding 12 months among 38 chronic
stroke survivors with low hip bone mineral density who had had stroke for a mean duration of 6.5 years (Pang & Eng, 2008). Memory self-efficacy refers to a person’s beliefs in own capability in using memory effectively in memory demanding situations. A cross-sectional study in the Netherlands reported that higher depression and neuroticism, and use of a more passive coping style were significantly associated with lower memory efficacy among 23 survivors during inpatient rehabilitation (Aben, Busschbach, Ponds, & Ribbers, 2008).

There is increasing interest in assessing stroke survivors’ self-efficacy in self-managing their health conditions. Jones, Partridge, and Reid (2008) developed a stroke-specific self-efficacy measure, the 13-item Stroke Self-Efficacy Questionnaire (SSEQ), to assess survivors’ self-efficacy in functional performance and self-management. Preliminary evidence indicated that the SSEQ is a reliable and valid measuring instrument for evaluating self-management interventions that aim at enhancing stroke survivors’ self-efficacy in self-management.

2.5.2.2 Outcome expectation and stroke recovery

Outcome expectation, is a construct closely related to self-efficacy as postulated by Bandura’s SCT (Bandura, 1997). However, outcome expectation has not been examined extensively in research, compared with the concept of self-efficacy. Furthermore, contrasting evidence was reported about the role of outcome expectation in recovery of people with chronic conditions including stroke. A descriptive study of 145 adult people with type 2 diabetes in Taipei found that 39.1% of variance in self-care behaviours was explained by the duration of diabetes, levels of self-efficacy and outcome expectation (Wu et al., 2007). Iannotti et al. (2006) conducted a study among 168 adolescents with type 1 diabetes in the US. Regression analyses showed that self-efficacy and positive outcome expectation were significantly associated with the adolescents’ adherence to diabetes self-management behaviours and better glycaemic control (Iannotti et al., 2006). A cross-sectional study of 320 middle-aged and older adults showed that higher self-efficacy was significantly associated with physical, self-evaluative, and social outcome expectation. More positive self-evaluative and physical outcome expectations were significantly associated with increased participation in physical activity (Wojcicki, White, & McAuley, 2009). In contrast, another cross-sectional study of 91 type 2 diabetes patients in the US found that there was no
significant relationship between self-efficacy and self-care behaviours, nor between outcome expectation and glycaemic control (Chlebowy & Garvin, 2006).

Similarly, contrasting evidence was reported on the role of self-efficacy and outcome expectation in stroke recovery outcomes. A recent study suggested that self-efficacy and outcome expectation were known predictors of exercise behaviours among older individuals including those with stroke (Shaughnessy, Michael, & Resnick, 2012). In an earlier study, Shaughnessy, Resnick, and Macko (2004) developed a Short Self-Efficacy for Exercise and a Short Outcome Expectations for Exercise scales for stroke survivors. Factor analyses showed that self-efficacy expectations contributed to 13% of variance in exercise, while outcome expectation explained another 2% of variance in exercise. Contrasting results were obtained from a recent study of 12 people with chronic stroke who participated in a task-specific, and repetitive upper extremity intervention. The results showed that there was no significant association between participants’ outcome expectations of the interventions with improvement in upper extremity function (Prager, Birkenmeier, & Lang, 2011). Bandura emphasised that self-efficacy causally influenced outcome expectation, but not vice versa (Bandura, 1997). However, debates exist in the literature about the causal relationship between self-efficacy and outcome expectation (Williams, 2010).

While there has been inconclusive evidence on the causal relationships between self-efficacy and outcome expectation, it is clear that both factors are crucial in influencing the initiation and continuation of a behaviour (Prager et al., 2011). Further examination of the interaction of the two factors and their influence on stroke survivors’ participation in self-management, and hence the changes in recovery outcomes, would be worthwhile for development of appropriate self-management interventions for community-dwelling stroke survivors.

2.6 EFFECTIVENESS OF SELF-MANAGEMENT INTERVENTIONS

Abundant evidence indicated that CDSMP was associated with significant positive improvement in the health outcomes and health services utilisation of participants with a variety of diagnoses. Lorig et al. (1999) found that 952 participants with a medical diagnosis of heart or lung diseases, stroke or arthritis had significant improvements in physical and psychosocial outcomes at six months after receiving the CDSMP, when compared with the control group. The physical and psychosocial
outcomes that improved included weekly duration of exercise, management of cognitive symptoms, communication with physicians, self-reported health, health distress, fatigue, disability, and limitations in social and role activities. The participants also had reduced admissions to hospitals and length of hospital stay. A follow-up study to this RCT also found that the participants who received the CDSMP had a significant decrease in visits to emergency or outpatient department and health distress, and a significant increase in self-efficacy up to two years after completion of the program (Lorig et al., 2001). However, these studies did not specifically report the stroke survivors’ changes in outcomes after receiving the CDSMP.

### 2.6.1 Effectiveness of self-management interventions for stroke survivors

During the last decade, studies have emerged that suggested self-management specific to stroke would be the preferred model of service delivery for promoting continuity and transition of care when stroke survivors are returned to the community (Cott, Wiles, & Devitt, 2007). Some studies incorporated stroke-specific components, such as physical rehabilitation and stroke prevention, into the CDSMP. For example Kendall et al. (2007) examined the effectiveness of a 7-week stroke self-management program based on an existing 6-week CDSMP with a stroke-specific session added. Fifty-eight of the participants were randomly allocated to receive the new program. The results showed that participants in the intervention group did not show declines in HRQoL domains of functioning in ADL, self-care, work productivity and family roles during the first year after stroke. However, participants in the control group reported declines in these HRQoL domains, though there was no significant difference between the two groups. There were also no significant differences in the levels of self-efficacy at follow-up assessments among participants in both groups.

Catalano, Dickson, Kendall, Kuipers, and Posner (2003) conducted semi-structured interviews with the stroke survivors at 18-month follow-up after completion of a 6-week stroke self-management program based on CDSMP. The findings showed that the participants valued the opportunities offered by the program in enhancing social contact. They commented that the program increased their awareness and knowledge about stroke; motivated them to pursue goals and activities; and promoted their sense of achievement. More importantly, the participants said that their self-efficacy was increased after receiving the program. However, the maintenance of gains was evident during the program and levelled out after the program.
There were also studies that examined newly developed stroke self-management programs based on Bandura’s construct of self-efficacy. Huijbregts, Myers, Streiner, and Teasell (2008) compared a new 8-week self-management program with a 6-week standard education program. The new program aimed to enhance stroke survivors’ self-efficacy in managing stroke. Each program integrated exercise components into the program in addition to provision of comprehensive stroke information. Participants were allocated to receive either of the programs according to their preference. Of the 30 stroke survivors of mean age 68 years and two years after stroke, 18 selected the new self-management program and 12 selected the standard program. The results showed that the stroke survivors had a significant increase in levels of social support, participation in exercise, and reintegration into normal living activities three months after completion of the new 8-week program. The new program was found to be more costly to deliver than the standard education program. However, the preliminary results indicated that the new program might be more effective in helping stroke survivors to deal with the challenges of living with stroke (Huijbregts et al., 2008). Taylor et al. (2009) reported the delivery of the new 8-week stroke self-management program via videoconference for 12 stroke survivors who lived in rural areas to address the transportation problems. Preliminary evidence showed improvements in goal-setting, mood, balance and confidence in balancing, and endurance in walking after receiving the program.

Another study developed a stroke self-management workbook based on Bandura’s construct of self-efficacy for patients after a first stroke (Jones et al., 2009). The workbook was designed to improve stroke survivors’ self-efficacy in performing self-management tasks, functional activity, participation and mood. Preliminary results showed statistically significant improvement in SSEQ scores and Recovery Locus of Control Scale scores following the intervention (Jones et al., 2009).

However, it is important to note that some methodological issues in the evaluation of self-management programs were reported, such as small sample size, reduced robustness of RCT designs, or whether analyses performed were based on ITT principles. These issues limited the interpretation and generalisability of the study results (Harrison et al., 2011). Furthermore, most of the studies measured the outcomes at four to six months with only a few studies measuring longer-term outcomes at 12 months after completion of the program (Jones et al., 2009; Lorig et al., 2001).
Accordingly, the effect of the program and its sustainability over longer periods are yet to be examined. Moreover, there was inconsistency in the use of validated and reliable tools in measuring outcomes such as self-efficacy, attitudes and performance of self-management behaviours. There were also few studies that examined the cost-effectiveness of the programs (Harrison et al., 2011). Heterogeneity among studies in the participants, interventions, outcome measures, and time for follow-up assessment makes it difficult to suggest the most effective approach, including the format and contents, to deliver stroke self-management programs (Zwerink et al., 2014).

A recent systematic meta-review of 13 systematic reviews, published between 2003 and 2012 on 101 individual trials examining stroke self-management support interventions found that previous studies seldom used the term “self-management”. However, the key elements of self-management support such as goal-setting, action-planning and problem-solving were core components of many stroke rehabilitation interventions. The results also showed that the self-management support interventions were associated with significant improvements in basic and extended ADL, and reduced poor outcomes such as dependence and death. There is also some evidence supporting the usefulness of problem-solving interventions in facilitating stroke survivors’ reintegration into the community (Parke et al., 2015). However, this review did not indicate whether a theoretical framework had underpinned the design, implementation and evaluation of the self-management interventions. Furthermore, the interventions included in the studies in this meta-review embraced a wide range of strategies which may have been informed by different theoretical frameworks. Accordingly, the results of the structured stroke self-management programs were not clear.

The discussion regarding the development of effective stroke self-management programs for community-dwelling stroke survivors continues. Different studies examined different stroke self-management programs for stroke survivors at different stages of recovery. It is important to identify the core elements in the programs that show promise for effecting enhanced outcomes among stroke survivors, as well as achieving best practice in evaluating the effectiveness of stroke self-management programs to inform future practice.
2.6.2 Factors influencing effectiveness of self-management interventions

Several factors in the literature are identified as possible influences on the effectiveness of self-management programs. The factors can be categorised into factors related to the person, the intervention, the facilitator and the environment.

2.6.2.1 Person-related factors

Studies reported that the beliefs and attitudes towards the disease, knowledge of the condition and management plan and perceived self-efficacy to manage own health conditions were significant factors influencing the effectiveness of diabetes self-management educational programs (Nagelkerk, Reick, & Meengs, 2006; Rodriguez, 2013; Sarkar, Fisher, & Schillinger, 2006). A cross-sectional study conducted in Beijing, China consistently reported that beliefs in the benefits of the treatment and diabetes self-efficacy influenced diabetes self-management among Chinese adults with type 2 diabetes. Such beliefs and perceived self-efficacy were in turn influenced by the persons’ knowledge (Xu, Toobert, Savage, Pan, & Whitmer, 2008). Abundant evidence also indicated significant association between stroke survivors’ level of self-efficacy and participation in stroke self-management behaviours (Jones et al., 2009; Korpershoek et al., 2011; Lennon, McKenna, & Jones, 2013).

Furthermore, a recent qualitative synthesis of 58 articles on self-management interventions reported that people’s decisions to adopt or retain the suggestions received in the self-management interventions were related to the way they rationalised the suggestions within their own contexts. The decisions were found to be influenced by the costs required to act according to the suggestions, the values placed or benefits experienced after acting according to the suggestions, and other moral, social, motivational and cultural factors. The study concluded that a person tended to adopt a solution if it could be constructively rationalised and be seen to have positive value. Adoption was decreased if a negative rationale was constructed due to the solution’s failure to meet people’s expectations (Harvey, Dopson, McManus, & Powell, 2015).

Health literacy is an individual’s ability to identify, synthesise and apply the relevant health information to their health decision-making (Rodriguez, 2013). Jordan, Briggs, Brand, and Osborne (2008) elaborated that health literacy extended to include the individual’s ability to know when to seek medical help, communicate effectively with healthcare professionals, and adhere to management regimens. Studies found that
health literacy played a central role in an individual’s participation in self-management decisions and behaviours (Jordan et al., 2008; Rodriguez, 2013). Stroke survivors, similar to people with other chronic conditions, need to identify, appraise and assimilate the health information related, for example, to exercise, diet and strategies to manage fatigue, to inform their health decisions for enhancing recovery.

2.6.2.2 Intervention-related factors

Given the importance of underpinning complex self-management interventions with a theoretical framework, a systematic approach to ensuring the appropriate application of frameworks in particular contexts is required (Noar, 2005). A systematic review by Davies, Walker, and Grimshaw (2010) of 235 studies that examined the interventions for guideline dissemination and implementation. The results showed that only 22.5% of the 235 studies employed theories of behaviour or behavioural change. There was poor justification for the choices of theories and interventions adopted in the studies (Davies et al., 2010). Another systematic review by Al-Durra et al. (2015) also found that only 20% of 85 Internet-based asthma self-management interventions applied at least one theoretical model or framework, or construct of a health behaviour theory as the underpinning premise. The results indicated that there was a lack of theory-driven strategies to facilitate individuals’ health behaviour change.

When it comes to self-management interventions for people with chronic conditions including stroke, the CDSMP, for example, has adopted multiple strategies to enhance participants’ self-efficacy for improved health outcomes (Lorig et al., 2001). However, there have been few studies which specifically mentioned how the theoretical framework was used to inform the design and implementation of the self-management program, or measured the variables of the theoretical framework. The study by Wu and Chang (2014) demonstrated an example of how the construct of self-efficacy was utilised to inform the development and selection of strategies for a cardiac-diabetes self-management program. In this study, the use of the construct of self-efficacy was justified with reference to the importance of self-efficacy in influencing people’s choice of health behaviours. Furthermore, there was a clear delineation of strategies for addressing the four principal sources of information of self-efficacy in each component of the self-management program. Such detailed description is valuable in enabling a more comprehensive understanding of how each
element integrated in the whole intervention, and hence allowing replication of the interventions in future studies with different participants and contexts.

Participants with chronic conditions who would be eligible for self-management interventions often have a wide spectrum of health needs in their own situational context. While the exact mechanism of change is yet to be determined, ensuring the accessibility of the self-management intervention is reported as a significant factor for enhancing intervention effectiveness (Lawn & Schoo, 2010). Furthermore, the content of the interventions should address the participants’ needs and preferences to better engage them in the intervention regimens (Lawn & Schoo, 2010). Helduser et al. (2013) found that topics about nutrition and exercise arranged at the beginning of the CDSMP were associated with increased completion of the program in a group of adults with type 2 diabetes, possibly due to the fact that these topics were very relevant to the participants’ needs.

Self-management interventions are often delivered in groups. Harrison et al. (2011) conducted a secondary analysis of results of RCTs which examined the effects of a CDSMP for people with chronic conditions. The results showed that the most consistent predictor of CDSMP outcomes was the participants’ perceptions of usefulness of the group process. The results highlighted the importance of group dynamics and the attributes arising from group interaction, such as inspiration, learning, support and opportunities to express and assert themselves.

While there are many self-management interventions for people with chronic conditions, there has been no consensus on the components and contents of the interventions that are most effective and beneficial. No one approach is necessarily superior to other approaches (Lawn & Schoo, 2010). However, key components of the self-management interventions can be identified from the literature. First, self-management interventions go beyond traditional didactic provision of knowledge or information with emphasis on developing participants’ capabilities in executing self-management skills such as goal-setting and problem-solving, improving self-efficacy, and applying the knowledge and skills learned to daily life events (Coleman & Newton, 2005). The interventions usually were structured with at least two contact moments that involved specific components for developing participants’ capabilities in executing core self-management skills such as the ability to formulate goals and action plans (Grady & Gough, 2014; Zwerink et al., 2014). While there are sessions that
commonly provide information about self-management in general, there are also sessions that provide specific topics about management of the particular chronic conditions. Such specificity enhances participants’ self-efficacy, and facilitates the management of their physical, psychological and social functioning (Plow, Finlayson, & Rezac, 2011; Swendeman, Ingram, & Rotheram-Borus, 2009).

The emerging stroke self-management programs have integrated some of the abovementioned strategies such as group sessions in enhancing stroke survivors’ self-management capabilities (Huijbregts et al., 2008; Kendall et al., 2007). However, there are slight differences such as the number of group sessions delivered or doses of the program, and the additional use of specially designed workbooks to supplement the information provided (Huijbregts et al., 2008; Jones et al., 2009; Kendall et al., 2007). Furthermore, it is important to note that stroke survivors often live with different degrees of physical disability which may affect their participation in the program. Taking these factors into consideration when designing stroke self-management programs is important.

2.6.2.3 Facilitator-related factors

Relationships between the facilitator and the participants matter. Studies have identified that effective strategies for providing self-management support included the development of a collaborative relationship between the participants and the facilitator. Healthcare professionals often assume the role of facilitators. The facilitator not only assesses and facilitates the participants’ development of core self-management skills, but also maintains a positive attitude that promotes proactive learning and active engagement, as well as provides feedback on the participants’ attainment or progress, and hence increases the participants’ confidence in executing self-management behaviours. Provision of encouragement is vital (Jordan et al., 2008; Nagelkerk et al., 2006; Rodriguez, 2013). Studies reported that supportive and effective communication with facilitators enhanced the participants’ positive perceptions of relevance and effectiveness of the self-management suggestions in their own contexts and promoted their participation in self-management behaviours (Harvey et al., 2015; Xu et al., 2008).

Healthcare professionals, including physicians, nurses, physiotherapists and occupational therapists, were reported as facilitators of self-management programs. There have been no criteria identified for guiding facilitators in the delivery of stroke self-management programs. However, studies consistently reported that the facilitators,
usually healthcare professionals needed to attend prior training (Huijbregts et al., 2008; Jones et al., 2009). Further exploration about the knowledge, skills, and types of training required for the facilitators is warranted to ensure consistent and high-quality facilitation of self-management programs for stroke survivors.

2.6.2.4 Environment-related factors

Environment-related factors for those with chronic conditions are mainly related to the social support available to the participants, which for people with type 2 diabetes affects self-management indirectly via beliefs and self-efficacy (Xu et al., 2008). Furthermore, family and community support was associated with patients’ self-management adherence and self-efficacy (Jordan et al., 2008; Rodriguez, 2013; Rosland, Heisler, Choi, Silveira, & Piette, 2010). Social and professional support has been discussed in earlier sections as facilitators of stroke survivors’ participation in physical activities and exercise. It is also important to encourage survivors’ social participation (Kuluski et al., 2014; Wang et al., 2014). Therefore, inclusion of this element into stroke self-management programs would be potentially beneficial.

The location and accessibility of the venue where the stroke self-management programs are delivered is important. Group sessions which are one of the key components of self-management programs, enable participants to observe and learn from each other with similar conditions (Lennon et al., 2013). However, stroke survivors often suffer from different degrees of physical impairment that limit their abilities to travel to the venue. Transportation problems are often reported as participants’ barriers to attending the program, and hence decrease their adherence to the program (Huijbregts, McEwen, & Taylor, 2009; Kendall et al., 2007). Taylor et al. (2009) examined the effectiveness of a stroke self-management program delivered via videoconference to address the transportation problems. However, the mode of delivery implied technological demands and increase in costs. Face-to-face interaction among group participants is also not allowed by videoconference. Therefore, an appropriate selection of the venue and strategies to facilitate stroke participants’ access is important.

2.7 GAPS IN THE LITERATURE

While there is substantial anecdotal evidence on the effectiveness of self-management interventions for people with chronic conditions, there are several questions to be answered before applying the concepts of self-management to stroke
survivors. First, it is the extent to which self-management interventions are effective for stroke survivors. Unlike people with other chronic conditions, stroke survivors usually suffer from a variety of physical disabilities, commonly one-sided weakness or paralysis that impair their physical independence. Difficulties in mobility may hinder their participation in self-management behaviours. Some stroke survivors have their cognitive functions affected, which in turn may affect their capabilities to learn and practise core self-management skills. More evidence is needed to determine the effectiveness of stroke self-management programs, in particular on improving physical, psychological and social outcomes, and HRQoL.

Second, there has been no consensus on the standard or most effective format or delivery approach for self-management interventions for people with chronic conditions. The literature on enhancing stroke survivors’ capabilities reviewed in the previous section also found that there was diverse variability in the format and contents of stroke self-management programs (Huijbregts et al., 2008; Jones et al., 2009; Taylor et al., 2009). In addition to knowing an intervention’s effectiveness, it is essential to identify effective strategies in formulating the stroke self-management interventions. This is not limited to identification of effective dose, format and contents of the interventions, and personnel to deliver the interventions, but also to the best-fitting theoretical framework to underpin the design, implementation and evaluation of the self-management interventions for stroke survivors.

Self-management interventions for people with chronic conditions commonly emphasised the enhancement of participants’ self-efficacy. However, there is insufficient evidence on the best-fitting theoretical framework for underpinning self-management interventions for stroke survivors. Acknowledging that self-management programs are complex interventions (Craig et al., 2008), a systematic review of effectiveness of self-management underpinned by a theoretical framework for stroke survivors is warranted. While there has been no consensus on the best approach to develop theory-based interventions, the results of the systematic review would be valuable in informing the strategies for selecting the appropriate theoretical framework and strategies to address the variables posited by the theoretical framework, as well as the appropriate evaluation approaches to best reflect the effectiveness of the interventions. The results would also help in standardising the promising components of best practice, stroke-specific formats and delivery methods for providing optimal
benefits for stroke survivors. This facilitates the interpretation of and comparison across studies, and replication of the interventions across different settings and populations.

Furthermore, the extent of stroke severity among the participants following stroke varied. Jones et al. (2009) reported that all participants had certain degrees of limitations in activity and participation. To tailor the self-management interventions for stroke survivors with diverse health needs during different stages of recovery post-stroke, it is important to have a comprehensive understanding about the extent to which stroke survivors with various demographic and clinical characteristics benefit from the interventions. The results would highlight the importance of providing detailed demographic and clinical information about participants to help in interpretation of generalisability of the results. In addition, the information would be helpful to inform decision-making for better allocation of resources, while addressing stroke survivors’ health needs and expectations.

When assessing the usefulness of stroke self-management interventions, it is also of paramount importance to assess the quality of the evidence and whether there are key methodological concerns in the studies to enable appropriate interpretation of the study results. The types of study design, outcome indicators and their reliability and validity, measurement time points, sample size and analytical methods are key aspects to assess. Furthermore, it is also important to assess whether the studies are reported according to the updated guidelines of the Consolidated Standards of Reporting Trials (CONSORT) 2010 statement (Schulz, Altman, & Moher, 2010). A systematic review of RCTs is warranted to gather more conclusive evidence about the effectiveness of stroke self-management programs. The evidence is important to inform future development and conduct of the studies, and allows replication of the interventions in different contexts.

Moreover, the previous intervention studies have been conducted predominantly in Western countries, and compared with standard or usual care. There has been no reported study which examined the effectiveness of stroke self-management programs specifically for Chinese stroke survivors. It would be worthwhile to examine the effectiveness of this type of program for this population to better understand the applicability of this approach to provision of support in a Chinese cultural context. This information is important for guiding future design and practice of self-management programs for Chinese community-dwelling stroke survivors.
2.8 SUMMARY AND CONCLUSION

Stroke recovery is long-term and complicated. Stroke survivors may encounter difficulties arising from physical, psychological or social aspects. There are also uncertainties regarding the extent of post-stroke recovery that is possible. Self-management has been recommended as an important intervention for enhancing health outcomes of people with chronic conditions. Self-management emphasises individuals’ active participation in managing their own health conditions, with the exercise of core self-management skills, including problem-solving, decision-making, goal-setting, action-planning, resources utilisation, and communication with healthcare professionals. Substantial evidence indicated that people with chronic conditions such as diabetes or arthritis who received self-management programs had significant improvements in health outcomes. With stroke survivors, an increasing amount of literature provided preliminary evidence on the effectiveness of stroke self-management programs on enhancing survivors’ recovery.

Stroke self-management programs are complex interventions. Underpinning the programs with a theoretical framework enables the program’s systematic development and evaluation. The constructs of self-efficacy and outcome expectation are common in health behaviour theories. While the former has been found to be associated with positive outcomes in stroke rehabilitation, further examination of the role of both self-efficacy and outcome expectation in stroke survivors’ participation in self-management would be worthwhile. In addition to the best fitting underpinning theoretical framework, there are still gaps to be addressed, particularly the best approach to implement and evaluate the program, and the program effectiveness. More evidence based on systematic reviews, as well as testing of the stroke self-management programs among Chinese community-dwelling stroke survivors is warranted.
3.1 INTRODUCTION

This chapter reports and discusses the methods and results of a systematic review conducted in the first phase of the research project. This research project consists of two phases. Phase One is to review all available research evidence to determine the effectiveness of theory-based stroke self-management programs for community-dwelling stroke survivors. Moreover, it is to identify the best approach to deliver stroke self-management programs and address the gaps in the literature discussed in the previous chapter. Evidence of all relevant RCTs were included and evaluated the effectiveness of the stroke self-management programs. Inclusion of RCTs only in the systematic review was based on the grounds that RCTs adopted rigorous designs to minimise bias in the data and allows for attribution of differences in outcomes to the intervention examined. RCTs are considered as the gold standard for appraisal of the effectiveness of interventions. The types of outcomes assessed included stroke survivors’ HRQoL, participation in stroke self-management behaviours, physical, psychological, social and other clinical outcomes. The results of the systematic review informed the development and evaluation of a new nurse-led community-based stroke self-management program for stroke survivors in Phase Two. The protocol and results of this systematic review were published in the Joanna Briggs Institute (JBI) Library of Systematic Reviews (Lo, Chau, Chang, & Gardner, 2011) and the JBI Database of Systematic Reviews and Implementation Reports (Lo, Chang, Chau, & Gardner, 2013) respectively.

3.2 SYSTEMATIC REVIEW OF THEORY-BASED STROKE SELF-MANAGEMENT PROGRAMS

In this section, the published work of the systematic review is included verbatim with minor editing to fulfil the requirements of the thesis. The published protocol, and the executive summary, references and appendices of the systematic review are shown in Appendices A and B respectively.
3.2.1 Background

Stroke is the second leading cause of death across the globe, causing a total of 6.15 million deaths in 2008, accounting for 10.8% of all deaths (WHO, 2013). The number of deaths attributed to stroke or other cerebrovascular events was much higher in the middle-income countries (4.19 million, 12.8% of all deaths) than that in high-income (0.79 million, 8.7% of all deaths) and low-income (0.45 million, 4.9% of all deaths) countries (WHO, 2008). Statistical reports in Hong Kong also showed that stroke has been ranked the fourth leading cause of death (Department of Health, 2012). People surviving a stroke are often left with different degrees of physical disability or cognitive impairment. They were found to have a higher risk of developing depressive symptoms and a compromised quality of life (Carod-Artal, & Egido, 2009; Lee et al., 2009). In addition to comprehensive care in a stroke unit during the acute stage, recent evidence and guidelines suggested that early supported discharge and continued support for community-dwelling stroke survivors were important (Hickey, Horgan, O’Neill, & McGee, 2012; Langhorne et al., 2005; National Institute for Health and Care Excellence, 2011).

Recovery after stroke is long-term and demanding. Stroke rehabilitation needs to be comprehensive and to encompass the three dimensions of physical, psychological and social. Stroke survivors are required to cope with the disability resulting from their stroke as well as learn to manage their conditions including but not limited to performing health-related behaviours to lower risks of further stroke or early detection of vascular dementia following stroke (Stein et al., 2009; Vanhook, 2009). Previous studies found that stroke survivors usually experience a decreased amount of support from their family or caregivers after hospital discharge, as their life gradually returns to normal (Kendall et al., 2007). However, the recovery process for stroke survivors still continues after discharge from hospital and/or rehabilitation centres. It is at this time they often encounter difficulties and uncertainties about coping with their physical disabilities, adapting to their psychosocial needs, reintegrating into their pre-stroke social life, or maintaining medication adherence, especially in the absence of feedback and support by healthcare professionals or carers (Chau et al., 2009; Olofsson et al., 2005). Therefore equipping stroke survivors with adequate knowledge and skills is prerequisite to optimise their capability to engage in daily activities, and most
importantly, to better self-manage their health conditions (National Institute for Health Research, 2009; NHS Improvement Programme, 2008).

Self-management refers to a person’s active participation in managing their symptoms, treatment, physical and psychosocial impact related to a chronic illness (Barlow et al., 2002). Problem-solving, decision-making, goal-setting, action-planning, resources utilisation, and communication with healthcare professionals are the core self-management skills that are crucial to attaining effective self-management (Lorig et al., 1999). An earlier systematic review of 71 studies examining the effects of self-management programs for people with chronic conditions showed small to moderate significant improvements in glycosylated haemoglobin, and systolic blood pressure levels among diabetic and hypertensive people respectively (Warsi, Wang, LaValley, Avorn, & Solomon, 2004). Numerous Cochrane reviews also reported small to moderate significant positive effects of self-management programs on people with chronic illnesses (Foster, Taylor, Eldridge, Ramsay, & Griffiths, 2007), diabetes (Deakin, McShane, Cade, & Williams, 2005), or COPD (Effing et al., 2007). More recent studies have examined the effects of self-management programs on community-dwelling stroke survivors. A multiple-participant, two-phase single subject design study found that a self-management workbook underpinned by the construct of self-efficacy was associated with increased self-efficacy in managing their conditions after stroke among 10 stroke survivors (Jones et al., 2009). Two observational cohort studies that examined the effects of a stroke self-management program also suggested potential benefits in enhancing stroke survivors’ quality of life and psychosocial well-being (Huijbregts et al., 2008; Huijbregts et al., 2009).

Stroke self-management programs are complex, comprising interventions with several interacting components such as the strength, dose, or contents of the programs. According to the Medical Research Council in United Kingdom guidance on developing and evaluating complex interventions (Craig et al., 2008), one important initial step in designing the intervention is to develop a theoretical understanding of the process of change to be expected within the context examined. Such theoretical understanding is important in providing a basis for developing and implementing the intervention systematically. Furthermore, it helps inform the variables to be evaluated, and predict and explain the change in behaviours or causal chain between components of the interventions and outcomes (Craig et al., 2008). In recent years, there has been
an increase in the number of studies which have examined the effectiveness of stroke self-management programs underpinned by cognitive-behavioural or psychosocial theories (Huijbregts et al., 2008; Huijbregts et al., 2009; Jones et al., 2009). For example, the stroke self-management program in Jones et al. (2009) was underpinned by the construct of self-efficacy. Strategies were adopted to enhance participants’ self-efficacy in performing stroke specific self-management behaviours. The participants’ self-efficacy in performing these behaviours was measured to evaluate the program effectiveness on this mediating factor and its association with the outcomes. The program examined by Huijbregts et al. (2008) and Huijbregts et al. (2009) was designed based on the SCT, to facilitate the participants’ self-efficacy in initiating behavioural change such as exercise. A recent systematic review was published to examine the effectiveness of stroke self-management programs with or without a theoretical premise (Lennon et al., 2013). Despite efforts to evaluate the outcomes of stroke self-management programs, no systematic review has been conducted to summarise the best available research evidence on the effectiveness of theory-based self-management programs on post-stroke recovery. Such evidence is imperative to guide future design, practice and evaluation of effective stroke specific self-management programs. Selecting an appropriate theoretical framework and comprehensively addressing the propositions in the theory are proposed to enhance and predict the effectiveness of the target stroke self-management behaviours (Craig et al., 2008). Use of outcome indicators as informed by the theory can further explain the mechanism of behavioural changes.

The purpose of this systematic review was to determine the effectiveness of theory-based stroke self-management programs on recovery of community-dwelling stroke survivors. The results of this review will inform future identification and evaluation of best strategies to deliver effective self-management programs underpinned by a theoretical or conceptual framework as recommended for this type of complex intervention (Craig et al., 2008). It is anticipated to ultimately optimise stroke survivors’ physical and psychosocial outcomes during their post-stroke recovery in the community.

3.2.2 Review aim and objectives

The systematic review was undertaken to answer the review question: “What is the effectiveness of theory-based self-management programs on community-dwelling
stroke survivors’ post-stroke recovery after discharge from hospital?”. The aim of this systematic review was to present the best available research evidence on the effectiveness of theory-based self-management programs on recovery of community-dwelling stroke survivors.

The specific review objectives were to assess the effectiveness of theory-based self-management programs on community-dwelling stroke survivors’:
- HRQoL;
- Participation in stroke self-management behaviours;
- Physical outcomes;
- Psychological outcomes;
- Social outcomes; and
- Other clinical outcomes.

### 3.2.3 Inclusion criteria

**Types of participants**

This review considered studies which included adults aged 18 years or over, who have had a clinical diagnosis of first or recurrent stroke, and community residing (either at home or in residential care settings), regardless of gender or ethnicity. According to WHO (2006), stroke is defined as “a focal neurological impairment of sudden onset, and lasting more than 24 hours, and of presumed vascular origin” (p.1). The types of stroke considered for the review included ischaemic stroke, intracerebral haemorrhage, and subarachnoid haemorrhage. Studies which included participants with transient ischaemic attack, subdural or epidural haemorrhage were excluded as they were not consistent with the WHO definition of stroke (WHO, 2006).

**Types of interventions**

The review considered studies which examined the effectiveness of a self-management program underpinned by a theoretical or conceptual framework on community-dwelling stroke survivors’ recovery. For the purpose of this review, self-management refers to “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition” (Barlow et al., 2002, p.78). The topics covered in the program included but were not limited to management of symptoms and emotion, adapting or coping with difficulties in performing ADL, lifestyle modification, stroke prevention, community reintegration, utilisation of community resources, and communication with
healthcare professionals. Core self-management skills including problem-solving, decision-making, resources utilisation, collaboration, goal-setting and action-planning also needed to have been emphasised in the program (Lorig et al., 2001). A program was considered as theory-based if the name of the theoretical or conceptual framework underpinning the program design was explicitly stated in the study, with citations of the original literature delineating the theoretical or conceptual framework. Included studies also needed to describe the ways in which the theoretical or conceptual framework informed the program design and selection of outcome indicators. Studies were also included if one or more constructs of a theory were adopted in developing the program (Davies et al., 2010; Green, 2000). The format of the program could have been either a single or multiple sessions, delivered by healthcare professionals or trained lay persons, and with or without the presence of family members, caregivers or volunteers. Studies were included if the self-management program was initiated and completed when the participants were residing in the community after hospital discharge. The comparison groups in the included studies needed to consider either a self-management program underpinned by a different theoretical or conceptual framework, a self-management program that was not underpinned by a theoretical or conceptual framework, usual care, or no intervention.

*Types of studies*

All RCTs which examined the effectiveness of a theory-based self-management program for community-dwelling stroke survivors were included.

*Types of outcomes*

This review considered studies which included either one or more of the following primary and secondary outcome measures:

The primary outcome measures included:

- HRQoL of the stroke survivors as assessed by standardised generic or disease-specific quality of life instruments.

- Self-management behaviours as assessed by measurement of medication adherence, lifestyle modification (for example, diet and exercise), and help-seeking behaviours.

The secondary outcome measures included:

- Physical outcomes: ADLs as assessed by standardised functional outcome measures such as Instrumental Activities of Daily Living Scale to measure the
program effectiveness on participants’ abilities in performing daily tasks (Lawton & Brody, 1969).

- Psychological outcomes: Self-efficacy as measured by general self-efficacy scale or stroke-specific self-efficacy scale; depressive symptoms as measured by standardised depression rating scales such as Geriatric Depression Scale to assess the incidence of depressive symptoms in stroke survivors, commonly older adults (Yesavage et al., 1983).

- Social outcomes: Community reintegration as assessed by questionnaires of community reintegration or participation; perceived social support as assessed by standardised measures such as Medical Outcomes Study Social Support Scale (Sherbourne & Stewart, 1991) or other disease-specific scales.

- Other outcomes: Level of attendance of the program, recruitment methods, or adverse events of the program.

Language

The systematic review considered studies published in English or Chinese given the limitation of the authors’ language abilities to review publications in other languages. There were also limited available resources so the reviewers were not able to employ translators for studies published in other languages.

3.2.4 Search strategy

The aim of the search strategy was to identify all published and unpublished studies in English or Chinese of relevance to the systematic review. A three-step approach was adopted. First, the electronic bibliographic databases were searched to identify relevant key words, index terms and matched subject headings. The search strategies specific to each database were developed in consultation with a university librarian. Second, an extensive search of the databases was performed using the developed search strategies to identify potentially relevant studies for inclusion. Finally, the reference lists of retrieved articles, relevant conference proceedings, postgraduate dissertations, journals, online databases, and websites were searched to identify additional studies which were not located by the search strategies. Forward search of the relevant studies identified from the electronic bibliographic databases was conducted.

The following electronic databases were searched from the inception of each to November 2011 for primary English studies: MEDLINE, CINAHL Plus, EMBASE,
EMBASE CLASSIC, ALL EBM Reviews, Cochrane Central Register of Controlled Trials, Cochrane Stroke Group Trials Register, British Nursing Index and Archive, Allied and Complementary Medicine, Science Citation Index, Social Sciences Citation Index, Conference Proceedings Citation Index-Science, Conference Proceedings Citation Index-Social Science and Humanities, PsycINFO, and Scopus. The search strategies for each database are shown in Appendix B.

For primary studies published in Chinese, the following electronic databases were searched from the inception of each to November 2011: WanFang Data, China Journal Net, Chinese Biomedical Literature Database, Chinese Medical Current Contents, Hong Kong Index to Chinese Periodical Literature, WanFang Data Chinese Dissertations Database: Medicine, and National Digital Library of Theses and Dissertations in Taiwan. The Chinese search terms used were based on the terminology adopted in China and Taiwan. It included 腦卒中 (stroke), 腦中風 (stroke), and 自我管理 (self-management).

The following online resources were searched to identify potentially relevant grey literature or unpublished studies: Mednar database, Netting the Evidence, Lancashire Care Library and Information Service, Grey Literature Report (via The New York Academy of Medicine), Networked Digital Library of Theses and Dissertations, ProQuest Dissertations and Theses, Index to Theses, Digital Dissertations Consortium, Theses Online@The University of Hong Kong, Etheses@The Hong Kong Polytechnic University, Australasian Digital Theses Program, Academic Archive On-line, Agency for Healthcare Research and Quality, and Clinical Trials registries including ClinicalTrials.gov, WHO International Clinical Trials Registry Platform, and HKClinicalTrials.com. The search terms used included stroke*, poststroke*, post stroke*, and self-manage*.

3.2.5 Methods of the review

Study selection

Two reviewers independently assessed the titles and abstracts of all publications identified from the search strategies for their eligibility. A form for verification of study eligibility was developed by the reviewers (Appendix B). Publications that were considered relevant to the systematic review or, for which there was doubt about their relevance, were retrieved in full-text for further assessment. The two reviewers independently determined which studies should be included in the
systematic review. Comparison of both reviewers’ studies for inclusion indicated no disagreement on the decision of the publications for inclusion.

*Assessment of methodological quality*

The methodological quality of the included studies was assessed independently by two reviewers using the JBI Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) for experimental studies (Appendix B). There was no disagreement between the two reviewers on the results of the methodological quality assessment.

*Data extraction*

Two reviewers independently extracted data from the included studies using the standardised data extraction tool from the JBI-MAStARI (Appendix B). Authors of some of the included studies were contacted via email for clarifications or further information about the study contents and results. There was no disagreement between the two reviewers on the results of data extraction.

*Data synthesis*

There were incomplete details about the number of participants in the intervention and control groups, and the results in two studies (Damush et al., 2011; Kendall et al., 2007), which made it impossible to perform a meta-analysis. A narrative summary of the effectiveness of the stroke self-management programs was therefore presented.

### 3.2.6 Review results

*Search results*

A total of 12,835 English and 817 Chinese citations were identified from the electronic bibliographic databases. After removing the duplicates and irrelevant records, 160 English and 18 Chinese citations were retrieved in full-text for assessment of eligibility. Eleven additional English citations were identified from the reference lists of retrieved articles and retrieved in full-text. One hundred and sixty-eight of the 171 English citations retrieved in full-text were excluded. The reasons for exclusion included ineligible participants and interventions (n=102), irrelevant topics (n=34), insufficient details about the theoretical or conceptual framework underpinning the programs (n=11), non-RCTs or non-empirical research papers (n=7), conference abstracts (n=6), and papers which were only the study protocol (n=2). A further six studies were excluded because the reviewers were unable to contact the authors for
further information about the study results or programs. Eighteen Chinese citations were excluded due to ineligible participants and interventions (n=7), irrelevant topics (n=5), no information about the theoretical or conceptual framework underpinning the programs (n=4), non-RCT or non-empirical research paper (n=1), and a Chinese version of an included paper in English (n=1). Three English citations met the review eligibility criteria and were assessed for methodological quality. A total of three English studies were included in the review. A flow chart of study retrieval and selection is shown in Figure 3.1. The list of excluded studies and reasons for exclusion are shown in Appendix B.

Methodological quality

Among the three studies assessed for methodological quality, the key issues of concern included insufficient information about the methods of random assignment and allocation concealment, inadequate details about reliability and validity of the measuring instruments, absence of ITT analysis, and small sample size. A summary of the methodological quality assessment of the three studies is shown in Appendix B.

Cadilhac et al. (2011) and Kendall et al. (2007) reported that the participants were randomly allocated to the intervention and control groups using a remote web-based telephone randomisation program at a 1:1:1 ratio of 50 participants per group and a two-dice roll respectively. However, Damush et al. (2011) did not provide clear information about methods of random assignment. All the three studies did not describe explicitly the methods for concealed allocation of treatment groups. One study did not provide information about the reliability and validity of the measuring instruments (Cadilhac et al., 2011). Two studies analysed the data using ITT analysis (Cadilhac et al., 2011; Damush et al., 2011). Kendall et al. (2007) reported that mixed-effects models were performed to assess the effects of treatment, time and their interaction. However, the number of participants in the intervention and control groups included in the statistical analyses was not clearly described. Attempts to contact the authors for further information were in vain.

Furthermore, the sample sizes of the three studies were 63 (Damush et al., 2011), 100 (Kendall et al., 2007) and 143 (Cadilhac et al., 2011) respectively. Estimation of sample size was reported to a minimal extent with one study (Cadilhac et al., 2011) having arbitrarily determined the sample size as 50 participants per group to estimate the feasibility of the program and participants’ safety. The other two studies did not estimate the sample size using power calculation.
Figure 3.1 Flow chart of the study retrieval and selection
One study reported only the estimated effect sizes of the outcomes (Cadilhac et al., 2011). The authors were contacted and information about the baseline and follow-up mean scores and standard deviations (SD) of the three comparison groups were obtained. One study did not provide information about blinding of the persons who performed the assessment, and comparability of the intervention and control groups (Kendall et al., 2007). Attempts to contact the authors for clarification were unsuccessful. Another study reported only the baseline means and mean changes from baseline of outcomes with significant or marginally significant changes (Damush et al., 2011). There were no specific mean and standard deviation scores of the two follow-up measurements reported. No information was provided about the program effects on participants’ depressive symptoms. However, the authors could not be contacted and no further information could be obtained.

**Description of the included studies**

A total of three studies involving 306 community-dwelling stroke survivors met the inclusion criteria for this systematic review. The flow chart (Figure 3.1) details study retrieval and selection. Two of the studies were conducted in Australia (Cadilhac et al., 2011; Kendall et al., 2007), and one in the US (Damush et al., 2011). The settings included community-based organisations (Cadilhac et al., 2011), Veterans Administration hospital sites (Damush et al., 2011), and community settings (Kendall et al., 2007). Appendix B summarises the details of the three studies.

**Types of studies**

All included studies were RCTs. Two studies compared the group receiving the stroke self-management program with the group receiving usual care (Kendall et al., 2007) or attention placebo intervention (Damush et al., 2011). The third study compared the groups receiving the stroke self-management program, the Stanford CDSMP, or usual care respectively (Cadilhac et al., 2011).

**Types of participants**

The total number of stroke survivors in each study ranged from 63 (Damush et al., 2011) to 143 (Cadilhac et al., 2011). The participants’ mean age (SD) ranged from 64 (8.40) (Damush et al., 2011) to 69 (11.00) (Cadilhac et al., 2011) years. The proportion of female participants ranged from 33% (Kendall et al., 2007) to 98% (Damush et al., 2011). Majority of the participants had ischaemic stroke (62%) (Cadilhac et al., 2011). In Damush et al. (2011) only participants with ischaemic stroke in the past month were recruited. All participants had first-ever stroke in the previous
three months before receiving the program (Kendall et al., 2007). Seventy-four percent of the participants had first stroke and the duration after stroke onset was 12 months or above among 70% of the participants (Cadilhac et al., 2011). The extent of participants’ severity of stroke varied. Cadilhac et al. (2011) reported that 51 (36%) participants scored 0-1 in the Modified Rankin scale. The baseline mean National Institutes of Health Stroke Scale (NIHSS) scores (SD) of the intervention and control groups were 3.27 (2.72) and 3.33 (3.37) respectively in another study. No significant difference was found between the two groups (Damush et al., 2011). One study did not provide the participants’ demographic and clinical information (Kendall et al., 2007). A summary of the demographic and clinical characteristics of the stroke survivors is shown in Appendix B.

Types of interventions

The three studies examined the effectiveness of a stroke self-management program on community-dwelling stroke survivors. The contents and format of the three programs were designed based on the generic Stanford CDSMP and were underpinned by the construct of self-efficacy. Two studies (Damush et al., 2011; Kendall et al., 2007) referred to the original citation describing self-management (Lorig et al., 1999; Lorig et al., 2001) and details of the construct of self-efficacy (Bandura, 1977), the strategies adopted in their studies to address the four sources of information of self-efficacy when designing the program, and measured the variable of self-efficacy. However, the third study (Cadilhac et al., 2011) only described in its published study protocol (Battersby et al., 2009) the original citation of self-management, and the strategies adopted to enhance participants’ participation in stroke self-management. This study did not link the program to the four sources of self-efficacy and did not measure self-efficacy.

The topics covered in the programs included but were not limited to an overview of stroke, medical management, rehabilitation services, stroke recovery and self-management, symptom and emotional management, risk factor management, medication adherence, diet and exercise, relaxation or coping strategies, roles and relationships, communication with healthcare professionals, social support, community reintegration, and sharing among stroke survivors. Core self-management skills emphasised in the programs included problem-solving, decision-making, goal-setting, action-planning, resources utilisation, and collaboration with healthcare professionals. All programs were delivered according to a written protocol. One study
also provided the participants with a standardised written manual to supplement the program information (Damush et al., 2011).

All programs were conducted in community settings and lasted from seven weeks (Kendall et al., 2007) to six months (Damush et al., 2011). The number of sessions ranged from six (each 20 minutes) with six additional telephone calls (Damush et al., 2011), to eight (each 2.5 hours) (Cadilhac et al., 2011). The sessions were held in face-to-face groups once a week in two programs (Cadilhac et al., 2011; Kendall et al., 2007), or were conducted in person and by telephone (Damush et al., 2011). Kendall et al. (2007) specified that each group consisted of 10 to 15 participants. The persons who delivered the programs included healthcare professionals and trained peer leaders (Cadilhac et al., 2011); a nurse, a physician assistant, and a master’s level social scientist (all received 18 hours of standardised training before the program) (Damush et al., 2011), and two trained healthcare professionals (Kendall et al., 2007). The participants could invite their family members, caregivers, children or friends to attend the program (Cadilhac et al., 2011; Kendall et al., 2007). Participants in the stroke self-management program were compared with those receiving the Stanford CDSMP (Cadilhac et al., 2011), an attention placebo intervention including stroke education pamphlets, a general stroke education session, and phone calls on assessment of stroke symptoms (Damush et al., 2011), or usual post-stroke care (Cadilhac et al., 2011; Kendall et al., 2007). A summary of the characteristics of the programs is shown in Appendix B.

**Types of outcome measures**

The three studies assessed the effectiveness of stroke self-management programs on participants’ HRQoL. One study adopted the 15-item Assessment of Quality of Life tool which measured five domains including illness, independent living, social relationships, physical senses and psychological well-being on four possible responses. The higher the utility score, the better the quality of life (Cadilhac et al., 2011). The other two studies (Damush et al., 2011; Kendall et al., 2007) adopted the Stroke Specific Quality of Life Scale (SSQOL) to measure 12 domains namely physical (energy, language, vision, mobility, fine motor tasks), psychological (mood, personality, thinking), social (social roles, family roles, work productivity), and self-care on a five-point Likert scale. The higher the score, the better the quality of life. One study measured the participants’ frequency of engaging in self-management behaviours including exercise, social and recreation activities, and cognitive or mental
relaxation in the past week using the Chronic Disease Self-management Behaviours scales (Damush et al., 2011). Two studies measured the program effects on mood as measured by the 18-item Irritability, Depression, and Anxiety scales on four subscales namely depression, anxiety, inward irritability and outward irritability based on four possible responses to each item (Cadilhac et al., 2011); and on frequency of depressive symptoms over the past two weeks using the nine-item Patient Health Questionnaire-9 on a three-point Likert scale (Damush et al., 2011). The higher the score in both scales, the more the depressive symptoms. Two studies measured participants’ levels of self-efficacy. Kendall et al. (2007) used six of the Chronic Disease Self-Efficacy Scales (CDSES) (Lorig, 1996) to measure participants’ self-efficacy in obtaining help and information, communicating with physicians, managing the symptoms, depression, and their diseases in general. Damush et al. (2011) used two subscales of the CDSES (Lorig, 1996) to measure participants’ self-efficacy in managing stroke symptoms, and communicating with their physicians. The items were rated from 1 (not at all confident) to 10 (totally confident). The higher the score, the higher the self-efficacy. One study measured the program effects on community participation using the domain of positive and active engagement in life of the Health Education Impact Questionnaire (Cadilhac et al., 2011). This questionnaire consisted of five items rated from 1 (strongly disagree) to 6 (strongly agree). The higher the score, the better the engagement in life activities (Cadilhac et al., 2011). All studies except one (Cadilhac et al., 2011) provide information about the reliability and validity of the measuring instruments. Other outcomes included level of attendance of the program (Cadilhac et al., 2011; Damush et al., 2011; Kendall et al., 2007), recruitment methods and adverse events of the program (Cadilhac et al., 2011). No study evaluated the physical outcomes. In addition to baseline data, two studies collected data at two to four weeks and six months after program completion (Cadilhac et al., 2011), and three and six months after program completion (Damush et al., 2011). The third study collected data at baseline, and one, four and seven months after program completion. It corresponds to three, six, nine, and 12 months after stroke respectively (Kendall et al., 2007).

Effectiveness of the programs

There were incomplete details in the published papers about the number of participants in the intervention and control groups (Kendall et al., 2007), and the results (Damush et al., 2011). The authors of these studies could not be contacted and no further information could be obtained. As it was not possible to combine the study
results using meta-analysis, a narrative summary of the effectiveness of theory-based stroke self-management programs is presented.

**Effectiveness on health-related quality of life**

Three studies evaluated the program effects on HRQoL. One study compared the changes from baseline between the group receiving the stroke self-management program and the attention placebo control group (Damush et al., 2011). There was significant difference in the mean change from baseline in SSQOL family and social role domains between the two groups at three months after program completion. No significant difference was reported at six months. However, this study only reported mean increase or decrease results from baseline to three months for the intervention and control groups respectively, with no actual three or six months mean scores reported. Significant difference was also reported in the mean change from baseline in SSQOL work productivity domain between the groups at six months after program completion. However, there was neither mean increase or decrease results from baseline, nor actual baseline, three or six months mean scores of this domain reported (Table 3.1).

Another study using the same scale SSQOL reported a significant interaction effect by treatment and time, after controlling for self-efficacy, for family roles (F(3, 136.69)=4.10, p<0.01), fine motor tasks (F(3, 83.37)=3.68, p<0.05), work productivity (F(3, 120.65)=3.17, p<0.05), and self-care (F(3, 138.37)=2.66, p=0.05) (Kendall et al., 2007). These results indicated that the impact of the program on the four domains of quality of life might have occurred independent of the participants’ levels of self-efficacy. A slightly improved trend in the four SSQOL domains from baseline to four months after program completion was observed in the group receiving the stroke self-management program, while a declining trajectory was found in the control group with usual care. The greatest difference in mean (SD) SSQOL domain levels between the intervention and control groups was at four months. Except for the self-care domain, the differences were not statistically significant. Both groups reached similar levels of quality of life seven months after program completion (Table 3.1).
Table 3.1 Differences in stroke-specific quality of life between groups over time

<table>
<thead>
<tr>
<th>Study/ outcome measure</th>
<th>Dimensions</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Comparison between groups</th>
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<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
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<tr>
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<td>NR</td>
<td>Increased by 0.5 points</td>
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<td></td>
<td></td>
<td>6 months</td>
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<td>NR</td>
<td>NR</td>
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<tr>
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<td>Increased by 0.3 points</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>Work productivity (range: 1-5)*</td>
<td>Baseline</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 months</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Kendal et al. 2007 SSQOL</td>
<td>Family roles^ (range: 3-15)</td>
<td>Baseline</td>
<td>10.71</td>
<td>3.77</td>
<td>10.31</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 month</td>
<td>10.00</td>
<td>4.02</td>
<td>11.19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 months</td>
<td>9.90</td>
<td>4.30</td>
<td>11.47</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 months</td>
<td>11.37</td>
<td>2.95</td>
<td>11.67</td>
</tr>
<tr>
<td></td>
<td>Fine motor tasks^ (range: 5-25)</td>
<td>Baseline</td>
<td>20.23</td>
<td>4.77</td>
<td>20.46</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 month</td>
<td>19.26</td>
<td>5.50</td>
<td>21.24</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 months</td>
<td>19.31</td>
<td>5.49</td>
<td>21.41</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 months</td>
<td>20.79</td>
<td>4.62</td>
<td>21.49</td>
</tr>
<tr>
<td></td>
<td>Work productivity^ (range: 3-15)</td>
<td>Baseline</td>
<td>9.67</td>
<td>4.09</td>
<td>10.07</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 month</td>
<td>9.37</td>
<td>4.73</td>
<td>11.06</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 months</td>
<td>10.00</td>
<td>4.35</td>
<td>11.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 months</td>
<td>11.14</td>
<td>3.36</td>
<td>11.62</td>
</tr>
<tr>
<td></td>
<td>Self-care^ (range: 5-25)</td>
<td>Baseline</td>
<td>19.59</td>
<td>5.34</td>
<td>20.98</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 month</td>
<td>19.38</td>
<td>6.11</td>
<td>21.92</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4 months</td>
<td>19.81</td>
<td>5.24</td>
<td>22.48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7 months</td>
<td>21.22</td>
<td>4.45</td>
<td>22.20</td>
</tr>
</tbody>
</table>

*The adjusted mean scores of the response scale were reported in the study.

^The mean scores of the sum of the domain scores were reported in the study.

Abbreviations: NR, Not reported in the study; NS, Reported as non-significant difference but the study did not specify p-value; SD, Standard deviation; Sig, Reported as significant difference but the study did not report p-value.
The third study reported improvement in HRQoL, measured by the Assessment of Quality of Life tool, among the participants receiving the stroke self-management program, Stanford CDSMP, or usual care (Cadilhac et al., 2011). However, there were no statistically significant differences between the three groups using ITT analysis. Information about the means and SDs of the three groups at the three time points was obtained from the authors (Table 3.2).

Table 3.2 Differences in quality of life between groups over time

<table>
<thead>
<tr>
<th>Study/outcome measure</th>
<th>Dimensions</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Stanford Chronic Disease Self-management group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Cadilhac et al. 2011</td>
<td>Range: -0.04 to 1 (good health)</td>
<td>Baseline</td>
<td>0.39</td>
<td>0.31</td>
<td>0.51</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2-4 weeks</td>
<td>0.46</td>
<td>0.30</td>
<td>0.55</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 months</td>
<td>0.43</td>
<td>0.33</td>
<td>0.54</td>
</tr>
</tbody>
</table>

Abbreviations: CI, Confidence interval; NR, Not reported in the study; SD, Standard deviation; SE, Standard error.

Effectiveness on stroke self-management behaviours

The study by Damush et al. (2011) found that the group receiving the stroke self-management program, compared with the attention placebo control group, increased the time spent in aerobic exercise in the past week from baseline to three months, and to six months after program completion. However, these mean changes from baseline to three and six months were not significantly different between the two groups (Table 3.3). There was no significant difference between the two groups in cognitive self-management practices at baseline or at follow-up. However, there was no actual baseline, three or six months mean scores, or the level of significance reported.
Effectiveness on physical outcomes

No study assessed the effectiveness of the program on physical outcomes.

Effectiveness on psychological outcomes

Two studies evaluated the effectiveness of the program on depressive symptoms. One study showed reduction in depressive symptoms for those who received the stroke self-management program, the comparison intervention (Stanford CDSMP), or usual care at six months after program completion (Cadilhac et al., 2011). Information about the means and SDs of the three groups at the three time points was obtained from the authors. The differences between the three groups were not statistically significant using ITT analysis (Table 3.4). The other study had measured depressive symptoms using the nine-item Patient Health Questionnaire. However, the study did not report results on this outcome and the authors could not be contacted for further information (Damush et al., 2011).

Table 3.3 Differences in the amount of time spent in self-management behaviours between groups over time

<table>
<thead>
<tr>
<th>Study/ outcome measure</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Comparison between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Damush et al. 2000</td>
<td>Baseline</td>
<td>107.4 min</td>
<td>NR</td>
<td>78.5 min</td>
</tr>
<tr>
<td>Weekly time spent in aerobic exercise</td>
<td>3 months Decreased by 3 min</td>
<td>NR</td>
<td>Increased by 47.6 min</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>6 months Increased by 4 min</td>
<td>NR</td>
<td>Increased by 24.4 min</td>
<td>NR</td>
</tr>
</tbody>
</table>

Abbreviations: NR, Not reported in the study; SD, Standard deviation.
Table 3.4 Differences in the scores of depression, anxiety, inward and outward irritability between groups over time

<table>
<thead>
<tr>
<th>Study/outcome measure</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Stanford Chronic Disease Self-management group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15.04</td>
<td>8.46</td>
<td>13.63</td>
</tr>
<tr>
<td></td>
<td>Baseline</td>
<td>13.83</td>
<td>7.85</td>
<td>12.17</td>
</tr>
<tr>
<td></td>
<td>2-4 weeks</td>
<td>14.19</td>
<td>8.51</td>
<td>12.39</td>
</tr>
<tr>
<td></td>
<td>6 months</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: CI, Confidence interval; NR, Not reported in the study; SD, Standard deviation; SE, Standard error.
### Table 3.5 Differences in the scores of self-efficacy between groups over time

<table>
<thead>
<tr>
<th>Study/outcome measure</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Comparison between groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td><strong>Damush et al. 2000</strong></td>
<td>Baseline</td>
<td>8.90</td>
<td>NR</td>
<td>8.50</td>
</tr>
<tr>
<td>Chronic Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(two scales)</td>
<td>3 months</td>
<td>NR</td>
<td>Mean decrease of 0.8 points</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>6 months</td>
<td>NR</td>
<td></td>
<td>NR</td>
</tr>
<tr>
<td><strong>Kendall et al. 2007</strong></td>
<td>Baseline</td>
<td>61.45</td>
<td>14.93</td>
<td>68.46</td>
</tr>
<tr>
<td>Chronic Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Efficacy Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(six scales)</td>
<td>1 month</td>
<td>62.68</td>
<td>15.73</td>
<td>67.88</td>
</tr>
<tr>
<td></td>
<td>4 months</td>
<td>60.88</td>
<td>20.44</td>
<td>68.80</td>
</tr>
<tr>
<td></td>
<td>7 months</td>
<td>61.68</td>
<td>18.16</td>
<td>69.42</td>
</tr>
</tbody>
</table>

Abbreviations: NR, Not reported in the study; SD, Standard deviation.
Table 3.6 Differences in the scores of positive and active engagement in life between groups over time

<table>
<thead>
<tr>
<th>Study/outcome measure</th>
<th>Data collection episode</th>
<th>Control group</th>
<th>Stroke-specific self-management group</th>
<th>Stanford Chronic Disease Self-management group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Cadilhac et al. 2011</td>
<td>Baseline</td>
<td>3.78</td>
<td>1.00</td>
<td>3.81</td>
</tr>
<tr>
<td>Health Education Impact Questionnaire (Positive and active engagement in life domain)</td>
<td>2-4 weeks</td>
<td>3.77</td>
<td>0.90</td>
<td>4.00</td>
</tr>
<tr>
<td></td>
<td>6 months</td>
<td>3.86</td>
<td>0.90</td>
<td>4.01</td>
</tr>
</tbody>
</table>

Abbreviations: CI, Confidence interval; NR, Not reported in the study; SD, Standard deviation; SE, Standard error.
Effectiveness on self-efficacy

Two studies assessed the effectiveness of the program on self-efficacy. One study found that the group receiving the stroke self-management program, compared with the attention placebo control group, had improved mean self-efficacy in communicating with physicians from baseline to six months after program completion (Damush et al., 2011). The mean change from baseline was significantly different between the two groups.

Another study found neither a main effect of time nor an interaction effect by treatment and time on self-efficacy (Kendall et al., 2007). This lack of effects is demonstrated by the consistency in the significantly lower mean self-efficacy scores of the control group compared to the intervention group at baseline, and one, four, and seven months after program completion (F(1, 93)=9.45, p=0.003) (Table 3.5).

Effectiveness on social outcomes

One study measured the effectiveness of the program on community reintegration. This study (Cadilhac et al., 2011) showed improvement from baseline to six months in community reintegration for participants in all three study groups: stroke self-management program, Stanford CDSMP, and usual care. However, no significant difference was found across the three groups using ITT analysis (Table 3.6).

Other outcomes

Program attendance

Three studies reported participants’ attendance at the stroke self-management program. One study found that more participants in the stroke self-management program (n=25, 52%) completed over 50% of the sessions than the group receiving the generic Stanford CDSMP (n=18, 38%) (p=0.18) (Cadilhac et al., 2011). More participants found the generic Stanford CDSMP not relevant to their recovery needs or their lack of interest in participating. Other reasons for not starting or completing the programs included unsuitable dates, adverse medical events not related to the programs, and no transportation. Another study reported that 37 (63.80%) participants attended at least four of the seven sessions of the stroke self-management program with most of them having attended all sessions (Kendall et al., 2007). There was no significant difference in scores for self-efficacy and HRQoL between those who attended four or more sessions and those who attended below four. The third study reported that the average number of sessions completed by the intervention group was five compared with that of 5.7 in the control group (Damush et al., 2011).
Adverse effects

One study measured the number of adverse effects reported by the participants during the program (Cadilhac et al., 2011). In this study, a total of 36 adverse events were reported by 32 (22%) participants at two to four weeks after program completion. No significant difference (p=0.30) was found in adverse events among the three groups in this study: 13 participants were from the stroke self-management program, 12 from the Stanford CDSMP, and seven from the control group. Most of them (n=26, 81%) had moderate or severe adverse effects and none was reported as attributed to the stroke self-management program. Thirty-five of the adverse events included: stroke (n=4), death (n=4), fall (n=4), hospitalisation (n=14), cancer (n=3), heart problems (n=2), shingles (n=2), and Bakers cyst (n=2). One adverse event was related to transfer to a residential care setting. However, the authors could not be contacted for the reasons of considering it as an adverse event.

Recruitment methods

One study reported the effectiveness of recruitment methods on attracting potential participants (Cadilhac et al., 2011). The study found that most of the participants were recruited from acute hospitals (75%), followed by rehabilitation hospitals (13%) and the community (12%). However, there was no information about the impact of these differences in participant setting on the results of the study.

3.2.7 Discussion

This systematic review was undertaken to examine the effectiveness of theory-based stroke self-management programs on recovery of community-dwelling stroke survivors. A total of three RCTs met the eligibility criteria and were included in the systematic review. There was insufficient information about the number of participants in the intervention and control groups in one study (Kendall et al., 2007), and incomplete details in the results of another study (Damush et al., 2011). Since it was not possible to perform meta-analysis, a narrative summary of the results was presented.

The key issues of concern about the methodological quality of the included studies were unclear information about the methods of random assignment, allocation concealment, reliability and validity of the measuring instruments, small sample sizes, and absence of ITT analysis. Some studies did not specify the number of participants included in the statistical analyses (Kendall et al., 2007), or reported the effect sizes of outcomes with significant changes only (Damush et al., 2011). Attempts to contact the
authors for further information were unsuccessful. The incomplete reporting of study details made meta-analysis of the results impossible. Therefore future studies are suggested to adhere to the CONSORT 2010 statement in reporting RCTs to enable a more comprehensive interpretation of risk of bias of the studies, and hence generalisability of the results (Schulz et al., 2010).

This systematic review is limited by the inclusion of English and Chinese publications only due to limitation of the authors’ language abilities to review publications in other languages. Secondly, limited resources were available so the reviewers were not able to employ translators for other languages. Moreover, only a narrative presentation of the study results was provided. It limited a more comprehensive and objective estimation of the effectiveness of stroke self-management programs on community-dwelling stroke survivors’ recovery.

Based on the results of the included studies, there is insufficient evidence to conclude the effectiveness of theory-based stroke self-management programs on recovery of community-dwelling stroke survivors. However, the results showed potential program benefits on improving stroke survivors’ quality of life particularly the domains of fine motor tasks, family and social roles, self-care and work productivity; and self-efficacy in communicating with physicians. The improvement in the intervention groups was evident at three and six months after program completion. The results were consistent with previous systematic reviews or meta-analysis on self-management programs with or without a theoretical basis for people with stroke (Lennon et al., 2013) or chronic conditions (Chodosh et al., 2005; Warsi et al., 2004).

Stroke rehabilitation services have been criticised for focusing on physical recovery with less attention to stroke survivors’ psychosocial needs (Kendall et al., 2007). The stroke self-management programs of the three included studies were designed based on the Stanford CDSMP. The program content was specifically adapted to address stroke survivors’ needs and covered both physical and psychosocial aspects, including emotional management, roles and relationships, communication with healthcare professionals, and community reintegration (Cadilhac et al., 2011; Damush et al., 2011; Kendall et al., 2007). Substantial previous studies reported difficulties encountered by stroke survivors in self-care and reintegrating into their pre-morbid family and social roles, and their work consequential to their physical disability after stroke (Kitzmüller, Asplund, & Häggström, 2012; Wolfenden & Grace, 2009). The stroke self-management programs offered relevant and tailor-made services to
help stroke survivors in maintaining their life after transition to the community. Although this systematic review was inconclusive about the effectiveness of stroke self-management programs, it showed potential benefits in enhancing HRQoL and self-efficacy among stroke survivors. However, only one study measured the participants’ changes in stroke self-management behaviours and there was no significant difference in the duration of aerobic exercise between the intervention and control groups (Damush et al., 2011). More evidence is needed to determine the effectiveness of the programs on promoting stroke survivors’ engagement in self-management behaviours and consequentially improve their clinical outcomes.

One major focus of this systematic review was to examine the extent to which stroke-specific self-management programs were informed by a theoretical framework. The three stroke self-management programs in the included studies were underpinned by the constructs of self-efficacy. Self-efficacy refers to a person’s beliefs in his own capability in pursuing a behaviour. The four sources of information to enhance self-efficacy include successful mastery, vicarious experience, verbal persuasion, and physiological or emotional arousals (Bandura, 1977). Only one study described explicitly the theory name and propositions with original citation, a clear association of the adopted strategies with the target variables proposed in the theory, and measured the participants’ change in self-efficacy (Damush et al., 2011). The other two studies either lacked a description of how the sources of information of self-efficacy were enhanced (Kendall et al., 2007), or did not link the program to self-efficacy, its sources of information, or change in self-efficacy (Cadilhac et al., 2011). However, such information about the studies is crucial to not only test the relevance of the theoretical framework to behavioural change in stroke-specific self-management behaviours, but also to determine the effectiveness of strategies to effect the target behavioural change.

Common strategies utilised in the programs to enhance self-efficacy included teaching the participants about problem-solving, setting goals and taking action on self-management behaviours, arranging group sessions, and providing individualised feedback on participants’ progress to facilitate participants’ successful accomplishment of the self-management behaviours (Cadilhac et al., 2011; Damush et al., 2011; Kendall et al., 2007). Additional strategies adopted in one study (Damush et al., 2011) included sharing of new behaviours by the facilitators and lay leaders to offer social modelling; promoting physician and therapeutic recommendations to provide verbal persuasion; discussing the strategies to diminish symptoms, and
encouraging the use of distraction methods or relaxation techniques to help reinterpret the physical state. Substantial literature found that stroke survivors often lack confidence in handling their conditions after transition from hospitals (Korpershoek et al., 2011). Designing the program to enhance stroke survivors’ self-efficacy in self-management would be helpful. However only two included studies (Damush et al., 2011; Kendall et al., 2007) measured this outcome and contrasting results were found. One of the studies also reported the program’s effects on quality of life after controlling for self-efficacy (Kendall et al., 2007). One possible reason for the contrasting results may be the inadequacy in addressing the four sources of self-efficacy information in the program (Kendall et al., 2007). Effective strategies to enhance self-efficacy via the four sources of information could be explored for increased quality and effectiveness of the program. Another reason may be related to the difference in use of a stroke-specific self-efficacy scale (Damush et al., 2011) and a generic self-efficacy scale for chronic conditions (Kendall et al., 2007) in the studies respectively. More data measured by a standardised tool is needed to understand the role of self-efficacy in stroke self-management behaviours as informed by the theory.

Although no adverse events were reported related to the interventions, it is important to note that one included study reported no significant differences in quality of life, depressive symptoms, and community reintegration between the groups receiving the stroke self-management program, Stanford CDSMP, and usual care respectively (Cadilhac et al., 2011). One important component of the self-management programs is educating participants on core self-management skills such as problem-solving and decision-making. However, the descriptions of strategies to facilitate participants’ learning of these skills in the three studies were unclear. It limited the evaluation of effective strategies to enable participants’ management of these core skills, and thus may affect the effectiveness of the program. More evidence on participants’ perception of and satisfaction with the teaching strategies of the programs would add valuable data to identify practical strategies and thus inform future program design. No study assessed the effectiveness of the program on physical outcomes. Given that one of the program aims was to enhance participants’ abilities in coping with post-stroke challenges, it would be worthwhile to evaluate physical outcomes such as ADLs.
The dose of the three stroke self-management programs and the participants’ completion rate of the program differed slightly. One study (Kendall et al., 2007) reported that 63.80% of the participants attended four or more of the seven sessions of the program. However, it is interesting that no significant differences in self-efficacy and HRQoL were found between those who attended at least four sessions and those who attended less than four. The study authors suggested that the opportunities to receive self-management education, and to interact and being supported by other stroke survivors or facilitators might be more important than the level of attendance in achieving positive outcomes. Participants’ level of attendance is an integral indicator to reflect the feasibility of the program, and the participants’ acceptance or satisfaction. It also has implications in the extent of resources, manpower and costs required. Further exploration of the association of attendance with participants’ recovery outcomes would help decide a minimum number of sessions for achieving positive outcomes.

A wide variety of personnel was employed to deliver the program such as nurses, health care professionals or trained lay leaders. In the United Kingdom, there is a program called “Expert Patients” where patients who successfully manage their chronic illnesses are trained to help others who are newly diagnosed or having problems in managing their illnesses. The project was associated with decreased symptoms, improved health behaviours, and self-efficacy (Lorig et al., 2008). Indeed the idea is congruent with the notion of self-efficacy (Bandura, 1977). A recent study supported that peer support group was beneficial to the participants through sharing helpful information, advice and making new connections (Morris & Morris, 2012). Further examination of the roles of trained stroke survivors in helping their peers would be warranted.

The three self-management programs were mainly delivered by face-to-face group sessions. This delivery format is advantageous at enabling interaction between stroke survivors and health care professionals or their peers. However, access problems such as transportation barriers or associated financial costs need to be considered for its implications on the level of attendance. One included study delivered some sessions individually via telephone (Damush et al., 2011). However, stroke survivors’ hearing ability that influence their participation in the program via phone needs to be considered. Preliminary evidence showed that programs delivered via teleconferencing were associated with improvement in participants’ physical tolerance, mood and depressive symptoms (Taylor et al., 2009). While enjoying the benefits
brought by in person group sessions, it is important to devise solutions to minimise the access difficulties when designing future stroke self-management programs.

Furthermore, the three included studies recruited participants who had first-ever or recurrent stroke within the first few months to over 12 months after the stroke onset, and with variable physical disability. Two studies also recruited stroke survivors who were able to communicate (Damush et al., 2011; Kendall et al., 2007). However, one study did not provide participants’ clinical information (Kendall et al., 2007). It is important to acknowledge the participants’ different needs at various stages of stroke recovery (Horgan, O’Regan, Cunningham, & Finn, 2009). For example, one study mentioned difficulties in recruiting stroke patients as they needed time to adjust to the acute event and could not commit to participating in the program (Damush et al., 2011). Tailoring the self-management programs to the target population based on the severity and duration of stroke is needed to enhance the relevance of the program to the participants, and increase the participants’ adherence to and acceptance of the programs. Moreover, this will ensure a more accurate interpretation about the applicability of the results and comparison of the results across studies.

3.2.8 Conclusion

To conclude, there is insufficient evidence to determine the effectiveness of theory-based stroke self-management programs on the recovery of community-dwelling stroke survivors. However, the preliminary evidence showed potential benefits of the programs on HRQoL and self-efficacy.

Implications for practice

Given the potential benefits of theory-based stroke self-management programs, it is recommended that future practice continue offer this service to stroke survivors particularly those who are at different stages of stroke recovery such as immediately after discharge from hospital, and those with different stroke severity such as dysphasia. The focus of the program content, although adjusted to address the participants’ needs, could be more on facilitating participants’ capability in interacting with their family and friends, and reintegrating into the community. Such programs could be designed based on the construct of self-efficacy with strategies adopted to promote participants’ self-efficacy in performing stroke-specific self-management behaviours. Stroke survivors who successfully manage their conditions could be invited to share their experiences with peers. While experience in successfully
accomplishing target behaviours is powerful in enhancing self-efficacy, more emphasis could be put on providing verbal persuasion and helping participants to re-interpret symptoms in future programs. Furthermore, providing individualised counselling to facilitate participants’ planning of their behaviours to achieve the self-management goals set, and to problem-solve and make decisions on challenges encountered, are integral components of the program. To ensure convenient access to the program, alternative modes of delivery via videoconference or Internet, or provision of transportation to the venue where the program is conducted, could be considered in future programs. A detailed protocol guiding the program implementation is also needed to ensure consistent delivery of the programs amid the changing conditions of the participants, program facilitators and the program venue.

*Implications for research*

Future research on theory-based stroke self-management programs for community-dwelling stroke survivors is needed to continue the exploration of the mediating effects of self-efficacy on self-management behaviours and of effective strategies to promote self-efficacy via the four sources of information. Comparison of effectiveness of self-management programs underpinned by other behavioural or psychosocial theories is important in determining an optimal theoretical framework for managing stroke-specific self-management behaviours. Examining factors associated with positive results of the program such as the effective dose of the programs, and participants’ demographic or clinical factors, are also important. Thus, a clear description of the participants’ demographic and clinical characteristics, and the interventions is needed. Future studies could also compare the differences in effectiveness of programs delivered by various health care professionals or trained stroke survivors, and according to whether group or individual sessions are used. The results would be important to inform future program design. Further studies evaluating the outcomes of self-management programs would benefit from the use of reliable and valid measuring instruments. It would also be worthwhile to examine the program effectiveness on stroke survivors’ physical outcomes and self-management behaviours. To enable accurate interpretation of the applicability of study results and comparisons across studies, future studies would benefit from adopting a randomised controlled study design and the use of more rigorous approaches to sample size estimation. Furthermore, ITT analysis should be performed. Adherence to the CONSORT statement in reporting RCTs is recommended to enable accurate and complete
reporting of the design and conduct of the study, statistical analysis, and appropriate interpretation of generalisability of the study results.
Chapter 4: Methods (Phase Two)

4.1 INTRODUCTION

This chapter reports and discusses the methods used in Phase Two of the research project. In this phase, an RCT was conducted to test the effectiveness of a new nurse-led self-efficacy enhancing stroke self-management program (SSMP) on recovery of community-dwelling stroke survivors. The results of the systematic review conducted in the first phase informed the design, development and evaluation of the new program. The underpinning theoretical framework, components, contents, and content validity of the SSMP are discussed in detail in this chapter. The RCT was conducted in Hong Kong. Stroke participants were recruited from acute hospitals and the study was commenced after the participants were discharged home. Eligible participants, after consenting to participate in the study, were randomised to either the intervention or the control group. Participants randomised to the intervention group received the 4-week SSMP, while participants in the control group received usual post-stroke care. The SSMP was delivered by the Ph.D. candidate who is a registered nurse experienced in stroke care and chronic disease management. Participants in both the intervention and the control groups were assessed at home at baseline and at eight weeks after randomisation. Primary outcomes included self-efficacy in and outcome expectation for stroke self-management. Secondary outcomes included satisfaction with performance in stroke self-management behaviours, HRQoL, depressive symptoms, and community reintegration. The Ph.D. candidate translated the original English version of the SSEQ and the SSQOL into Chinese for adoption in the RCT to assess stroke participants’ level of self-efficacy and HRQoL. Appendices C and D show the published articles on the translation and testing of equivalence of these two tools. The Ph.D. candidate also developed two new tools, namely the SSOES and the SSBPS for adoption in the RCT to assess stroke participants’ outcome expectation and satisfaction with performance in stroke self-management behaviours. Details about the development and reliability and validity testing of the two new tools are reported in the next chapter. Participants in the intervention group were also contacted by phone at five weeks after randomisation to elicit their feedback on usefulness of the SSMP. The conduct and reporting of the RCT adhered to the updated guidelines of the
4.2 CLINICAL TRIAL REGISTRATION

This trial, entitled “A randomised controlled trial of the effectiveness of a nurse-led self-efficacy enhancing stroke self-management program for community-dwelling stroke survivors”, was registered in the ClinicalTrials.gov. (ClinicalTrials.gov identifier: NCT02112955). This trial registry was chosen because of the large-scale and historical development of, the standardised reporting and quality of data required for publication of this registry, and convenient open access to trial information in the registry. In the registry, the title, purpose and design of the RCT, eligibility criteria for the participants, settings, detailed descriptions for the assigned interventions for the experimental/intervention group and the comparator/control group, primary and secondary outcomes, and the results of the trial were described. The contact information for the principal investigator (the Ph.D. candidate) was provided. Information about the RCT is available at https://clinicaltrials.gov/ct2/show/NCT02112955. Appendix E shows the trial record at the ClinicalTrials.gov.

4.3 RESEARCH QUESTIONS

An RCT was undertaken to answer the following research question: “What is the effectiveness of a new nurse-led community-based self-efficacy enhancing stroke self-management program implemented after discharge from hospital, compared with usual care, on promoting recovery among Chinese community-dwelling stroke survivors?”.

The results of the systematic review conducted in Phase One showed potential benefits of theory-based stroke self-management programs in improving community-dwelling stroke survivors’ HRQoL and self-efficacy in managing their post-stroke conditions. However, there was no consistent evidence about the best theoretical framework, regimen and dose of the stroke self-management program; nor has there been any empirical examination of such a program reported for Chinese stroke survivors. While previous studies have examined the influence of self-efficacy in enhancing stroke survivors’ capabilities in self-management, no studies have evaluated stroke survivors’ outcome expectation, a factor closely related to self-
efficacy; or their satisfaction with own performance in stroke self-management behaviours, which is a direct reflection of how they self-manage their post-stroke conditions. In view of the clinical relevance and potential benefits of stroke self-management programs, it is worthwhile to examine the usefulness and effective dose of the program in a Chinese population. A research question was formulated based on the PICO (Population, Intervention, Comparison, Outcomes) format (Farrugia, Petrisor, Farrokhyar, & Bhandari, 2010). The protocol of the RCT (Appendix F) has been published in the journal, *BMC Health Services Research*. In this section, the submitted work of the study protocol is included verbatim with some editing to fulfil the requirements of the thesis.

### 4.4 RESEARCH AIM AND OBJECTIVES

The aim of this RCT was to develop and evaluate the effectiveness of a new 4-week SSMP on post-stroke recovery among Chinese community-dwelling stroke survivors. Specific objectives were to examine the differences between the Chinese community-dwelling stroke survivors who received a new 4-week SSMP plus usual care and those who received usual stroke care, in the scores of the following outcome measures at one month after completion of the program:

1. Self-efficacy in stroke self-management as measured by the Stroke Self-Efficacy Questionnaire (SSEQ);
2. Outcome expectation for stroke self-management as measured by the Stroke Self-management Outcome Expectation Scale (SSOES);
3. Satisfaction with performance in stroke self-management behaviours as measured by the Stroke Self-management Behaviours Performance Scale (SSBPS);
4. HRQoL as measured by the Stroke Specific Quality of Life Scale (SSQOL);
5. Depressive symptoms as measured by the Geriatric Depression Scale (GDS); and
6. Level of community reintegration as measured by the Reintegration to Normal Living Index (RNLI).

### 4.5 RESEARCH HYPOTHESES

Driven by the research question, the null hypotheses formulated were:

1. There is no significant difference in post-stroke recovery outcomes between community-dwelling stroke survivors who received the new 4-week SSMP plus
usual care and those who received usual care only at 8-weeks follow-up after completion of the program, including:

- Self-efficacy in stroke self-management;
- Outcome expectation for stroke self-management;
- Satisfaction with performance in stroke self-management behaviours;
- HRQoL;
- Depressive symptoms; and
- Community reintegration.

### 4.6 RESEARCH DESIGN

This study adopted a two-arm, outcome assessor-blinded RCT research design. The study consisted of two groups, including the intervention group and the control group. Eligible participants, after consenting to participate and receiving the baseline assessments, were randomly assigned to either the intervention group to receive the new SSMP plus usual stroke care, or the control group to receive usual stroke care. Participants in both the intervention and control groups were assessed for primary and secondary outcomes at baseline and at eight weeks after randomisation (8-weeks follow-up). Both baseline and 8-weeks follow-up assessments were conducted at the stroke participants’ homes. Participants in the intervention group were also contacted by phone at five weeks after randomisation to elicit their feedback on usefulness of the SSMP. Figure 4.1 shows the research design and flow of participants in the study.

An RCT was appropriate to answer the study question, as it is an experimental design which is characterised by the application of the intervention being examined to the intervention group, while withholding the intervention from the control group (Sullivan, 2011). Randomly assigning eligible participants to either the intervention or the control group concurrently balances the unknown and unmeasured variables of the two groups. The differences in the outcomes measured between the two groups can then be attributed to the intervention. With the use of randomisation, RCTs are considered superior to non-randomised or uncontrolled experimental designs, or observational studies in establishing causal relationships between the intervention and the outcomes (Sullivan, 2011).
However, adopting an RCT as the research design is not always seen as the gold standard for evaluating the effectiveness of an intervention. The reliability of the results of an RCT lies in how rigorously the trial is conducted (Grossman & Mackenzie, 2005). In addition to randomisation, the appropriate conduct of concealed allocation of treatment group, use of a control group, blinding of the participants and the outcome assessor, avoidance of exclusions after trial entry, and analysis based on the ITT principles are crucial methodological components of RCTs (Schulz et al., 2010).

The CONSORT 2010 Statement recommended adherence to the guidelines for reporting parallel group randomised trials (Schulz et al., 2010). The SPIRIT 2013 Statement is an international initiative aimed at enhancing the quality of clinical trial protocols by suggesting an evidence-based set of items to report in the protocols (Chan et al., 2013). These international guidelines or recommendations in turn serve as a framework for proper and transparent conduct of the randomised trial. In the following sections, the conduct and reporting of the RCT are described according to the requirements of the CONSORT 2010 Statement and the SPIRIT 2013 Statement.

Figure 4.1 Research design and flow of participants

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Chapter 4: Methods (Phase Two)
4.7 SETTINGS

4.7.1 Acute stroke units

Potential study participants were recruited from the acute stroke units in three acute public hospitals in Hong Kong, namely Hospital A, Hospital B and Hospital C. In Hong Kong, all public hospitals are managed by a statutory body named the Hospital Authority. The Hospital Authority has been established since 1990 under the Hospital Authority Ordinance and is currently responsible for managing 42 hospitals and institutions, 47 Specialist Out-patient Clinics and 73 General Out-patient Clinics in Hong Kong (Hospital Authority, 2016). The hospitals, institutions and clinics are geographically organised into seven hospital clusters. In this study, Hospital A and Hospital B are located in Kowloon and the New Territories of Hong Kong respectively. Both hospitals are of the same hospital cluster. Hospital C is located in the New Territories of Hong Kong and is of another hospital cluster (Hospital Authority, 2016).

The three study hospitals are acute hospitals, which provide about 1,100, 720 and 1,500 hospital beds respectively. The three hospitals provide 24-hour accident and emergency services. Thrombolytic therapy is also available for ischaemic stroke. The acute stroke units in the three hospitals are located in general medical wards with high dependency units. The acute stroke unit in Hospital A provides 14 beds for male or female stroke patients, while those in Hospital B and Hospital C provide 14 and 22 beds respectively. There are stroke nurses who have received specialised training in acute stroke care. One of the stroke nurses who is an advanced practice nurse for all of the acute stroke units served as the liaison person for this study.

The acute stroke units provide comprehensive multidisciplinary acute stroke services. The units adhere to the protocol on acute stroke care endorsed by the Hospital Authority (Hospital Authority Head Office, 2012). The protocol covers areas including the selection and logistics for providing thrombolytic therapy, acute stroke management including referrals, medications, nursing management such as prevention of falls and pressure ulcers, diet, and regular monitoring. There is a standardised stroke care pathway of flow of stroke patients after admission to the Accident and Emergency Department until discharge to the community. The care pathway suggests that stroke patients will receive acute stroke services at the acute stroke unit. After three to five days when their medical conditions were stabilised, stroke patients will either be transferred to rehabilitation hospitals for further rehabilitation, or discharged directly.
to their home, old aged homes or residential care settings. The stay in a rehabilitation hospital may take one to four weeks depending on the stroke patients’ conditions. Therefore, the stroke care services received by stroke patients in the three acute stroke units are similar (Hospital Authority Head Office, 2012).

Acute stroke units were chosen as the point of recruitment of participants because all patients diagnosed with stroke in Hong Kong will be admitted to such units after admission to public hospitals.

4.7.2 A nurse-led clinic and home setting

The study intervention, or the SSMP, was conducted at the stroke participants’ homes and at a nurse-led clinic after the participants were discharged to home from the hospital. The nurse-led clinic is located in the New Territories of Hong Kong. It is located closest to Hospital B. The nurse-led clinic serves the population of a nearby public housing estate with over 3,000 residents. An advanced practice nurse who has specialised in community nursing is in charge of the clinic. The clinic provides the residents with health services for example, regular health screening, health talks, group-based health activities, and health consultation. The clinic opens five days a week. There is one functional room, which is large enough for organising group activities of 10 to 15 persons at one time. The room is well equipped with audio-visual facilities, computers, projectors, tables and chairs, handrails and a toilet. Health education materials or leaflets, health promotion activities, basic health screening equipment including body weight and height calibre, and electronic blood pressure measuring devices are available in the nurse-led clinic. Study participants were welcome to use the facilities during their participation in the SSMP. The function room was available for the study during weekends, thus providing greater flexibility in organising the group sessions for the SSMP.

The participants in this RCT lived in either public housing (n=74, 58%) or private housing (n=42, 42%). In Hong Kong, public housing refers to affordable housing provided by the Government for low-income residents. The Government heavily subsidises the rental price, and people rent flats in public housing estates at very low rental prices compared with the market. About half of the population in Hong Kong reside in public housing. Private housing consists of one or several tall buildings built as a single development or an estate by real-estate developers. The private housing estates usually have better facilities such as shopping centres, supermarkets,
and leisure facilities. People either buy a flat themselves and the flat is privately owned, or rent the flat at rental prices much higher than prices for public housing.

4.8 PARTICIPANTS

The target participants of the RCT included Chinese community-dwelling adult stroke survivors. The study recruited all stroke survivors admitted to the acute stroke units of the three acute public hospitals in Hong Kong.

4.8.1 Inclusion criteria

Participants were recruited if they met the following inclusion criteria:

1. Are aged 18 years or above;
2. Had a clinical diagnosis of a first or recurrent ischaemic or haemorrhagic stroke (inclusive of intracerebral haemorrhage and subarachnoid haemorrhage) (Sacco et al., 2013);
3. Will be discharged to home in one week as determined by the physician-in-charge;
4. Have a Mini Mental State Examination (MMSE) score of above 18 assessed by the research assistants at the time of consenting to participate in the study (Kase et al., 1998);
5. Speak Cantonese;
6. Are capable of giving informed consent;
7. Can attend sessions of the SSMP; and
8. Are able to use a phone.

According to the updated definition of stroke (Sacco et al., 2013), stroke broadly includes the episodes of neurological dysfunction attributable to focal cerebral, spinal, or retinal infarction; a non-traumatic focal collection of blood in the brain parenchyma or ventricular system; or non-traumatic bleeding into the subarachnoid space; or infarction or haemorrhage in the brain, spinal cord, or retina as a result of thrombosis of a cerebral venous structure. There are four main types of stroke including ischaemic stroke, stroke caused by intracerebral haemorrhage, subarachnoid haemorrhage, or cerebral venous thrombosis (Sacco et al., 2013). The same criteria were adopted in the study.

The new SSMP was aimed at enhancing stroke survivors’ capabilities in managing their post-stroke conditions, thus enabling better reintegration into their pre-stroke lives and roles after being discharged to home (Lorig et al., 2001). Therefore,
only participants who continued their rehabilitation at home were recruited. Furthermore, it is expected that all stroke survivors will be required to possess the capabilities of self-management to manage their conditions after stroke (Lorig et al., 2001). Therefore, participants with a clinical diagnosis of stroke regardless of the type and number of stroke were recruited.

Exercising self-management requires the individual to problem-solve, make decisions, and establish their goals and action plans for enhancing recovery (Lorig et al., 2001). A MMSE score of 19 to 23 indicates mild cognitive impairment while a score of 24 to 30 indicates normal (Kase et al., 1998). Studies showed that community-dwelling stroke survivors had mild cognitive impairment with MMSE scores ranging from 18 to 30 (Cumming, Churilov, Linden, & Bernhardt, 2013; Huijbregts et al., 2008). Therefore, a cut-off point of 18 was selected as one of the inclusion criteria to recruit participants who could potentially benefit from the program, while assuring that the participants were cognitively able to give informed consent to participate in the study.

Cantonese is the language spoken by the majority of the Hong Kong Chinese people. All components of the research study and program sessions were conducted in Cantonese. Therefore, the participants were required to be able to speak Cantonese to comprehend the conversations with the Ph.D. candidate and research assistants, and to interact and share experiences with other participants with similar experiences in the program to which they were assigned.

4.8.2 Exclusion criteria

Participants were excluded if they 1) were diagnosed with transient ischaemic attack, subdural or epidural haemorrhage (Sacco et al., 2013); 2) had cerebrovascular events due to malignancy or head trauma; 3) had limited comprehension and receptive aphasia; 4) had been diagnosed with mental illnesses such as depression, schizophrenia, bipolar disorder, or personality disorders; 5) had been diagnosed with conditions which affected their cognitive abilities such as dementia; or 6) had received a stroke self-management program in the previous 12 months.

Participants who had dysphasia or slurred speech after stroke were recruited if they met the above inclusion and exclusion criteria except when their speech was completely incomprehensible, or they had difficulty in comprehending others’ conversations.
4.9 SAMPLE SIZE CALCULATION

The primary outcome of this trial was stroke survivors’ self-efficacy in stroke self-management as measured by the SSEQ at 8-weeks follow-up assessment. The sample size required for the RCT was calculated based on the population SDs of this primary outcome to detect a clinically meaningful difference. The population SD for this scale was estimated from a previous two-group RCT that examined the effects of a stroke self-management program among 100 community-dwelling stroke survivors (Kendall et al. 2007). Kendall et al. (2007) adopted a similar Chronic Disease Self-Efficacy Scale for measuring stroke survivors’ self-efficacy in stroke self-care. The study reported the SDs for the baseline intervention and control groups of 14.93 and 15.31, and for the post-intervention control group of 18.16. Therefore, the averaged population SD for self-care self-efficacy was 16.13. Taking a conservative estimate of treatment effect size of 0.50, the sample size required to detect a minimally statistically significant mean difference of 8.07 in self-efficacy in stroke self-management using two-sided independent t-tests with a significance level of 0.05 and a power of 0.80 is 64 per group (128 for two groups) (Cohen, 1992). The sample size was increased to take account of the attrition rate of 19% over six months among stroke survivors (Kendall et al., 2007). Therefore, the final sample size for the RCT was 160 (80 participants in each group).

4.10 RECRUITMENT

Participants were recruited from the acute stroke units of the three study hospitals in Hong Kong. Two trained research assistants attended the three acute stroke units respectively at least three times per week during visiting hours from six to eight o’clock in the evening. Details about the training for the research assistants are provided in section 4.17.

The trained research assistants reviewed the medical records of the patients admitted to the acute stroke units. The eligibility of the patients was assessed against the inclusion and exclusion criteria based on the information available on the medical records or information obtained from the stroke nurses or ward nurses, if present. If the patients potentially met the eligibility criteria, the trained research assistants approached the patients and their family members or carers face-to-face at the study venue to assess their eligibility and willingness to participate in the study. For those who were interested in participating in the study, the trained research assistants
obtained informed consent from the stroke patients. A card indicating the participants’ enrolment in the study and contact details of the Ph.D. candidate was then provided to the patients and the family members or carers.

4.11 RANDOMISATION

Eligible participants in this study, after providing baseline assessment data, were randomly assigned in a 1:1 ratio to the intervention or the control group according to a computer-generated random schedule in permuted blocks of six with no stratification. A statistician who was not involved in the recruitment, treatment allocation or outcome assessment generated the sequence of randomisation numbers using computer software package before collecting baseline assessment data. The computer software is available at www.randomisation.com. A sequence of 180 random numbers was generated.

In this study, block randomisation with a block size of six was used for random assignment of participants to treatment groups. There are several types of randomisation, such as simple randomisation, block randomisation, stratified randomisation, and covariate adaptive randomisation (Suresh, 2011). Compared with simple randomisation, block randomisation using a permuted block of six is advantageous at ensuring an equal number of and even distribution of participants into two groups over time (Suresh, 2011). Stratified randomisation is not appropriate as the participants were recruited continuously. The baseline characteristics of all participants were not available before assignment. Covariate adaptive randomisation was not necessary, as block randomisation was sufficient to help generate comparable groups (Suresh, 2011).

4.12 ALLOCATION CONCEALMENT

In this study, the use of sealed envelopes was used as it is deemed more practical in terms of manpower and resources in the study. The procedure to perform the concealed allocation in this study was that, based on the random sequence, the statistician put the randomly sequenced numbers indicating group assignment into sealed, identical, opaque envelopes that contained sheets of carbon paper, and were sequentially numbered. Upon completion of the baseline assessment of each participant, a research assistant who was not involved in recruitment and outcome assessment took an envelope consecutively,
wrote the participant’s study identifier on the envelope, opened it and informed the Ph.D. candidate about the treatment allocation.

4.13 BLINDING

In this study, the research assistant (RA-O, outcome assessor) who administered the baseline and 8-weeks follow-up assessments, and the research assistant (RA-D, data entry assistant) who assisted in entering data were blinded to treatment allocation. The outcome assessor and the data entry assistant were not involved in implementation of the SSMP or treatment of the participants at any stage. The participants were also asked not to tell the outcome assessor about the participants’ treatment allocation. However, due to the nature of the intervention, the stroke participants and the Ph.D. candidate who delivered the SSMP were not blinded to treatment allocation. Furthermore, the research assistant (RA-C, caller) who made phone calls to participants in the intervention group at five weeks after randomisation was not blinded to treatment allocation. This was because the caller needed to know this information to collect the participants’ feedback on usefulness of the SSMP.

4.14 INTERVENTION

Participants who were randomly assigned to the intervention group received the new 4-week SSMP plus usual stroke care.

4.14.1 Theoretical framework

The results of the systematic review conducted in Phase One of this research project found that the construct of self-efficacy (Bandura, 1997) is the theoretical framework most commonly adopted in previous studies to underpin the design, implementation and evaluation of stroke self-management programs. These studies showed that stroke self-management programs underpinned by the construct of self-efficacy were associated with significant improvement in self-efficacy and HRQoL (Lo et al., 2013). Self-efficacy refers to an individual’s confidence to perform an action to reach a desired goal. Judgment of one’s self-efficacy determines the course of action and amount of effort required, and perseverance to continue an action even in face of obstacles. Self-efficacy is developed through four sources of information namely mastery experience, vicarious experience, verbal persuasion, and minimising physiological or emotional arousal (Bandura, 1997). A substantial amount of literature
has reported that increased self-efficacy was associated with better health outcomes such as HRQoL and perceived health status among stroke survivors (Lennon et al., 2013; Lo et al., 2013).

Outcome expectation is another central construct of the SCT (Bandura, 1997). According to the theory, outcome expectation refers to an individual’s judgement of the likelihood that performance of a particular action will produce a certain outcome. It takes three major forms, that is, physical, social and self-evaluative effects. Within each form, positive expectations serve as incentives to performance of an activity, while negative expectations serve as disincentives (Bandura, 1977). Bandura suggests that the initiation and continuation of a particular activity or behaviour would be best predicted by the combined influence of self-efficacy beliefs and types of outcome expectation. The more one believes in one’s own ability to perform a specific activity and the outcome of that activity, the more likely it is that one will initiate and maintain the behaviour (Bandura, 1977; Williams, 2010).

In this study, the influences of self-efficacy and outcome expectancy beliefs on stroke survivors’ performance in stroke self-management behaviours were addressed when designing the new SSMP. Figure 4.2 outlines the theoretical framework of the SSMP developed for this study. It is expected that enhancing participants’ self-efficacy and outcome expectancy beliefs would increase their participation and performance in stroke self-management behaviours, and ultimately improve health outcomes including HRQoL, depressive symptoms and community reintegration. To enhance participants’ self-efficacy and outcome expectancy beliefs in performing stroke self-management behaviours, specific strategies based on the results of the systematic review reported in Chapter Three were adopted in the SSMP (Table 4.1). The four sources of information of self-efficacy and the physical, social and self-evaluative effects of outcome expectation were addressed in the SSMP.
Figure 4.2 Theoretical framework of the new nurse-led self-efficacy enhancing stroke self-management program developed for this study

Table 4.1 Strategies adopted to enhance participants’ self-efficacy and outcome expectancy beliefs in performing stroke self-management behaviours

<table>
<thead>
<tr>
<th>Sources of information of self-efficacy</th>
<th>Strategies adopted</th>
<th>Program components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mastery experience</td>
<td>- Establish a short-term goal and an action plan</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Assist to divide difficult tasks into simple steps</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Practice core self-management skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Revise the action plan if necessary</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Encourage to record implementation of the plan</td>
<td></td>
</tr>
<tr>
<td>Vicarious experience</td>
<td>- Guide the viewing of videos about experience sharing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Facilitate experience sharing in group sessions</td>
<td></td>
</tr>
<tr>
<td>Verbal persuasion</td>
<td>- Acknowledge incremental successes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Provide positive reinforcement</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Reinforce the importance of “taking an active role”</td>
<td></td>
</tr>
<tr>
<td>Physiological and emotional states</td>
<td>- Assist to reinterpret negative physiologic and emotional states</td>
<td></td>
</tr>
<tr>
<td>Outcome expectation</td>
<td>- Assess and reinforce positive outcomes valued by the participants after performing stroke self-management behaviours</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: GS, Group sessions; HV, Home visit; PF, Follow-up phone calls.
4.14.2 Outline of the program

The aim of the newly designed SSMP was to enhance the community-dwelling stroke survivors’ capabilities in self-managing their post-stroke health conditions. The SSMP consisted of one 1.5-hour individual home visit, two 1.5-hour group sessions held in a nurse-led clinic, and three follow-up phone calls (Table 4.2). The SSMP is underpinned by Bandura’s constructs of self-efficacy and outcome expectation (Bandura, 1977). The program was delivered by the Ph.D. candidate who is a registered nurse experienced in stroke care and chronic disease management. Each participant received a program workbook and two Digital Versatile Discs (DVDs) specifically designed for this program. A protocol detailing the program contents and delivery methods was developed to ensure consistent delivery of the program. The SSMP commenced when six participants were randomly assigned to the intervention group and it was repeated to accommodate all participants randomly assigned to the intervention group. Family members or informal carers of each participant who were interested were invited to join the program as accompanying persons.

Table 4.2 Overview of the new nurse-led self-efficacy enhancing stroke self-management program for community-dwelling stroke survivors

<table>
<thead>
<tr>
<th>Week</th>
<th>Program components</th>
<th>Key contents</th>
</tr>
</thead>
</table>
| 1    | One home visit at participant’s home | - Perform an individualised assessment  
- Discuss the importance of stroke self-management  
- Establish a short-term goal and an action plan  
- Video viewing |
| 2    | Two group sessions in a nurse-led clinic | - Discuss the physical and psychosocial consequences of stroke  
- Discuss the practical tips of managing post-stroke challenges  
- Facilitate reflection and experience sharing among the group  
- Explore alternative ways to better implement the action plans  
- Practice core self-management skills  
- Video viewing |
| 3 & 4| Three follow-up phone calls | - Review progress towards goal attainment  
- Provide individualised feedback and positive reinforcement  
- Encourage to continue, revise or set a new short-term goal depending on the participant’s progress |
During the program, the participants received education on stroke self-management and sharing among peers, viewed video clips of experiences shared by stroke survivors who had successfully managed their strokes, and received individualised follow-up on progress of their recovery. Each participant in the program was assisted to set goals related to their stroke recovery, and established action plans to achieve the goals set. Participants in the control group received usual care, including health services, talks, and/or educational materials provided by hospitals or other health organisations without additional interventions.

4.14.3 Components of the program

The SSMP started with an individual home visit. During the home visit, the Ph.D. candidate (the nurse) assessed the participant’s current medical, emotional and role management of their post-stroke conditions (Barlow et al., 2002; Lorig et al., 2001), and their self-efficacy and outcome expectancy beliefs of performing self-management behaviours. Based on the assessment, the nurse worked with the participant to establish a short-term goal of importance to stroke recovery, and to develop a realistic action plan to achieve the goal (Lorig et al., 2001). Information about stroke self-management and core self-management skills such as problem-solving and decision-making was provided. Furthermore, participants were guided to view one to two videos on the DVDs to enable them to learn from other stroke survivors’ experiences. Positive reinforcement was provided to promote confidence in implementing their action plans (Bandura, 1977). The participant was encouraged to view the videos, read the program workbook, and record the implementation of the action plans after the home visit. Each home visit lasted for about one and a half hours.

The SSMP included an individual home visit to enable a more comprehensive and individualised assessment of each participant, as this was lacking in the stroke self-management programs examined in the three RCTs included in the systematic review (Lo et al., 2013) reported in Chapter Three. The assessment findings obtained from the home visit were important for setting goals and devising action plans which were appropriate for the participant. Moreover, the interaction between the participant and the Ph.D. candidate facilitated the development of a trusting relationship and established rapport (Hadidi et al., 2012).

In the following week after the home visit, two consecutive 1.5-hour group sessions were held in the same afternoon in the study nurse-led clinic. During the group
sessions, participants were provided with information about the physical and psychosocial consequences of stroke, and practical tips for effective stroke self-management. More importantly, the Ph.D. candidate acted as a facilitator to encourage the participants to reflect and share their barriers to and facilitators of implementing their action plans. Based on the common problems among the group, relevant videos of sharing by stroke survivors were presented. Participants were facilitated to explore their own ways to address their barriers. Examples were provided to guide their practice of core self-management skills to better implement their plans. If necessary, their action plans were revised. Positive reinforcement was provided and participants were encouraged to visualise their expected positive outcomes after performing the self-management behaviours (Bandura, 1977). Participants were also encouraged to continue to implement their action plans and record their progress after the sessions. Participants’ family members or carers were welcome to attend the group sessions with the participants. Similar to the three included studies in the systematic review (Lo et al., 2013), group sessions with participants who had similar conditions provided vicarious experience and were a significant source of information of self-efficacy (Bandura, 1997).

Three weekly follow-up phone calls by the Ph.D. candidate were provided after the group sessions to review the participants’ progress, and the barriers to and facilitators of implementing the action plans. Individualised feedback and positive reinforcement were provided. Furthermore, the participants’ expected positive outcomes of achieving the goals were reinforced. At the end of the last follow-up phone call, the participant’s extent of goal attainment was evaluated. The participant was guided to continue, revise, or establish a new short-term goal for the next month. Each follow-up phone call lasted for about five to ten minutes. Only one (Damush et al., 2011) of the three included studies in the systematic review (Lo et al., 2013) incorporated phone calls as a delivery method of the contents of the stroke self-management program. It was found that delivery by phone solved stroke participants’ transportation problems in accessing community-based group sessions as a result of limitations in mobility (Damush et al., 2011). A total of three follow-up phone calls for each participant were included in the SSMP to allow for continued assessment, reinforcement, and interim evaluation regarding future progress after completion of the SSMP.
4.14.4 Role models in videos

The SSMP developed for the study featured the innovative use of videotaped experience sharing by role models. These role models were volunteer stroke survivors who had managed their stroke successfully. Experiences shared in the videos formed the basis for discussion and reflection among stroke participants in the SSMP.

Findings from the systematic review (Lo et al., 2013) reported in Chapter Three found that stroke survivors encountered different physical and psychosocial challenges after discharge from hospital. While the stroke self-management programs examined in the three included studies incorporated information about practical self-management strategies, the information was provided in the form of either a paper-based workbook, or sharing by volunteer stroke survivors during group sessions in the program. These methods were limited in that the stroke participants might not be able to read, or travel to join the community-based group sessions. Sharing in group sessions was considered a one-off experience only. Furthermore, studies consistently reported that visual stimulation was associated with better retention of information delivered compared with auditory stimulation only (Sanders et al., 2014; Yoon & Byles, 2002).

The videos in the form of two DVDs were introduced and distributed to the study participants during home visit in the SSMP. The Ph.D. candidate guided the participants to view several selected videos during the home visit and group sessions. The videos were selected on the basis of maximum similarity between the participant and the role model in terms of their demographic and clinical characteristics. The viewing of videos facilitated the participants’ recall of specific events, experiences, emotions and thoughts related to their stroke recovery, that they had often forgotten. It also enabled them to note new or unexpected aspects of recovery (Henry & Fetters, 2012). After viewing the videos, the participants were encouraged to reflect on and discuss their own experiences of stroke recovery, challenges encountered and how they addressed them.

Additionally the videos provided the participants with vicarious experience and served as a powerful source of information of self-efficacy (Bandura, 1997). Through observing other stroke survivors’ experiences in successfully managing their post-stroke conditions well, the participants obtained a picture of what they were supposed to do to achieve the level of health they expected. It in turn motivated them to continue their action plans set in the SSMP (Lorig et al., 2001). Furthermore, the videos were
advantageous at enabling flexible, repeated and unlimited viewing by the participants at home or other places.

*Video production*

A purposeful sample of stroke survivors who had a first or recurrent ischaemic or haemorrhagic stroke, currently lived at home, spoke Cantonese, managed their post-stroke challenges successfully, and volunteered to share their experiences of post-stroke recovery in a videotaped interview were recruited from two stroke support groups in Hong Kong.

A total of 15 stroke survivors (mean age 60.87 years, SD 10.11) volunteered to participate in the interviews. Majority of the stroke survivors were male (n=8), married and retired (n=10), had ischaemic stroke (n=10), and walked with a stick (n=7). Three of the volunteer stroke survivors had dysphasia. However, they were able to express themselves at a slower pace. All except three had a first-ever stroke (mean duration after the first stroke 10.37 years, SD 7.45). Table 4.3 summarises the stroke survivors’ demographic and clinical characteristics.

Table 4.3 Demographic and clinical characteristics of the stroke survivors who participated in the videotaped semi-structured interviews

<table>
<thead>
<tr>
<th>ID</th>
<th>Age (yrs) / Gender</th>
<th>Marital status</th>
<th>Educational level</th>
<th>Employment</th>
<th>First/ recurrent stroke</th>
<th>Duration since first stroke (yrs)</th>
<th>Type of stroke</th>
<th>Mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>64 / M</td>
<td>Married</td>
<td>Primary</td>
<td>Retired</td>
<td>First</td>
<td>22</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>2</td>
<td>60 / M</td>
<td>Married</td>
<td>Primary</td>
<td>Retired</td>
<td>First</td>
<td>13</td>
<td>I</td>
<td>Unaided</td>
</tr>
<tr>
<td>3</td>
<td>60 / F</td>
<td>Married</td>
<td>Primary</td>
<td>Retired</td>
<td>Recurrent</td>
<td>16</td>
<td>H</td>
<td>Stick</td>
</tr>
<tr>
<td>4</td>
<td>52 / M</td>
<td>Married</td>
<td>Primary</td>
<td>Full-time</td>
<td>Recurrent</td>
<td>3</td>
<td>I</td>
<td>Unaided</td>
</tr>
<tr>
<td>5</td>
<td>65 / M</td>
<td>Married</td>
<td>Primary</td>
<td>Retired</td>
<td>First</td>
<td>3</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>6</td>
<td>70 / M</td>
<td>Married</td>
<td>Illiterate</td>
<td>Retired</td>
<td>First</td>
<td>2.5</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>7</td>
<td>57 / F</td>
<td>Single</td>
<td>Secondary</td>
<td>Part-time</td>
<td>First</td>
<td>22</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>8</td>
<td>54 / M</td>
<td>Married</td>
<td>Primary</td>
<td>Retired</td>
<td>First</td>
<td>2</td>
<td>H</td>
<td>Stick</td>
</tr>
<tr>
<td>9</td>
<td>66 / M</td>
<td>Single</td>
<td>Secondary</td>
<td>Retired</td>
<td>First</td>
<td>11</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>10</td>
<td>35 / M</td>
<td>Single</td>
<td>Secondary</td>
<td>Retired</td>
<td>First</td>
<td>3</td>
<td>H</td>
<td>Stick</td>
</tr>
<tr>
<td>11</td>
<td>64 / F</td>
<td>Single</td>
<td>Primary</td>
<td>Retired</td>
<td>First</td>
<td>8</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>12</td>
<td>56 / F</td>
<td>Married</td>
<td>Secondary</td>
<td>Retired</td>
<td>Recurrent</td>
<td>21</td>
<td>H</td>
<td>Unaided</td>
</tr>
<tr>
<td>13</td>
<td>70 / F</td>
<td>Married</td>
<td>Primary</td>
<td>Housewife</td>
<td>First</td>
<td>14</td>
<td>H</td>
<td>Unaided</td>
</tr>
<tr>
<td>14</td>
<td>80 / F</td>
<td>Married</td>
<td>Secondary</td>
<td>Retired</td>
<td>Recurrent</td>
<td>4</td>
<td>I</td>
<td>Stick</td>
</tr>
<tr>
<td>15</td>
<td>60 / F</td>
<td>Married</td>
<td>Primary</td>
<td>Housewife</td>
<td>First</td>
<td>11</td>
<td>I</td>
<td>Stick</td>
</tr>
</tbody>
</table>

Abbreviations: F, Female; H, Haemorrhagic stroke; I, Ischaemic stroke; ID, Identification number; M, Male; yrs, Years.

The Ph.D. candidate introduced the purposes of the videotaped interviews in a regular meeting of each stroke support group. Then the Ph.D. candidate scheduled via
phone with the volunteer stroke survivors who were interested in participating in interviews. The survivors were invited to participate in individual semi-structured interviews which took place in a room in a community rehabilitation centre where they usually attended activities or a quiet area outside the centre.

During the interviews, the Ph.D. candidate invited the volunteer stroke survivors to share their experiences of recovery after stroke, the physical and psychosocial challenges encountered after returning home, and the facilitators of and barriers to managing their post-stroke conditions. They were invited to share practical tips for self-managing their health, their current lives, personal goals, and expectations and plans for the near future. Furthermore, they were invited to share words of encouragement with those who were working hard to manage stroke. Appendix G shows the interview guide. All interviews were videotaped with a video camera set on a tripod placed in front of the volunteer stroke survivor. The Ph.D. candidate was standing behind the video camera. The video camera was switched on when the volunteer stroke survivor was ready and paused when necessary. Each interview took about one and a half hour. The interviews and video production were conducted over a six-month period.

Written informed consent (Appendix H) was obtained from each participant before the interviews and video taking. All stroke survivors were informed that the interviews were to be videotaped. The video footage was used to produce videos contained in two DVDs as one of the deliverables of a new stroke self-management program to be tested in a research study. The stroke survivors were assured that the DVDs containing the videos would be distributed to the study participants only. All the information collected in the interviews was used for research purposes only. The volunteer stroke survivors agreed to display their faces and have their actual voices in the videos. No blurring effects or sound modification were used. No other identifiable personal information such as the interviewee’s name was displayed in the videos or other publications related to the study.

The Ph.D. candidate was responsible for video shooting and editing, designing the DVD cover, and follow-up with the production company producing the DVDs. Discussions between the Ph.D. candidate and two nurse academics in the research team were made on the arrangement of the contents in the videos. Since each interview lasted for over an hour, therefore only the information which was deemed important
for the volunteer stroke survivors was included in the videos. For example, some videos included more experience sharing on role management if the volunteer stroke survivors shared much on this aspect, while some videos included more on exercise, emotional management, or relationships with friends or family members. One video was produced for each volunteer stroke survivor’s experience sharing. A total of 15 videos (total duration: 205 minutes) were produced. Table 4.4 shows the titles and duration of the 15 videos. The first eight videos were included in one DVD and the remaining seven were included in another DVD.

Table 4.4 Titles and duration of the 15 videos

<table>
<thead>
<tr>
<th>Video</th>
<th>Video title (English translation)</th>
<th>Video duration (min)</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Setting goals • Confidence enhancing</td>
<td>16</td>
</tr>
<tr>
<td>02</td>
<td>My life in my hands</td>
<td>15</td>
</tr>
<tr>
<td>03</td>
<td>Take care of myself</td>
<td>13</td>
</tr>
<tr>
<td>04</td>
<td>Be confident • All is possible</td>
<td>16</td>
</tr>
<tr>
<td>05</td>
<td>Continuous practice • Memory and mobility</td>
<td>15</td>
</tr>
<tr>
<td>06</td>
<td>Live in the present</td>
<td>16</td>
</tr>
<tr>
<td>07</td>
<td>Help others and self-help</td>
<td>17</td>
</tr>
<tr>
<td>08</td>
<td>Stay strong</td>
<td>8</td>
</tr>
<tr>
<td>09</td>
<td>Meet new friends • Integrate into the community</td>
<td>15</td>
</tr>
<tr>
<td>10</td>
<td>I wish I can continue</td>
<td>13</td>
</tr>
<tr>
<td>11</td>
<td>Walk down the roads</td>
<td>13</td>
</tr>
<tr>
<td>12</td>
<td>Be positive</td>
<td>16</td>
</tr>
<tr>
<td>13</td>
<td>Talk more • Feeling good</td>
<td>13</td>
</tr>
<tr>
<td>14</td>
<td>Exercise tips</td>
<td>14</td>
</tr>
<tr>
<td>15</td>
<td>After volunteering</td>
<td>5</td>
</tr>
</tbody>
</table>

Total duration: 205 min (3 hr 25 min)

The contents of each video were arranged in a similar sequence which started from a brief introduction to the video, experiences immediately after returning home, challenges and solutions in self-management and current life, and finally words of encouragement. Chinese subtitles were added in each video to facilitate viewing. Appendix I shows the original Chinese and English translation of the subtitles in the 15 videos. Information about the aim of the research study and research team members was also provided at the beginning and end of each video. Appendix J shows the video content page and the design of the DVD cover.
4.14.5 Deliverable of SSMP – A program workbook

A program workbook was designed to supplement information for the participants. Provision of a booklet or workbook is a common traditional way of education to reinforce the information provided, and to provide handy information that can easily be checked for reference. The program workbook consisted of 20 A4 pages and was written in Traditional Chinese. The workbook provided a brief background to the study and the key components of the new SSMP. It introduced the key concepts of stroke self-management, the five core self-management skills, and provided examples of stroke self-management behaviours, strategies to enhance self-efficacy and outcome expectation, and tips for developing the realistic recovery goal and action plans. The workbook provided spaces for the participants to record their goal(s) in stroke recovery and their action plans established to achieve the goal(s). A section similar to a calendar was designed for participants to record the implementation of their action plans. Specifically, participants put a tick to the box provided if they had implemented the plan, while a cross was added if they had not implemented it. This enhanced participants’ self-efficacy by providing a record for them to review their progress and enhanced their experience of mastery (Bandura, 1997). Furthermore, there were spaces designed to ask the participants to think about the next step after attainment, partial attainment, or inability to attain the goal(s) set. This encouraged participants to continue to adopt self-management skills to enhance their recovery.

More importantly, the workbook was designed to act as a support resource for participants by including excerpts showing positive reinforcement from the videos provided by stroke survivors who had successfully managed their conditions. Introduction to the content of each of the 15 videos were also available in the workbook. These materials were included to allow participants to learn from others’ experience in stroke recovery (Bandura, 1997). At the end of the workbook, there were spaces provided for participants to record their feelings or experiences throughout their participation in the SSMP.

To cater for the needs of the participants who were illiterate, the workbook was designed to use pictures to convey the messages. The words used were simple, short, and of large font size for easy reading and understanding. The program workbook was distributed to participants during home visit. Appendix K shows the cover page of the workbook in Chinese and an English translation of the workbook contents.
4.14.6 Content validity and pilot test of SSMP

Testing of the content validity of the SSMP including the program contents and the workbook was conducted by a panel of five experts. The panel included two nurse academics, two advanced practice nurses, one nurse manager and one physician, who were experienced in acute and rehabilitation stroke care and had a wealth of knowledge in community-dwelling stroke survivors’ health needs. In addition, the two nurse academics were experts in the use of Bandura’s constructs of self-efficacy and outcome expectation, and development of strategies to enhance stroke survivors’ self-efficacy and outcome expectation. The five experts were provided with the program outline and contents, and the workbook. The Ph.D. candidate had meetings with the expert panel members to collect their comments. Overall, the comments were positive in that the expert panel members commented that the SSMP and the workbook were relevant to community-dwelling stroke survivors’ health needs. They supported the use of videotaped experience sharing by role models in the SSMP to provide vicarious experiences and motivate stroke survivors to practise self-management. Minor changes were made by using simpler wordings to replace the terms “self-efficacy”, “problem-solving” and “decision-making”. It was suggested that the font size could be larger and the line spacing could be increased slightly. Relevant modifications were made and the program contents and the workbook were finalised.

The Ph.D. candidate then conducted a pilot test of the SSMP among six of the 15 volunteer stroke survivors (mean age 55 years, SD 10.35, range 35-64 years) who participated in the videotaped semi-structured interviews discussed in the previous section. Four were male and two were female. Four had attained an educational level of primary school while the remaining two had attained secondary school level. One worked as a part-time clerk while the remaining survivors were retired. Three had ischaemic stroke and the other three had haemorrhagic stroke. All except one of them had a first-ever stroke. They had a mean duration of 13 years (SD 8.84) since the last stroke onset. The Ph.D. candidate introduced the six stroke survivors to the SSMP, and showed them the videos in the DVDs, and the workbook. They were asked if the SSMP was helpful to them, whether the readability of the workbook was appropriate, and whether the arrangement of the program contents was acceptable.

Overall, the stroke survivors appreciated the provision of the SSMP for community-dwelling stroke survivors. They liked the videos most as they recalled that
they were worried about their conditions and prognoses after they returned home. They wanted to learn more from others’ experiences in recovery. Commonly they suggested that more real examples of daily challenges in self-care and possible solutions could be shared in the SSMP. Furthermore, transportation could be provided to facilitate access and incentives could be provided to enhance participation. To address the comments, key findings from the videotaped semi-structured interviews about stroke survivors’ post-stroke recovery experiences and needs were incorporated to supplement discussions between the Ph.D. candidate and the stroke participants during the SSMP. Transportation was not provided due to manpower and financial limitations. However, cash incentives and reimbursement of transportation fares were provided to participants as approved by the research ethics committees.

4.15 USUAL CARE

Participants randomly assigned to the control group received the usual care provided to stroke survivors discharged to their home without any additional interventions. The three study acute hospitals followed the same stroke care protocol endorsed by the Hospital Authority in Hong Kong. Therefore, the components of usual care provided to stroke survivors after discharge to home were similar across study venues. Usual care included some or all of the following services:

- Regular medical follow-up consultations at specialist out-patient clinics;
- Regular rehabilitation training program at ambulatory day care hospitals;
- Integrated care services after discharge, for example, disease management;
- Regular follow-up appointment with allied healthcare professionals including physiotherapists, occupational therapists, dieticians and speech therapists;
- Attendance for complementary and alternative therapies at Traditional Chinese Medicine Clinics at the hospitals for receiving acupuncture or herbal medicinal therapy;
- Hospital-based health education, for example, talks or leaflets on stroke and stroke care;
- Referrals to or provision of information about community-based services for people with stroke or disabilities for example the Hong Kong Society for Rehabilitation or Meals on Wheels services.
4.16 STUDY OUTCOMES

The design of the SSMP was underpinned by Bandura’s constructs of self-efficacy and outcome expectation (Bandura, 1997). Various strategies were adopted in the SSMP to enhance the stroke participants’ self-efficacy in and outcome expectation for stroke self-management. This study postulated that stroke participants who had increased self-efficacy in and more positive outcome expectation for stroke self-management would have higher satisfaction with their performance in stroke self-management behaviours, which in turn promote their health outcomes (Bandura, 1997). Therefore, self-efficacy in and outcome expectation for stroke self-management were selected as the primary outcomes of this RCT (Table 4.5). Stroke survivors’ satisfaction with their performance in stroke self-management behaviours and key health outcomes expected of after performing stroke self-management behaviours were selected as secondary outcomes. The key health outcomes included HRQoL, risk of depression, and level of community reintegration (Table 4.5). The results of the systematic review reported in Chapter Three showed that these health outcomes were commonly assessed in studies examining the effectiveness of stroke self-management programs. Enhancing HRQoL, reducing depressive symptoms, and promoting community reintegration are also of top priorities in stroke care, as recommended in international guidelines (SIGN, 2010). Therefore, these three health outcomes were selected as the secondary outcomes of the RCT.

Table 4.5 Summary of measurements and study outcomes

<table>
<thead>
<tr>
<th>Study outcomes</th>
<th>Measures</th>
<th>Group</th>
<th>Baseline</th>
<th>8-weeks</th>
<th>FU</th>
<th>1°</th>
<th>2°</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>SSEQ</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome expectation</td>
<td>SSOES</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction with performance</td>
<td>SSBPS</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of SSMB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRQoL</td>
<td>SSQOL</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>GDS</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community reintegration</td>
<td>RNLI</td>
<td>IG, CG</td>
<td>×</td>
<td>×</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: CG, Control group; FU, Follow-up assessment; GDS, Geriatric Depression Scale; HRQoL, Health-related quality of life; IG, Intervention group; RNLI, Reintegration to Normal Living Index; SSBPS, Stroke Self-management Behaviours Performance Scale; SSEQ, Stroke Self-Efficacy Questionnaire; SSMB, Stroke self-management behaviours; SSOES, Stroke Self-management Outcome Expectation Scale; SSQOL, Stroke Specific Quality of Life Scale.

1°: Primary outcomes; 2°: Secondary outcomes.
4.16.1 Translation of tools

Since there were no validated tools in Chinese to measure self-efficacy in stroke self-management and HRQoL, the Ph.D. candidate back-translated the original SSEQ (Jones et al., 2009) and SSQOL (Williams, Weinberger, Harris, Clark, et al., 1999) in English into the target Chinese language version. Appendix C shows the published work of translation and test of equivalence of the Chinese version of SSEQ in the journal, *Topics in Stroke Rehabilitation*. Appendix D shows the published work of translation and test of equivalence of the Chinese version of SSQOL in the journal, *Disability and Rehabilitation*. In this section, the published work of these two articles is included verbatim with some editing to fulfil the requirements of the thesis.

Translation and cultural adaptation of validated measuring tools are common in health care research. It enables the use of standardised instruments, measuring the constructs that are expected to be measured, for better comparison of results across studies (Gjersing, Caplehorn, & Clausen, 2010). The Brislin’s model with forward and backward translation is one well-known, classical and commonly used method to translate and adapt a measuring instrument from one language to another (Brislin, 1970). The Brislin’s model highlights the importance of conducting forward followed by backward translation for ensuring semantic equivalence of the source and target versions. It also emphasises the evaluation of meanings, instead of wordings, in both versions with reference to the origin cultural context (Brislin, 1970). However, this model using only one version of back-translation is believed to be more likely to generate translation issues related to the translator (Duffy, 2006). Moreover, the number of translators and time required to perform forward and backward translations until there is no error in meanings can be unpredictable. The need to test the source and target versions with bilingual people may present difficulties to studies with limited resources or time (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001).

Since then, various modified or new processes of translation and cross-cultural adaptation of measuring instruments have been developed (Chang, Chau, & Holroyd, 1999; Gjersing et al., 2010; Sidani, Guruge, Miranda, Ford-Gilboe, & Varcoe, 2010). While there are considerable variations among studies, certain common and core stages in the process can be identified. First, the process involves multi-steps and a centralised panel to review and decide on the relevance and translation quality of the instrument. Second, it requires at least one forward and one backward translation to
ensure semantic equivalence. If more than one version is used, the translation is usually performed simultaneously. A synthesised version may be produced after the forward and backward translations respectively by a third translation or the centralised panel. Third, it requires comparison of meanings with reference to the original culture among the source, back-translated and/or translated versions for possible errors in translation. When errors are identified, it is necessary to either revise the translation or repeat the forward and backward translations until there is no error and the panel reaches consensus on the translation. Fourth, several techniques are employed to test equivalence of the source and translated versions. Common techniques include consultation with experts in the field for relevance of the items and appropriateness of translation, or pre-testing of the translated version among target language-speaking participants for understanding and acceptability. The translated version can be tested in a study for reliability and validity (Gjersing et al., 2010).

There has been no universal recommendation on the “best approach” for translating and adapting a measuring tool from its original language to the target language. Nevertheless, it is of the utmost importance to document clearly the steps taken to develop the target language version, in order to judge the translation quality (Gjersing et al., 2010).

In this study, the original SSEQ and SSQOL in English were translated into Chinese using the forward and backward translation process. The original English version was translated into Chinese by two independent bilingual senior baccalaureate-nursing students. Two bilingual members of the research team examined the differences in the translated versions and came to consensus on a draft Chinese version. Another two independent bilingual senior baccalaureate-nursing students who did not know the original English version back-translated the draft Chinese version into English. The two bilingual members of the research team examined the differences between the back-translated and the original versions. The resultant Chinese version and the original English version were administered to 60 bilingual baccalaureate-nursing students who were asked to rate the appropriateness of the translation on a 4-point Likert scale (1=“very inappropriate” to 4=“very appropriate”).

Content validity was conducted by an expert panel of two physicians, one nurse academic, one nurse manager, one advanced practice nurse and two registered nurses. Panel members rated the relevance of each item to stroke self-management on a
4-point Likert scale (1=“not relevant” to 4=“very relevant and succinct”). Content validity index (CVI) was calculated as the percentage of items with a rating of three or above. Then the Chinese version was tested on a convenience sample of five Chinese community-dwelling stroke survivors (aged 35-60 years) to determine the readability of the language used. Revisions in the items were made according to the comments by the panel members and the stroke survivors. The Chinese versions of the SSEQ and SSQOL were then tested in a convenience sample of 135 Chinese community-dwelling stroke survivors (mean age 58.90 years, SD 9.75). Forty-nine of them were females (36.30%) and 86 were males (63.70%). Most of them had ischaemic stroke (55.6%). The average years after diagnosis of the first stroke were 6.08 (SD 5.24). Thirty of the participants were invited to complete the same questionnaires again after four weeks.

4.16.2 Development of new tools

Since there had been no validated tools to measure outcome expectation for stroke self-management and satisfaction with performance in stroke self-management behaviours respectively, the Ph.D. candidate developed new tools to measure these two outcome variables respectively. The process of development and testing of reliability and validity of the two new tools are reported and discussed in Chapter Five.

4.16.3 Primary outcomes

The primary outcomes of the RCT included stroke participants’ self-efficacy in and their outcome expectation for stroke self-management.

4.16.3.1 Self-efficacy in stroke self-management

The SSEQ was adopted to measure the participants’ self-efficacy in performing daily functional activities and self-management (Jones et al., 2008). The SSEQ was chosen as it was the first stroke-specific measure of stroke survivors’ self-efficacy in performing self-management. The SSEQ consists of 13 items. Each item asks participants about their perceived level of confidence in performing a number of activities after stroke in the preceding week. The activities include getting in and out of bed, walking indoors, walking around the house to do things, walking outdoors, using both hands to eat, dressing and undressing, preparing meals, persevering to make progress, exercising regularly, overcoming frustrations, continuing to do things they were interested in before stroke, and doing things faster. Each item was rated on an 11-point Likert scale from 0 “not at all confident” to 10 “very confident”. The score
of all items was summed to yield the total score (range 0-130). A higher score represented higher self-efficacy in performing daily functional activities and self-management. The SSEQ has high internal consistency (Cronbach’s alpha 0.90) and significant positive correlations with the Falls Efficacy Scale (Spearman’s rho \( \rho = 0.80, \ p<0.001 \)), and the Modified Rivermead Mobility Index (\( \rho = 0.46, \ p<0.001 \)), suggesting acceptable convergent validity (Jones et al., 2008).

The Ph.D. candidate back-translated the original English version of SSEQ into the target Chinese language and tested for equivalence in a convenience sample of 135 Chinese community-dwelling stroke survivors. The results suggested a two-factor model namely “Live with new challenges” and “Activity and exercise engagement” in contrast to the single factor model for the original questionnaire. The Chinese version of SSEQ had high internal consistency (Cronbach’s alpha 0.92). Test-retest reliability was satisfactory with an intraclass correlation coefficient of the total scale of 0.52. Positive correlations were found between the total scores of SSEQ, General Self-Efficacy Scale (GSES), Frenchay Activities Index (FAI) and SSQOL (\( \rho = 0.48-0.68, \ p<0.01 \)), suggesting acceptable convergent validity. Appendices L and M show the original English and the translated Chinese versions of SSEQ. Cronbach’s alpha for the translated Chinese version of SSEQ was 0.94 in this study.

4.16.3.2 Outcome expectation for stroke self-management

Since there had been no existing validated measuring tool on this variable, the Ph.D. candidate developed a new tool to measure this variable. The Stroke Self-management Outcome Expectation Scale (SSOES) is newly developed based on Bandura’s construct of self-efficacy (Bandura, 1977), and literature on stroke self-management (Lorig et al., 2001) and outcome expectation (Dougherty, Johnston, & Thompson, 2007; Resnick, Zimmerman, Orwig, Furstenberg, & Magaziner, 2000). The SSOES consists of 11 items that ask about participants’ current level of confidence that the desired outcomes will result after performing the self-management behaviours. The expected outcomes include do things that they want to do independently, improvement in health condition, know more about own health, feel at ease, be happier and feel supported, have a closer relationship with family and friends, have a comfortable family and social life, participate more in own rehabilitation, and improved HRQoL. Each item was rated on an 11-point Likert scale from 0 “not
confident at all” to 10 “very confident”. The total score was summed (range 0-110). A higher score indicated higher confidence in the likelihood of the outcomes to occur.

The Ph.D. candidate back-translated the original SSOES in English into the target Chinese language version. An expert panel of two nurse academics, one nurse manager, three advanced practice nurses and two physicians assessed content validity (CVI: 0.98). The panel commented that the SSOES was relevant to stroke survivors’ outcome expectations. No further amendments were made to the items. The SSOES was then piloted among a convenience sample of six Chinese community-dwelling stroke survivors (mean age 55 years, SD 10.35, range 35-64 years) to determine the readability of the language used. Most were male (n=4), and four had attained primary education and two had attained secondary education. Three had first-ever ischaemic stroke, two had first-ever haemorrhagic stroke and one had recurrent haemorrhagic stroke. The mean duration since stroke onset was 13 years (SD 8.85). All participants completed the questionnaire without further clarification or suggestions for additional items. No modifications were made to the items, instructions or response options.

The Chinese version of the SSOES was tested in a convenience sample of 83 Chinese community-dwelling stroke survivors (mean age 60.37 years, SD 9.16). Most were male (73.50%) and married (77.20%). Over half attained secondary level of education or above (69.90%). Nearly eighty percent of the participants had a first-ever stroke (mean duration after onset of last stroke was 9.46 years, SD 5.66). Over half of the participants had ischaemic stroke (56.60%). The results showed that the SSOES had a high internal consistency with Cronbach’s alpha of 0.94. Appendix N shows the English version of SSOES and Appendix O shows the translated Chinese version of SSOES. Cronbach’s alpha of the Chinese version of SSOES was 0.93 in this study.

4.16.4 Secondary outcomes

The secondary outcomes of the RCT included the stroke participants’ satisfaction with performance in stroke self-management behaviours, HRQoL, depressive symptoms, and community reintegration.

4.16.4.1 Satisfaction with performance in stroke self-management behaviours

Since there had been no existing validated tool to measure this variable, the Ph.D. candidate developed a new tool to measure this variable. The SSBPS was developed based on literature about stroke recovery to measure participants’ satisfaction with their current performance in stroke self-management behaviours (Battersby, Ask,
Reece, Markwick, & Collins, 2003; Cramm, Strating, de Vreede, Steverink, & Nieboer, 2012; Lorig et al., 2001). The SSBPS consists of 11 items. Each item asks participants about their current level of satisfaction with their performance in stroke self-management behaviours. The self-management behaviours include exercise regularly, adopt a healthy lifestyle, attend follow-up medical appointments, manage emotions, participate in social activities, keep contact with family and friends, assume pre-stroke or new family and social roles, establish plans for recovery with healthcare professionals, and implement different ways to manage post-stroke conditions. Each item was rated on an 11-point Likert scale from 0 “very dissatisfied” to 10 “very satisfied”. The total score was obtained by summing the scores of all items (range 0-110). A higher score indicates a higher level of satisfaction with own performance in self-management behaviours.

The Ph.D. candidate back-translated the original SSBPS in English into the target Chinese language version. An expert panel of two nurse academics, one nurse manager, three advanced practice nurses and two physicians performed assessment of content validity (CVI: 0.98). The panel members commented that the SSBPS was relevant to stroke survivors’ stroke self-management behaviours. No further amendments were made to the items. The SSBPS was then piloted among a convenience sample of six Chinese community-dwelling stroke survivors (mean age 55 years, SD 10.35, range 35-64 years) to determine the readability of the language used. Most were male (n=4), and four had attained primary education and two had attained secondary education. Three had first-ever ischaemic stroke, two had first-ever haemorrhagic stroke and one had recurrent haemorrhagic stroke. The mean duration since stroke onset was 13 years (SD 8.85). All participants completed the questionnaire without further clarification or suggestions for additional items. No modifications were made to the items, instructions or response options.

The Chinese version of the SSBPS was tested in a convenience sample of 83 Chinese community-dwelling stroke survivors (mean age 60.37 years, SD 9.16). Most were male (73.50%) and married (77.20%). Over half had attained secondary level of education or above (69.90%). Nearly eighty percent of the participants had a first-ever stroke (mean duration after onset of last stroke was 9.46 years, SD 5.66). Over half of the participants had an ischaemic stroke (56.6%). The results showed that the SSBPS had high internal consistency, with Cronbach’s alpha of 0.93. Appendix P shows the
English version of SSBPS and Appendix Q shows the translated Chinese version of SSBPS. Cronbach’s alpha of the Chinese version of SSBPS was 0.88 in this study.

4.16.4.2 Health-related quality of life

The SSQOL was adopted to measure the stroke participants’ HRQoL (Williams, Weinberger, Harris, & Biller, 1999; Williams, Weinberger, Harris, Clark, et al., 1999). The SSQOL was chosen as it is a stroke-specific measure of HRQoL. Compared with the other two commonly used stroke-specific tools, the Stroke Impact Scale and the HRQoL in stroke patients questionnaire, SSQOL has the advantages of containing a comprehensive battery of stroke-related domains, and of generating total and domain scores. The total number of items can reasonably be completed by stroke survivors (Ewert & Stucki, 2007; Ojo Owolabi, 2010). The SSQOL consists of 49 items organised into 12 domains including self-care, vision, language, mobility, work/productivity, upper extremity function, critical-thinking, personality, mood, family roles, social roles, and energy. The first part of the scale asks participants about their perceived level of trouble in performing daily tasks or activities in the preceding week. Each item is rated on a 5-point Likert scale from 1 “couldn’t do it at all” to 5 “no trouble at all”. Examples of the items are bathing, toileting, speaking, reaching over to pick up things, writing, and doing household work. The second part of the scale asks participants about their levels of agreement with statements based on their health condition in the preceding week. Each item was rated on a 5-point Likert scale from 1 “strongly agree” to 5 “strongly disagree”. Examples of the items include difficult to concentrate, being inpatient, feeling myself as a burden to the family, my health condition interferes with my family or social life, having no confidence in myself, or being too tired to do things that I want to do. The item scores were summed to yield the total score (range 49-245) and the domain scores. A higher total score indicates better HRQoL (Williams, Weinberger, Harris, Clark, et al., 1999). The SSQOL has high internal consistency (Cronbach’s alpha for all domains ≥0.73). Most domains are moderately correlated with similar domains of established outcome measures (r²=0.3-0.5) (Williams, Weinberger, Harris, Clark et al., 1999).

The Ph.D. candidate back-translated the original English version of SSQOL into the target Chinese (Cantonese) language and tested it for equivalence with a convenience sample of 135 Chinese community-dwelling stroke survivors. The results showed that the Chinese version of SSQOL consisted of 47 items in 11 domains. The
domains included activities, mood, energy and family role, language, upper extremity function, thinking, vision, relationships, personality, basic needs, leisure and work, and transfer. This new 11-factor model accounted for 67.25% of the total variance. It had high internal consistency. Cronbach’s alpha for the total scale was 0.93 and Cronbach’s alpha for all 11 domains ranged from 0.63 to 0.90. The test-retest reliability after four weeks was high, with an intraclass correlation coefficient for the total score of 0.57 (95% confidence interval: 0.27-0.77). Most domains had moderate to high correlations with the total scores of similar dimensions of the Chinese versions of the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), SSEQ, FAI and Barthel ADL Index (rs: 0.40-0.77, p<0.01), suggesting acceptable convergent validity. Appendices R and S show the original English and the translated Chinese versions of the SSQOL respectively. Cronbach’s alpha for the translated Chinese version of SSQOL in this study was 0.96.

**4.16.4.3 Depressive symptoms**

The Geriatric Depression Scale (GDS) was used to measure participants’ presence of depressive symptoms in the past week (Yesavage et al., 1983). The GDS has been applied extensively in clinical settings as a screening tool for depression among older people (Chau, Martin, Thompson, Chang, & Woo, 2006). It was originally developed as a 30-item questionnaire. Each item represented symptoms of depression and was rated on a yes/no format. A score of one was given to each “yes” item. The total score was calculated by summing the item scores (range 0-30). A score of 11 indicates mild depression while a score of 17 indicates severe depression. The 30-item GDS had high internal consistency with a Cronbach’s alpha of 0.94 and a test-retest reliability of 0.85. The discriminant validity was within 0.80 (Yesavage et al., 1983). A shorter version which consists of 15 items was later developed. The scoring method is the same in that a score of one is given to each “yes” item. The total score is calculated by summing each item score (range 0-15). A score of six or above suggests the presence of depression. The 15-item GDS was also found to have high internal consistency and validity (Yesavage et al., 1983).

The Chinese versions of the 30-item and 15-item GDS are available. Both versions were found to have high internal consistency and validity (Chan, 1996; Lee et al., 1993). Chau et al. (2006) compared the factor structure of the 30-item, 15-item and 4-item GDS. The results showed that both the 30-item and 15-item GDS had high
internal consistency, with Cronbach’s alphas of 0.88 and 0.78 respectively. A significant strong negative correlation was found between the London Handicap Scale scores and the 30-item GDS ($r=-0.31$, $p<0.01$), and 15-item GDS ($r=-0.30$, $p<0.01$). However, the performance of the 4-item GDS was marginal. In view of its high internal consistency and convergent validity, and ease of use, the 15-item GDS was adopted in this study. Participants in this study were asked about their agreement with each item based on their condition in the past week. Appendix T shows the original English version of GDS, and Appendix U shows the Chinese version of GDS. Cronbach’s alpha for the Chinese version of GDS in this study was 0.40.

4.16.4.4 Community reintegration

The 11-item RNLI developed by Wood-Dauphinee, Opzoomer, Williams, Marchand, and Spitzer (1988) was used to measure participants’ level of community reintegration after stroke. Participants were asked about the extent to which each statement related to six domains (mobility, self-care, activities, role within the family, comfort with relationships, and ability to handle life events) described their current situation. There are various response options developed for the RNLI. They include a 4-point ordinal scale, a 3-point ordinal scale, and a 10-cm visual analogue scale. The RNLI has been applied to people with different conditions such as stroke, traumatic brain injury, and spinal cord injury, with good internal consistency and construct validity. The RNLI has the advantage of taking less than 10 minutes to administer, in contrast with other measures of the same construct (Pang, Lau, Yeung, Liao, & Chung, 2011; Wood-Dauphinee et al., 1988).

The 11-item Chinese version of the RNLI developed by Pang et al. (2011) was used in this study to measure participants’ levels of community reintegration after stroke. The Chinese version adopted a 4-point scale from 1 “does not describe my situation” to 4 “fully describes my situation” to rate each item. Factor analysis showed that the Chinese version of RNLI had a two-factor structure, namely “daily functioning” and “perception of self”. A total score was derived by summing the items and normalising to 100 (range 25-100). A higher score indicated higher perceived community participation. The index had high internal consistency (Cronbach’s alpha 0.92) and good convergent validity. Significant associations were reported between the RNLI and FAI ($r=0.44$, $p<0.001$) (Pang et al., 2011). Appendix V shows the
original English version of RNLI and Appendix W shows the Chinese version of RNLI. Cronbach’s alpha of the Chinese version of RNLI in this study was 0.94.

4.16.5 Feedback on SSMP

Participants in the intervention group were contacted via phone by a research assistant (RA-C) immediately after completion of the SSMP (equivalent to five weeks after randomisation). The RA-C was not involved in administering any part of the SSMP. During the phone call, the participants were asked if they were satisfied with the program including the home visit, group sessions, follow-up phone calls, videos and program workbook. They were also asked about the most helpful and the least helpful part of the program.

4.16.6 Demographic and clinical information

Demographic information about the participants, including age, gender, educational level, occupation, marital status, living conditions, accommodation, main carer, social history, and financial assistance was recorded. Clinical information including duration after stroke onset, type and location of stroke, past health history, current medication regimen, medical follow-up, smoking habits, use of alcohol, use of assistive devices and health services utilisation was also recorded. Furthermore, physical examination was performed by the research assistants using instruments namely MMSE, Glasgow Coma Scale, NIHSS, and the Barthel ADL Index.

4.17 TRAINING FOR RESEARCH ASSISTANTS

Six research assistants assisted in the conduct of the RCT. Two served as recruiters, one as a scheduler, one as a caller, one as a data entry assistant, and one as an outcome assessor. Two research assistants (RA-Rs, two recruiters) helped with the recruitment of participants at the study venues. The third research assistant (RA-S, scheduler) assisted with scheduling for participants who were eligible and consented to participate in the study for baseline and 8-weeks follow-up assessments. The fourth research assistant (RA-C, caller) made phone calls at five weeks after randomisation to participants in the intervention group to elicit their feedback on the SSMP. The fifth research assistant (RA-D, data entry assistant) assisted in data entry. All five research assistants were final-year baccalaureate-nursing students who had good academic performance and had undertaken courses in nursing research. Another research assistant (RA-O, outcome assessor) conducted the baseline and 8-weeks follow-up
assessments at participants’ homes. The RA-O was a registered nurse and engaged in this study as a research assistant as approved by the respective employer hospital. All research assistants were provided with a half-day intensive training conducted by the Ph.D. candidate before commencement of recruitment and data collection. During the training, they were informed about the study aim, objectives and procedures. The importance of maintaining confidentiality and secure storage of data collected was emphasised. All research assistants were required to read and sign a confidentiality pledge to keep all data collected from this study strictly confidential (Appendix X).

In addition, the two recruiters (RA-Rs) were trained to assess stroke patients’ eligibility, obtain informed consent, and communicate with the stroke patients, their family members or carers, and the ward nurses. They were trained to record accurately the demographic and clinical information required of the participants who agreed to participate in the study. The RA-Rs were reminded of the importance of observing standard precautions. They wore a name badge indicating their identities as research assistants for the study when they were working in the wards.

The scheduler (RA-S) was trained in appropriate telephone etiquette for recruiting and scheduling. A script containing the areas to be covered during the phone calls was provided to the RA-S for reference. The Ph.D. candidate had regular discussions with the RA-S regarding appropriate responses to different reactions or queries by the participants, or their family members or carers.

The outcome assessor (RA-O) was trained in appropriate administration of all measuring instruments, and ethical considerations in obtaining informed consent. The RA-O was reminded to administer the assessment tools consistently and non-judgmentally. Inter-rater reliability between the RA-O and the Ph.D. candidate checked by Kappa statistics before data collection was high. To ensure safety, the RA-O was required to inform the Ph.D. candidate before and after completion of data collection at the participants’ homes.

The caller (RA-C) was trained in appropriate phone interview and questioning skills. Use of a consistent and non-judgemental tone of voice in questioning was emphasised. The information to be collected from the participants was provided to RA-C to ensure consistent collection of information. The RA-C was required to document the results accurately and clearly.
The data entry assistant (RA-D) who performed data entry was trained in the use of the statistical software for data entry. The RA-D was required to perform the data entry twice to ensure that the data were entered correctly.

The Ph.D. candidate coached all research assistants until their performance was satisfactory as assessed by the Ph.D. candidate before they were allowed to work independently. Regular meetings were held between the Ph.D. candidate and the research assistants to review the progress, and any difficulties or concerns encountered. There were no complaints or adverse events related to the research assistants reported by the ward nurses or the participants throughout the study.

4.18 DATA COLLECTION PROCEDURE

The research assistants (RA-Rs) visited the three study venues during visiting hours at least three times a week to screen and recruit eligible participants. Informed consent was obtained if the participants agreed to participate in the study. After the participants were discharged from the hospitals to their homes, another research assistant (RA-S) who was responsible for calling and scheduling with the participants, phoned the participants to determine if they were eligible to enter the study. If they were preliminarily deemed eligible, baseline assessment was scheduled with the participants at their homes at times convenient to the participants. This research assistant (RA-S) was also responsible for scheduling the 8-weeks follow-up assessments for all participants.

One research assistant (RA-O) was responsible for conducting baseline and 8-weeks follow-up assessments. During baseline assessments, the RA-O assessed the participants’ cognitive abilities by obtaining MMSE scores and assessed the participants’ eligibility to enter the study against the inclusion and exclusion criteria. The RA-O obtained written informed consent again with the participants if they met the eligibility criteria. Eligible participants, after consenting to participate, were invited to complete a questionnaire administered by the RA-O face-to-face. The participants’ demographic and clinical information were also collected. The baseline data collection was stopped if the participants did not meet any of the eligibility criteria. During administration of the questionnaire, cards displaying the meanings of scores for each measuring instrument were displayed to help the participants indicate their ratings. The baseline assessment took about one hour.
After the baseline assessments were completed, the participants were randomised to either the intervention or the control group. Immediately after completion of the SSMP, another research assistant (RA-C) who did not participate in any other part of the study phoned the participants in the intervention group to collect their feedback on usefulness of the SSMP. Each phone interview took about 10 to 15 minutes.

At eight weeks after randomisation or one month after completion of the SSMP, the RA-O performed the follow-up assessment. The format and procedure of the follow-up data collection were the same as that at baseline.

If the risks in particular the experience of negative psychological responses such as distress occurred during any part of the study or the participants were assessed to have a GDS score of six or above, and that were outside the scope of the SSMP examined in the study for management, the stroke nurse in the hospital where the participants were recruited would be consulted for re-scheduling of the participants’ medical follow-up appointment at the hospitals, or for referral to a medical social worker or a clinical psychologist if needed. The participants might also be referred to the community social worker to arrange relevant social services.

4.19 STATISTICAL ANALYSES

Statistical analyses were performed using the IBM SPSS Statistics version 22 (SPSS Inc., Chicago, IL, USA). A research assistant (RA-D) who was not involved in other part of the study performed double data entry. All continuous variables were first assessed for normality in distribution. Normal distribution of the data was assumed if the data had a skewness and kurtosis statistics within -1 and 1, and there was a reasonable fit of points to the straight diagonal line in the normal Q-Q plots (Portney & Watkins, 2009). Significance level was set at two-tailed p<0.05.

4.19.1 Baseline comparison

Descriptive statistics were used to summarise the participants’ baseline demographic and clinical characteristics, and outcome measures. Continuous variables were presented in means and SDs if the data followed a normal distribution, while the variables were presented in medians and interquartile range if normality of the data could not be assumed. Categorical variables were presented as frequencies and percentages. Independent-samples t-tests and Mann-Whitney U tests were used for
continuous variables, and Chi-square tests and Fisher’s exact tests were used for categorical variables as appropriate (Portney & Watkins, 2009), to compare the differences in baseline characteristics and outcome measures between the intervention and the control groups. Comparisons between the participants who continued and discontinued the study were performed to determine any significant differences between the two groups.

4.19.2 Analysis of outcome variables

Generalised estimating equations (GEE) (Zeger & Liang, 1986; Zeger, Liang, & Albert, 1988) were employed to examine the differential changes of outcome variables including SSEQ, SSOES, SSBPS, SSQOL, GDS, and RNLI across time points (from baseline to 8-weeks follow-up) between the intervention and the control groups. The GEE model is a multilevel regression technique, which is increasingly employed in longitudinal studies. There are several benefits of using GEE models compared with the traditional repeated measures analysis of variance (ANOVA). The GEE models can account for data with different distributions, such as continuous, binary, ordinal, categorical and count. They can also appropriately accommodate different inherent correlations of repeated observations taken from the same individual. Moreover, GEE models are more flexible in handling missing data due to dropouts and incomplete visits, provided that the data are missed completely at random. While traditional repeated measures ANOVA requires listwise deletion to handle missing data, however GEE models can include data with incomplete measurements and hence keep the number of cases. Furthermore, since GEE models do not require imputation to replace the missing data, it minimises type I error and avoids an underestimation of standard errors and validity problems (Ghisletta & Spini, 2004; Hardin & Hilbe, 2013; Twisk, 2004).

To use GEE models, the distribution of the repeated measures outcome variables including SSEQ, SSOES, SSBPS, SSQOL, GDS, and RNLI was first examined before entering into the GEE models to determine the most appropriate link function. The identity link function was considered the most appropriate for a normally distributed outcome variable (Hardin & Hilbe, 2013; Zeger & Liang, 1986). All skewed continuous variables were log-transformed to correct them to a normal distribution. Reverse score log10 transformation was used to transform negatively
skewed data, while log10 transformation was used to transform positively skewed data (Portney & Watkins, 2009).

The working correlation structure is specified to define the hypothesised relationship between the repeated measures of a participant. In this study, GEE models with a first-order autoregressive correlation structure (AR-1) were fitted to assess the outcome variables over time while accounting for the effects of potential confounding factors. This assumption is appropriate for balanced longitudinal data that are more correlated when it is closer in time compared with data that are measured farther apart in time. Balanced data are resulted in RCTs that the participants are assessed at the same time interval. However, GEE models are robust to misspecification of the working correlation structure regardless of the specification (Zeger & Liang, 1986).

The GEE models were also used to adjust for potential confounding factors which might have caused confounding effects on the outcome variables examined. The potential confounding factors included the demographic and clinical variables that had a p-value of <0.25 for the difference between the intervention and the control groups. A cut-off point of p<0.25 as recommended by Mickey and Greenland (1989) indicated unbalance between the two groups (Hosmer, Lemeshow, & Sturdivant, 2013; Mickey & Greenland, 1989). Both GEE models which were adjusted and unadjusted for potential confounding factors are presented for comparison.

A dummy variable of time points was set to correspond “Time” with the 8-weeks follow-up, with the baseline used as the reference. Another dummy variable of treatment groups was set to correspond “Group” with the intervention group, and the control was used as the reference. The interaction term Group*Time was included in the GEE models to assess the differential changes in outcome variables across time between the intervention and the control groups.

4.19.3 Intention-to-treat population

Analyses of outcome variables were performed for participants included in the ITT population, per-protocol population, and population with different doses of the SSMP received. Analyses based on the principles of ITT were performed to maintain the integrity of randomisation and strengthen the internal validity of the study (Polit & Gillespie, 2010). The CONSORT 2010 Statement advocates the ITT principles. True or classic ITT is one that includes every participant who is randomised regardless of the treatments received, study withdrawal and protocol deviations. It allows the
comparison of the effectiveness of the intervention offered rather than the intervention received, and reflects the situation that would actually happen in clinical practice. Therefore, confounding between the treatment groups is minimised. The ITT analyses are important, as a systematic review found that the effect size estimates were about 25% higher when the data were analysed using per-protocol analyses (Gupta, 2011). However, ITT analyses may underestimate the treatment effect among participants who adhered to the intervention regimens if there are participants who do not complete the full intervention (Gupta, 2011).

4.19.4 Per-protocol population

Analyses of the per-protocol population included the comparison between the participants who received all sessions of the SSMP (full completers) and those who were allocated to the usual care control group. All the per-protocol population provided both baseline and follow-up assessment data. Those participants who did not meet the definition of full completers including those who did not attend any program sessions were excluded from the analyses. Per-protocol analyses may introduce selection bias and consequently threaten the internal validity of the results. It may also underestimate withdrawal due to adverse effects related to the intervention. However, per-protocol analyses can provide an indication of the maximum treatment efficacy in patients who adhered fully to the intervention received (Tilbrook et al., 2014).

4.19.5 Analyses of effective dose

Secondary analyses were conducted to explore the association of dose of the SSMP received by participants with changes in outcome variables. The GEE models were conducted to examine the differential changes in outcome variables across time between groups of participants who received different doses of the SSMP. The participants were divided into three groups according to their attendance of the SSMP and whether they had provided complete baseline and follow-up assessment data. The three groups included full completers who received all sessions of the program; partial completers who attended at least one session but did not fully adhere to the program; and the control group.

4.20 ETHICAL CONSIDERATIONS

Ethical approvals were obtained from the research ethics committees concerned before conducting the RCT. Ethical approval was first obtained from the
Kowloon West Cluster Research Ethics Committee, Hospital Authority, Hong Kong (Ethical Approval No.: KW/EX-14-021(71-21)) (Appendix Y) in March 2014 for conducting the study in two study hospitals. Ethical approval was also obtained from the Human Research Ethics Committee of the Queensland University of Technology (Ethical Approval No.: 1400000333) (Appendix Z) in June 2014. After obtaining the ethical approvals, one of the study hospitals (Hospital B) decided not to grant access to the study for recruitment of participants at the acute stroke unit due to manpower concerns. Discussions were held with Hospital B again, and they then agreed to support the study in June 2014. The research team decided to add one more study venue to facilitate the recruitment of participants. Ethical approval to conduct the RCT at the third hospital was obtained from the Joint Chinese University of Hong Kong- New Territories East Cluster Clinical Research Ethics Committee, Hong Kong (CREC Ref. No.: 2014.375-T) (Appendix AA) in August 2014. An update in the ethical application to the Human Research Ethics Committee of the Queensland University of Technology was approved in November 2014. The ethical application was updated and approved in December 2014 again for changes in the study protocol, including changing from two weekly group sessions of the SSMP to two consecutive group sessions held in one day, providing incentives in the form of supermarket coupons for all participants who completed both the baseline and follow-up assessments of the study, and reimbursement of travel fares on request for participants to attend the group sessions held in the nurse-led clinic. The research ethics committees of the two hospital clusters in Hong Kong approved the relevant updates in the study protocol.

Informed written consent was obtained from all participants before commencing data collection. Appendix BB shows the information sheet and informed consent form for participants. Research assistants provided adequate time (about one hour) for the potential participants to consider joining the study. All potential participants received a full explanation by a research assistant about the purpose and data collection process of the study, and the potential participants’ right to voluntarily participate, or to refuse to participate, or to withdraw from the study without any negative consequences on their stroke care management offered by the hospital. Furthermore, the potential benefits and risks of participating in the study were explained to the participants. The likely benefits of participating in the study would be to help provide valuable evidence to determine the best approach for delivering stroke
self-management programs for community-dwelling stroke survivors for improving their recovery.

The potential risks included the risk to the participants in the intervention group. Since the participants had just been discharged to home settings, they might be vulnerable and have different negative psychological responses to stroke such as anxiety. They might recall their health problems while participating in the discussion about medical, emotional and role management after stroke. It might cause them discomfort or negative psychological responses. If the participants in the intervention group were required to arrange their own transport to get to the nurse-led clinic to join the group sessions of the program, the identified potential risks included inconvenience or discomfort when they travelled to the nurse-led clinic. However, the likelihood of the risk occurring was expected to be low. The participants in the control group received usual care only. It was expected that there would be no identified potential risk related to joining the study.

It was expected that the potential benefits would far outweigh the minimal risks that might result from the stroke participants’ participation in the study. However if any of these risks, in particular the experience of negative psychological responses such as distress, occurred during the study or arose after the completion of the study, for were outside the scope of the self-management program examined in the study, the stroke nurse in the hospital where the participants were recruited would be consulted whether re-scheduling of medical follow-up appointment, or for referral to a medical social worker or clinical psychologist was needed. The participants might also be referred to the community social worker for arranging relevant social services. Adverse events, if any, would be reported immediately in writing to the Kowloon West Cluster Research Ethics Committee, Hospital Authority, Hong Kong; the Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee, Hong Kong; and the Human Research Ethics Committee of the Queensland University of Technology.

All questionnaires collected were anonymous and were used for research purposes only. All information collected was kept strictly confidential and would be destroyed six years after completion of the study. The federal and institutional ethical standards, Hong Kong Personal Data (Privacy) Ordinance, Declaration of Helsinki, and ICH-GCP were upheld.
All personal data and identifying information including the participants’ names, addresses, phones, hospitals, and wards, were kept in a locked cabinet in an office before and after the study. The personal identifying information was removed and replaced by study codes after being collected. Softcopies of the data were stored in files with encryption and in a secure private computer. All information collected was kept strictly confidential. No personal identifying information would be reported in publications.

A brief summary of the study results was mailed to all participants on request when the results were available. During the follow-up assessments, the research assistant asked about the participants’ willingness to receive a copy of the summary of study results.

4.21 TIMELINE OF THE STUDY

Table 4.6 shows the timeline of the conduct of the RCT. The translation and testing of equivalence of the SSEQ and SSQOL took about one year in 2012/2013 in order to obtain research ethics approval, recruit participants, and conduct face-to-face interviews to administer the questionnaires, data entry and statistical analyses.

Table 4.6 Timeline of the conduct of the randomised controlled trial

<table>
<thead>
<tr>
<th>Tasks</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Translation and testing of equivalence of</td>
<td></td>
</tr>
<tr>
<td>the SSEQ and SSQOL</td>
<td></td>
</tr>
<tr>
<td>Development of the SSMP, workbook, and</td>
<td></td>
</tr>
<tr>
<td>videos</td>
<td></td>
</tr>
<tr>
<td>Development and testing of the SSOES and</td>
<td></td>
</tr>
<tr>
<td>SSBPS</td>
<td></td>
</tr>
<tr>
<td>Obtained ethical approvals</td>
<td></td>
</tr>
<tr>
<td>Recruitment of participants</td>
<td></td>
</tr>
<tr>
<td>Delivery of the intervention</td>
<td></td>
</tr>
<tr>
<td>Baseline and follow-up assessments</td>
<td></td>
</tr>
<tr>
<td>Statistical analyses</td>
<td></td>
</tr>
<tr>
<td>Writing up reports</td>
<td></td>
</tr>
<tr>
<td>Dissemination of results</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: SSBPS, Stroke Self-management Behaviours Performance Scale; SSEQ, Stroke Self-Efficacy Questionnaire; SSMP, Self-efficacy enhancing stroke self-management program; SSOES, Stroke Self-management Outcome Expectation Scale; SSQOL, Stroke Specific Quality of Life Scale.
It took about 10 months to obtain ethical approvals from the research ethics committees concerned before commencing participant recruitment for the RCT in Hospital A and Hospital B in Hong Kong. It took another six months to obtain ethical approval from the research ethics committee to conduct participant recruitment for the RCT in Hospital C, and to update the research ethics committees concerned about the changes in the study protocol.

The conduct of the videotaped semi-structured interviews, production of videos, and development of the SSMP and the program workbook were conducted simultaneously. It took about eight months in 2013/2014 to complete the preparation, literature reviews and development. Then it took about two months in 2014 to conduct the content validity assessment and pilot test of the SSMP and the program workbook, and make revisions based on the comments of the expert panel. The development and pilot testing of the two new instruments, SSOES and SSBPS, were conducted simultaneously with the development of the SSMP and the videos. It took about 10 months to review the literature, generate the items, conduct content validity and pilot testing, and validate and finalise the items in the two new instruments.

The recruitment of the study participants from the acute stroke units took about 16 months in 2014/2015 to obtain 128 participants who consented to and completed the study. The SSMP was repeatedly conducted to accommodate the 64 participants assigned to join the intervention group. The conduct of follow-up assessment required two more months beyond the end of the recruitment period, and was completed in December 2015. Statistical analyses and preparation of the thesis were performed immediately after completion of data collection.

4.22 SUMMARY

This chapter reports the conduct of an RCT, in Phase Two of the Ph.D. research project, which was aimed to examine the effectiveness of a new nurse-led self-efficacy enhancing stroke self-management program (SSMP) on recovery of Chinese community-dwelling adult stroke survivors. As informed by the results of the systematic review conducted in Phase One, the new stroke self-management program was underpinned by Bandura’s constructs of self-efficacy and outcome expectation. The program lasted for four weeks and consisted of three components, namely one individual home visit, two group sessions held at a nurse-led clinic and three follow-
up phone calls. The program featured the use of videotaped experience sharing by role models who had successfully managed stroke. A specifically designed program workbook was also provided. The participants were recruited from three acute stroke units and the new program commenced after they were discharged to home. All participants were assessed at home at baseline before randomisation and at eight weeks after randomisation. Primary outcomes included stroke participants’ self-efficacy in and outcome expectation for stroke self-management. Secondary outcomes included stroke participants’ satisfaction with performance in stroke self-management behaviours, HRQoL, depressive symptoms and community reintegration. Details about the development of two new measuring instruments for adoption in the RCT, and the results of the RCT are reported in the following two chapters. It is expected that the new program would enhance Chinese community-dwelling stroke survivors’ self-efficacy in and outcome expectation for stroke self-management, increase their satisfaction with performance in stroke self-management behaviours, improve HRQoL, reduce depressive symptoms, and improve community reintegration. The results of the RCT would provide valuable evidence to inform future identification, implementation, and evaluation of the best approach for delivering community-based stroke self-management programs. It is anticipated that this program can be integrated into current health services for stroke survivors after transition from hospital.
Chapter 5: Development of Measuring Instruments (Phase Two)

5.1 INTRODUCTION

This chapter discusses and reports the methods and results of the development and examination of the reliability and validity of two new measuring instruments, the Stroke Self-management Outcome Expectation Scale (SSOES) and the Stroke Self-management Behaviours Performance Scale (SSBPS). As informed by the results of the systematic review in Phase One, Bandura’s constructs of self-efficacy and outcome expectation were adopted as the theoretical framework to underpin the design, implementation and evaluation of a new stroke self-management program examined in Phase Two. Adoption of reliable and valid instruments to measure stroke survivors’ outcome expectation for stroke self-management and their perceived performance in the behaviours is important. However, there were no validated instruments in Chinese for assessing these two outcomes. Therefore, the SSOES and the SSBPS were developed and adopted in the RCT in the second phase for evaluation of the effectiveness of the new stroke self-management program.

5.2 OUTCOME EXPECTATION FOR STROKE SELF-MANAGEMENT

Outcome expectation is one of the key constructs of Bandura’s SCT. It refers to a person’s judgement of the likelihood of occurrence of an outcome after performing a particular behaviour (Bandura, 1977). Bandura (1997) suggested that human behaviours are not only explained by a person’s beliefs in self-efficacy in performing a behaviour, but also the person’s beliefs in the outcomes associated with performing the behaviour. The more a person believes in the likely occurrence of positive outcomes associated with performing the behaviour, the more likely the person will perform the behaviour. The relationships between self-efficacy, outcome expectation and the behaviours are depicted in Figure 2.3.

Outcome expectation takes three major forms, namely physical, social and self-evaluative effects that accompany the behaviour. These effects can be positive and negative within each form. Positive effects serve as incentives for performing the behaviours, while negative effects serve as disincentives (Bandura, 1977). The types
of outcome expectation differs among individuals and may change over time. Bandura (1997) suggested that outcome expectation is affected by cultural, social, economic, and sexual factors, and racial differences.

Positive physical effects include positive sensory experiences and physical pleasure, while negative physical effects include negative sensory experiences, pain and discomfort (Bandura, 1977). For example, stroke survivors may have increased self-efficacy, increased perceived social interaction and support, and self-satisfaction in their ADL independence after exercising (Kuluski et al., 2014; Nicholson et al., 2014). These positive expectations may serve as facilitators to increase their participation in rehabilitation training. On the contrary, stroke survivors may decrease their motivation and participation in physical activities if they expect fatigue or have fear about deterioration in health conditions after exercising, or expect negative emotions such as embarrassment arising from performing physical activities (Duncan et al., 2012; Nicholson et al., 2014). Hence, this may slow their rate of post-stroke recovery.

Positive social effects include social reactions of others, such as social recognition, increased opportunities for social reactions, attaining social approval, and expressions of interest. Negative social effects include disinterest, disapproval and social rejection (Bandura, 1997). Studies found that stroke survivors welcomed the development of a social support network after participating in community-based group activities such as self-management programs (Huijbregts et al., 2008; Kendall et al., 2007). However, they might feel isolated or discriminated if community resources were not easily accessible, or other people were doubtful about their working ability when the stroke survivors returned to work (Wang et al., 2014; Wolfenden & Grace, 2009). It might affect their determination and attempts to return to work after stroke.

Self-evaluative effects include reactions to own behaviours. They can be positive such as self-satisfaction and anticipated superior attainment. They can also be negative, such as self-criticism and anticipated social disapproval (Bandura, 1977). For example, stroke survivors enjoyed a sense of life satisfaction and self-worth after continuing to participate in valued or leisure activities. They might also have a sense of self-criticism if they failed to perform a task compared with other people with or without stroke (Kuluski et al., 2014).
Some studies found that outcome expectation was one of the significant predictors of exercise behaviours among older individuals including those with stroke (Shaughnessy et al., 2012). Shaughnessy et al. (2004) showed that self-efficacy beliefs accounted for 13% of the variance in exercise, while outcome expectation accounted for another 2% of the variance in exercise. However, there is a dearth of studies that have examined the stroke survivors’ outcome expectation accompanying stroke self-management behaviours. The findings from further studies would be worthwhile for informing effective strategies to promote positive outcome expectation among stroke survivors. There has also been no published instrument to measure the outcomes expected after accomplishing the behaviours. A reliable and valid measuring instrument is warranted.

5.3 PERFORMANCE IN STROKE SELF-MANAGEMENT BEHAVIOURS

Self-management, as the name implies, is about managing one’s condition by oneself to live well with the consequences associated with a chronic condition. Effective self-management relies heavily on the active participation of the persons with chronic conditions (Barlow et al., 2002). Moreover, it requires the management of three major aspects, including physical, psychological and social (Barlow et al., 2002). Lorig et al. (2012) suggested that practising self-management behaviours is required and common among people with different chronic conditions. Furthermore, people with chronic conditions need to learn and practise five core self-management skills such as goal-setting, action planning, or problem-solving to attain effective self-management.

Medical management refers to managing physical symptoms consequential to a chronic illness or adopting the health practices required to live with the chronic illness. In addition to those mentioned above, medical management also includes symptom management, attending medical follow-up appointment, healthy eating and adequate rest (Lorig et al., 2012). Common to stroke survivors, these self-management behaviours are important. Additional self-management behaviours include regular therapeutic exercise, speech therapy and exercise, ADL training, cognitive training, and fatigue management. Depending on the stroke severity, stroke survivors may engage in these self-management behaviours to different intensities or priorities (SIGN, 2010).
Emotional management refers to managing the negative emotions associated with living with a chronic condition (Lorig et al., 2012). Stroke is a traumatic experience for stroke survivors and their families. Studies reported different emotional trajectories after stroke, including gradual improvement, fluctuating mood, resilience or constant depressive symptoms (White et al., 2012). Stroke survivors need to develop confidence and skills in managing their depressive symptoms, staying positive, and enhancing their self-efficacy in managing their conditions in the light of future uncertainties (Pallesen, 2014).

Role management refers to assuming previous or taking up new family, social or life roles after the chronic condition. These include helping with household chores, returning to work, joining family or social activities, or meeting up with friends (Lorig et al., 2001). Stroke survivors are also expected to resume their pre-stroke family, social and life roles, or to learn new skills to assume new family, social or life roles (Lorig et al., 2012). Stroke survivors are encouraged to return to work depending on their capabilities. In addition, they are encouraged to participate in valued or leisure activities to enhance their sense of self-worth and identity (Kuluski et al., 2014).

Managing the three aspects well can be difficult, and the practice of core self-management skills facilitates the daily judgement of priorities and performance of the behaviours. The five core self-management skills are problem-solving, making decisions on daily health behaviours, establishing goals and action plans related to stroke recovery, efficiently utilising community or other resources to improve health, and communicating effectively with healthcare professionals (Lorig et al., 2001).

Results of the systematic review conducted in Phase One showed that the construct of self-efficacy (Bandura, 1997) had been commonly adopted to underpin stroke self-management programs. As postulated in the construct, enhancing stroke survivors’ self-efficacy enables behavioural changes in participation in the target stroke self-management behaviours, and in turn achieving improved health outcomes (Bandura, 1997). Stroke survivors’ participation in self-management behaviours and exercise of self-management skills are prerequisites for attaining improved health outcomes. Measuring stroke survivors’ participation in these behaviours and skills would be integral for assessing the effectiveness of stroke self-management programs. It enables better interpretation of changes in health outcomes in relation to behavioural changes after receiving the program.
However, the systematic review results showed that only one of the three included studies measured stroke self-management behaviours. This study measured the duration in minutes of exercise performed, level of social and recreation activities, and frequency of performing cognitive or mental relaxation in the past week using the Chronic Disease Self-management Behaviours scales (Damush et al., 2011). However, the scales were limited in that the use of core self-management skills is not assessed. There has been no validated measuring instrument which assesses the performance in stroke self-management behaviours and core self-management skills. Availability of such these instruments would enable the identification of stroke self-management behaviours and skills that require more support by healthcare professionals.

5.4 AIM AND OBJECTIVES

The aim of this study was to develop and test the reliability and validity of two new measuring instruments for assessing stroke survivors’ outcome expectation and satisfaction with performance in stroke self-management behaviours respectively.

Specific objectives were to:

1. Develop and establish the reliability and validity of the Stroke Self-management Outcome Expectation Scale (SSOES) for assessing stroke survivors’ outcome expectation for stroke self-management; and

2. Develop and establish the reliability and validity of the Stroke Self-management Behaviours Performance Scale (SSBPS) for assessing stroke survivors’ satisfaction with their own performance in stroke self-management behaviours.

5.5 METHODS

The study was divided into four phases. First, the items in each of the two measuring instruments, namely the SSOES and the SSBPS were generated in English from in-depth interviews with 15 community-dwelling stroke survivors and a critical literature review. Second, the SSOES and the SSBPS were translated into Traditional Chinese using forward- and back-translation. Next, the preliminary Chinese versions of the two instruments were subjected to content validity assessment by an expert panel of eight members, followed by pilot testing with another six community-dwelling stroke survivors. Amendments were made based on the panel’s comments. The stroke survivors in the pilot test completed the SSOES and the SSBPS without the need for
further explanations, and no amendment was made. Finally, the Chinese versions of the two instruments were administered to a convenience sample of 83 community-dwelling stroke survivors to test reliability and convergent validity.

5.5.1 In-depth interviews with stroke survivors

The Ph.D. candidate conducted individual face-to-face semi-structured interviews with a purposive sample of 15 Chinese community-dwelling stroke survivors to generate a pool of patient-initiated items. Among the stroke survivors, eight were male and seven were female. The mean age of the survivors was 60.87 years (SD 10.11, range 35-80 years). Most were married (n=11) and retired (n=11). The mean duration since the last stroke was 10.37 years (SD 7.45). Ten of the survivors had ischaemic stroke and five had haemorrhagic stroke. All except four walked with a stick and seven had slurred speech. One was illiterate and nine had attained primary school education. The remaining five had attained secondary school education. The stroke survivors’ demographic and clinical information are presented in Table 4.4 in Chapter Four.

During the interviews, the stroke survivors were asked about the outcomes that they expected to occur after performing stroke self-management behaviours. It was found that performance of one self-management behaviour was associated with at least one form of outcome expectation, namely physical, social and self-evaluative effects (Bandura, 1997). Most stroke survivors commented that they performed exercise regularly as they believed that exercise carried the physical effects of keeping them healthier and making them more physically independent. It also carried the social effects of enjoying a sense of belonging and support among friends. Furthermore, it was accompanied by the self-evaluative effects of self-satisfaction. While positive effects of outcome expectation were cited, negative effects were also verbalised. Some stroke survivors associated exercise with increased pain and discomfort. They might perceive themselves as defeated due to failure to perform the exercises (Table 5.1). Furthermore, the same outcome expectation might be achieved by different self-management behaviours, for example, listening to music, talking with family or friends, or participating in social activities are accompanied by physical comfort and pleasure, interests in other people or events, and a sense of self-satisfaction (Table 5.2 and Table 5.3). The most frequently mentioned physical, social, and self-evaluative effects of outcome expectation for stroke self-management were physical comfort, ADL
independence, interest in other people or events, and feelings of self-worth (Tables 5.1 to 5.3).

During the interviews, respondents were also asked about the behaviours that they performed to manage their post-stroke health, and the importance of these behaviours in their stroke recovery. A list of 17 key stroke self-management behaviours was identified from the interviews. Based on the findings of the interviews, certain skills were frequently cited as important in daily life to solve the challenges encountered. The skills included establishing goals and action plans, fostering self-confidence, and evaluating and modifying strategies to improve their current situations. Exercise of these skills was important to enhance one’s readiness and capabilities to change, and to sustain self-management behaviours to promote physical and psychosocial health (Table 5.4). It was found that these skills were in line with the suggestions by Lorig et al. (2001) for developing core self-management skills for effective self-management. In particular, these related to the development of skills in goal-setting and action-planning, problem-solving and decision-making. Other behaviours that were cited by the stroke survivors as important to their stroke recovery could be categorised into three aspects. They included 1) behaviours performed to promote physical health; 2) behaviours performed to promote psychological well-being; and 3) behaviours performed to promote community reintegration (Table 5.5). These three aspects of stroke self-management behaviours were consistent with the three aspects of self-management, namely medical, emotional and role management. In turn, they addressed health needs in relation to the three domains of stroke recovery, namely physical, psychological, and social domains (Vanhook, 2009).
<table>
<thead>
<tr>
<th>Stroke self-management behaviours for medical management</th>
<th>Outcomes likely to be achieved</th>
<th>Physical</th>
<th>Social</th>
<th>Self-evaluative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Exercise regularly</td>
<td></td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Healthier and stronger</td>
<td>- Sense of belonging and support among peers</td>
<td>- Self-satisfaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- More physically independent</td>
<td>- Able to achieve something</td>
<td>- Able to overcome something</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Reduced joint stiffness and pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative:</td>
<td>- Increased pain and discomfort</td>
<td></td>
<td>- Self-defeated</td>
</tr>
<tr>
<td>2. Consume a low salt, low fat, high fibre diet</td>
<td></td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Healthier</td>
<td>- Recognition by family members or carers</td>
<td>- Self-evaluation as “within normal range” in blood cholesterol test and blood pressure level</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Lower risk of recurrent stroke</td>
<td>- Disapproval by family members or carers</td>
<td>- Deficient level of attainment</td>
</tr>
<tr>
<td>3. Have adequate sleep and rest</td>
<td></td>
<td>Positive:</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Less fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Take medications as prescribed</td>
<td></td>
<td>Positive:</td>
<td>--</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Maintain good health</td>
<td></td>
<td>- Able to manage health</td>
</tr>
<tr>
<td>5. Attend follow-up medical appointments as scheduled</td>
<td></td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Ensure staying healthy</td>
<td>- Reassurance and encouragement by healthcare professionals</td>
<td>- Anticipated recognition by healthcare professionals</td>
</tr>
</tbody>
</table>
### Table 5.2 Stroke survivors’ outcome expectation for performing self-management behaviours related to emotional management of stroke

<table>
<thead>
<tr>
<th>Stroke self-management behaviours for emotional management</th>
<th>Physical</th>
<th>Social</th>
<th>Self-evaluative</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Stay positive</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Expressions of interests in other people or events</td>
<td>- Sense of self-worth</td>
</tr>
<tr>
<td>7. Think of things other than stroke</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Expressions of interests in other people or events</td>
<td>- Sense of hope in future</td>
</tr>
<tr>
<td></td>
<td>--</td>
<td>- Social support and recognition</td>
<td>- Self-satisfaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Social disapproval</td>
<td>- Judgement of self-efficacy</td>
</tr>
<tr>
<td>8. Listen to music</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Develop closer relationships with others</td>
<td>- Self-satisfaction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Expressions of interests in other people or events</td>
<td>- Anticipated social disapproval</td>
</tr>
<tr>
<td>9. Talk with family or friends</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Develop closer relationships with others</td>
<td>- Judgement of self-efficacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Expressions of interests in other people or events</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Social support and recognition</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Social disapproval</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Disinterest or rejection by others</td>
<td></td>
</tr>
</tbody>
</table>
Table 5.3 Stroke survivors’ outcome expectation for performing self-management behaviours related to role management of stroke

<table>
<thead>
<tr>
<th>Stroke self-management behaviours for role management</th>
<th>Outcomes likely to be achieved</th>
<th>Physical</th>
<th>Social</th>
<th>Self-evaluative</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. Maintain relationships with family and friends</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Develop closer relationships with others</td>
<td>- Sense of self-worth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Fatigue</td>
<td>- Expressions of interests in other people or events</td>
<td>- Sense of hope in future</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Pain or increased discomfort</td>
<td>- Social support and recognition</td>
<td>- Self-satisfaction</td>
<td></td>
</tr>
<tr>
<td>11. Participate in social activities</td>
<td>Negative:</td>
<td>Negative:</td>
<td>Negative:</td>
<td>Negative:</td>
</tr>
<tr>
<td>12. Join support groups</td>
<td></td>
<td>- Social disapproval</td>
<td>- Judgement of self-efficacy</td>
<td></td>
</tr>
<tr>
<td>13. Maintain or develop leisure activities or hobbies</td>
<td></td>
<td>- Disinterest or rejection by others</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Physical comfort and pleasures</td>
<td>- Develop closer relationships with others</td>
<td>- Sense of self-worth</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Increased ADL independence</td>
<td>- Expressions of interests in other people or events</td>
<td>- Sense of hope in future</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Social support and recognition</td>
<td>- Self-satisfaction</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Monetary compensation</td>
<td>- Judgement of self-efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Negative:</td>
<td>Negative:</td>
<td>Negative:</td>
<td>Negative:</td>
</tr>
<tr>
<td></td>
<td>- Fatigue</td>
<td>- Social disapproval</td>
<td>- Anticipated social disapproval</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Pain or increased discomfort</td>
<td>- Disinterest or rejection by others</td>
<td>- Self-defeated</td>
<td></td>
</tr>
</tbody>
</table>
Table 5.4 Behaviours performed by stroke survivors that were important for successful management of post-stroke health condition

<table>
<thead>
<tr>
<th>Stroke self-management behaviours</th>
<th>Aspects of self-management</th>
<th>Domains of stroke recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Performed to promote physical health</td>
<td>Medical</td>
<td>Physical</td>
</tr>
<tr>
<td>1. Exercise regularly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Consume a low salt, low fat, high fibre diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Have adequate sleep and rest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Take medications as prescribed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Attend follow-up medical appointments as scheduled</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performed to promote psychological well-being</td>
<td>Emotional</td>
<td>Psychological</td>
</tr>
<tr>
<td>6. Stay positive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Think of things other than the stroke</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Listen to music</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Talk with family or friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performed to promote community reintegration</td>
<td>Role</td>
<td>Social</td>
</tr>
<tr>
<td>10. Maintain relationships with family and friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Participate in social activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Join support groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Maintain or develop leisure activities or hobbies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Return to work</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.5 Stroke survivors’ perceptions of skills that were important for successful management of post-stroke health condition

<table>
<thead>
<tr>
<th>Core self-management skills</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>To enhance readiness to change and sustain stroke self-management behaviours</td>
<td></td>
</tr>
<tr>
<td>15. Establish goal(s) in recovery and an action plan</td>
<td></td>
</tr>
<tr>
<td>16. Foster confidence in oneself</td>
<td></td>
</tr>
<tr>
<td>17. Think of, try and evaluate possible solutions to improve a current situation or a challenge</td>
<td></td>
</tr>
</tbody>
</table>

5.5.2 Stroke survivors’ outcome expectation and self-management behaviours

Outcome expectation

In addition to the views of stroke survivors the relevant literature was examined to identify stroke survivors’ outcome expectations of successful management of post-stroke health conditions, and benefits of managing post-stroke challenges (Dougherty
et al., 2007; Lorig et al., 2001; Lorig et al., 2012; Resnick et al., 2000). The outcome expectations reported in the literature were similar to those mentioned by the stroke survivors recruited in the interviews mentioned in the previous section. However, some additional outcomes identified from the literature included: facilitation of initiation and sustainability of self-management behaviours for physical comfort and sensory pleasure; judgement of self-efficacy; anticipated control over life events; perceived capabilities to solve challenges; and self-satisfaction (Lorig et al., 2012) (Table 5.6).

Table 5.6 Stroke survivors’ outcome expectation for exercising core self-management skills to manage stroke

<table>
<thead>
<tr>
<th>Core self-management skills</th>
<th>Outcomes likely to be achieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Establish goal(s) in recovery and an action plan</td>
<td>Positive:</td>
</tr>
<tr>
<td>- Foster confidence in oneself</td>
<td>- Facilitate initiation and sustainability of self-management</td>
</tr>
<tr>
<td>- Think of, try and evaluate possible solutions to improve a current situation or a challenge</td>
<td>behaviours for physical comfort and sensory pleasures</td>
</tr>
<tr>
<td></td>
<td>(Lorig et al., 2012)</td>
</tr>
<tr>
<td></td>
<td>Positive:</td>
</tr>
<tr>
<td></td>
<td>- Judgement of self-efficacy</td>
</tr>
<tr>
<td></td>
<td>- Anticipated control in life events</td>
</tr>
<tr>
<td></td>
<td>- Perceived capabilities to solve challenges</td>
</tr>
<tr>
<td></td>
<td>- Self-satisfaction</td>
</tr>
<tr>
<td></td>
<td>(Lorig et al., 2012)</td>
</tr>
</tbody>
</table>

Furthermore, instruments which measured stroke survivors’ outcome expectation for undertaking a range of behaviours were reviewed in regard to response scales used: undertaking exercise (Shaughnessy et al., 2012), older adults’ outcome expectation of doing exercise (Resnick et al., 2000; Wojcicki, White, & McAuley, 2009), male adolescents’ outcome expectation of leisure time physical activity (Abasi, Eslami, & Rakhshani, 2015); and alcoholics’ outcome expectation of changing their drinking behaviours (Soloman & Annis, 1989). The response options ranged from level of confidence in the likelihood of occurrence of the outcomes on an 11-point Likert scale (from 0 “no confidence at all” to 10 “extremely confident”) (Chang & Crowe, 2011), beliefs in the likelihood and value of the consequences of performing the leisure-time physical activity on a 5-point Likert scale (from 1 “absolutely correct”
to 5 “absolutely incorrect”) (Abasi et al., 2015), to agreement with statements about benefits of exercise on a 5-point Likert scale from 1 “strongly agree” to 5 “strongly disagree” (Resnick et al., 2000) or from 1 “strongly disagree” to 5 “strongly agree” (Shaughnessy et al., 2012; Soloman & Annis, 1989; Wojcicki et al., 2009). An 11-point Likert scale (from 0 “no confidence at all” to 10 “extremely confident”) (Chang & Crowe, 2011) was adopted in this study as it was comprehensively developed from the construct of outcome expectation.

**Self-management behaviours**

Examination of the literature on stroke recovery, self-management, and stroke self-management behaviours revealed additional behaviours (Battersby et al., 2003; Cramm et al., 2012; Lorig et al., 2001). As well as the 17 behaviours mentioned by the stroke survivors in the interviews, additional self-management behaviours identified included behaviours performed to promote physical health: fatigue management, training and exercise of the hemiplegic upper extremities, facilitate pain management such as hemiplegic shoulder pain; to promote psychological well-being: meditation; and to promote social/community reintegration: learning life skills.

Additionally, the literature reporting the development and psychometric evaluation of instruments for assessing self-management behaviours was reviewed. The results showed that instruments measuring stroke self-management behaviours either assessed self-reported frequency of or participation in the behaviours (Lorig et al., 1996; Tokunaga-Nakawatase, Taru, & Miyawaki, 2012; Willaing, Rogvi, Bøgelund, Almdal, & Schiotz, 2013), or satisfaction regarding own performance in the behaviours (Daly & Bialocerkowski, 2009). The former requires the participants to keep a diary-like record of their performance in the self-management behaviours. The reliability of the records may be doubtful if the participants forget to record it. Accordingly satisfaction with own performance was deemed more acceptable and more easily understandable by stroke survivors.

### 5.5.3 Item generation

Based on the findings of both the semi-structured interviews and the literature review, specific item statements for the two measuring tools, the SSOES and the SSBPS for assessing outcome expectation and satisfaction with performance in stroke self-management behaviours respectively, were devised. For the SSOES, a total of 11
items in English were generated. Each item asked the stroke survivors about their confidence in the likelihood of occurrence of the outcomes after performing the particular stroke self-management behaviours. The items were integrated into three forms of outcome expectation, including physical, social, and self-evaluative effects (Bandura, 1997). The first two items were related to physical effects including ADL independence and improved health status. Items 3-4 and 11 concerned the self-evaluative effects including self-satisfaction, anticipated understanding of own health, and anticipated increase in HRQoL. Items 5-10 were related to social effects, which included social recognition and support, closer relationships with family and friends, comfortable family and social life, and interests in rehabilitation activities. For easier comprehension by stroke survivors, only positive effects of outcome expectation were included in the items. Each item was rated on an 11-point Likert scale from 0 “not confident at all” to 10 “very confident”. The total score was derived by summing the scores of all items (range 0-110). A higher score indicated a higher level of confidence in the likelihood of occurrence of positive outcomes after performing the stroke self-management behaviours.

For the SSBPS, a total of 11 items in English were generated. Each item asked the stroke survivors about their level of satisfaction with their own performance in the particular stroke self-management behaviours. Each item was related to one stroke self-management behaviour. The 11 behaviours were the same as those in the SSOES and covered all three aspects of self-management (Lorig et al., 2001). The first three items were related to medical management, including regular exercise, adopting a healthy lifestyle, and attending medical follow-up consultations. The fourth item was related to emotional management which was management for stable moods. Items 5-9 were related to role management, which included participation in social activities, maintaining relationships with family and friends, and resuming or assuming previous or new family and social roles. Items 10-11 were related to exercise of core self-management skills including planning care regimens with healthcare professionals, and practising different strategies to manage their own post-stroke health. Each item was rated on an 11-point Likert scale from 0 “very dissatisfied” to 10 “very satisfied”. The total score was derived by summing the scores of all items (range 0-110). A higher score indicated a higher level of satisfaction with their own performance in the stroke self-management behaviours.
During the drafting of item statements, guidelines in writing item statements were adhered to. Accordingly simple sentences were employed, repetition of nouns rather than use of pronouns, and avoiding the use of metaphor, colloquialisms, English passive tense, hypothetical phrasings and subjunctive mood were used (Brislin, 1970). All items, instructions and response options for the two instruments were reviewed in detail by all members of the research team, who were experts in self-efficacy and outcome expectation, and were experienced in scale development. Comments were made on the relevance of the items to stroke self-management, comprehensiveness of the items, clarity of the language used, readability for the target participants, and appropriateness of the instructions and response options. Common concerns related to stroke survivors’ understanding of items about “taking up or adjusting” family and social roles. The wording of these items were revised to improve the clarity of the items. The first drafts of the SSOES and the SSBPS in English were then generated.

5.5.4 Translation from English into Chinese

The original English versions of the SSOES and the SSBPS were translated into Chinese by two independent bilingual senior baccalaureate-nursing students. Two bilingual members of the research team examined the differences in the translated versions and the original English versions with consensus used to decide the most appropriate wording resulting in a first draft Chinese version of the SSOES and SSBPS respectively. Another two independent bilingual senior baccalaureate-nursing students, who did not know the original English version, back-translated the SSOES and the SSBPS into English to ensure semantic equivalence (Chang et al., 1999). The two bilingual members of the research team examined the differences between the back-translated and the original versions. Suggestions made to change the wording of “family roles” and “social roles” were adopted for easier understanding by Chinese stroke survivors, resulting in the second draft of the SSOES and SSBPS. The resultant Chinese and the original English versions of the two instruments were administered to 40 bilingual baccalaureate-nursing students. They were asked to rate the appropriateness of the translation on a 4-point Likert scale (1=“very inappropriate” to 4=“very appropriate”). As all items were rated either as “appropriate” or “very appropriate” no further amendments were made.
5.5.5 **Content validity and pilot test**

An expert panel of eight members who were experienced in stroke care, including two nurse academics, one nurse manager, three advanced practice nurses and two physicians, were invited to assess the content validity of the second draft of the SSOES and the SSBPS. Panel members rated the relevance of each item of the SSOES to expected outcomes valued by stroke survivors and the items of the SSBPS to stroke self-management behaviours. They rated each item of the two instruments on a 4-point Likert scale from 1 “not relevant” to 4 “very relevant and succinct”. The CVI was calculated for each scale as the percentage of items with a rating of three or above. The CVI for the SSOES was 0.98 and the CVI for the SSBPS was 0.98. Values greater than or equal to 0.80 are considered acceptable for content validity (Lynn, 1986). No further modifications were made to the items.

The second draft versions of the two instruments were tested on a convenience sample of six Chinese community-dwelling stroke survivors (mean age 55 years, SD 10.35, range 35-64 years) to determine the readability of the language used. Most were male (n=4), and four had attained primary school education and two had attained secondary school education. Three had first-ever ischaemic stroke, two had first-ever haemorrhagic stroke and one had recurrent haemorrhagic stroke. The mean duration since stroke onset was 13 years (SD 8.85). Two of them had slurred speech. Five of them walked with a stick and one walked unaided. All participants completed the questionnaire without further clarification or suggestions for additional items. No modification was made to the items, instructions or response options. The second draft versions of the SSOES and the SSBPS were ready for testing of reliability and validity (Appendices O and Q).

5.5.6 **Reliability and convergent validity**

A cross-sectional and descriptive study was conducted. A convenience sample of community-dwelling stroke survivors was recruited from a stroke support group in Hong Kong to complete the SSOES and the SSBPS. Stroke survivors were included if they had either first-ever or recurrent ischaemic or haemorrhagic stroke, currently lived at home, were able to read Traditional Chinese, and were capable of providing informed written consent. The Ph.D. candidate approached the potential participants after they had attended social activities at the community centre. After assessing the participants’ eligibility to participate in the study, informed written consent was
obtained from the eligible participants. The Ph.D. candidate explained in detail to the participants about the purpose, procedure and duration of the study, the nature of voluntary participation, and their rights to consent to participate, refuse to participate, or withdraw from the study. They were advised that participants’ decision to participate or not to participate would in no way impact on their receipt of care or activities from the centre. The participants were also informed that all identifiable information obtained would be destroyed six years after completion of the study. However, it was not possible to withdraw completed questionnaires, as these were submitted anonymously. Up to one hour was given to the participants to consider their decision to participate. After they consented to participate, the Ph.D. candidate asked the participants to complete the translated Chinese version of the SSOES and the SSBPS themselves in a quiet room in the community centre. The participants could ask the Ph.D. candidate questions if they had queries regarding the questionnaires. A similar response was given to all inquiries about the tool, namely that it is important to have the participants’ view on the items and ask the participants to write down what they think. Each participant took about 10 minutes to complete the two questionnaires.

5.5.7 Measuring instruments

The two new measuring instruments were administered. An 11-item Chinese version of the SSOES was administered to assess the participants’ current level of confidence in the likelihood of occurrence of the desired outcomes after performing specific stroke self-management behaviours (Appendix O). The expected outcomes included, for example, doing things independently, feeling at ease, knowing more about own health condition, and improved HRQoL. Each item was rated on an 11-point Likert scale (0 “not confident at all” to 10 “very confident”). The total score was the sum of all item scores. A higher score indicated higher confidence in likelihood of the outcomes occurring.

A Chinese version of the SSBPS was administered to assess participants’ satisfaction with their current performance in stroke self-management behaviours (Appendix Q). It consisted of 11 items on common stroke self-management behaviours, such as exercising regularly, adopting a healthy lifestyle, and assuming pre-stroke or new roles after stroke. Each item was rated on an 11-point Likert scale (0 “very dissatisfied” to 10 “very satisfied”). The total score was obtained by summing the
scores of all items (range 0-110). A higher score indicated a higher level of satisfaction with own performance in stroke self-management behaviours.

5.5.8 Demographic and clinical information

Information was collected on the participants’ demographic and clinical characteristics, including age, gender, marital status, educational level, occupation, living condition, type and number of strokes, and number of years after stroke onset.

5.5.9 Data analyses

Statistical analyses were performed using IBM SPSS Statistics 22. Descriptive statistics were conducted to summarise the participants’ demographic and clinical characteristics. The reliability of the two instruments, SSBPS and SSOES, were tested using Cronbach’s alpha coefficient. Values exceeding 0.70 were considered acceptable. Corrected item-total correlations were performed to assess the contribution of each item to internal consistency. An item-total correlation score of above 0.30 and below 0.80 was considered satisfactory. Pearson’s correlation coefficient was used to examine the convergence between the two instruments, which measured similar constructs (Portney & Watkins, 2009). The significance level was set at p<0.05.

5.5.10 Ethical considerations

Approvals to conduct the study were obtained from the University Human Research Ethics Committee of the Queensland University of Technology, Brisbane, Australia (Approval Number: 1400000333) (Appendix Z), the stroke support group and the community centre before commencing data collection. Informed written consent (Appendix CC) was obtained before collecting data from all participants by the Ph.D. candidate. A card indicating participants’ involvement in the study and means of urgent contact was provided to each participant after obtaining consent. An information sheet about the study and a copy of the signed informed consent form was given to the participants. All questionnaires were anonymous. All information obtained from the study was kept strictly confidential and would be destroyed six years after completion of the study. The federal and institutional ethical standards, Hong Kong Personal Data (Privacy) Ordinance, Declaration of Helsinki, and ICH-GCP were upheld throughout the study.
5.6 RESULTS

5.6.1 Participants’ demographic and clinical characteristics

A total of 95 Chinese community-dwelling stroke survivors were invited to participate in the study and 83 of them completed the questionnaires (response rate: 87.40%). The reasons given for not joining the study included being not interest in the study (n=8) and having no time for interviews (n=4). The participants had a mean age of 60.37 years (SD 9.16). Most were male (73.50%) and married (77.20%). Over half had attained secondary level of education or above (69.87%). Nearly eighty percent of the participants had a first-ever stroke. The mean duration after onset of last stroke was 9.46 years (SD 5.66). The percentage of participants who had ischaemic stroke (56.63%) was slightly greater than those who had haemorrhagic stroke (40.96%). Table 5.7 shows the participants’ demographic and clinical characteristics.

<table>
<thead>
<tr>
<th>Table 5.7 Demographic and clinical characteristics of the participants (n=83)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
</tr>
<tr>
<td>Never married</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Divorced/ Separated/ Widow/ Widowed</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
</tr>
<tr>
<td>Informal school or primary</td>
</tr>
<tr>
<td>Secondary</td>
</tr>
<tr>
<td>Tertiary</td>
</tr>
<tr>
<td><strong>Type of stroke</strong></td>
</tr>
<tr>
<td>Ischaemic</td>
</tr>
<tr>
<td>Haemorrhagic</td>
</tr>
<tr>
<td>Both</td>
</tr>
<tr>
<td><strong>Number of strokes</strong></td>
</tr>
<tr>
<td>First-ever</td>
</tr>
<tr>
<td>Recurrent</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
</tr>
<tr>
<td>Retired</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td><strong>Living condition</strong></td>
</tr>
<tr>
<td>Live alone</td>
</tr>
<tr>
<td>Live with family/ friends</td>
</tr>
<tr>
<td><strong>Mean age, years (SD, range)</strong></td>
</tr>
<tr>
<td><strong>Mean years since first stroke (SD, range)</strong></td>
</tr>
</tbody>
</table>

Abbreviation: SD, Standard deviation.
5.6.2 Internal consistency and validity

Table 5.8 shows the descriptive and reliability statistics for the SSOES. The results showed that the SSOES had high internal consistency (Cronbach’s alpha 0.94). The values of Cronbach’s alpha ranged slightly from 0.93 to 0.94 when each item was deleted. All 11 items had item-total correlations of 0.70 to 0.81 (p≤0.50). Based on the reliability results, all items could be retained.

Table 5.8 Descriptive and reliability statistics of the Stroke Self-management Outcome Expectation Scale (n=83)

<table>
<thead>
<tr>
<th>SSOES items</th>
<th>Mean (SD)</th>
<th>Item-Total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If I exercise regularly, I will be more physically independent to do what I want.</td>
<td>6.80 (1.98)</td>
<td>0.70</td>
<td>0.94</td>
</tr>
<tr>
<td>2. If I adopt a healthy lifestyle, I will have improved physical functioning.</td>
<td>6.98 (1.68)</td>
<td>0.74</td>
<td>0.94</td>
</tr>
<tr>
<td>3. If I attend follow-up appointment, I will understand my health condition better.</td>
<td>7.49 (1.72)</td>
<td>0.70</td>
<td>0.94</td>
</tr>
<tr>
<td>4. If I deal with my emotional reactions to my stroke and daily events, I will feel more at ease.</td>
<td>7.00 (1.85)</td>
<td>0.73</td>
<td>0.94</td>
</tr>
<tr>
<td>5. If I participate in social activities regularly, I will feel happier and supported.</td>
<td>7.54 (1.78)</td>
<td>0.77</td>
<td>0.93</td>
</tr>
<tr>
<td>6. If I keep regular contact with my family, I will have a closer relationship with them.</td>
<td>7.46 (1.78)</td>
<td>0.73</td>
<td>0.94</td>
</tr>
<tr>
<td>7. If I keep regular contact with my friends, I will have a closer relationship with them.</td>
<td>6.40 (1.59)</td>
<td>0.73</td>
<td>0.94</td>
</tr>
<tr>
<td>8. If I continue to take up or adjust my family roles after stroke, I will have a family life that I am comfortable with.</td>
<td>7.05 (2.01)</td>
<td>0.76</td>
<td>0.93</td>
</tr>
<tr>
<td>9. If I continue to take up or adjust my social roles after stroke, I will have a social life that I am comfortable with.</td>
<td>6.86 (1.80)</td>
<td>0.77</td>
<td>0.93</td>
</tr>
<tr>
<td>10. If I develop my plan of care with my health care providers, I will be more involved in my recovery process.</td>
<td>6.90 (1.93)</td>
<td>0.74</td>
<td>0.94</td>
</tr>
<tr>
<td>11. If I continuously practice strategies to self-manage my life after stroke, my quality of life will be enhanced.</td>
<td>7.28 (1.89)</td>
<td>0.81</td>
<td>0.93</td>
</tr>
<tr>
<td>Total score (0-110)</td>
<td>77.75 (15.86)</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

Abbreviations: SD, Standard deviation; SSOES, Stroke Self-management Outcome Expectation Scale.
Table 5.9 shows the descriptive and reliability statistics of the SSBPS. The results showed that the SSBPS had high internal consistency (Cronbach’s alpha 0.93). Cronbach’s alpha changed slightly when each item was deleted. The values ranged from 0.92 to 0.93. All 11 items had item-total correlation of 0.70 to 0.81 (p≤0.50). Based on the reliability results, all items could be retained.

There was significant and high correlation between the total scores of the SSOES and the SSBPS (convergence) (r=0.85, p<0.001).

Table 5.9 Descriptive and reliability statistics of the Stroke Self-management Behaviours Performance Scale (n=83)

<table>
<thead>
<tr>
<th>SSBPS items</th>
<th>Mean (SD)</th>
<th>Corrected Item-Total correlation</th>
<th>Cronbach’s alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Exercise regularly.</td>
<td>7.20 (1.91)</td>
<td>0.75</td>
<td>0.92</td>
</tr>
<tr>
<td>2. Adopt a healthy lifestyle.</td>
<td>7.10 (1.85)</td>
<td>0.78</td>
<td>0.92</td>
</tr>
<tr>
<td>3. Attend follow-up appointment.</td>
<td>8.66 (1.82)</td>
<td>0.54</td>
<td>0.93</td>
</tr>
<tr>
<td>4. Deal with my emotional reactions to my stroke and daily events.</td>
<td>7.22 (1.80)</td>
<td>0.70</td>
<td>0.93</td>
</tr>
<tr>
<td>5. Participate in social activities regularly.</td>
<td>7.45 (1.77)</td>
<td>0.73</td>
<td>0.93</td>
</tr>
<tr>
<td>6. Keep regular contact with my family.</td>
<td>7.52 (1.78)</td>
<td>0.71</td>
<td>0.93</td>
</tr>
<tr>
<td>7. Keep regular contact with my friends.</td>
<td>6.47 (1.41)</td>
<td>0.79</td>
<td>0.92</td>
</tr>
<tr>
<td>8. Continue to take up or adjust my family roles after stroke.</td>
<td>6.70 (2.02)</td>
<td>0.80</td>
<td>0.92</td>
</tr>
<tr>
<td>9. Continue to take up or adjust my social roles after stroke.</td>
<td>6.73 (1.75)</td>
<td>0.75</td>
<td>0.92</td>
</tr>
<tr>
<td>10. Develop my plan of care with my health care providers.</td>
<td>6.11 (1.99)</td>
<td>0.64</td>
<td>0.93</td>
</tr>
<tr>
<td>11. Continuously practice strategies to self-manage my life after stroke.</td>
<td>6.67 (1.69)</td>
<td>0.74</td>
<td>0.92</td>
</tr>
<tr>
<td>Total score (0-110)</td>
<td>77.83 (15.31)</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

Abbreviations: SD, Standard deviation; SSBPS, Stroke Self-management Behaviours Performance Scale.

5.7 DISCUSSION

The aim of this study was to develop and test the reliability and validity of two newly developed measuring instruments, the SSOES and SSBPS for assessing stroke survivors’ outcome expectation of performing stroke self-management behaviours and
satisfaction with performance in the behaviours respectively. Preliminary evidence showed that both the SSOES and the SSBPS were reliable and valid.

The items generated for the two instruments were based on stroke survivors’ health needs and their perceptions of post-stroke recovery. They were closely linked with their perceptions of self-efficacy and outcome expectation of performing stroke self-management behaviours (Lo et al., 2013). Previous studies, which examined outcome expectations, had commonly developed scales of self-efficacy and outcome expectation together. However, it is not difficult to note that these scales were also based on specific behaviours for quantifying the associated self-efficacy and outcome expectations. Since there is already a stroke-specific scale on self-efficacy in self-management (Jones et al., 2009), and the scale is reliable and valid, it is unnecessary to duplicate efforts to develop another instrument to measure stroke survivors’ self-efficacy in self-management.

It is important to note that both scales could be adopted for community-dwelling stroke survivors. The SSBPS in particular is useful for assessing stroke survivors’ subjective perception of how they perform stroke self-management behaviours. Objective measurement is needed to quantify the actual participation in or performance of stroke self-management behaviours, for example, the amount of time spent in performing the behaviour each week. The adoption of objective measurement may be helpful for supplementing information about the stroke survivors’ overall performance of the behaviours.

Limitations of the study included, first, that the sample size for testing the tools was small in that there were only 83 community-dwelling stroke survivors who completed the study. It is recommended that a subject-to-item ratio should be at least 10:1 for principal component analysis. A minimum of 110 participants was required for the study (Osborne & Costello, 2004). More stroke participants are required in future studies to confirm the reliability and validity of the SSOES and the SSBPS. Second, this study tested only the internal consistency, and content and convergent validity of the SSOES and the SSBPS. No factor analyses were performed to examine the factor structure of the two measuring instruments. Although the results showed high reliability and validity, more tests are required to establish the convergent validity and factor structures of the SSOES and the SSBPS.
5.8 SUMMARY

Preliminary evidence showed that the two Chinese versions of the new measuring instruments, SSOES and SSBPS, were reliable and valid for assessing Chinese community-dwelling stroke survivors’ outcome expectation for stroke self-management and their satisfaction with own performance in stroke self-management behaviours. Further exploration of factor structures of the SSOES and the SSBPS with sufficient sample size is warranted to provide further evidence regarding the reliability and validity of the two measuring instruments.
Chapter 6: Results (Main Study)

6.1 INTRODUCTION

This chapter presents the results of the RCT, which examined the effectiveness of an innovative nurse-led self-efficacy enhancing stroke self-management program (SSMP) for community-dwelling stroke survivors. This chapter first summarises the recruitment process and flow of participants in the study, followed by the participants’ baseline characteristics. Comparison between participants in the intervention and the control groups, and between participants who completed and discontinued the study are presented. Then the results of the generalised estimating equation (GEE) models for determining changes in primary and secondary outcome variables from baseline to follow-up assessment between the intervention and the control groups included in the ITT population are presented. The GEE models which were adjusted and unadjusted for potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index are reported for comparison. Next, the results of the adjusted and unadjusted GEE models for differential changes in primary and secondary outcome variables from baseline to follow-up assessment between the intervention and the control groups included in the per-protocol population are reported. Analyses among participants who received all, part and none of the sessions of the SSMP are also reported. Finally, feedback from the participants in the intervention group on usefulness of the SSMP, their common goals established, and the extent of goal attainment in the SSMP are reported.

6.2 RECRUITMENT AND STUDY FLOW

Recruitment of study participants was conducted between July 2014 and October 2015 (a total of 16 months). Baseline and follow-up assessments of all study participants, and delivery of the SSMP to the participants randomly assigned to the intervention group were conducted between July 2014 and December 2015 (a total of 18 months).

Ethical approvals to recruit stroke participants from the two study venues (Hospitals A and B) in Hong Kong were obtained in March 2014. However, Hospital B declined to grant access in April 2014 due to manpower concerns although ethics
approval had been obtained at this venue. The research team decided to add the third study venue (Hospital C) in Hong Kong in May 2014. Discussions were held with Hospital B again, and they then agreed to support the study in June 2014. Ethical approval was obtained to recruit participants at Hospital C in August 2014. Recruitment of participants was commenced in Hospitals A and B in July 2014 and in Hospital C in December 2014.

A total of 1,105 stroke patients admitted to the acute stroke units of the three acute hospitals during the study period were screened and assessed for eligibility to participate in the study. Among them, 662 (59.91%) stroke patients were excluded as they either did not meet the inclusion criteria (n=517), or were discharged before the research assistants (RA-Rs) had the opportunity to introduce the study (n=145). Among the remaining 443 stroke patients, 400 (90.29%) expressed interest in participating in the study and consented to be contacted again after they had returned home from the hospital (Figure 6.1). A total of 43 (9.71%) patients declined to have further contact about study participation. Table 6.1 summarises the reasons for exclusion of patients from the study at the time of recruitment in acute stroke units.
Figure 6.1 Flow of stroke participants through the study in Hong Kong from July 2014 to December 2015

(Abbreviations: ASUs, Acute stroke units; ITT, Intention-to-treat; SSMP, Stroke self-management program.)
Table 6.1 Reasons for exclusion of participants at time of recruitment at acute stroke units (n=662)

<table>
<thead>
<tr>
<th>Reasons for exclusion</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not meet the inclusion criteria (n=517)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed with dementia/ cognitive impairment</td>
<td>98</td>
<td>14.80</td>
</tr>
<tr>
<td>Diagnosed with other neurological or medical problems (e.g. Bell’s palsy, seizures, pneumonia, vertigo, meningitis)</td>
<td>96</td>
<td>14.50</td>
</tr>
<tr>
<td>Planned discharge to residential care homes</td>
<td>78</td>
<td>11.78</td>
</tr>
<tr>
<td>Diagnosed with transient ischaemic attack</td>
<td>73</td>
<td>11.03</td>
</tr>
<tr>
<td>Diagnosed with mental illnesses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>38</td>
<td>5.74</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>8</td>
<td>1.21</td>
</tr>
<tr>
<td>Others (e.g. delusional disorder, adjustment disorder)</td>
<td>15</td>
<td>2.27</td>
</tr>
<tr>
<td>Death</td>
<td>40</td>
<td>6.04</td>
</tr>
<tr>
<td>Language barriers e.g. dialect-speaking</td>
<td>19</td>
<td>2.87</td>
</tr>
<tr>
<td>Aphasia</td>
<td>18</td>
<td>2.72</td>
</tr>
<tr>
<td>Did not live in Hong Kong</td>
<td>16</td>
<td>2.42</td>
</tr>
<tr>
<td>Severe hearing impairment</td>
<td>13</td>
<td>1.96</td>
</tr>
<tr>
<td>Concomitant cancers requiring chemotherapy or radiation</td>
<td>5</td>
<td>0.76</td>
</tr>
<tr>
<td>Discharged before recruitment (n=145)</td>
<td>145</td>
<td>21.90</td>
</tr>
</tbody>
</table>

Abbreviation: N, Number of participants.

Table 6.2 summarises the reasons for participants declining to have further contact about participation in the study either at the time of recruitment in acute stroke units or after the stroke patients had returned home.

Table 6.2 Reasons for decline to participate in the study

<table>
<thead>
<tr>
<th>Reasons for decline to participate</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>In acute stroke units (n=43)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not interested in research studies</td>
<td>24</td>
<td>5.42</td>
</tr>
<tr>
<td>Not interested in group-based sessions/ using phones</td>
<td>5</td>
<td>1.13</td>
</tr>
<tr>
<td>Lack of time</td>
<td>5</td>
<td>1.13</td>
</tr>
<tr>
<td>Unavailability of carers to accompany</td>
<td>5</td>
<td>1.13</td>
</tr>
<tr>
<td>Inconvenient access to the study venue</td>
<td>4</td>
<td>0.90</td>
</tr>
<tr>
<td>After discharge from hospital (n=54)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not interested in research studies</td>
<td>23</td>
<td>12.64</td>
</tr>
<tr>
<td>Lack of time</td>
<td>18</td>
<td>9.89</td>
</tr>
<tr>
<td>Inconvenient access to the study venue</td>
<td>8</td>
<td>4.40</td>
</tr>
<tr>
<td>Unavailability of carers to accompany</td>
<td>5</td>
<td>2.75</td>
</tr>
</tbody>
</table>

Abbreviation: N, Number of participants.
The 400 stroke patients were contacted again upon their discharge from the hospital. Slightly over half of them (55%) were excluded as they either could not be located or no longer met the inclusion criteria. Table 6.3 summarises the reasons for exclusion of patients from the study when the patients had returned home. Fifty-four (29.67%) patients declined to participate. Finally, 128 patients were eligible and attended the baseline assessment (response rate: 70.33%) (Figure 6.1).

Among the 128 study participants, fifty-eight participants (45.31%) were recruited from Hospital A, 39 (30.47%) from Hospital B, and 31 (24.22%) from Hospital C. The 128 participants were randomly assigned to either the intervention group (n=64, 50%) or the control group (n=64, 50%).

Twenty-four (37.50%) of the 64 participants in the intervention group received all sessions of the SSMP and all of these participants provided the 8-weeks follow-up assessment data. Both baseline and 8-weeks follow-up assessment data were provided by 52 (81.25%) participants in the intervention group and 55 (85.94%) in the control group.

Table 6.3 Reasons for participant exclusion after stroke patients returned home (n=218)

<table>
<thead>
<tr>
<th>Reasons for exclusion</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not be located</td>
<td>182</td>
<td>83.49</td>
</tr>
<tr>
<td>Did not meet inclusion criteria (n=36)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharged to residential care homes</td>
<td>13</td>
<td>5.96</td>
</tr>
<tr>
<td>Not living in Hong Kong</td>
<td>10</td>
<td>4.59</td>
</tr>
<tr>
<td>Mini Mental State Examination score &lt; 18</td>
<td>9</td>
<td>4.13</td>
</tr>
<tr>
<td>Death</td>
<td>4</td>
<td>1.83</td>
</tr>
</tbody>
</table>

Abbreviation: N, Number of participants.

Below is a summary of the total number of participants included in the ITT analysis sample, per-protocol analysis sample, and the sample for analyses of effective dose of the SSMP (Table 6.4).

1. A total of 128 participants were included in the ITT population with 64 participants in the intervention group and 64 participants in the control group.

2. A total of 79 participants were included in the per-protocol population. This included 24 participants in the intervention group who completed all sessions of the SSMP and 55 participants in the control group. All provided the 8-weeks follow-up assessment data.
3. A total of 107 participants were included in the analyses of effective dose of the SSMP. This included 24 participants who received all sessions of the SSMP in the intervention group (full completers), 28 participants who received at least one but not all sessions of the SSMP in the intervention group (partial completers), and 55 participants in the control group. All provided the 8-weeks follow-up assessment data.

Table 6.4 Total number of participants in different types of data analyses

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Group</th>
<th>Control group</th>
<th>Intervention group</th>
<th>Total sample per analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>(completed all sessions)</td>
<td>(completed some sessions)</td>
</tr>
<tr>
<td>Intention-to-treat</td>
<td></td>
<td>64</td>
<td>64</td>
<td>128</td>
</tr>
<tr>
<td>Per-protocol</td>
<td></td>
<td>55</td>
<td>24</td>
<td>--</td>
</tr>
<tr>
<td>Dose effect</td>
<td></td>
<td>55</td>
<td>24</td>
<td>28</td>
</tr>
</tbody>
</table>

6.3 BASELINE CHARACTERISTICS OF PARTICIPANTS

The mean age of the participants in the study was 67.46 years (SD 11.95, range 38-95 years). There were more male (59.38%) than female (40.62%). Majority of the participants were married (74.22%) and lived with family or friends (89.84%). Slightly over half of them had a highest educational level of primary education (56.25%). Majority of the participants had ischaemic stroke (87.50%) and first-ever stroke (75%). About half walked with the aid of a stick (52.34%).

Tables 6.5 to 6.7 show the baseline demographic and clinical characteristics of the participants. The mean age of the participants in the control group (mean 68.59 years, SD 11.52) was slightly higher than that of the intervention group (mean 66.33 years, SD 12.34). However, the difference between the two groups was not significant (p=0.285). Compared with the control group, the intervention group had a significantly longer duration in days between stroke onset and baseline assessment (p=0.04). There was no significant difference in other baseline demographic and clinical characteristics between the two groups.
Table 6.5 Comparison of baseline demographic characteristics of participants (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
<th>Chi-square</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.39</td>
</tr>
<tr>
<td>35-44</td>
<td>2 (1.56)</td>
<td>2 (3.13)</td>
<td>0 (0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>18 (14.06)</td>
<td>9 (14.06)</td>
<td>9 (14.06)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>31 (24.22)</td>
<td>16 (25.00)</td>
<td>15 (23.44)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>35 (27.35)</td>
<td>17 (26.56)</td>
<td>18 (28.13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td>32 (25.00)</td>
<td>15 (23.44)</td>
<td>17 (26.56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 or above</td>
<td>10 (7.81)</td>
<td>5 (7.81)</td>
<td>5 (7.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.72</td>
</tr>
<tr>
<td>Male</td>
<td>76 (59.38)</td>
<td>39 (60.94)</td>
<td>37 (57.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>52 (40.62)</td>
<td>25 (39.06)</td>
<td>27 (42.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.54</td>
</tr>
<tr>
<td>Single/ Divorced/ Widow/ Widowed</td>
<td>33 (25.78)</td>
<td>15 (23.44)</td>
<td>18 (28.12)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>95 (74.22)</td>
<td>49 (76.56)</td>
<td>46 (71.88)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.54</td>
</tr>
<tr>
<td>Primary or below</td>
<td>72 (56.25)</td>
<td>35 (54.69)</td>
<td>37 (57.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>39 (30.47)</td>
<td>22 (34.38)</td>
<td>17 (26.56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary</td>
<td>17 (13.28)</td>
<td>7 (10.93)</td>
<td>10 (15.63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.38</td>
</tr>
<tr>
<td>Live alone</td>
<td>13 (10.16)</td>
<td>8 (12.50)</td>
<td>5 (7.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with family or friends</td>
<td>115 (89.84)</td>
<td>56 (87.50)</td>
<td>59 (92.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.14</td>
</tr>
<tr>
<td>Unemployed or retired</td>
<td>108 (84.38)</td>
<td>57 (89.06)</td>
<td>51 (79.69)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>20 (15.62)</td>
<td>7 (10.94)</td>
<td>13 (20.31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.38</td>
</tr>
<tr>
<td>Has religion</td>
<td>26 (20.31)</td>
<td>15 (23.44)</td>
<td>11 (17.19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No religion</td>
<td>102 (79.69)</td>
<td>51 (76.56)</td>
<td>53 (82.81)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial assistance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Yes</td>
<td>84 (65.63)</td>
<td>42 (65.63)</td>
<td>42 (65.63)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>44 (34.37)</td>
<td>22 (34.37)</td>
<td>22 (34.37)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking habit</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.70</td>
</tr>
<tr>
<td>Never smoked</td>
<td>88 (68.75)</td>
<td>43 (67.19)</td>
<td>45 (70.31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ever smoked</td>
<td>40 (31.25)</td>
<td>21 (32.81)</td>
<td>19 (29.69)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinker of alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.53</td>
</tr>
<tr>
<td>Non-drinker</td>
<td>99 (77.34)</td>
<td>48 (75.00)</td>
<td>51 (79.69)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current drinker</td>
<td>29 (22.66)</td>
<td>16 (25.00)</td>
<td>13 (20.31)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Chi-square tests were performed for nominal variables.
Abbreviation: N, Number of participants.
### Table 6.6 Comparison of baseline health status and length of inpatient stay of participants (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>p</td>
</tr>
<tr>
<td>MMSE score</td>
<td>26.44 (3.02)</td>
<td>26.95 (2.88)</td>
<td>25.92 (3.09)</td>
<td>0.05</td>
</tr>
<tr>
<td>NIHSS score</td>
<td>2.83 (2.49)</td>
<td>3.02 (2.69)</td>
<td>2.64 (2.29)</td>
<td>0.40</td>
</tr>
<tr>
<td>Modified ADL Index score</td>
<td>17.19 (3.15)</td>
<td>16.95 (3.13)</td>
<td>17.42 (3.18)</td>
<td>0.40</td>
</tr>
<tr>
<td>Duration since stroke, days</td>
<td>45.40 (26.16)</td>
<td>50.14 (27.29)</td>
<td>40.66 (24.26)</td>
<td>0.04*</td>
</tr>
<tr>
<td>LOS, days</td>
<td>23.68 (23.99)</td>
<td>26.31 (25.26)</td>
<td>21.05 (22.54)</td>
<td>0.29</td>
</tr>
</tbody>
</table>

Note: Independent-sample t tests were performed. *p<0.05

Abbreviations: ADL, Activities of daily living; LOS, Length of inpatient stay; MMSE, Mini Mental State Examination; n, Number of participants; NIHSS, National Institutes of Health Stroke Scale; SD, Standard deviation.

### Table 6.7 Comparison of baseline clinical characteristics of participants (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
<th>Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td>p</td>
</tr>
<tr>
<td>Type of stroke</td>
<td></td>
<td></td>
<td></td>
<td>0.11</td>
</tr>
<tr>
<td>Ischaemic</td>
<td>112 (87.50)</td>
<td>53 (82.81)</td>
<td>59 (92.19)</td>
<td></td>
</tr>
<tr>
<td>Haemorrhagic</td>
<td>16 (12.50)</td>
<td>11 (17.19)</td>
<td>5 (7.81)</td>
<td></td>
</tr>
<tr>
<td>Prior stroke</td>
<td></td>
<td></td>
<td></td>
<td>0.68</td>
</tr>
<tr>
<td>First-ever</td>
<td>96 (75.00)</td>
<td>47 (73.44)</td>
<td>49 (76.56)</td>
<td></td>
</tr>
<tr>
<td>Recurrent</td>
<td>32 (25.00)</td>
<td>17 (26.56)</td>
<td>15 (23.44)</td>
<td></td>
</tr>
<tr>
<td>Prior transient ischaemic attack†</td>
<td></td>
<td></td>
<td></td>
<td>0.44</td>
</tr>
<tr>
<td>Yes</td>
<td>7 (5.47)</td>
<td>5 (7.81)</td>
<td>2 (3.13)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121 (94.53)</td>
<td>59 (92.19)</td>
<td>62 (96.87)</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
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<td></td>
<td>0.48</td>
</tr>
<tr>
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<td>60 (46.88)</td>
<td>32 (50.00)</td>
<td>28 (43.75)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>68 (53.12)</td>
<td>32 (50.00)</td>
<td>36 (56.25)</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
<td>0.70</td>
</tr>
<tr>
<td>Yes</td>
<td>38 (29.69)</td>
<td>18 (28.13)</td>
<td>20 (31.25)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>90 (70.31)</td>
<td>46 (71.87)</td>
<td>44 (68.75)</td>
<td></td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td></td>
<td></td>
<td></td>
<td>0.80</td>
</tr>
<tr>
<td>Yes</td>
<td>19 (14.84)</td>
<td>9 (14.06)</td>
<td>10 (15.63)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>109 (85.16)</td>
<td>55 (85.94)</td>
<td>54 (84.37)</td>
<td></td>
</tr>
<tr>
<td>Hypercholesterolaemia</td>
<td></td>
<td></td>
<td></td>
<td>0.72</td>
</tr>
<tr>
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<td>68 (53.13)</td>
<td>35 (54.69)</td>
<td>33 (51.56)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>60 (46.87)</td>
<td>29 (45.31)</td>
<td>31 (48.44)</td>
<td></td>
</tr>
<tr>
<td>Expressive dysphasia</td>
<td></td>
<td></td>
<td></td>
<td>0.65</td>
</tr>
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<td>Yes</td>
<td>24 (18.75)</td>
<td>11 (17.19)</td>
<td>13 (20.31)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>104 (81.25)</td>
<td>53 (82.81)</td>
<td>51 (79.69)</td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td></td>
<td>0.65</td>
</tr>
<tr>
<td>Walk unaided</td>
<td>47 (36.72)</td>
<td>25 (39.06)</td>
<td>22 (34.37)</td>
<td></td>
</tr>
<tr>
<td>Walk with a stick</td>
<td>67 (52.34)</td>
<td>31 (48.44)</td>
<td>36 (56.25)</td>
<td></td>
</tr>
<tr>
<td>Walk with a walking frame</td>
<td>14 (10.94)</td>
<td>8 (12.50)</td>
<td>6 (9.38)</td>
<td></td>
</tr>
<tr>
<td>Modified Rankin scale score</td>
<td></td>
<td></td>
<td></td>
<td>0.42</td>
</tr>
<tr>
<td>0-1</td>
<td>49 (38.28)</td>
<td>21 (32.81)</td>
<td>28 (43.74)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>41 (32.03)</td>
<td>23 (35.94)</td>
<td>18 (28.13)</td>
<td></td>
</tr>
<tr>
<td>3-4</td>
<td>38 (29.69)</td>
<td>20 (31.25)</td>
<td>18 (28.13)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Chi-square tests were performed for nominal variables unless specified otherwise.

†Fisher’s exact test was performed.

Abbreviations: n / N, Number of participants.
In comparing the baseline data between study groups, the intervention group had a significantly lower score in the SSQOL basic needs domain (mean 12.28, SD 2.54) than the control group (mean 13.16, SD 1.82) (p=0.03) (Table 6.8). There were no significant differences in other outcome variables between the two groups (Tables 6.8 and 6.9).

Table 6.8 Comparison of baseline primary outcome variables according to study group (n=128)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
<th>t-test p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>SSEQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>98.06 (23.55)</td>
<td>95.84 (22.55)</td>
<td>100.28 (24.49)</td>
<td>0.29</td>
</tr>
<tr>
<td>AE subscale</td>
<td>46.45 (11.36)</td>
<td>45.41 (11.16)</td>
<td>47.48 (11.55)</td>
<td>0.30</td>
</tr>
<tr>
<td>LNC subscale</td>
<td>51.62 (13.34)</td>
<td>50.44 (12.79)</td>
<td>52.80 (13.86)</td>
<td>0.32</td>
</tr>
<tr>
<td>SSOES Total</td>
<td>83.95 (16.02)</td>
<td>82.08 (16.24)</td>
<td>85.81 (15.70)</td>
<td>0.19</td>
</tr>
</tbody>
</table>

Note: Independent-sample t tests were performed for all continuous variables.

Abbreviations: AE, Activities and exercise engagement; LNC, Living with new challenges; n, Number of participants; SD, Standard deviation; SSEQ, Stroke Self-Efficacy Questionnaire; SSOES, Stroke Self-management Outcome Expectation Scale.
Table 6.9 Comparison of baseline secondary outcome variables according to study group (n=128)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
<th>t-test</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GDS Total</td>
<td>5.35 (3.64)</td>
<td>5.64 (3.77)</td>
<td>5.06 (3.51)</td>
<td>0.37</td>
<td></td>
</tr>
<tr>
<td>RNLI Total</td>
<td>31.76 (8.20)</td>
<td>30.84 (8.12)</td>
<td>32.67 (8.24)</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>DF subscale</td>
<td>20.49 (5.81)</td>
<td>19.89 (5.75)</td>
<td>21.09 (5.85)</td>
<td>0.24</td>
<td></td>
</tr>
<tr>
<td>PS subscale</td>
<td>8.38 (2.07)</td>
<td>8.15 (2.08)</td>
<td>8.61 (2.05)</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>SSQOL Total</td>
<td>177.01 (32.26)</td>
<td>172.39 (30.93)</td>
<td>181.63 (33.12)</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Activities domain</td>
<td>26.30 (6.83)</td>
<td>25.70 (7.24)</td>
<td>26.91 (6.40)</td>
<td>0.32</td>
<td></td>
</tr>
<tr>
<td>MEFR domain</td>
<td>27.62 (8.61)</td>
<td>26.75 (8.39)</td>
<td>28.50 (8.81)</td>
<td>0.25</td>
<td></td>
</tr>
<tr>
<td>Language domain</td>
<td>21.94 (2.98)</td>
<td>21.47 (3.13)</td>
<td>22.41 (2.77)</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>UEF domain</td>
<td>20.99 (4.28)</td>
<td>20.75 (4.12)</td>
<td>21.23 (4.46)</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td>Relationships domain</td>
<td>11.39 (3.80)</td>
<td>10.77 (3.60)</td>
<td>12.02 (3.92)</td>
<td>0.06</td>
<td></td>
</tr>
<tr>
<td>Thinking domain</td>
<td>8.55 (3.53)</td>
<td>8.45 (3.44)</td>
<td>8.64 (3.65)</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>Vision domain‡</td>
<td>15 (12-15)</td>
<td>14.00 (12-15)</td>
<td>15 (13-15)</td>
<td>0.23</td>
<td></td>
</tr>
<tr>
<td>Basic needs domain</td>
<td>12.72 (2.24)</td>
<td>12.28 (2.54)</td>
<td>13.16 (1.82)</td>
<td>0.03*</td>
<td></td>
</tr>
<tr>
<td>Personality domain</td>
<td>9.65 (3.41)</td>
<td>9.28 (3.34)</td>
<td>10.02 (3.48)</td>
<td>0.23</td>
<td></td>
</tr>
<tr>
<td>LW domain</td>
<td>8.95 (3.20)</td>
<td>8.44 (3.01)</td>
<td>9.45 (3.33)</td>
<td>0.07</td>
<td></td>
</tr>
<tr>
<td>Transfer domain</td>
<td>8.12 (1.84)</td>
<td>7.95 (1.90)</td>
<td>8.28 (1.79)</td>
<td>0.32</td>
<td></td>
</tr>
<tr>
<td>SSBPS Total</td>
<td>75.91 (17.48)</td>
<td>73.53 (17.14)</td>
<td>78.28 (17.62)</td>
<td>0.13</td>
<td></td>
</tr>
</tbody>
</table>

Notes: All values are presented as means and standard deviations unless specified otherwise. Independent-sample t tests were performed for continuous variables unless specified otherwise. ‡Values are presented as medians and interquartile ranges. Mann-Whitney U test was performed. *p<0.05

Abbreviations: DF, Daily functioning; GDS, Geriatric Depression Scale; LW, Leisure and work; MEFR, Mood, energy and family role; n, Number of participants; PS, Perception of self; RNLI, Reintegration to Normal Living Index; SD, Standard deviation; SSBPS, Stroke Self-management Behaviours Performance Scale; SSQOL, Stroke Specific Quality of Life Scale; UEF, Upper extremity function.

6.4 ATTRITION AND ADHERENCE TO PROGRAM

6.4.1 Attrition

Fifty-two participants in the intervention group and fifty-five participants in the control group completed the 8-weeks follow-up assessment on primary and secondary outcome variables. The attrition rate was 12 (18.75%) in the intervention group and 9 (14.06%) in the control group giving an overall attrition rate of 16.41%.

For the intervention group, the reasons for discontinuing the study for four participants was a deterioration in health, six could not be located, and two refused to continue due to lack of time. For the control group, the reasons for discontinuing the study were similar. Four participants could not be located, three had deterioration in their health.
and two refused to continue as they found it time-consuming to complete the questionnaires.

The mean age of the participants who discontinued the study (mean 71.71 years, SD 9.86) was slightly higher than that of the participants who completed the study (mean 66.63 years, SD 12.18). However, there was no significant difference between the two groups (p=0.07). Compared with those who discontinued the study, the participants who completed the study had a significantly higher Barthel ADL Index (p=0.01). A higher score on the Barthel ADL Index indicates better physical function score. There were no significant differences in other baseline demographic and clinical characteristics (Tables 6.10 to 6.12), and outcome variables between the two groups (Tables 6.13 and 6.14).

### 6.4.2 Adherence to SSMP

Twenty-four (37.50%) participants in the intervention group received all six sessions of the SSMP, 21 (32.81%) received four sessions except the group sessions, and 19 (29.69%) received two sessions including the home visit and one follow-up phone call. For the 12 participants who dropped out from the intervention group, 10 received home visits and one follow-up phone call, and two (9.5%) received all program sessions except the group sessions. The main reasons for partial completion of the study included unavailability of family members or carers to accompany them, time clashes with the participants’ other personal commitments such as family gathering or work, and lack of interest in talking on phones. There was no significant difference in the baseline demographic and clinical characteristics, and outcome measures between the participants who had full and partial completion of the SSMP, and those in the control group.

Five sub-groups with four to six participants each were formed for the 24 participants who participated in the group sessions. The main reasons for not participating in the group sessions included lack of time, inconvenient access to the venue due to mobility and transportation problems, and not being interested in or comfortable with engaging in group sessions.
Table 6.10 Comparison of baseline demographic characteristics of participants who completed and discontinued the study (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Completed (n=107)</th>
<th>Discontinued (n=21)</th>
<th>Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td><strong>Age, years</strong></td>
<td></td>
<td></td>
<td>0.10</td>
</tr>
<tr>
<td>35-64</td>
<td>47 (43.93)</td>
<td>4 (19.05)</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>27 (25.23)</td>
<td>8 (38.10)</td>
<td></td>
</tr>
<tr>
<td>75 or above</td>
<td>33 (30.84)</td>
<td>9 (42.85)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td>0.48</td>
</tr>
<tr>
<td>Male</td>
<td>65 (60.75)</td>
<td>11 (52.38)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>42 (39.25)</td>
<td>10 (47.62)</td>
<td></td>
</tr>
<tr>
<td><strong>Marital status†</strong></td>
<td></td>
<td></td>
<td>0.59</td>
</tr>
<tr>
<td>Single/ Divorced/ Widow/ Widower</td>
<td>29 (27.10)</td>
<td>4 (19.05)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>78 (72.90)</td>
<td>17 (80.95)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td>0.29</td>
</tr>
<tr>
<td>Primary or below</td>
<td>58 (54.21)</td>
<td>14 (66.67)</td>
<td></td>
</tr>
<tr>
<td>Secondary or above</td>
<td>49 (45.79)</td>
<td>7 (33.33)</td>
<td></td>
</tr>
<tr>
<td><strong>Living condition†</strong></td>
<td></td>
<td></td>
<td>0.69</td>
</tr>
<tr>
<td>Live alone</td>
<td>12 (11.21)</td>
<td>1 (4.76)</td>
<td></td>
</tr>
<tr>
<td>Live with family or friends</td>
<td>95 (88.79)</td>
<td>20 (95.24)</td>
<td></td>
</tr>
<tr>
<td><strong>Employment†</strong></td>
<td></td>
<td></td>
<td>1.00</td>
</tr>
<tr>
<td>Unemployed or retired</td>
<td>90 (84.11)</td>
<td>18 (85.71)</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>17 (15.89)</td>
<td>3 (14.29)</td>
<td></td>
</tr>
<tr>
<td><strong>Religion†</strong></td>
<td></td>
<td></td>
<td>0.56</td>
</tr>
<tr>
<td>Has religion</td>
<td>23 (21.50)</td>
<td>3 (14.29)</td>
<td></td>
</tr>
<tr>
<td>No religion</td>
<td>84 (78.50)</td>
<td>18 (85.71)</td>
<td></td>
</tr>
<tr>
<td><strong>Financial assistance</strong></td>
<td></td>
<td></td>
<td>0.27</td>
</tr>
<tr>
<td>Yes</td>
<td>68 (63.55)</td>
<td>16 (76.19)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>39 (36.45)</td>
<td>5 (23.81)</td>
<td></td>
</tr>
<tr>
<td><strong>Smoking habit</strong></td>
<td></td>
<td></td>
<td>0.82</td>
</tr>
<tr>
<td>Never smoked</td>
<td>74 (69.16)</td>
<td>14 (66.67)</td>
<td></td>
</tr>
<tr>
<td>Ever smoked</td>
<td>33 (30.84)</td>
<td>7 (33.33)</td>
<td></td>
</tr>
<tr>
<td><strong>Drinker of alcohol†</strong></td>
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<td></td>
<td>0.57</td>
</tr>
<tr>
<td>Non-drinker</td>
<td>84 (78.50)</td>
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<td></td>
</tr>
<tr>
<td>Current drinker</td>
<td>23 (21.50)</td>
<td>6 (28.57)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Chi-square tests were performed for nominal variables.
†Fisher’s exact test was performed.
Table 6.11 Comparison of baseline assessment and length of inpatient stay of participants who completed and discontinued the study (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Completed (n=107)</th>
<th>Discontinued (n=21)</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>p</td>
</tr>
<tr>
<td>MMSE score</td>
<td>26.63 (2.92)</td>
<td>25.48 (3.43)</td>
<td>0.11</td>
</tr>
<tr>
<td>NIHSS score</td>
<td>2.85 (2.38)</td>
<td>2.71 (3.07)</td>
<td>0.82</td>
</tr>
<tr>
<td>Modified ADL Index score</td>
<td>17.57 (2.95)</td>
<td>15.24 (3.51)</td>
<td>0.002**</td>
</tr>
<tr>
<td>Duration since stroke, days</td>
<td>44.12 (25.32)</td>
<td>51.90 (29.87)</td>
<td>0.21</td>
</tr>
<tr>
<td>LOS, days</td>
<td>22.07 (22.69)</td>
<td>31.90 (28.98)</td>
<td>0.09</td>
</tr>
</tbody>
</table>

Note: Independent-sample t tests were performed for continuous variables.

**p<0.01

Abbreviations: ADL, Activities of daily living; LOS, Length of inpatient stay; MMSE, Mini Mental State Examination; NIHSS, National Institutes of Health Stroke Scale; SD, Standard deviation.

Table 6.12 Comparison of baseline clinical characteristics of participants who completed and discontinued the study (n=128)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Completed (n=107)</th>
<th>Discontinued (n=21)</th>
<th>Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>p</td>
</tr>
<tr>
<td>Type of stroke†</td>
<td></td>
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<td>0.47</td>
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<tr>
<td>Ischaemic</td>
<td>92 (85.98)</td>
<td>20 (95.24)</td>
<td></td>
</tr>
<tr>
<td>Haemorrhagic</td>
<td>15 (14.02)</td>
<td>1 (4.76)</td>
<td></td>
</tr>
<tr>
<td>Prior stroke</td>
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<td></td>
<td>0.34</td>
</tr>
<tr>
<td>First-ever</td>
<td>82 (76.64)</td>
<td>14 (66.67)</td>
<td></td>
</tr>
<tr>
<td>Recurrent</td>
<td>25 (23.36)</td>
<td>7 (33.33)</td>
<td></td>
</tr>
<tr>
<td>Prior transient ischaemic attack†</td>
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<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>6 (5.61)</td>
<td>1 (4.76)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>101 (94.39)</td>
<td>20 (95.24)</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
<td></td>
<td>0.30</td>
</tr>
<tr>
<td>Yes</td>
<td>48 (44.86)</td>
<td>12 (57.14)</td>
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<tr>
<td>No</td>
<td>59 (55.14)</td>
<td>9 (42.86)</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td>0.90</td>
</tr>
<tr>
<td>Yes</td>
<td>32 (29.91)</td>
<td>6 (28.57)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>75 (70.09)</td>
<td>15 (74.43)</td>
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</tr>
<tr>
<td>Atrial fibrillation†</td>
<td></td>
<td></td>
<td>0.74</td>
</tr>
<tr>
<td>Yes</td>
<td>17 (15.89)</td>
<td>2 (9.52)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>90 (84.11)</td>
<td>19 (90.48)</td>
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</tr>
<tr>
<td>Hypercholesterolaemia</td>
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<td>0.69</td>
</tr>
<tr>
<td>Yes</td>
<td>56 (52.34)</td>
<td>12 (57.14)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>51 (47.66)</td>
<td>9 (42.86)</td>
<td></td>
</tr>
<tr>
<td>Expressive dysphasia†</td>
<td></td>
<td></td>
<td>0.76</td>
</tr>
<tr>
<td>Yes</td>
<td>21 (19.63)</td>
<td>3 (14.29)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>86 (80.37)</td>
<td>18 (85.71)</td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td></td>
<td>0.18</td>
</tr>
<tr>
<td>Walk unaided</td>
<td>42 (39.25)</td>
<td>5 (23.81)</td>
<td></td>
</tr>
<tr>
<td>Walk with a stick/walking frame</td>
<td>65 (60.75)</td>
<td>16 (76.19)</td>
<td></td>
</tr>
<tr>
<td>Modified Rankin scale score</td>
<td></td>
<td></td>
<td>0.14</td>
</tr>
<tr>
<td>0-1</td>
<td>45 (42.05)</td>
<td>4 (19.05)</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>32 (29.91)</td>
<td>9 (42.85)</td>
<td></td>
</tr>
<tr>
<td>3-4</td>
<td>30 (28.04)</td>
<td>8 (38.10)</td>
<td></td>
</tr>
</tbody>
</table>

Note: Chi-square tests were performed for nominal variables unless specified otherwise.

†Fisher’s exact tests were performed.
Table 6.13 Baseline primary outcome variables of participants who completed and discontinued the study (n=128)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>Completed (n=107)</th>
<th>Discontinued (n=21)</th>
<th>t-test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSEQ Total</td>
<td>99.47 (22.73)</td>
<td>90.90 (26.82)</td>
<td>0.13</td>
<td></td>
</tr>
<tr>
<td>AE subscale</td>
<td>47.01 (11.24)</td>
<td>43.57 (11.80)</td>
<td>0.21</td>
<td></td>
</tr>
<tr>
<td>LNC subscale</td>
<td>52.46 (12.74)</td>
<td>47.33 (15.66)</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>SSOES Total</td>
<td>84.10 (16.06)</td>
<td>83.14 (16.22)</td>
<td>0.06</td>
<td></td>
</tr>
</tbody>
</table>

Note: Independent-sample t tests were performed for continuous variables.
Abbreviations: AE, Activities and exercise engagement; LNC, Living with new challenges; SD, Standard deviation; SSEQ, Stroke Self-Efficacy Questionnaire; SSOES, Stroke Self-management Outcome Expectation Scale.

Table 6.14 Comparison of baseline secondary outcome variables of participants who completed and discontinued the study (n=128)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>Completed (n=107)</th>
<th>Discontinued (n=21)</th>
<th>t-test</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatric Depression Scale Total</td>
<td>5.51 (3.69)</td>
<td>4.52 (3.33)</td>
<td>0.26</td>
<td></td>
</tr>
<tr>
<td>RNLI Total</td>
<td>32.29 (8.30)</td>
<td>29.05 (7.26)</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Daily functioning subscale</td>
<td>20.88 (5.84)</td>
<td>18.48 (5.38)</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Perception of self subscale</td>
<td>8.47 (2.12)</td>
<td>7.92 (1.78)</td>
<td>0.27</td>
<td></td>
</tr>
<tr>
<td>SSQOL Total</td>
<td>177.80 (33.09)</td>
<td>172.95 (27.96)</td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td>Activities domain</td>
<td>26.60 (6.79)</td>
<td>24.81 (7.00)</td>
<td>0.27</td>
<td></td>
</tr>
<tr>
<td>MEFR domain</td>
<td>28.00 (8.87)</td>
<td>25.71 (6.99)</td>
<td>0.27</td>
<td></td>
</tr>
<tr>
<td>Language domain</td>
<td>21.77 (3.00)</td>
<td>22.81 (2.77)</td>
<td>0.14</td>
<td></td>
</tr>
<tr>
<td>Upper extremity function domain</td>
<td>20.92 (4.39)</td>
<td>21.38 (3.75)</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>Relationships domain</td>
<td>11.43 (3.96)</td>
<td>11.19 (2.91)</td>
<td>0.79</td>
<td></td>
</tr>
<tr>
<td>Thinking domain</td>
<td>8.57 (3.62)</td>
<td>8.43 (3.11)</td>
<td>0.87</td>
<td></td>
</tr>
<tr>
<td>Vision subscale†</td>
<td>14 (12-15)</td>
<td>15 (13-15)</td>
<td>0.69</td>
<td></td>
</tr>
<tr>
<td>Basic needs domain</td>
<td>12.81 (2.22)</td>
<td>12.24 (2.34)</td>
<td>0.28</td>
<td></td>
</tr>
<tr>
<td>Personality domain</td>
<td>9.64 (3.44)</td>
<td>9.67 (3.37)</td>
<td>0.98</td>
<td></td>
</tr>
<tr>
<td>Leisure and work domain</td>
<td>9.15 (3.27)</td>
<td>7.90 (2.66)</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Transfer domain</td>
<td>8.21 (1.81)</td>
<td>7.67 (2.01)</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>SSBPS Total</td>
<td>77.27 (17.95)</td>
<td>68.95 (13.11)</td>
<td>0.80</td>
<td></td>
</tr>
</tbody>
</table>

Notes: All values are presented as means and standard deviations unless specified otherwise. Independent-sample t tests were performed for continuous variables unless specified otherwise. †Values are presented as medians and interquartile ranges. Mann-Whitney U test was performed.
Abbreviations: MEFR, Mood, energy and family role; RNLI, Reintegration to Normal Living Index; SD, Standard deviation; SSBPS, Stroke Self-management Behaviours Performance Scale; SSQOL, Stroke Specific Quality of Life Scale.
6.5 NORMALITY OF DATA

All variables entered into the GEE models were assessed for normality. The skewness statistics for all except six outcome variables were within 1 and -1. The skewness statistics of five of these outcome variables were: SSEQ activities and exercise engagement subscale (-1.08), and SSQOL domains of language (-1.03), upper extremity function (-1.49), basic needs (-1.30), and transfer (-1.13), were slightly greater than -1. However, the normal Q-Q plots showed a reasonable fit of data to the straight diagonal lines. The skewness statistic of the SSQOL vision domain score was -2.18, and the normal Q-Q plot in Figure 6.2 shows that some points departed from the diagonal line. After applying reverse score log-transformation, the skewness statistic was 0.891, and the normal Q-Q plot showed that the points fell close to the diagonal line (Figure 6.3). Normality of all outcome variables including the log-transformed data was assumed.

6.6 POTENTIAL CONFOUNDING VARIABLES

The potential confounding factors entered in the GEE models included the baseline Barthel ADL Index score and those baseline characteristics with a p-value below 0.25 (see the Methods chapter (Chapter Four)) shown in Tables 6.5 to 6.7, namely employment status (p=0.14), type of stroke (p=0.11), duration between stroke onset and baseline (p=0.04), and MMSE score (p=0.05). The Barthel ADL Index score, duration between stroke onset and baseline, and MMSE score were continuous variables and met the criteria for normal distribution. The normal Q-Q plots showed a reasonable fit of points to the diagonal line. Normality of the potential confounding factors was assumed.

![Normal Q-Q Plot of SSQOL Vision Domain](image)

Figure 6.2 Normal Q-Q plot of SSQOL vision domain (before log-transformation)
6.7 INTENTION-TO-TREAT POPULATION

6.7.1 Self-efficacy in stroke self-management

Table 6.15 shows the scores of the SSEQ total and the two subscales of the participants at baseline and at 8-weeks follow-up assessments. Table 6.16 shows the GEE models comparing self-efficacy (SSEQ) between the intervention and the control groups across time. The results showed that participants in the control group changed by 0.52, -0.12, and 0.57 points in the scores of mean SSEQ total, activities and exercise engagement subscale, and living with new challenges subscale respectively from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE models. However, the changes over time in the control group were not significant. Compared with the control group, participants in the intervention group increased further by 7.50, 3.86, and 3.60 points in the three outcome variables respectively at 8-weeks follow-up (and increased by a total of 8.02, 3.74 and 4.17 points respectively from baseline) when potential confounding factors were adjusted in the GEE models. The changes across time in the intervention group were all significant (p<0.05). Similar results were obtained in the unadjusted GEE models. To conclude, there were significant differences in the changes in the scores of mean SSEQ total, activities and exercise engagement subscale, and living with new challenges subscale at 8-weeks follow-up relative to baseline assessment between the intervention and the control groups.
Table 6.15 Means and standard deviations of self-efficacy in stroke self-management at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>SSEQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Baseline</td>
<td>98.06 (23.55)</td>
<td>95.84 (22.55)</td>
<td>100.28 (24.49)</td>
<td></td>
</tr>
<tr>
<td>8-week</td>
<td>108.79 (20.01)</td>
<td>109.65 (19.01)</td>
<td>107.96 (21.06)</td>
<td></td>
</tr>
<tr>
<td>AE subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>46.45 (11.36)</td>
<td>45.41 (11.16)</td>
<td>47.48 (11.55)</td>
<td></td>
</tr>
<tr>
<td>8-week</td>
<td>51.32 (9.44)</td>
<td>51.85 (9.08)</td>
<td>50.82 (9.81)</td>
<td></td>
</tr>
<tr>
<td>LNC subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>51.62 (13.34)</td>
<td>50.44 (12.79)</td>
<td>52.80 (13.86)</td>
<td></td>
</tr>
<tr>
<td>8-week</td>
<td>57.47 (11.53)</td>
<td>57.81 (11.50)</td>
<td>57.15 (11.65)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: AE, Activities and exercise engagement; LNC, Living with new challenges; SD, Standard deviation; SSEQ, Stroke Self-Efficacy Questionnaire.

Table 6.16 GEE models for self-efficacy in stroke self-management across time

<table>
<thead>
<tr>
<th>SSEQ</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B 95% CI</td>
<td>p</td>
</tr>
<tr>
<td></td>
<td>Lower Upper</td>
<td>p</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-4.44 -12.53</td>
<td>0.28 -0.81</td>
</tr>
<tr>
<td>Time</td>
<td>6.07 2.09</td>
<td>10.04 &lt;0.01**</td>
</tr>
<tr>
<td>Group×Time</td>
<td>7.38 2.11</td>
<td>12.65 &lt;0.01**</td>
</tr>
<tr>
<td>Activities and exercise engage</td>
<td>Group</td>
<td>-2.08 -5.98</td>
</tr>
<tr>
<td>Time</td>
<td>2.59 0.59</td>
<td>4.59 0.01*</td>
</tr>
<tr>
<td>Group×Time</td>
<td>3.79 1.23</td>
<td>6.35 &lt;0.01**</td>
</tr>
<tr>
<td>Living with new challenges</td>
<td>Group</td>
<td>-2.36 -6.94</td>
</tr>
<tr>
<td>Time</td>
<td>3.52 1.18</td>
<td>5.87 &lt;0.01**</td>
</tr>
<tr>
<td>Group×Time</td>
<td>3.56 0.23</td>
<td>6.89 0.04*</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

* p<0.05, ** p<0.01

Abbreviations: CI, Confidence interval; SSEQ, Stroke Self-Efficacy Questionnaire.

6.7.2 Outcome expectation for stroke self-management

Table 6.17 shows the scores of the SSOES total of the participants at baseline and at 8-weeks follow-up assessments. Table 6.18 shows the GEE model comparing the intervention and the control group’s outcome expectation (SSOES) across time. The results showed that the mean SSOES score of participants in the control group
decreased by 0.15 points from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE model. However, the change was not significant (p=0.92). Compared with the control group, the mean SSOES score of participants in the intervention group increased further by 9.74 points at 8-weeks follow-up (and increased by a total of 9.59 points from baseline) when potential confounding factors were adjusted in the GEE model. The change was significant (p<0.01). Similar results were obtained in the unadjusted GEE model. To conclude, there was a significant difference between the intervention and the control groups in the change in mean SSOES score at 8-weeks follow-up relative to baseline.

Table 6.17 Means and standard deviations of outcome expectation for stroke self-management at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>SSOES Total</td>
<td>Baseline</td>
<td>83.95 (16.02)</td>
<td>82.08 (16.24)</td>
<td>85.81 (15.70)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>90.80 (14.28)</td>
<td>93.25 (13.08)</td>
<td>88.49 (15.09)</td>
</tr>
</tbody>
</table>

Abbreviations: SD, Standard deviation; SSOES, Stroke Self-management Outcome Expectation Scale.

Table 6.18 GEE model for outcome expectation for stroke self-management across time

<table>
<thead>
<tr>
<th>SSOES Total</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B 95% CI</td>
<td>B 95% CI</td>
</tr>
<tr>
<td></td>
<td>Lower Upper</td>
<td>Lower Upper</td>
</tr>
<tr>
<td>Group</td>
<td>-3.73 -9.23 1.76</td>
<td>-2.90 -7.99 2.20</td>
</tr>
<tr>
<td>Time</td>
<td>2.10 -1.12 5.31</td>
<td>-0.15 -3.20 2.90</td>
</tr>
<tr>
<td>Group×Time</td>
<td>9.54 5.15 13.92</td>
<td>9.74 5.47 14.01</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

**p<0.01

Abbreviations: CI, Confidence interval; SSOES, Stroke Self-management Outcome Expectation Scale.

6.7.3 Satisfaction with performance in stroke self-management behaviours

Table 6.19 shows the scores of the SSBPS total of the participants at baseline and at 8-weeks follow-up assessments. Table 6.20 shows the GEE model comparing
the intervention and the control group’s satisfaction with performance in stroke self-management behaviours (SSBPS) across time. The results showed that the mean SSBPS score of participants in the control group increased by 1.70 points from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE model. The change was not significant (p=0.38). Compared with the control group, the mean SSBPS score of participants in the intervention group increased further by 8.63 points at 8-weeks follow-up (and increased by a total of 10.33 points from baseline) when potential confounding factors were adjusted in the GEE model. The change was significant (p<0.01). Similar results were obtained in the unadjusted GEE model. To conclude, there was a significant difference in the change in mean SSBPS score at 8-weeks follow-up relative to baseline between the intervention and the control groups.

Table 6.19 Means and standard deviations of satisfaction with performance in stroke self-management behaviours at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>SSBPS Total</td>
<td>Baseline</td>
<td>75.91 (17.48)</td>
<td>73.53 (17.14)</td>
<td>78.28 (17.62)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>85.81 (14.99)</td>
<td>87.62 (14.28)</td>
<td>84.11 (15.57)</td>
</tr>
</tbody>
</table>

Abbreviations: SD, Standard deviation; SSBPS, Stroke Self-management Behaviours Performance Scale.

Table 6.20 GEE model for satisfaction with performance in stroke self-management behaviours across time

<table>
<thead>
<tr>
<th>SSBPS Total</th>
<th>Unadjusted model</th>
<th>Adj usted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Group</td>
<td>-4.75</td>
<td>-10.73</td>
</tr>
<tr>
<td>Time</td>
<td>4.87</td>
<td>1.01</td>
</tr>
<tr>
<td>Group×Time</td>
<td>8.60</td>
<td>3.18</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

*p<0.05, **p<0.01

Abbreviations: CI, Confidence interval; SSBPS, Stroke Self-management Behaviours Performance Scale.
6.7.4 Health-related quality of life

Table 6.21 shows the scores of the SSQOL total and the 11 domains of the participants at baseline and at 8-weeks follow-up assessments. Table 6.22 shows the GEE models for HRQoL between the intervention and the control groups across time. The results showed that participants in the control group had changes in the scores of mean SSQOL total (3.43), and in the domains of activities (0.51); mood, energy and family role (1.29); language (-0.21); upper extremity function (0.12); relationships (0.21); thinking (0.36); basic needs (-0.17); personality (0.15); leisure and work (0.17); and transfer (-0.02), from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE models. However, the changes were not significant. Compared with the control group, participants in the intervention group had a further increase of 14.03 in the total score, 1.20 in activities domain, 2.71 in mood, energy and family role domain, 1.04 in language domain, 1.03 in upper extremity function domain, 1.68 in relationships domain, 1.51 in thinking domain, 0.74 in basic needs domain, 1.28 in personality domain, 1.72 in leisure and work domain, and 0.40 in transfer domain at 8-weeks follow-up when potential confounding factors were adjusted in the GEE models. The total changes in scores were 17.46 (total), 1.71 (activities domain), 4.00 (mood, energy and family role domain), 0.83 (language domain), 1.15 (upper extremity function domain), 1.89 (relationships domain), 1.87 (thinking domain), 0.57 (basic needs domain), 1.43 (personality domain), 1.89 (leisure and work domain), and 0.38 (transfer domain) points respectively. The changes were significant (p<0.05) except for the domains of activities, upper extremity function and transfer.

The results also showed that the log-transformed score of the vision domain of the participants in the control group increased by 0.02 points from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE model. However, the change was not significant (p=0.52). Compared with the control group, the log-transformed score of participants in the intervention group had a further increase of 0.11 points at 8-weeks follow-up when potential confounding factors were adjusted in the GEE model. The total change from baseline was 0.13 points. However, the change was not significant (p=0.05).
Similar results were obtained in the unadjusted GEE models except that there were no significant differences in changes in the domains of mood, energy and family role; language; basic needs; and personality between the two groups across time.

To conclude, there were significant differences in the changes in the scores of mean SSQOL total and the domains of mood, energy and family role; language; relationships; thinking; basic needs; personality; and leisure and work at 8-weeks follow-up relative to baseline between the intervention and the control groups. There were no significant differences in the domains of activities; upper extremity function; vision; and transfer.

Table 6.21 Means and standard deviations of health-related quality of life at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>SSQOL Total</td>
<td>Baseline</td>
<td>177.01 (32.26)</td>
<td>172.39 (30.93)</td>
<td>181.63 (33.12)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>194.68 (32.30)</td>
<td>197.17 (32.08)</td>
<td>192.33 (32.62)</td>
</tr>
<tr>
<td>Activities domain</td>
<td>Baseline</td>
<td>26.30 (6.83)</td>
<td>25.70 (7.24)</td>
<td>26.91 (6.40)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>29.40 (5.98)</td>
<td>29.38 (5.99)</td>
<td>29.42 (6.04)</td>
</tr>
<tr>
<td>MEFR domain</td>
<td>Baseline</td>
<td>27.62 (8.61)</td>
<td>26.75 (8.39)</td>
<td>28.50 (8.81)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>31.91 (8.29)</td>
<td>32.38 (8.90)</td>
<td>31.45 (7.73)</td>
</tr>
<tr>
<td>Language domain</td>
<td>Baseline</td>
<td>21.94 (2.98)</td>
<td>21.47 (3.13)</td>
<td>22.41 (2.77)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>22.50 (2.94)</td>
<td>22.52 (2.58)</td>
<td>22.49 (3.27)</td>
</tr>
<tr>
<td>UEF domain</td>
<td>Baseline</td>
<td>20.99 (4.28)</td>
<td>20.75 (4.12)</td>
<td>21.23 (4.46)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>22.40 (3.69)</td>
<td>22.65 (3.15)</td>
<td>22.16 (4.16)</td>
</tr>
<tr>
<td>Relationships domain</td>
<td>Baseline</td>
<td>11.39 (3.80)</td>
<td>10.77 (3.60)</td>
<td>12.02 (3.92)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>12.82 (4.09)</td>
<td>13.04 (4.37)</td>
<td>12.62 (3.84)</td>
</tr>
<tr>
<td>Thinking domain</td>
<td>Baseline</td>
<td>8.55 (3.53)</td>
<td>8.45 (3.44)</td>
<td>8.64 (3.65)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>9.93 (3.51)</td>
<td>10.63 (3.38)</td>
<td>9.27 (3.52)</td>
</tr>
<tr>
<td>Basic needs domain</td>
<td>Baseline</td>
<td>12.72 (2.24)</td>
<td>12.28 (2.54)</td>
<td>13.16 (1.82)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>13.61 (1.82)</td>
<td>13.52 (1.96)</td>
<td>13.69 (1.70)</td>
</tr>
<tr>
<td>Personality domain</td>
<td>Baseline</td>
<td>9.65 (3.41)</td>
<td>9.28 (3.34)</td>
<td>10.02 (3.48)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>10.62 (3.07)</td>
<td>10.90 (3.16)</td>
<td>10.35 (2.98)</td>
</tr>
<tr>
<td>LW domain</td>
<td>Baseline</td>
<td>8.95 (3.20)</td>
<td>8.44 (3.01)</td>
<td>9.45 (3.33)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>10.59 (3.07)</td>
<td>11.00 (3.10)</td>
<td>10.20 (3.02)</td>
</tr>
<tr>
<td>Transfer domain</td>
<td>Baseline</td>
<td>8.12 (1.84)</td>
<td>7.95 (1.90)</td>
<td>8.28 (1.79)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>8.87 (1.67)</td>
<td>8.90 (1.65)</td>
<td>8.84 (1.70)</td>
</tr>
</tbody>
</table>

Notes: All values are presented as means and standard deviations unless specified otherwise.
‡Values are presented as medians and interquartile ranges.
Abbreviations: LW, Leisure and work; MEFR, Mood, energy and family role; SD, Standard deviation; SSQOL, Stroke Specific Quality of Life Scale; UEF, Upper extremity function.
Table 6.22 GEE model for health-related quality of life across time

<table>
<thead>
<tr>
<th>SSQOL</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Total</td>
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<td></td>
</tr>
<tr>
<td>Group</td>
<td>-9.23</td>
<td>-20.25</td>
</tr>
<tr>
<td>Time</td>
<td>10.59</td>
<td>4.70</td>
</tr>
<tr>
<td>Group×Time</td>
<td>13.23</td>
<td>4.64</td>
</tr>
<tr>
<td>Activities domain</td>
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<td></td>
</tr>
<tr>
<td>Group</td>
<td>-1.20</td>
<td>-3.55</td>
</tr>
<tr>
<td>Time</td>
<td>2.38</td>
<td>1.38</td>
</tr>
<tr>
<td>Group×Time</td>
<td>0.99</td>
<td>-0.58</td>
</tr>
<tr>
<td>Mood, energy and family role domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
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<td>-4.71</td>
</tr>
<tr>
<td>Time</td>
<td>2.76</td>
<td>1.01</td>
</tr>
<tr>
<td>Group×Time</td>
<td>2.61</td>
<td>-0.15</td>
</tr>
<tr>
<td>Language domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.94</td>
<td>-1.95</td>
</tr>
<tr>
<td>Time</td>
<td>0.23</td>
<td>-0.54</td>
</tr>
<tr>
<td>Group×Time</td>
<td>0.89</td>
<td>-0.10</td>
</tr>
<tr>
<td>Upper extremity function domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.48</td>
<td>-1.96</td>
</tr>
<tr>
<td>Time</td>
<td>1.00</td>
<td>0.19</td>
</tr>
<tr>
<td>Group×Time</td>
<td>0.97</td>
<td>-0.12</td>
</tr>
<tr>
<td>Relationships domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-1.25</td>
<td>-2.54</td>
</tr>
<tr>
<td>Time</td>
<td>0.56</td>
<td>-0.40</td>
</tr>
<tr>
<td>Group×Time</td>
<td>1.74</td>
<td>0.36</td>
</tr>
<tr>
<td>Thinking domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.19</td>
<td>-1.41</td>
</tr>
<tr>
<td>Time</td>
<td>0.68</td>
<td>-0.09</td>
</tr>
<tr>
<td>Group×Time</td>
<td>1.42</td>
<td>0.25</td>
</tr>
<tr>
<td>Vision domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>0.06</td>
<td>-0.05</td>
</tr>
<tr>
<td>Time‡</td>
<td>-0.04</td>
<td>-0.10</td>
</tr>
<tr>
<td>Group×Time‡</td>
<td>-0.10</td>
<td>-0.21</td>
</tr>
<tr>
<td>Basic needs domain</td>
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<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.88</td>
<td>-1.63</td>
</tr>
<tr>
<td>Time</td>
<td>0.50</td>
<td>0.07</td>
</tr>
<tr>
<td>Group×Time</td>
<td>0.68</td>
<td>0.01</td>
</tr>
<tr>
<td>Personality domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.73</td>
<td>-1.91</td>
</tr>
<tr>
<td>Time</td>
<td>0.37</td>
<td>-0.50</td>
</tr>
<tr>
<td>Group×Time</td>
<td>1.22</td>
<td>-0.03</td>
</tr>
<tr>
<td>Leisure and work domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-1.02</td>
<td>-2.11</td>
</tr>
<tr>
<td>Time</td>
<td>0.70</td>
<td>-0.07</td>
</tr>
<tr>
<td>Group×Time</td>
<td>1.66</td>
<td>0.64</td>
</tr>
<tr>
<td>Transfer domain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.33</td>
<td>-0.96</td>
</tr>
<tr>
<td>Time</td>
<td>0.54</td>
<td>0.19</td>
</tr>
<tr>
<td>Group×Time</td>
<td>0.33</td>
<td>-0.24</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models. †GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index. ‡The negative sign (-) indicates an improvement in the condition. *p<0.05, **p<0.01
Abbreviations: CI, Confidence interval; SSQOL, Stroke Specific Quality of Life Scale.
6.7.5 Depressive symptoms

Table 6.23 shows the scores of the GDS total of the participants at baseline and at 8-weeks follow-up assessments. Table 6.24 shows the GEE model for depressive symptoms between the intervention and the control groups across time. The results showed that the mean GDS score of the participants in the control group decreased by 0.83 points from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE model. The change was significant (p=0.02). Compared with the control group, the mean GDS score of the participants in the intervention group decreased further by 0.83 points at 8-weeks follow-up (and decreased by a total of 1.66 points from baseline) when potential confounding factors were adjusted in the GEE model. However, the change was not significant (p=0.19). Similar results were obtained in the unadjusted GEE model. To conclude, there was no significant difference in the change in mean GDS score at 8-weeks follow-up relative to baseline between the intervention and control groups.

Table 6.23 Means and standard deviations of depressive symptoms at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>GDS Total</td>
<td>Baseline</td>
<td>5.35 (3.64)</td>
<td>5.64 (3.77)</td>
<td>5.06 (3.51)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>3.76 (3.12)</td>
<td>3.65 (3.41)</td>
<td>3.85 (2.84)</td>
</tr>
</tbody>
</table>

Abbreviations: GDS, Geriatric Depression Scale; SD, Standard deviation.

Table 6.24 GEE model for depressive symptoms across time

<table>
<thead>
<tr>
<th>GDS Total</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (95% CI)</td>
<td>p</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Group</td>
<td>0.58 (-0.67)</td>
<td>1.83 0.37</td>
</tr>
<tr>
<td>Time</td>
<td>-1.31 (-2.05)</td>
<td>-0.57 &lt;0.01**</td>
</tr>
<tr>
<td>Group×Time</td>
<td>-0.76 -1.99</td>
<td>0.48 0.23</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

*p<0.05

Abbreviations: CI, Confidence interval; GDS, Geriatric Depression Scale.
6.7.6 Community reintegration

Table 6.25 shows the scores of the RNLI total and the two subscales of the participants at baseline and at 8-weeks follow-up assessments. Table 6.26 shows the GEE model for community reintegration between the intervention and the control groups across time. The results showed that the mean RNLI total, daily functioning subscale, and perception of self subscale scores of participants in the control group changed by 0.79, 0.79, and -0.10 points respectively from baseline to 8-weeks follow-up assessment when potential confounding factors were adjusted in the GEE models. The changes were not significant. Compared with the control group, the mean RNLI total, daily functioning subscale, and perception of self subscale scores of participants in the intervention group increased further by 2.15, 1.26 and 0.69 points respectively at 8-weeks follow-up (increased by a total of 2.94, 2.05 and 0.59 points respectively from baseline) when potential confounding factors were adjusted in the GEE models. The changes were significant (p=0.03) except the daily functioning subscale (p=0.07). Similar results were obtained in the unadjusted GEE models. To conclude, there were significant differences in the changes in mean RNLI total and perception of self subscale scores at 8-weeks follow-up relative to baseline between the intervention and the control groups. No significant difference was found for the daily functioning subscale score.

Table 6.25 Means and standard deviations of community reintegration at baseline and 8-weeks follow-up assessments

<table>
<thead>
<tr>
<th>Outcome variable</th>
<th>Time</th>
<th>All (n=128)</th>
<th>Intervention (n=64)</th>
<th>Control (n=64)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>RNLI</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Baseline</td>
<td>31.76 (8.20)</td>
<td>30.84 (8.12)</td>
<td>32.67 (8.24)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>35.80 (7.03)</td>
<td>35.94 (6.72)</td>
<td>35.67 (7.37)</td>
</tr>
<tr>
<td>DF subscale</td>
<td>Baseline</td>
<td>20.49 (5.81)</td>
<td>19.89 (5.75)</td>
<td>21.09 (5.85)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>23.50 (5.02)</td>
<td>23.55 (4.82)</td>
<td>23.45 (5.24)</td>
</tr>
<tr>
<td>PS subscale</td>
<td>Baseline</td>
<td>8.38 (2.07)</td>
<td>8.15 (2.08)</td>
<td>8.61 (2.05)</td>
</tr>
<tr>
<td></td>
<td>8-week</td>
<td>9.05 (1.74)</td>
<td>9.13 (1.68)</td>
<td>8.98 (1.81)</td>
</tr>
</tbody>
</table>

Abbreviations: DF, Daily functioning; SD, Standard deviation; PS, Perception of self; RNLI, Reintegration to Normal Living Index.
Table 6.26 GEE models for community reintegration over time

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (95% CI)</td>
<td>B (95% CI)</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-1.83 (4.64, 0.99)</td>
<td>0.20 (0.99, -3.11)</td>
</tr>
<tr>
<td>Time</td>
<td>2.63 (1.19, 4.06)</td>
<td>&lt;0.01** (0.79, -0.57)</td>
</tr>
<tr>
<td>Group × Time</td>
<td>2.08 (0.06, 4.09)</td>
<td>0.04* (2.15, 0.22)</td>
</tr>
<tr>
<td>Daily functioning subscale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-1.21 (-3.20, 0.79)</td>
<td>0.24 (-0.58, -2.08)</td>
</tr>
<tr>
<td>Time</td>
<td>2.12 (1.13, 3.12)</td>
<td>&lt;0.01** (0.79, -0.14)</td>
</tr>
<tr>
<td>Group × Time</td>
<td>1.20 (-0.22, 2.62)</td>
<td>0.10 (1.26, -0.10)</td>
</tr>
<tr>
<td>Perception of self subscale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group</td>
<td>-0.46 (-1.16, 0.26)</td>
<td>0.21 (-0.31, -0.93)</td>
</tr>
<tr>
<td>Time</td>
<td>0.28 (-0.17, 0.74)</td>
<td>0.22 (-0.10, -0.55)</td>
</tr>
<tr>
<td>Group × Time</td>
<td>0.67 (0.04, 1.31)</td>
<td>0.04* (0.69, 0.07)</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for main effects of treatment groups and measurement time points, and interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

*p<0.05, **p<0.01

Abbreviations: CI, Confidence interval; RNLI, Reintegration to Normal Living Index.

6.8 COMPARISON BETWEEN PER-PROTOCOL AND ITT POPULATION

Table 6.27 shows the GEE models for outcome variables between the intervention and the control groups included in the per-protocol population. For the primary outcome variables, there were greater increases in the mean scores of SSEQ total, SSEQ activities and exercise engagement subscale, SSEQ living with new challenges subscale, and SSOES total among participants in the intervention group at 8-weeks follow-up relative to baseline, compared with the control group, when potential confounding factors were adjusted in the GEE models. The positive increase in scores indicated an improvement in the condition. All changes were significant (p<0.05).

For the secondary outcome variables, there was a greater decrease in the mean score of GDS and a greater increase in the mean scores of all remaining outcome variables among participants in the intervention group at 8-weeks follow-up relative to baseline, compared with the control group, when potential confounding factors were adjusted in the GEE models. The changes in scores indicated an improvement in the condition. The changes were significant in all secondary outcome variables except the SSQOL domains of activities; mood, energy and family role; upper extremity function; relationships; thinking; vision; basic needs; and transfer; GDS; and RNLI total and
subscales of daily functioning and perception of self. Similar results were obtained in the unadjusted GEE models.

Table 6.27 GEE models for outcome variables (per-protocol population)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>Unadjusted models</th>
<th></th>
<th>Adjusted models†</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
<td>p</td>
<td>B</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td>SSEQ Total</td>
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<td>2.98</td>
<td>16.13 &lt;0.01**</td>
<td>9.30</td>
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<tr>
<td>AE subscale</td>
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<td>1.27</td>
<td>7.42 &lt;0.01**</td>
<td>4.33</td>
</tr>
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<td>LNC subscale</td>
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<td>0.73</td>
<td>9.69 0.02*</td>
<td>4.96</td>
</tr>
<tr>
<td>SSOES Total</td>
<td>11.25</td>
<td>5.85</td>
<td>16.64 &lt;0.01**</td>
<td>11.34</td>
</tr>
<tr>
<td>SSBPS Total</td>
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<td>0.88</td>
<td>14.94 0.03*</td>
<td>7.71</td>
</tr>
<tr>
<td>SSQOL Total</td>
<td>16.73</td>
<td>5.26</td>
<td>28.20 &lt;0.01**</td>
<td>16.65</td>
</tr>
<tr>
<td>Activities domain</td>
<td>1.16</td>
<td>-1.07</td>
<td>3.38 0.31</td>
<td>1.20</td>
</tr>
<tr>
<td>MEFR domain</td>
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<td>-0.80</td>
<td>6.74 0.12</td>
<td>2.91</td>
</tr>
<tr>
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<td>2.64 0.01*</td>
<td>1.53</td>
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<td>0.86</td>
</tr>
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<td>4.40 0.02*</td>
<td>2.36</td>
</tr>
<tr>
<td>Thinking domain</td>
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<td>-0.07</td>
<td>3.07 0.06</td>
<td>1.59</td>
</tr>
<tr>
<td>Vision domain‡</td>
<td>-0.14</td>
<td>-0.29</td>
<td>0.01 0.07</td>
<td>-0.15</td>
</tr>
<tr>
<td>Basic needs domain</td>
<td>0.61</td>
<td>-0.08</td>
<td>1.30 0.08</td>
<td>0.58</td>
</tr>
<tr>
<td>Personality domain</td>
<td>2.29</td>
<td>1.00</td>
<td>3.58 &lt;0.01**</td>
<td>2.24</td>
</tr>
<tr>
<td>Leisure and work domain</td>
<td>1.87</td>
<td>0.55</td>
<td>3.19 &lt;0.01**</td>
<td>1.86</td>
</tr>
<tr>
<td>Transfer domain</td>
<td>0.22</td>
<td>-0.68</td>
<td>1.12 0.63</td>
<td>0.24</td>
</tr>
<tr>
<td>GDS Total</td>
<td>-0.81</td>
<td>-2.56</td>
<td>0.94 0.37</td>
<td>-0.83</td>
</tr>
<tr>
<td>RNLI Total</td>
<td>1.24</td>
<td>-1.28</td>
<td>3.76 0.33</td>
<td>1.16</td>
</tr>
<tr>
<td>Daily functioning subscale</td>
<td>0.64</td>
<td>-1.17</td>
<td>2.45 0.49</td>
<td>0.58</td>
</tr>
<tr>
<td>Perception of self subscale</td>
<td>0.49</td>
<td>-0.30</td>
<td>1.28 0.23</td>
<td>0.47</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for interaction effects between treatment groups and measurement time points were shown in the GEE models.
†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.
‡The negative sign (-) indicates an improvement in the condition.
*p<0.05, **p<0.01
Abbreviations: AE, Activities and exercises; CI, Confidence interval; GDS, Geriatric Depression Scale; LNC, Living with new challenges; MEFR, Mood, energy and family role; RNLI, Reintegration to Normal Living Index; SSEQ, Stroke Self-Efficacy Questionnaire; SSBPS, Stroke Self-management Behaviours Performance Scale; SSOES, Stroke Self-management Outcome Expectation Scale; SSQOL, Stroke Specific Quality of Life Scale; UEF, Upper extremity function.
Table 6.28 Adjusted GEE models for outcome variables (ITT population versus per-protocol population)

| Outcome variables | ITT Population Adjusted models† | Per-protocol population Adjusted models† |  |
|-------------------|---------------------------------|------------------------------------------|  |
|                   | B 95% CI                         | p 95% CI                                 | p 95% CI                                 |
|                   | Lower Upper                      | p Lower Upper                            | p Lower Upper                            |
| SSEQ              |                                  |                                          |                                          |
| Total             | 7.50 2.55 12.45 <0.01**          | 9.30 2.22 16.38 0.01*                    |                                          |
| AE subscale       | 3.86 1.35 6.38 <0.01**           | 4.33 0.91 7.75 0.01*                     |                                          |
| LNC subscale      | 3.60 0.52 6.68 0.02*             | 4.96 0.37 9.54 0.03*                     |                                          |
| SSQOL             |                                  |                                          |                                          |
| Total             | 14.03 5.69 22.37 <0.01**         | 16.65 4.14 29.15 <0.01**                 |                                          |
| Activities domain | 1.20 -0.29 2.68 0.12             | 1.20 -1.26 3.67 0.34                     |                                          |
| MEFR domain       | 2.71 0.10 5.33 0.04*             | 2.91 -0.81 6.62 0.13                     |                                          |
| Language domain   | 1.04 0.05 2.02 0.04*             | 1.53 0.32 2.73 0.01*                     |                                          |
| UEF domain        | 1.03 -0.07 2.13 0.07             | 0.86 -0.45 2.16 0.20                     |                                          |
| Relationships     | 1.68 0.30 3.06 0.02*             | 2.36 0.37 4.35 0.02*                     |                                          |
| domain            |                                  |                                          |                                          |
| Thinking domain   | 1.51 0.33 2.70 0.01*             | 1.59 -0.09 3.26 0.06                     |                                          |
| Vision domain‡    | -0.11 -0.21 <0.01               | 0.05 -0.15 <0.01                        | -0.30 <0.01                             |                                          |
| Basic needs       | 0.74 0.10 1.39 0.03*             | 0.58 -0.27 1.44 0.18                     |                                          |
| domain            |                                  |                                          |                                          |
| Personality       | 1.28 0.04 2.51 0.04*             | 2.24 0.91 3.56 0.01*                     |                                          |
| domain            |                                  |                                          |                                          |
| Leisure and work  | 1.72 0.66 2.78 <0.01**           | 1.86 0.43 3.29 0.01*                     |                                          |
| domain            |                                  |                                          |                                          |
| Transfer domain   | 0.40 -0.12 0.93 0.13             | 0.24 -0.62 1.09 0.59                     |                                          |
| GDS Total         | -0.83 -2.08 0.41 0.19            | -0.83 -2.65 0.98 0.37                   |                                          |
| RNLI              |                                  |                                          |                                          |
| Total             | 2.15 0.22 4.08 0.03*             | 1.16 -1.50 3.83 0.39                     |                                          |
| Daily functioning  | 1.26 -0.10 2.62 0.07             | 0.58 -1.33 2.50 0.55                     |                                          |
| subscale           | 0.69 0.07 1.30 0.03*             | 0.47 -0.33 1.27 0.25                     |                                          |

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for interaction effects between treatment groups and measurement time points were shown in the GEE models.
†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.
‡The negative sign (-) indicates an improvement in the condition.
*p<0.05, **p<0.01
Abbreviations: AE, Activities and exercises; CI, Confidence interval; GDS, Geriatric Depression Scale; LNC, Living with new challenges; MEFR, Mood, energy and family role; RNLI, Reintegration to Normal Living Index; SSEQ, Stroke Self-Efficacy Questionnaire; SSBPS, Stroke Self-management Behaviours Performance Scale; SSOES, Stroke Self-management Outcome Expectation Scale; SSQOL, Stroke Specific Quality of Life Scale; UEF, Upper extremity function.
Table 6.28 shows that the comparison of results of adjusted GEE models for primary and secondary outcome variables across time between the intervention and the control groups included in the ITT and per-protocol populations. The results showed that at 8-weeks follow-up assessment relative to baseline, the direction of changes in the scores of all outcome variables among participants in the intervention group, compared with the control, was the same for both the ITT and per-protocol populations when potential confounding factors were adjusted in the GEE models. The changes were negative for the mean GDS score and positive for the remaining variables. All changes represented an improvement in the condition.

Analysis of the magnitude of changes in scores showed that the standardised coefficients B shown in the adjusted GEE models for both per-protocol and ITT populations were comparable. However, the standardised coefficients B for the per-protocol population were greater than those for the ITT population in all outcome variables except eight. The eight variables were SSBPS, SSQOL domains of upper extremity function, basic needs, and transfer, GDS, and RNLI total and two subscales of daily functioning and perception of self. Among these eight variables, the magnitude of changes in the mean scores of SSQOL activities domain and GDS within the ITT and per-protocol populations were the same.

More outcome variables showed significant changes in the scores of outcome variables at 8-weeks follow-up among participants in the intervention group relative to the control for the ITT population compared with the per-protocol population. For the per-protocol population, outcome variables which showed no significant changes included SSQOL domains of mood, energy and family role, thinking, vision, and basic needs, and RNLI total and perception of self subscale. However, these outcome variables showed significant changes in the analyses based on the ITT principles.

To conclude, the changes in scores of outcome variables across time between the intervention and the control groups for the ITT and per-protocol populations were comparable in terms of the direction, magnitude and significance of change.

6.9 ANALYSES OF EFFECTIVE DOSE

Tables 6.29 to 6.31 show the GEE models for primary and secondary outcome variables between the participants who had full and partial completion of the SSMP, and the control group across time. Compared with the control group, both the full and
partial completers consistently had further increases in the mean scores of SSEQ total and subscales of activities and exercise engagement, and living with new challenges, and SSOES total, at 8-weeks follow-up assessment relative to baseline when potential confounding factors were adjusted in the GEE models. The changes in both full and partial completers were all significant. However, the magnitude of changes were consistently greater for the full completers compared with the partial completers in all primary outcome variables. Similar results were obtained in the unadjusted GEE models (Table 6.29).

Table 6.29 GEE models for primary outcome variables across time (groups with different doses of the program)

<table>
<thead>
<tr>
<th></th>
<th>Unadjusted model</th>
<th></th>
<th>Adjusted model†</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
<td>p</td>
<td>B</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td>SSEQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>9.56</td>
<td>2.98</td>
<td>&lt;0.01**</td>
<td>9.52</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>6.29</td>
<td>0.10</td>
<td>0.05*</td>
<td>6.81</td>
</tr>
<tr>
<td>Activities and exercise subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>4.35</td>
<td>1.27</td>
<td>&lt;0.01**</td>
<td>4.39</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>3.71</td>
<td>0.61</td>
<td>0.02*</td>
<td>4.02</td>
</tr>
<tr>
<td>Living with new challenges subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>5.21</td>
<td>0.73</td>
<td>0.02*</td>
<td>5.14</td>
</tr>
<tr>
<td>time×Group (Partial)</td>
<td>2.59</td>
<td>-1.18</td>
<td>6.36</td>
<td>0.18</td>
</tr>
<tr>
<td>SSOES Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>11.25</td>
<td>5.85</td>
<td>&lt;0.01**</td>
<td>11.39</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>8.95</td>
<td>3.56</td>
<td>14.34</td>
<td>&lt;0.01**</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

*p<0.05, **p<0.01
Abbreviations: CI, Confidence Interval; SSEQ, Stroke Self-Efficacy Questionnaire; SSOES, Stroke Self-management Outcome Expectation Scale.

Compared with the control group, both full and partial completers consistently had further increases in the mean scores of SSBPS, and RNLI total and two subscales; and a further decrease in the mean GDS scores at 8-weeks follow-up assessment relative to baseline when potential confounding factors were adjusted in the GEE models. However, the magnitude of change was relatively greater among partial completers than full completers except for the GDS scores. The changes in the scores of SSBPS were significant for both full and partial completers. However, the change
was significant in the scores for RNLI total and the two subscales for partial completers, but not the full completers. The changes were not significant in the GDS scores for both full and partial completers (Table 6.30).

Table 6.30 GEE models for depressive symptoms and community reintegration across time (groups with different doses of the program)

<table>
<thead>
<tr>
<th>Outcome variables</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td><strong>GDS Total</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>-0.81</td>
<td>-2.56</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>-0.67</td>
<td>-2.22</td>
</tr>
<tr>
<td><strong>RNLI Total</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>1.24</td>
<td>-1.28</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>2.78</td>
<td>0.26</td>
</tr>
<tr>
<td><strong>Daily functioning subscale</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>0.64</td>
<td>-1.17</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>1.62</td>
<td>-0.14</td>
</tr>
<tr>
<td><strong>Perception of self subscale</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>0.49</td>
<td>-0.30</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.91</td>
<td>0.10</td>
</tr>
<tr>
<td><strong>SSBPS Total</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>7.91</td>
<td>0.88</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>9.60</td>
<td>2.85</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for interaction effects between treatment groups and measurement time points were shown in the GEE models.

†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.

*p<0.05, **p<0.01

Abbreviations: CI, Confidence interval; GDS, Geriatric Depression Scale; RNLI, Reintegration to Normal Living Index; SSBPS, Stroke Self-management Behaviours Performance Scale.

Compared with the control group, both the full and partial completers consistently had a further increase in the mean scores of SSQOL total and all domains at 8-weeks follow-up assessment relative to baseline when potential confounding factors were adjusted in the GEE models. The magnitude of change was relatively greater among full completers than partial completers for the total and domain scores except for upper extremity function, basic needs and transfer. However, the changes were significant in the scores of SSQOL total and domains of language, relationships, personality, and leisure and work for full completers. For partial completers, only the
changes in the scores of SSQOL total and leisure and work domain were significant (Table 6.31).

Table 6.31 GEE models for health-related quality of life between the three groups across time (groups with different doses of the program)

<table>
<thead>
<tr>
<th>SSQOL</th>
<th>Unadjusted model</th>
<th>Adjusted model†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>95% CI</td>
</tr>
<tr>
<td></td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>16.73</td>
<td>5.26</td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>9.79</td>
<td>-0.21</td>
</tr>
<tr>
<td><strong>Activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>1.16</td>
<td>-1.07</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.76</td>
<td>-1.10</td>
</tr>
<tr>
<td><strong>Mood, Energy and Family Role</strong></td>
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</tr>
<tr>
<td>Time×Group (Full)</td>
<td>2.97</td>
<td>-0.80</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>2.24</td>
<td>-1.16</td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>1.46</td>
<td>0.29</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.32</td>
<td>-0.88</td>
</tr>
<tr>
<td><strong>Upper Extremity Function</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>0.90</td>
<td>-0.27</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>1.02</td>
<td>-0.43</td>
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<tr>
<td><strong>Relationships</strong></td>
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</tr>
<tr>
<td>Time×Group (Full)</td>
<td>2.43</td>
<td>0.46</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>1.22</td>
<td>-0.26</td>
</tr>
<tr>
<td><strong>Thinking</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>1.50</td>
<td>-0.07</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>1.22</td>
<td>-0.23</td>
</tr>
<tr>
<td><strong>Vision</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)†</td>
<td>-0.14</td>
<td>-0.29</td>
</tr>
<tr>
<td>Time×Group (Partial)†</td>
<td>-0.07</td>
<td>-0.19</td>
</tr>
<tr>
<td><strong>Personality</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>2.29</td>
<td>1.00</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.15</td>
<td>-1.52</td>
</tr>
<tr>
<td><strong>Basic Needs</strong></td>
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<tr>
<td>Time×Group (Full)</td>
<td>0.61</td>
<td>-0.08</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.71</td>
<td>-0.29</td>
</tr>
<tr>
<td><strong>Leisure and Work</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>1.87</td>
<td>0.55</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>1.33</td>
<td>0.15</td>
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<tr>
<td><strong>Transfer</strong></td>
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<td></td>
</tr>
<tr>
<td>Time×Group (Full)</td>
<td>0.22</td>
<td>-0.68</td>
</tr>
<tr>
<td>Time×Group (Partial)</td>
<td>0.33</td>
<td>-0.26</td>
</tr>
</tbody>
</table>

Notes: The working correlation matrix of auto-regression and identity link function were used in the GEE models. Only the model estimates of dummy variables for interaction effects between treatment groups and measurement time points were shown in the GEE models.
†GEE models were adjusted for employment status, type of stroke, duration between stroke onset and baseline, MMSE score, and Barthel ADL Index.
‡The negative sign (-) indicates an improvement in the condition.
* p<0.05, ** p<0.01
Abbreviations: CI, Confidence Interval; SSQOL, Stroke Specific Quality of Life Scale.
6.10 USER FEEDBACK

A research assistant contacted fifty-nine participants in the intervention group via phone immediately after completion of the SSMP. Five participants in the 64 allocated to the intervention group could not be contacted via phone. Three of them were lost to follow-up and two declined due to lack of time. Among the 59 participants, 24 of them received all six sessions of the SSMP.

Overall, the participants expressed satisfaction with the SSMP received. They indicated that the SSMP was helpful in addressing their health needs. The majority said that they had not previously heard of the concept of stroke self-management. They learned about it in the SSMP and learned skills in setting goals and action plans. They also attributed the maintenance of their motivation and hardship towards pursuing their goals of stroke recovery to the goals and action plans set, and the reinforcement of outcomes expected of them after performing target stroke self-management behaviours in the SSMP. There was no adverse event reported by the participants throughout the delivery of the SSMP.

Nearly all participants greatly appreciated the usefulness of the videos and regarded them as the most helpful component of the SSMP in enhancing their confidence in post-stroke recovery. The participants found that they could learn from these experiences and were motivated to engage in stroke self-management behaviours. Some said that they were frustrated about their prognosis after stroke and felt they had lost control of their own lives. Although they were not sure about the extent of their recovery, viewing the videos enabled them to have the confidence to do well in their daily life roles. However, there were some participants who were concerned that their unfamiliarity with the use of DVD players and computers limited their immediate access to the information contained in the videos.

Nearly all of the participants welcomed the individual home visit in the SSMP offered by the Ph.D. candidate who was a registered nurse. They appreciated the opportunity to discuss their care regimens with a nurse, which was often not available for all stroke survivors who are discharged to home for usual post-stroke care. The stroke participants said that the nurse played an important role in helping to clarify their queries about stroke care. More importantly, they had a sense of support by healthcare professionals during their transition to home.
Majority of the participants who had attended the group sessions appreciated the usefulness of the group sessions. These sessions provided them with a helpful experience which enabled them to meet, interact and share with the group participants. They described it as allowing them to know more about others’ experiences, difficulties or concerns after returning home, as this was often not provided in usual stroke care after discharge. They particularly found the sharing of practical tips in daily management of stroke helpful. It motivated them to think about new but simple ways to address their recovery needs. Most found the duration of the sessions appropriate.

Other participants who refused to attend the group sessions commented that the venue for these sessions was too far away from their home. There were also a few participants who said they were not keen on sharing in groups.

Some participants appreciated the flexibility of the follow-up phone calls. It saved time and money to travel to a venue for consultation. The phone calls served as reminders to pursue their efforts in achieving their goals and action plans, and provided an alternative support mechanism. Some participants, however, found the phone calls were not very helpful, as they wanted to have a closer relationship with the nurse.

Some participants enjoyed reading the excerpts about positive reinforcement provided in the program workbook, which encouraged them when they felt lonely or tired. Overall, the participants found the readability of the program workbook appropriate. There were a few of the participants who had not read the workbook as they did not know how to read.

6.11 SUMMARY

This chapter presents the results of the main study in Phase Two of the research project, which aimed to examine the effectiveness of a new 4-week nurse-led self-efficacy enhancing stroke self-management program for Chinese community-dwelling stroke survivors. A total of 128 stroke participants were randomised to receive either the SSMP plus usual stroke care, or the usual stroke care only. The results of this RCT showed that the SSMP was effective in enhancing the stroke participants’ self-efficacy in and outcome expectation for stroke self-management, satisfaction with performance in stroke self-management behaviours, HRQoL, and community reintegration at one month after completion of the program compared with the control group. However, there was no significant decrease in depressive symptoms among participants in the
intervention group at one month after completion of the program compared with the control group. The changes in the scores of outcome variables across time between the intervention and the control groups for the ITT and per-protocol populations were comparable in terms of the direction, magnitude and significance of change. When comparing the results of the participants who received different doses of the program, the magnitude of change from baseline to 8-weeks follow-up assessment was consistently greater for those who undertook all program sessions (full completers) compared with those who completed at least one but not all sessions (partial completers) in all primary outcome variables including self-efficacy in and outcome expectation for stroke self-management. The changes from baseline to 8-weeks follow-up assessment were significant in the scores of SSQOL total and domains of language, relationships, personality, and leisure and work for full completers. For partial completers, only changes in the scores of SSQOL total and leisure and work domain were significant. Significant changes in RNLI total and the two subscales were shown for partial completers, but not for the full completers. The changes in the GDS scores were not significant for both full and partial completers. Overall, the participants were satisfied with the SSMP, particularly the videos of experience sharing and the individual home visits. Some participants supported the usefulness of the group sessions, while some participants found it inconvenient to access the community-based nurse-led clinic. There were no adverse events reported among the stroke participants throughout the study. Detailed discussion about the comparability of the participants’ characteristics, and interpretation of the study results in comparison with that of previous studies examining the effectiveness of stroke self-management programs, issues related to application of a theoretical framework to underpin a complex stroke self-management program, and challenges in participant recruitment and delivery of the program will be provided in the next chapter. To conclude, the results of this RCT are valuable in laying the groundwork for informing future design, implementation and evaluation of stroke self-management programs for Chinese community-dwelling stroke survivors.
Chapter 7: Discussion (Main Study)

7.1 INTRODUCTION

This research project entailed two phases. Phase One was the conduct of a systematic review to examine the current research evidence on the effectiveness of theory-based stroke self-management programs on promoting recovery of community-dwelling stroke survivors. A total of three RCTs in English involving 306 community-dwelling stroke survivors were included. There was insufficient evidence to conclude the effectiveness of theory-based stroke self-management programs. However, the results showed potential program benefits on improving stroke survivors’ HRQoL and self-efficacy in self-management up to six months after program completion. The results of the systematic review also showed that Bandura’s construct of self-efficacy was the most commonly adopted theoretical framework to underpin the stroke self-management programs. However, more evidence is needed on the best theory-driven approaches to deliver the stroke self-management program, including its contents, format of delivery, and dose. All of the three included studies were conducted in Western countries. Further examination of applicability of the stroke self-management programs to Chinese stroke survivors is warranted. Phase Two of the research project was the development, implementation, and evaluation in a two-arm, assessor-blinded RCT the effectiveness of a new 4-week nurse-led self-efficacy enhancing stroke self-management program (SSMP) on promoting recovery among Chinese community-dwelling stroke survivors. The new program was underpinned by Bandura’s constructs of both self-efficacy and outcome expectation. A total of 128 community-dwelling stroke participants were recruited after discharge from hospital. The results of the current RCT showed that the SSMP was effective in enhancing the stroke participants’ self-efficacy, outcome expectation, and satisfaction with performance in stroke self-management behaviours, HRQoL, and level of community reintegration.

The results of the systematic review has been discussed in Chapter Three and will not be discussed in this chapter. This chapter is aimed at discussing the results of the current RCT and the effective approaches to deliver the stroke self-management program. The chapter starts with discussing the comparability of the participants in the current RCT with those of the previous studies examining the effectiveness of stroke
self-management programs. Next, the results of the current RCT are discussed in terms of its effectiveness on primary outcomes including self-efficacy in and outcome expectation for stroke self-management, and on secondary outcomes including satisfaction with performance in stroke self-management behaviours, and health outcomes, namely HRQoL, depressive symptoms, and community reintegration. Comparisons with the findings of previous studies on effectiveness of stroke self-management programs are made. Then, the appropriate approach to adopt a theoretical framework to underpin the design, implementation, and evaluation of a stroke self-management program is discussed. Next, the discussion centres on the effectiveness of approaches for enhancing stroke participants’ self-efficacy in and outcome expectation for stroke self-management. This is followed by an examination of the challenges in recruiting participants and implementing the SSMP within the context in Hong Kong, and the possible solutions to address the challenges. Finally, the roles and responsibilities of the nurse who served as the facilitator of the SSMP are discussed.

7.2 BASELINE CHARACTERISTICS OF PHASE TWO STUDY PARTICIPANTS

The RCT conducted in Phase Two of the research project was aimed at examining the effectiveness of the SSMP on recovery of Chinese community-dwelling stroke survivors. Comparison with previous studies of this population will examine the age and gender distribution of these stroke survivors, the education level, type and severity of stroke as well as daily activity level.

The 128 participants recruited in the current RCT had a mean age of 67.46 years (SD 11.95, range 38-95 years), with most of them except two were aged 45 and older. The stroke participants’ age in the current RCT was comparable with that reported in previous studies. Damush et al. (2011) which examined a 12-week stroke self-management program among 63 participants in the US reported an age range of 40.10 to 86.90 years. Cadilhac et al. (2011), examining the effectiveness of an 8-week stroke self-management program in Australia, reported a mean age of 69 years (SD 11) among 143 participants. Similarly, Kendall et al. (2007), examining the effectiveness of a 7-week stroke self-management program among 100 participants in Australia reported a mean age of 66.38 years (SD 10.90) and 66.36 years (SD 10.40) for the intervention and the control groups respectively.
According to a recent review of the electronic database of all stroke patients admitted to public hospitals in Hong Kong over an 8-year period from 1999 to 2007 (Woo, Ho, Goggins, Chau, & Lo, 2014), the age-standardised incidence of stroke increased sharply with each decade of age from 35-44 years to 85 years or above. In the current RCT, the percentage of participants in each decade of age increased from 1.56% (30-44 years) to 27.34% (65-74 years). The percentage decreased to 25.00% for those aged 75-84 years and it decreased sharply to 7.81% for those 85 years and above. As the three studies by Cadilhac et al. (2011), Damush et al. (2011), and Kendall et al. (2007) did not report the percentage of participants in each decade of age no comparison can be made. However, the lower percentage of participants aged 75 years and above in the current RCT is likely to be due to their exclusion for other reasons including comorbidities such as dementia that limited their cognitive functioning and resulted in a MMSE score of below 18. Lower numbers of participants in the 75 years and above age group might also have occurred because of more severe physical impairments or hearing loss that limited their ability to attend the SSMP, particularly to attend the community-based group sessions. Hence, these stroke survivors either declined to participate or were excluded from the study.

Woo et al. (2014), in a review of the electronic database of all stroke patients admitted to public hospitals in Hong Kong from 1999 to 2007, reported that the age-standardised incidence of stroke was higher in males than in females. Consistent with the local data reported by Woo et al. (2014), a greater proportion (60%) of male than female participants were recruited in the current RCT. Previous studies examining the effectiveness of stroke self-management programs in Western countries reported a wide range of the proportion of male participants, from 41% (Cadilhac et al., 2011), 67% (Kendall et al., 2007), to 98% (Damush et al., 2011). However, these three studies did not discuss the possible reasons for the lower or very high proportion of male compared to female participants.

The participants in the current study had a high mean MMSE score of 26.44 (SD 3.02) indicating a normal cognition, which was similar to the high MMSE mean score of 27 (SD 3.2) reported in the quasi-experimental study by Huijbregts et al. (2008), that examined the effectiveness of a stroke self-management program among 30 stroke survivors in Canada.
Comparing the educational level, slightly below half of the participants (43%) in the current RCT had attained secondary education or above which indicates a lower level of secondary education, in comparison to Cadilhac et al. (2011) who reported that 56% of the participants had attained education greater than or equal to 12 years.

More participants in the current RCT had ischaemic stroke (88%), in comparison with that of 62% of the 143 participants reported in a previous study examining the effectiveness of a stroke self-management program in the US (Cadilhac et al., 2011). Compared with the findings reported by Chau et al. (2011), a review of the electronic database of all stroke patients admitted to public hospitals in Hong Kong between 1999 and 2007, ischaemic strokes constituted over two-thirds of all stroke subtypes (71.30%) while haemorrhagic strokes constituted only 20.30%. However, this review included transient ischaemic attack as one of the stroke subtypes. Since patients with transient ischaemic attack were excluded from the current RCT, the percentage of ischaemic and haemorrhagic strokes reported by Chau et al. (2011) would be slightly greater, and comparable with that of the current RCT, if transient ischaemic attack was removed from the calculation.

The participants in the current study had a low NIHSS score of 2.83 (SD 2.49) which indicated minor stroke symptoms. Thirty-eight percent of them had a modified Rankin Scale (mRs) score between 0 and 1 which indicated no symptoms, or that the participants were able to perform all daily usual activities despite some symptoms. Likewise, relatively low NIHSS scores of 3.27 (SD 2.72) and 3.33 (SD 3.37) for the intervention and the control groups respectively were reported by Damush et al. (2011). Cadilhac et al. (2011) also reported that 36% of the participants had a mRs score between 0 and 1.

In conclusion, the age and gender distribution, cognitive status, educational level, proportion of ischaemic and haemorrhagic stroke, stroke severity, and degree of independence in ADLs of the participants in this current RCT were comparable with participants in other studies conducted in Western countries which examined the effectiveness of stroke self-management programs.

7.3 EFFECTIVENESS OF THE NEW PROGRAM

In this section, the effectiveness of the new stroke self-management program (SSMP) examined in the current RCT on promoting the stroke participants’ recovery
is discussed, in terms of the primary and secondary outcomes. The primary outcomes were self-efficacy in and outcome expectation for stroke self-management. The secondary outcomes included satisfaction with performance in stroke self-management behaviours, and health outcomes namely HRQoL, depressive symptoms, and community reintegration.

7.3.1 Effectiveness on self-efficacy in stroke self-management

Analysed using ITT principles, the results of the current RCT showed that the participants in the intervention group had a significantly greater increase in mean levels of total self-efficacy in self-management (SSEQ) compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel ADL Index and MMSE scores were adjusted in the GEE models. The hypothesis on improved self-efficacy for those receiving the stroke self-management program was supported by the results of this study.

A previous multiple-participant single-subject design study by Jones et al. (2009) also reported significant improvements in self-efficacy in self-management (SSEQ) among 10 community-dwelling stroke survivors after immediately receiving an individualised self-management workbook designed based on Bandura’s construct of self-efficacy. Other studies used different measuring instruments and data collection times in evaluating stroke self-management programs. Damush et al. (2011) in their RCT of 63 community-dwelling stroke survivors in the US reported a statistically significant improvement in self-efficacy in communicating with physicians at six months after receiving a 12-week stroke self-management program underpinned by Bandura’s construct of self-efficacy. Damush et al. (2011) adopted the CDSES (Lorig, 1996), a different measuring tool from the SSEQ in the current RCT, to measure self-efficacy in performing self-management behaviours common among people with chronic conditions. The stroke self-management program examined in Damush et al’s (2011) study was delivered by telephone for six 20-minute sessions biweekly.

Kendall et al. (2007) in an RCT examined the effectiveness of a 7-week stroke self-management program modified from the Stanford CDSMP. Contrary to the findings of the current RCT, Kendall et al. (2007) reported no significant improvement in the mean CDSES scores among 100 community-dwelling stroke survivors in
Australia at one month after program completion. Compared with the current RCT, Kendall et al. (2007) adopted a different instrument to measure self-efficacy in stroke self-management; making direct comparison across studies not possible. Furthermore, the stroke self-management program examined in Kendall et al.’s (2007) study consisted of seven weekly community-based group sessions only. There was no detailed description about the strategies adopted to address the four sources of information of self-efficacy. Unlike the SSMP in the current RCT, which offered an individualised home visit, two group sessions, three follow-up phone calls, videos of experience sharing by stroke survivors, and a program workbook. Multiple theory-driven strategies were adopted to enhance stroke participants’ self-efficacy. The differences in the program components might account for the differences in the mean self-efficacy levels.

7.3.2 Effectiveness on outcome expectation for stroke self-management

Analysed using ITT principles, the results of the current RCT showed that the participants in the intervention group had significantly greater increase in mean levels of outcome expectation for stroke self-management (SSOES) compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel ADL Index, and MMSE scores were adjusted in the GEE models. The results of the current RCT supported the hypothesis on improved outcome expectation for those receiving the stroke self-management program.

There have been few studies reporting stroke participants’ outcome expectation for stroke self-management. However, the improved results in the current RCT could be compared with a previous study about outcome expectancy beliefs for exercise (Shaughnessy et al., 2012). Such a comparison is limited as outcome expectancy in Shaughnessy et al.’s (2012) study was for exercise only while exercise was one of the stroke self-management outcome expectations examined in the current RCT. Shaughnessy et al. (2012), conducting an RCT of 64 stroke survivors, found improvement in outcome expectation associated with exercise in both the intervention group receiving a 6-month treadmill training program, and the control group receiving a stretching program. However, there was no significant difference in outcome expectation between the two groups. While the follow-up period of six months after
program completion was much longer than that of the current RCT, Shaughnessy et al. (2012) attributed the absence of significant differences between the two groups to the lack of theory-driven strategies to enhance outcome expectation in the program. The current RCT, which underpinned the stroke self-management program with a theoretical framework, did find significant differences in outcome expectation for stroke self-management between the intervention and the control groups. Furthermore, Shaughnessy et al. (2012) indicated that the two study groups were possibly exposed to similar interventions which was likely to have diminished the treatment effect.

7.3.3 Effectiveness on satisfaction with performance in stroke self-management behaviours

Analysed using ITT principles, the results of the current RCT showed that the participants in the intervention group had significantly greater increase in mean levels of satisfaction with performance in stroke self-management behaviours (SSBPS) compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel ADL Index, and MMSE scores were adjusted in the GEE models. The results of the current RCT supported the hypothesis on improved satisfaction with performance in stroke self-management behaviours for those receiving the stroke self-management program.

There has been no study reporting the effectiveness of stroke self-management programs on the levels of satisfaction with performance in stroke self-management behaviours. However, the improved results in the current RCT could be compared with previous studies about actual participation in self-management behaviours. Previous studies have shown that participation in self-management behaviours were commonly measured by either objective measurement of actual participation (Lorig et al., 1996; Tokunaga-Nakawatase et al., 2012; Willaing et al., 2013), or measurement of the person’s satisfaction with own performance in the behaviours (Daly & Bialocerkowski, 2009). Damush et al. (2011) reported in an RCT of 63 stroke survivors that the intervention group had a greater increase, though non-significant, in the total amount of time in minutes spent in aerobic activity than the control group at both three and six months after receiving a 12-week telephone-based stroke self-management program designed based on Bandura’s construct of self-efficacy. Indeed, Damush et al. (2011) also reported significant improvement in self-efficacy in communicating with
physicians among participants in the intervention group at six months after program completion. The overall increase in satisfaction with performance in stroke self-management behaviours might be related to a significant increase in self-efficacy according to Bandura’s construct of self-efficacy (Bandura, 1997). Although in a different population a survey of 203 women with cardiovascular disease in Canada by Blanchard, Arthur, and Gunn (2015) similarly found that women with cardiovascular disease who had a higher self-efficacy and outcome expectations for performing self-management behaviours were more likely to participate actively in physical activities during and after cardiac rehabilitation.

7.3.4 Effectiveness on health-related quality of life

Analysed using ITT principles, the current RCT showed that the participants in the intervention group had a significantly greater increase in the mean levels of total SSQOL compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel ADL Index, and MMSE scores were adjusted in the GEE models. The results of the current RCT supported the hypothesis on improved HRQoL following the stroke self-management program.

The results of the current RCT were contrary to that of a previous study. Cadilhac et al. (2011) reported in a three-arm RCT of 143 stroke survivors that both the intervention and the control groups had improved HRQoL from baseline to six months after completion of the stroke self-management program. However, there was no statistically significant difference between the two groups. The authors attributed the absence of significant changes to the small sample size limiting the statistical power of the study. Furthermore, Cadilhac et al. (2011) used the Assessment of Quality of Life tool, a different measuring instrument from the current RCT to measure HRQoL; limiting direct comparison of the results. The follow-up period of six months after program completion was also much longer than that of the current RCT. Additionally, the stroke self-management program in Cadilhac et al. (2011) consisted of eight weekly community-based group sessions only. It was different from the SSMP in the current RCT which offered multiple components including an individual home visit, two group sessions, three follow-up phone calls, videos of experience sharing, and a
program workbook. These differences might account for the differences in the changes in HRQoL between the two studies.

A systematic review of 17 studies found that stroke survivors’ HRQoL was positively associated with their levels of self-efficacy, mobility, and ADLs (Korpershoek et al., 2011). However the results of the current RCT showed that there were no significant differences between baseline and 8-weeks follow-up in the participants’ mean Barthel ADL Index scores and the proportion of participants who walked unaided or not. Thus, the improvement in HRQoL in the current RCT might be due to the increase in the participants’ self-efficacy in stroke self-management but not related to ADLs or mobility.

7.3.5 Effectiveness on depressive symptoms

Analysed using ITT principles, the results of the current RCT showed that the participants in the intervention group did not have significant decreases in the mean levels of depressive symptoms (GDS) compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel ADL Index, and MMSE scores were adjusted in the GEE models. The hypothesis on improved depressive symptoms following the stroke self-management program was not supported by the study results.

Previous studies, though adopting different measuring instruments and follow-up periods from the current RCT, consistently reported no statistically significant improvement in depressive symptoms or mood after receiving the stroke self-management programs. Jones et al. (2009) reported no statistically significant change in the mood scores, as measured by the Hospital Anxiety and Depression Scale, among 10 participants immediately after receiving a self-efficacy enhancing stroke self-management workbook. However, Jones et al. (2009) had a small sample size and did not involve a control group in the study. It limited the interpretation of the causal relationship between the intervention and the results. A three-arm RCT of 143 stroke survivors in the US by Cadilhac et al. (2011) also reported no statistically significant difference in mood, as measured by the irritability, depression, and anxiety scales, between the participants receiving the stroke self-management program and the control group receiving usual stroke care at six months after program completion. The authors
attributed the absence of significant changes to the small sample size limiting the statistical power of the study.

Indeed, the experiences of stroke recovery often fluctuate with good and bad times (Liddy et al., 2014). An earlier large-scale study reported that approximately one-third of stroke survivors had depressive symptoms at some stage post-stroke (Hackett, Yapa, Parag, & Anderson, 2005). Ostir, Berges, Ottenbacher, and Ottenbacher (2011) in their study of change in depression for stroke survivors over time reported that the initial highest rates of depression during acute phase lessoned over the following 12 months. The participants in the current RCT were on average three months post-stroke. The lack of significant improvement in the mean GDS scores of the participants in the intervention group might be indicating that improvement in depressive symptoms or psychological well-being may be evident after a longer-term follow-up period.

Furthermore, management of psychological well-being is demanding and it takes time. A qualitative study of 23 stroke survivors also echoed that stroke survivors who had psychological symptoms after stroke demonstrated sustained improvements in their mood by 12 months following stroke. The results also showed that improvement in survivors’ mood was facilitated by improvement in their physical independence and self-esteem, and by having increased internal locus of control over their health. The results indicated that interventions of a longer duration was required to enhance survivors’ psychological outcomes (White et al., 2015). A meta-review of seven reviews of 130 studies highlighted that provision of psychological and emotional support is important throughout stroke survivors’ stroke recovery trajectory, even after a plateau of physical recovery (Pearce et al., 2015). The results of the current RCT suggest that more effective strategies for improving stroke survivors’ psychological well-being need to be incorporated into the stroke self-management program.

7.3.6 Effectiveness on community reintegration

Analysed using ITT principles, the results of the current RCT showed that the participants in the intervention group had significant increases in the mean levels of community reintegration (RNLI) compared with the control group at 8-weeks follow-up relative to baseline, when potential confounding variables including employment status, type of stroke, duration between stroke onset and baseline, and baseline Barthel
ADL Index, and MMSE scores were adjusted in the GEE models. The hypothesis on improved community reintegration following the stroke self-management program was supported by the results of the current RCT.

This study’s findings are in contrast with previous studies which examined the effectiveness of stroke self-management programs, consistently reported no significant change in the levels of community reintegration. A single-subject pre- and post-design by Jones et al. (2009) found no statistically significant change in community reintegration as measured by the Subjective Index of Physical and Social Outcome among 10 stroke participants immediately after receiving a self-efficacy enhancing stroke self-management workbook. Huijbregts et al. (2009) reported no significant differences in the mean RNLI scores at two weeks after program completion, between the intervention group receiving a 9-week stroke self-management program and the waiting list control group. An RCT of 143 stroke survivors in the US by Cadilhac et al. (2011) also reported no statistically significant differences in the positive and active engagement in life scale between the intervention and the control groups at six months after completion of a stroke self-management program. However, it is important to note that some studies adopted different measuring instruments from the current RCT (Cadilhac et al., 2011; Jones et al., 2009). Furthermore, the follow-up periods were either shorter or much longer than that of the current RCT.

Further understanding of the findings obtained in the current RCT may be gained from the study by Chau et al. (2009) who reported in their longitudinal descriptive study that stroke survivors at risk of restrictions in participating in social activities at 12 months after discharge from hospital included those who had depressive symptoms and low self-esteem. A recent systematic literature review of 18 qualitative studies echoed that the stroke survivors’ ability to overcome emotional challenges was one of the significant factors associated with increased community reintegration in the first 12 months after stroke (Walsh, Galvin, Loughnane, Macey, & Horgan, 2015). A recent meta-synthesis of 11 qualitative studies found that successful community reintegration demands the stroke survivors’ capabilities in exercising problem-solving and decision-making skills to adapt their behaviours to post-stroke conditions (Woodman, Riazi, Pereira, & Jones, 2014). The results of the current RCT found no significant improvement in depressive symptoms at one month after receiving the SSMP. However, it is important to note that some items contained in the RNLI were about
perceptions of ability to handle daily tasks effectively, which to a certain extent, is consistent with perceived self-efficacy in managing tasks (Pang et al., 2011). The significant improvement in mean levels of total RNLI might be due to a significant increase in self-efficacy in stroke self-management.

Additionally, the stroke survivors’ functional ability may impact on their level of community reintegration (Hamzat, Olaleye, & Akinwumi, 2014). An RCT of 143 stroke survivors in Australia, that randomly assigned stroke participants to receive either a stroke self-management program or usual care, reported a significant inverse association between community reintegration and global impairment status (Cadilhac et al., 2016). The participants in the current RCT had a relatively high mean modified ADL Index scores. The better functional abilities might have contributed to the positive results. On the other hand, a systematic literature search of 18 qualitative studies also suggested that convenience of public transport and ease of community access was one of the factors impairing stroke survivors’ community reintegration (Walsh et al., 2015). However, the current RCT did not collect information on these factors and hence no conclusion regarding its impact on the participants’ level of community reintegration could be drawn.

7.3.7 Adverse effects of the SSMP

No adverse effect was reported by the participants throughout the conduct of the current RCT. The results were consistent with that reported by Cadilhac et al. (2011), where none of the 36 adverse events reported by 32 of the 143 participants at two to four weeks after receiving the 8-week stroke self-management program were found associated with the program. Cadilhac et al. (2011) also found no significant differences in the proportion of severe adverse events between the intervention and the control groups. Reviews of efficacy of stroke self-management programs consistently reported no adverse effects associated with the program delivery (Boger, Demain, & Latter, 2015; Jones, Dean, Hush, Dear, & Titov, 2015).

7.3.8 Effective dose of the SSMP

The results of the RCT showed that, compared with the control group, the magnitude of increase at 8-weeks follow-up relative to baseline were significantly greater for the participants who received all sessions of the SSMP than for those who received at least one but not all sessions, in the mean levels of total SSEQ, SSOES,
and SSQOL. Another study by Kendall et al. (2007), examined the impact of the dose of the program among the 58 participants in the intervention group receiving the stroke self-management program, and compared the differences in the mean HRQoL and self-efficacy scores for those with full attendance, and those who attended at least four out of the seven sessions. Kendall et al. (2007) found that there were no significant differences between the two groups at one month after program completion. Kendall et al. (2007) suggested that the mere exposure, instead of full attendance, of the participants to the stroke self-management program was adequate to result in improvement. However, it is important to note that the sample sizes included in the secondary analyses of effective dose of the SSMP in the current RCT and Kendall et al.’s (2007) study were small. It is likely to limit the statistical power of the study to detect significant changes in the outcomes (Portney & Watkins, 2009). Future studies with adequate sample size are needed for more conclusive evidence on the significance of changes in outcome variables with reference to the dose of the SSMP received.

7.4 SYSTEMATIC APPLICATION OF A THEORETICAL FRAMEWORK

The systematic review conducted in Phase One of this research project found that Bandura’s construct of self-efficacy was commonly adopted to underpin stroke self-management programs (Cadilhac et al., 2011; Damush et al., 2011; Kendall et al., 2007). Distinct from the previous programs, the new 4-week nurse-led stroke self-management program (SSMP) examined in the current RCT was underpinned by Bandura’s constructs of both self-efficacy and outcome expectation. The current RCT showed significantly greater improvements in self-efficacy and outcome expectation for stroke self-management among participants in the intervention group at 8-weeks follow-up, as compared with the control group. Significant improvements were also shown in secondary outcomes including satisfaction with performance in stroke self-management behaviours, HRQoL, and community reintegration. The positive results obtained supported the approach of using theory-driven strategies to enhance stroke survivors’ self-efficacy in and outcome expectation for stroke self-management.

The current RCT adapted the criteria of a theory-based intervention suggested by Davies et al. (2010) and Green (2000) as the framework to guide the selection of theory-driven strategies. The adapted framework consisted of four steps, namely an explicit description of the original citation of the theory or construct, an explicit description of the
variables and their relationships postulated in the theory or construct, an explicit description of the comprehensive selection of evidence-based strategies to address each of the variables, and an explicit description of measurement of the variables. This current RCT delineated in detail the type and dose of mapped strategies adopted in the SSMP to the four sources of information of self-efficacy and outcome expectation. Such a four-step approach was described in the study of Damush et al. (2011) and Jones et al. (2009). Both of the studies reported a significant increase in the participants’ self-efficacy after receiving their theory-based stroke self-management programs.

In contrast are the findings from an RCT in the US by Shaughnessy et al. (2012) which aimed at enhancing the outcome expectation for exercise, one of the stroke self-management behaviours, among 64 stroke survivors. However, there was no significant difference in outcome expectation associated with exercise between the intervention group receiving a 6-month treadmill training program and the control group receiving a stretching program at six months after program completion. Shaughnessy et al. (2012) attributed the absence of significant differences between the two groups to the lack of theory-driven strategies to enhance outcome expectation in the program. Kendall et al. (2007) examined the effectiveness of a stroke self-management program modified from the Stanford CDSMP. The results showed absence of significant improvement in self-efficacy in stroke self-management at one month after receiving the program. However, there was no information about mapped strategies adopted according to the construct of self-efficacy reported in Kendall et al.’s (2007) study. The lack of detailed, mapped strategies to address the four sources of information of self-efficacy might be one of the possible reasons to account for the absence of significant improvement in self-efficacy.

There has been no consensus recommendation on the appropriate approach to adopt a theoretical framework (Craig et al., 2008). The positive results obtained in the current RCT supported that the four-step approach as mentioned above are deemed integral to ensuring that all variables posited in the theory or construct have been addressed systematically. Such an approach was consistent with the roles of theories suggested by Bartholomew and Mullen (2011). It included specifying the health problem concerned, delineating a mechanism explaining the change in behaviours of interest, guiding the selection of strategies to achieve the changes in health behaviours, evaluating the theoretical mediating variables, and reporting of the active ingredients of the intervention together with the evaluation results.
However, it is important to note that Michie and Prestwich (2010) suggested that interventions were coded as theory-based in terms of how theories were used in the intervention design. Additionally, the influence of theory on the interventions is based on how the intervention evaluations tested the theory. The current RCT demonstrated changes in the primary and secondary outcomes following the implementation of the SSMP. However, the interrelationships between the mediating and outcome variables as postulated in the constructs of self-efficacy and outcome expectation were still not well-known (Figure 7.1). The evidence would be of particular importance amid the longstanding but unresolved debate about the causal relationship between self-efficacy and outcome expectation (indicated by the double-lined arrow), and their influences on the behavioural outcome variable (indicated by the dashed arrows), and in turn the health outcome variables (indicated by the dotted arrow) (Figure 7.1) (Williams, 2010). Further examination of the associations between variables would be helpful to better interpret the applicability of the constructs to enhancing stroke survivors’ self-management of post-stroke conditions.

![Theoretical framework of the new nurse-led self-efficacy enhancing stroke self-management program developed for this study](Adapted from Bandura, 1997)

Figure 7.1 Theoretical framework of the new nurse-led self-efficacy enhancing stroke self-management program developed for this study
7.5 STRATEGIES TO ENHANCE SELF-EFFICACY IN AND OUTCOME EXPECTATION FOR STROKE SELF-MANAGEMENT

The aim of the SSMP examined in this current RCT was to enhance the stroke survivors’ self-efficacy in and outcome expectation for stroke self-management, and in turn to increase their participation in stroke self-management behaviours, and hence to enhance their health outcomes. In this section, the effective strategies to enhance the stroke survivors’ self-efficacy in and outcome expectation for stroke self-management, and how the strategies are incorporated in the stroke self-management programs are discussed.

Program components

The SSMP examined in this RCT consisted of one individual home visit, followed by two community-based group sessions, and three follow-up phone calls. The arrangement of multiple components in the current SSMP was distinct from previous studies. However, the positive results obtained in the current RCT supported the effectiveness of this package in enhancing stroke survivors’ self-efficacy in and outcome expectation for stroke self-management.

The addition of a home visit in the current SSMP was found helpful to enable the conduct of individualised assessment in a more private and comfortable environment. The facilitator could take into the consideration the possible impact of home environment on the participants’ engagement in self-management behaviours. It provided a good opportunity for the participants to discuss personal or sensitive issues related to care or adaptation after stroke, and establish rapport which often not possible in group sessions or over the phone. Furthermore, Lou, Carstensen, Jørgensen, and Nielsen (2016) reviewing seven qualitative reviews of 108 primary studies reported that stroke survivors valued the visits by healthcare professionals. They felt they were being cared for and supported. Likewise, the participants in the SSMP welcomed the visit by the facilitator who was a registered nurse, and were willing to discuss their experiences in post-stroke recovery. Furthermore, Lou et al. (2016) found that stroke survivors needed more tailored information to be better prepared for self-management. Likewise, the facilitator in the current study provided tailored health information during the home visit, which was found more appropriate than during group sessions.
In addition to the home visit, the current SSMP delivered the two group sessions for a total of three hours in one afternoon (that is in one visit). The arrangement was distinct from previous studies, which often involved seven to 18 community-based group sessions in the stroke self-management programs (Cadilhac et al., 2011; Huijbregts et al., 2008; Kendall et al., 2007). The duration of each session, shorter than the current SSMP, lasted for about 1.5 to two hours. The group sessions in previous studies commonly provided comprehensive information on stroke, stroke care, stroke self-management, challenges and tips for self-management. The contents covered in the current SSMP, unlike the previous programs, were modified to focus on reinforcing the concepts of self-management, and the practice of core self-management skills. Similar to previous studies, group discussion and reflection were incorporated. The results of the current RCT supported that the current approach in delivering group sessions was feasible and helpful. There were no complaints received from the participants about the three-hour combined sessions. Some participants were eager to talk and share even after the sessions ended.

The provision of follow-up phone calls was found important in enhancing participants’ flexibility in attending the SSMP. Problems in scheduling group sessions were reported in some studies with stroke participants having difficulty in accessing the community venues to attend the stroke self-management programs due to different degrees of physical limitations (Jones et al., 2009; Kendall et al., 2007). Similarly, some participants in the current SSMP raised concerns about transportation problems in accessing the venue of group sessions. Damush et al. (2011) in delivering a 12-week telephone-based stroke self-management program found that less than 10% of the 63 participants needed to receive the program in person due to hearing difficulties. Participants who were not able to use a cell phone were excluded from the current RCT. However, there were no complaints or adverse effects related to use of phones received during the conduct of the SSMP.

**Mastery experience**

Establishing goals and action plans were adopted in the SSMP examined in the current RCT as the primary strategies to enhance the stroke participants’ mastery experience of successful accomplishment of the stroke self-management behaviours. Such strategies were consistently adopted in previous stroke self-management
programs. Several recent systematic reviews and meta-reviews identified that goal-setting and action-planning were core components of stroke self-management programs (Parke et al., 2015; Pearce et al., 2015; Warner, Packer, Villeneuve, Audulv, & Versnel, 2015). Sugavanam, Mead, Bulley, Donaghy, and van Wijck (2013) suggested that goal-setting positively influenced stroke survivors’ perceptions of their capabilities in performing daily care activities, and hence enhanced their performance and goal achievement. An RCT of 63 stroke survivors in the US (Damush et al. 2011) who examined the effectiveness of a stroke self-management program underpinned by Bandura’s construct of self-efficacy also adopted this approach to enhance stroke participants’ self-efficacy. The findings were associated with a significant increase in self-efficacy in communicating with physicians at six months after receiving the program (Damush et al., 2011).

Consistent with that adopted by Damush et al. (2011), the facilitator of the current SSMP assessed the stroke participants’ current health condition, cooperated in developing a goal of recovery valued by the participant and a workable action plan at the beginning of the program, and monitored throughout the SSMP for the participants’ progress. The goals and action plans might be revised to be better tailored to the participants’ capabilities and progress. The goals set were mainly short-term goals. Specifically, participants in Damush et al.’s (2011) study were guided to set at least one goal to work on within a two-week period. Similarly, participants’ in the current SSMP were guided to set goals to work within the four weeks of the program. Such gradual increase in the demands in goals was found helpful to enhance the successful performance of the target self-management behaviours.

The progress in pursuance of the goals was reviewed at each follow-up encounter. Though not specifically mentioned in Damush et al. (2011), based on the criteria of SMART (Smart, Measurable,, Attainable, Realistic, Timely) goal, the goals consistent with the current RCT, needed to be specific to when, where and length of time needed to do the specific behaviour. The goals needed to be realistic and achievable (Damush et al., 2011). This current RCT mainly adopted the principles of breaking difficult tasks into simpler steps during goal setting and action planning, which was also adopted in some studies of stroke self-management programs, and were associated with positive results in self-efficacy (Damush et al., 2011; Jones et al., 2015; Kendall et al., 2007). A systematic review of 12 papers examining self-efficacy strategies to improve
exercise in patients with heart failure supported that paced, step-by-step implementation facilitated the achievement of target behaviours, and enhanced an individual’s self-efficacy (Rajati et al., 2014).

Additionally, the stroke participants in the current SSMP were asked for their level of confidence in achieving the goal set. As suggested by Lorig et al. (2012), a goal with a confidence level of seven or above out of 10 was regarded as having an increased likelihood of attainment by the participant. This approach was also explicitly mentioned by Damush et al. (2011). However, some studies which modified their stroke self-management programs from the Stanford CDSMP did not mention the assessment of confidence level in achieving the goal in their programs examined (Huijbrechts et al., 2008; Kendall et al., 2007). If more details about the program, may be able to judge or assess the approach compared with the current RCT.

More importantly, the facilitator in the current SSMP asked the stroke participants about the outcomes that they expected to attain upon accomplishing the goal set. Indeed, Damush et al. (2011) also mentioned about encouraging the stroke participants in their study to know more stroke rehabilitation and to have associated realistic expected outcomes. Damush et al. (2011) suggested devising plans to overcome past failures. It is similar to the current RCT as to assist the participants to problem-solve and make decisions regarding their difficulties encountered during the pursuance of the goals and action plans. However, some studies did not provide details about how the goal setting and action planning were implemented in the program (Cadilhac et al., 2011; Kendall et al., 2007). To conclude, the results of the current RCT indicated that the approach was effective as part of the package to provide mastery experience for Chinese community-dwelling stroke survivors.

**Vicarious experience**

Two community-based group sessions were arranged in the current SSMP. During the group sessions, the participants themselves served as role models for each other. The facilitator enabled live interaction and sharing among group members, thereby promoting more effective learning from each other’s experience as well as via observation. The approach was consistently adopted in previous studies of stroke self-management programs, which commonly organised community-based group sessions for stroke participants to observe and learn from experiences of others with similar
conditions (Cadilhac et al., 2011; Damush et al., 2011). These studies also found positive results in self-efficacy. While previous studies provided only group sessions in stroke self-management programs, the group sessions in the current SSMP were arranged after completing the home visit. Such arrangement was found helpful in establishing the rapport between the facilitator and the participants, and increasing the interest of the participants in attending the group sessions.

Indeed, the SSMP in this RCT was pioneering in using videos by role models to provide vicarious experience for stroke participants. The videos contained sharing of experiences by 15 volunteer stroke survivors who were successfully managing post-stroke challenges. The use of videos in this way had not been reported in previous studies. Previous studies provided stroke participants with modelling or vicarious experiences commonly via demonstration of new self-management behaviours by facilitators or lay leaders, or sharing of experiences among stroke participations during community-based group sessions (Damush et al., 2011; Kendall et al., 2007). Jones et al. (2009) provided stroke survivors’ vignettes and practical tips to address common post-stroke challenges in the self-management workbook. However, these strategies were limited in providing merely a one-off experience, or were limited for stroke participants who were unable to travel to the venues to join group sessions or read the written information.

The videos in forms of two DVDs were provided to the participants during home visit. They were encouraged to view the videos themselves during their free time. Stroke participants often suffer from different degrees of physical disability even for a minor stroke (Green & King, 2010). The participants in the current RCT were active mainly in their neighbourhood, with a few of them having resumed work with a reduced workload after discharge from hospital. They seldom had opportunities to meet and share with other stroke survivors on experiences of stroke recovery. The role models in the videos were important in being their main resource to learn from other’s experiences.

Indeed, videotaped experience-sharing adopted in self-management programs for people with diabetes was associated with positive results. A recent quasi-experimental study of 228 people with diabetes reported a significant increase in self-efficacy level among those participants who had watched videos of experience sharing
by other people with diabetes in a diabetes self-management program (Wu, Liang, Lee, Yu, & Kao, 2014). Chau et al. (2012) developed a web-based diabetes education program to enhance diabetes clients’ capabilities in self-management. The results showed that the older adults with diabetes commented that having videos of experience-sharing by other people with diabetes enabled flexibility in viewing and were helpful in increasing their confidence in self-managing diabetes. Stalker and Elander (2015) found that video materials increased the impact of a pain self-management program among those with less education by supplementing the written information provided. Consistent with previous study results, the innovative use of videos in the SSMP in the current RCT strengthened the stroke participants’ learning by enabling repeated viewing without time and place restriction. Those who were illiterate were also able to understand the video contents (Chau et al., 2012; Wu et al., 2014). Use of videos helped solve the challenges in which participants were not able to read, commonly reported as barriers in stroke self-management programs (Damush et al., 2011).

More importantly during the home visit the facilitator, with each participant receiving the SSMP, viewed one to two videos in which the role models were most similar to the participant. The participants were then guided to reflect on their difficulties and possible solutions. Using the selected videos as a reference, was found helpful in facilitating the participants to recall the relevant events, and notice their feelings. Moreover, the videos motivated the participants to identify new aspects or ways to enhance their stroke recovery (Henry & Fetters, 2012). The stroke participants were found more confident to establish, and refine or review their goals and action plans after video viewing and reflection. In the SSMP examined in this RCT, the way of selecting and presenting the videos with guided reflection and discussion by the facilitator was deemed appealing to enhance the stroke participants’ self-efficacy.

Increasing numbers of studies have examined the effectiveness of online or mobile telehealth-based applications incorporating videos to support self-management among people with chronic conditions, such as COPD (Hardinge et al., 2015) and dermatitis (van Os-Medendorp, van Leent-de Wit, de Bruin-Weller, & Knulst, 2015). Taylor et al. (2009) also examined the effectiveness of a stroke self-management program delivered via videoconference. While acknowledging the potential benefits of role modelling via videos in providing self-management support, it is important to
note that the role of face-to-face care provided during the programs cannot be underestimated. van Os-Medendorp et al. (2015) reported that adult patients with atopic dermatitis chose to receive both the online self-management programs and face-to-face care. Maslakpak and Shams (2015) suggested using video education along with face-to-face education on enhancing self-management abilities among haemodialysis patients for optimising the impact on HRQoL.

**Verbal persuasion**

In the SSMP, three parties namely the role models in the videos, the stroke participants themselves in the group sessions, and the registered nurse facilitator provided verbal persuasion. The nurse reinforced the participants’ ability to self-manage, provided feedback on progress, and provided positive reinforcement to motivate them to continue to implement the action plans. Consistent with previous studies (Damush et al., 2011; Kendall et al., 2007), the healthcare professional or the nurse who served as facilitator in the current study played a major role in providing verbal persuasion for stroke participants throughout the SSMP. Bandura (1997) suggested that verbal persuasion provided by those with similar conditions is the most influential in developing self-efficacy. However, it cannot be denied that verbal persuasion by the facilitator who was a registered nurse played an important role in enhancing the stroke participants’ self-efficacy. A systematic review by Rajati et al. (2014) about effective strategies to improve exercise participation among heart failure patients found that self-efficacy could be enhanced by expert personnel as healthcare professionals. Skills in providing verbal persuasion were comparable with the present RCT, such as reinforcing performances and focusing on benefits of target behaviours.

In addition, the stroke participants themselves who joined the group sessions of the SSMP provided verbal persuasion, which is common across previous studies examining stroke self-management programs (Cadilhac et al., 2011; Damush et al., 2011). Specific to the SSMP examined in this RCT, verbal persuasion was also provided by the 15 volunteer stroke survivors or role models who shared their experiences in the videos, and verbalised words of encouragement at the end of the videos. Such arrangement of multiple sources of verbal persuasion in the SSMP was deemed helpful in strengthening the program effectiveness on the stroke participants’ self-efficacy.
Reinterpretation of physiological or emotional states

The SSMP strategies used in the current study assisted the stroke participants to reinterpret their physiological and emotional arousal such as shoulder pain or frustration. Similar strategies which were adopted in another RCT that the mapped strategies to this source of information of self-efficacy (Damush et al. 2011) included discussion of post-stroke symptoms and ways to diminish them, and education on use of distraction or relaxation techniques. Although the Damush et al.’s (2011) study had not measured the changes in the stroke participants’ outcome expectancy beliefs for stroke self-management, the study found significant increase in self-efficacy in communicating with physicians and HRQoL. However, it is important to note that some participants in the current SSMP verbalised that they were not used to use this strategy as the way of thinking was new to them. The study by Damush et al. (2011) did not provide details about the receipt of this strategy by the participants. A systematic review of 20 studies examining effectiveness of stroke self-management programs underpinned by Bandura’s social cognitive theory (SCT) also found that the strategies about reinterpretation of symptoms by debriefing or discussion were not reported by any of the studies (Jang & Yoo, 2012). In addition, to allow more time for participants to get used to this strategy, recent systematic reviews found that cognitive strategies, for example prioritising conditions, regulating the amount of attention given to their situation, dealing with it, engaging in life, relinquishing control to another source, could be used to facilitate the management of physiological or emotional arousal (Harvey et al., 2015; Liddy et al., 2014). Further examination of the usefulness of these strategies for promoting effective reinterpretation of physiological or emotional states encountered by stroke survivors would be worthwhile.

Enhancing outcome expectation

In this RCT, the majority of the stroke participants in the SSMP were aged over 65 years. They thought that they no longer had the privilege to think or plan for the future, let alone to hope for the future. The role models in the videos played an important role in conveying messages to stroke participants that certain positive outcomes could be realised after persistent engagement in stroke self-management behaviours. For example, more independence in ADLs after repetitive exercise training, increased satisfaction with life after developing a leisure activity appropriate
to own physical abilities. The use of positive outcome expectancy beliefs was consistent with an RCT of 40 cardiac patients (Millen & Bray, 2009) which promoted the cardiac patients’ positive outcome expectancy by associating physical, functional or behavioural outcomes, such as easier performance of common ADLs, with specific types of resistance training (Millen & Bray, 2009). The results showed that the intervention group, after receiving an intervention involving an instructional manual based on the SCT, had higher levels of, though not significant, outcome expectations for resistance training post-cardiac rehabilitation at 4-week follow-up when compared with the control group (Millen & Bray, 2009). Despite of the non-significant results, the study by Millen and Bray (2009) supported that fostering positive outcome expectations was helpful to motivate people with cardiac diseases in performing resistance training. Likewise, promoting the stroke survivors’ positive outcome expectation helped focus their attention to the positive experiences of performing stroke self-management behaviours, amid uncertainties in stroke recovery (Bright, Kayes, McCann, & McPherson, 2011; White et al., 2014).

Additional strategies including the reinforcement of positive outcome expectations by the facilitator throughout the current SSMP, and the encouragement of recording outcome expectations in a calendar-like record in the program workbook are also believed to augment strengthening the positive outcome expectations among the stroke participants. This approach was consistent with the study by Williams, Anderson, and Winett (2005) who reported that personal barriers were regarded as the most predictive of negative outcome expectancy (Williams et al., 2005).

7.6 CHALLENGES AND SOLUTIONS

In this section, the challenges in recruiting the participants from the acute stroke units to join the community-based RCT and the solutions to address the challenges are first discussed. Then, the challenges in implementing the SSMP and the solutions to address the challenges are discussed.

7.6.1 Challenges in recruiting participants and solutions

The current RCT had a recruitment rate of 11.58%. The results were greater compared to that of 6.49% from a similar RCT which examined the effectiveness of a stroke self-management program (Damush et al., 2011). The participants’ reasons for refusal to participate in the current RCT were comparable to that reported in Damush
et al.’s (2011) study. Damush et al. (2011) reported that the reasons for ineligibility was similar with 673 out of 868 with no stroke diagnosis, followed by 37 who had died prior to discharge, 24 had substance abuse, 23 had dementia or Alzheimer’s diseases, 17 had severe aphasia, and 10 had active psychiatric illnesses. Several challenges were encountered during the recruitment of participants into the current RCT.

**Time of recruitment**

One major challenge encountered during recruitment was that the stroke patients were still at the acute stage when they were introduced to the study. Patients or family members’ prior concerns at that time were about the acute stage care regimens rather than the issues about rehabilitation and long-term recovery. The prognosis for recovery and destination of discharge of the stroke patients were often unclear. This challenge was also reported in Damush et al. (2011) who recruited stroke participants in acute care settings for their study examining the effectiveness of a stroke self-management program. Roberts et al. (2012) reported that cultural and environmental dynamics, including the patients’, and family members’ or carers’ psychosocial status might be a factor influencing participation in research. In the current RCT, some patients or their family members were resistant to learn more about the current study. They expressed that they would prefer to learn more about the current medical management regimen. On the contrary, there were also some patients, or their family members or carers who were interested in participating for that they wanted to receive more support at that time to enhance their recovery. Nevertheless, these patients might not have finally joined the study after their discharge, possibly because their perceived need for support was not as great as that during the acute stage. Nearly half of the participants who gave initial consent at the acute stroke units in the current RCT were unavailable for commencement of the study due to inability to be contacted after discharge. The remaining participants who gave initial consent were excluded as they no longer met the eligibility criteria or for other reasons such as now not living in Hong Kong. Similar situations were reported in Damush et al. (2011) with 55% of the eligible patients screened while in hospital were finally not enrolled. The majority of them had either refused to participate or they were lost to contact after discharge.

In view of stroke survivors’ priority of concerns during the acute stage, they were reassured that they could reconsider their consent to participate in the current RCT.
after the patients had returned home. Participation in the current study was entirely voluntary without negative consequences on their current medical regimens. However, they were required to consent for recording patients’ demographic and clinical information by the researcher if they agreed to join the study at that time to maintain research integrity.

The first encounter by the research assistants with the patients or family members at the acute stroke units for introducing and inviting them to participate in the study is a crucial moment to establish an effective communication between both parties. The importance of a positive relationship between the researchers and the participants, with effective communication are significant factors for participant recruitment and retention (Hadidi et al., 2012; Taylor-Piliae, Boros, & Coull, 2013). Adopting a supportive attitude and addressing the concerns of the patients and the family members are helpful instead of mere provision of study information and urging them to give consent.

Other participant-related factors

About 3% of the stroke patients screened in the current RCT declined to participate in the study. They verbalised that they did not understand the nature of research, and their responsibilities or commitment required. Some of them feared the costs incurred or perceived it as a waste of time. There were also stroke patients who thought that the intervention examined in the current study was at a testing phase only, or they simply had connoted negative feelings to research. These observations were consistent with the reports of previous studies where potential participants had a lack of knowledge and trust in the research process, and held negative perceptions in research which are common barriers to recruitment (Hadidi et al., 2012).

There were also participants who had their own priority for treatment or management research regimens that they preferred to join (Roberts et al., 2012). For example, some participants said they were more interested in joining research studies examining different types of exercises or acupuncture. Therefore, explanation of the study aim and contents needed to be clear and avoided misunderstanding of the patients. Some participants also asked if they had the opportunity to receive the stroke self-management program if they were assigned to the control group. While reviews suggested that provision of the treatment for control groups at the end of the study after
the last follow-up assessment of the participants or use of a wait-list group could possibly enhance retention (Roberts et al., 2012), it was not attempted in this current study due to manpower and resources limitation. Therefore, the information related to the arrangement and commitment of the potential participants needed to be made explicit during recruitment at the acute stroke units to avoid confusion.

7.6.2 Challenges in implementing the SSMP and solutions

In this section, the challenges in implementing the SSMP and the solutions to address the challenges are discussed.

Complex individual conditions

The current RCT highlights the complex nature of self-management and the exercise of the core self-management skills in stroke participants, particularly when many were new to the concepts. Focus group interviews of 16 community-dwelling stroke survivors in the Netherlands found that most perceived themselves as not ready for self-management after discharge from hospital (Satink, Cup, de Swart, & Nijhuis-van der Sanden, 2015). Similar problems were noted among the stroke participants in the current RCT, who were overwhelmed by different priorities of health care needs.

Furthermore, different stroke participants are likely to face different challenges in their life and roles. Boger et al. (2015) found in a qualitative study of 28 stroke participants in the United Kingdom that the individual’s characteristics or capacities, including their physical impairment, confidence and determination, decision-making and communication skills, influenced their receipt of self-management interventions. The emerging life and role challenges after discharge from hospital might impair the participants’ confidence in handling the challenges, and hence it would further complicate their development of core self-management skills.

Participants in the current SSMP generally held traditional Chinese beliefs of healthcare professionals’ authoritative or paternalistic positions in determining their course of stroke recovery, consistent with a previous study (Hu, Yin, Bao, & Nie, 2014). It was not uncommon to note that some stroke participants in the current SSMP depended largely on healthcare professionals’ instructions on their care regimens after stroke. Consistent with previous findings about Chinese stroke survivors’ post-stroke experiences (Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015; Lutz et al., 2011), there were also participants in the SSMP who depended on their spouse, family,
or carers to determine their rehabilitation activities for improvement, or on the prescribed medications or medical management for stabilising their health conditions. However, these beliefs are in contrast to the notion of self-management that the individual is an active manager who is responsible for making his/her health decisions (Lorig & Holman, 2003). Such beliefs may lower the stroke participants’ participation in setting and pursuing goals of recovery and plans during the SSMP.

To address the challenge, the facilitator conducted a comprehensive assessment during home visit the current health condition of the participants, their level of self-efficacy and outcome expectation, and performance in stroke self-management behaviours. Based on the priority in health and the stroke participant’s preference, a short-term goal was selected for pursuing during the current SSMP. Consistent with the findings of Bos-Touwen et al. (2015) in a qualitative study of 15 nurses delivering self-management support, such assessment process is considered of paramount importance in understanding the current capabilities and possible constraints encountered by them. To address this challenge, comprehensive assessment is needed to determine the survivors’ readiness to set goals, and their attitudes and knowledge towards their stroke recovery (Laver, Halbert, Stewart, & Crotty, 2010).

Additionally, the use of videos facilitated the participants to think about possible solutions to address their challenges. However, the facilitator also needed to be equipped with the knowledge and practical tips, and provide suggestions to the stroke participants for their consideration at the beginning of the SSMP. More information provision tailored to the individual participants’ needs were provided throughout the SSMP including during follow-up phone calls. An individualised approach with structured education, in particular on core self-management skills such as problem-solving, decision-making, and communication with healthcare professionals is necessary to facilitate survivors’ mastery of stroke self-management behaviours (Warner et al., 2015). A systematic review of 21 trials involving 2,289 patients and 1,290 carer participants found that information provision with planned follow-up for clarification and reinforcement had a greater effect on stroke patient mood (Forster et al., 2012).
Broad short-term goals and action plans

Previous studies adopting goal-setting and action-planning as one of the strategies in the stroke self-management programs did not provide details on the difficulties in setting goals and action plans with the stroke participants (Cadilhac et al., 2011; Damush et al., 2011). However, this current RCT found that one of the major challenges in implementing the SSMP was the difficulty in getting the stroke participants to set realistic short-term goals and action plans. It is common to note that the participants in the current SSMP did not have a comprehensive understanding of the nature of stroke recovery and prognosis. They were hesitant to set goals and action plans. Furthermore, Chinese people often tend to adopt an attitude of adapting to what has already happened or progressing naturally without taking particular actions. These participants often verbalised that they did not demand much on improvement after stroke despite different degrees of limitations in physical and psychosocial functioning. Brown et al. (2014) who reviewed literature on stroke survivors’ psychological trajectory after stroke named this attitude as “natural progression” while carrying a hidden eagerness to progress continually or even recover completely. Indeed, when asked about their goal of recovery, the participants in the current SSMP often wanted to improve continually every day in whatever aspects that needed to be improved. Consistent with previous findings (Sugavanam et al., 2013), difficulties arise in facilitating Chinese stroke participants understanding and in them setting specific goals according to the SMART goal criteria.

To address this challenge, the facilitator in the SSMP repeated the emphasis on the importance of SMART goal criteria. More time was devoted to provide examples of specific and realistic goals related to the individual participants’ context, or based on the situations of the “role models” in the videos. However, such examples have to be introduced carefully as too many examples might limit the room for participants to think for themselves. Furthermore, the facilitator in the SSMP allowed flexibility for participants to pursue goals that they perceived as worthy even though they might not fully fit with the SMART goal criteria or consistent with the healthcare professionals’ perspective. Brown et al. (2014) reported that stroke respondents took the goals as indicators of their existence. Their participation in goal setting indicated their achievement and helped enhance their self-efficacy in stroke self-management (Brown
et al., 2014). The facilitator made a balance in adjusting the goals to a more specific format while maintaining the participants’ preferences of goals to be achieved.

**Possible negative vicarious experience**

In the current RCT, a sub-group was formed when four to six participants were randomised to join the SSMP without stratification. However, the group participants who would serve as models for each other varied considerably in terms of their demographic and clinical characteristics, including severity of stroke, physical independence, types of health needs, and goals of stroke recovery. Similarly, the 15 role models in videos offered in the SSMP were of different ages, number of years after stroke onset, stroke severity, socioeconomic status, and cultural backgrounds. Bandura (1997) suggested that the effectiveness of vicarious experience lay in the extent to which one associated himself or herself to the “model”. The perceived similarity with the “model” matters. Such heterogeneity in the models might cause the participants to think that the experiences from others, either in group sessions or videos, were not applicable to their situation. There had been instances in the current SSMP where some participants disagreed that the application of the successful experiences shown in the videos to their own situation was appropriate. Furthermore, the worst effect of not having an appropriate model is that their self-efficacy may be negatively impacted due to the association with a wrong “model” (Bandura, 1997).

However, previous studies about community-based group sessions for stroke self-management programs did not report such a challenge (Damush et al., 2011; Kendall et al., 2007). The facilitator in optimising the vicarious experience for the stroke survivors participating in the group sessions of the current SSMP, emphasised the learning and practice of common tasks which were the core self-management skills. The facilitator directed the discussions among the group members on their common experiences which were the post-stroke experiences, importance of self-management, difficulties and possible solutions or tips to use self-management skills to problem-solve or address the participants’ needs flexibly given their particular unique context. Specific information on stroke recovery tailored to each participants’ needs was provided during home visit or follow-up phone calls.

Likewise, during video viewing, while acknowledging the uniqueness of each stroke survivor’s recovery process by the facilitator, the participants’ common health
needs in exercising self-management skills for effective stroke self-management, and make sense of the practical tips in addressing post-stroke challenges were highlighted by the facilitator. Key factors for enhancing self-management such as hard work, persistence and perseverance, importance of role of self as the person in-charge were identified from the videos. Furthermore, the facilitator augmented the videos with additional demographic and clinical information, as well as stroke recovery experiences of the volunteer stroke survivors in the videos. Consistent with the findings of Boger et al. (2015), such strategies were helpful in facilitating the participants understanding of their common needs for self-management. It enabled more appropriate associations between the participants and the role models, as well as ensuring appropriate engagement in the stroke self-management behaviours.

*Transportation and mobility problems*

Previous studies often cited transportation and mobility problems as a main reason for stroke participants’ non-attendance of community-based group sessions of stroke self-management programs (Damush et al., 2011; Huijbregts et al., 2008; Kendall et al., 2007). The current RCT encountered similar challenges. The nurse-led clinic where the group sessions were held was located close to one of the study hospitals. Participants, in particular those recruited from the other two study hospitals, found it relatively far away to access the nurse-led clinic. The difficulties encountered by the stroke participants, especially those with one-sided weakness, to travel from home to the nurse-led clinic could not be underestimated. For example, selection of a safe and convenient route, duration, and ways to overcome environmental barriers such as stairs. Similar to that reported by Jones et al. (2009), some participants in the current RCT were concerned about the cost of transport. Kendall et al. (2007) mentioned that the participants were reimbursed for travel expenses related to joining the group sessions. Likewise, the current RCT reimbursed the participants who joined the group sessions for their taxi fare. It appears to have modestly improved the attendance.

Furthermore, this RCT found that the family members’ or carers’ availability to accompany the stroke participant was one of the important factors influencing their decisions to attend the group sessions, in particular those who were only partially independent in ADLs. These participants often were concerned about falls or injuries.
during the travel. Some of them also mentioned the fear of others’ negative reactions to their physical impairments during the travel. Similar worries had been mentioned in Lou et al. (2016) with negative reactions from public being one of the significant factors influencing stroke participants’ avoidance of going outdoors. Therefore, the group sessions of the SSMP were scheduled at weekends to better accommodate the schedule of the accompanying persons’ who were often at work during the week. Additionally weekends provided a quieter environment due to fewer numbers of people visiting the clinic at weekends.

An increasing number of studies found potential benefits of delivering stroke self-management programs via teleconferencing, or online (Huijbregts et al., 2009; Jones et al., 2015; Taylor et al., 2009). Using these modes of delivery may help address the transportation and mobility problems. However, attention is needed to preserve the elements of group discussion and interaction, and hence ensure enabling the provision of vicarious experience for stroke survivors.

Hesitation in sharing during group sessions

The organisation of group sessions in the SSMP had been readily accepted by the Chinese stroke participants. Most of them were observed to participate actively in the sharing of experiences and reflection with other participants in the group. It may be partly due to the influence of the Chinese philosophy indicating that people should be responsible for managing themselves well before managing others. The belief of “self-discipline” has been reported in a study examining the effectiveness of a CDSMP for Chinese older adults (Chan, Siu, Poon, & Chan, 2005). Such beliefs contribute to the ready adoption of the notion of self-management with the Chinese older adults in the current study seeming willing to share their successful experiences with others.

Some of the participants attending the group sessions of the SSMP were seen to be hesitant or not feeling at ease in sharing experiences. However, previous studies examining the effectiveness of stroke self-management programs did not report such behaviour of the participants (Cadilhac et al., 2011; Damush et al., 2011; Jones et al., 2016; Kendall et al., 2007). Such reluctance might be due to Chinese people in the current study were not used to sharing in groups of people who they had only recently met for the first time. Furthermore, some groups undertaking the SSMP consisted of four participants, excluding their family members or carers, due to the non-attendance
of some participants, and the lower-than-expected rate of recruitment. The small number of participants also made it difficult to foster a participative atmosphere for sharing.

This challenge was addressed by the facilitator introducing the video viewing at the beginning of group sessions in order to direct the participants’ attention to their condition and feelings post-stroke. This approach is consistent with that suggested in a previous study in which the videos served as an elicitation tool to help participants recall their situations (Sieber, Newsome, & Lillie, 2012). Furthermore, skills in leading groups such as use of sense of humour, recall of discussions during home visits, discussing the progress in attaining the goals set, and introducing knowledge-based information, leaving the discussions to the latter part of the group sessions were also practical to encourage discussion and interaction.

**Over-support by family members or carers**

A systematic review of six RCTs, two quasi-experimental studies and one pre–post test study suggested the inclusion of family members in stroke self-management programs might facilitate the provision of self-management support (Warner et al., 2015). However, the presence of family members or carers in the SSMP examined in the current RCT presented challenges. Some of the family members or carers who accompanied the stroke participants in attending sessions of the SSMP were noted to be either dominant in the discussion between the facilitator and the stroke participant, or were overly helpful in performing self-care tasks for the stroke participants. A previous study by Kendall et al. (2007) did not report such a challenge in their study although family members or carers had also been invited to attend their stroke self-management programs. However, Liddy et al. (2014) in their qualitative synthesis of 23 studies exploring the challenges of exercising self-management among people with multiple chronic conditions highlighted that over-support by family members or carers might interfere with the stroke participants’ development of core self-management skills. Indeed, the stroke participants’ in the current SSMP were noted to be hesitant in expressing their views or feelings in front of their family members or carers.

The facilitator in the current SSMP addressed this challenge by emphasising to both the participants and the family members or carers during the program, the important role of “self” in managing the stroke. The stroke participants were invited
actively to participate in the discussion; while the family members or carers were encouraged to provide support and positive reinforcement. Maintaining eye contact between the facilitator and the stroke participant was also found a helpful strategy to defer the family members or carers from over-participation.

**Difficulty in using DVDs**

Some of the stroke participants in the current SSMP had difficulties in operating either the player or the computer for viewing the videos, or did not possess a player or a computer. These participants had to rely on the facilitator for viewing the videos during home visit or group sessions. Alternatively, the participants were encouraged by the facilitator in the SSMP to read the program workbook for descriptions of the videos and the excerpts of the volunteer stroke survivors’ positive reinforcement. In another study Chau et al. (2009) made portable DVD players available in the clinic to facilitate diabetes clients’ viewing of videos about diabetes self-management. However, this practice was not feasible in the current SSMP due to limitations in resources. Further exploration of resource support is needed to optimise the use of the videos for providing vicarious experience.

### 7.7 ROLES AND RESPONSIBILITIES OF NURSES AS PROGRAM FACILITATORS

The SSMP examined in the current RCT was delivered solely by a registered nurse. This is different from the stroke self-management programs examined in previous studies, which often involved a team of trained healthcare professionals (Damush et al., 2011; Kendall et al., 2007) in the delivery of the program. These facilitators often needed to receive training before delivering the program. For example, Damush et al. (2011) conducted a 12-week telephone-based stroke self-management program which was delivered either by a nurse, a physician assistant, or a social scientist with a Master degree. All facilitators had received a total of 18 hours of standardised training prior to commencement of the program. Kendall et al. (2007) conducted a 7-week modified Stanford CDSMP by two trained health professionals according a structured course protocol. However, there was no information about the qualifications, type and training provided to the health professionals before delivering the program reported by Kendall et al. (2007).
Recently a mixed method study in the UK, reported the development and evaluation of a 4-week stroke self-management intervention led by stroke nurses (Kidd, Lawrence, Booth, Rowat, & Russell, 2015). Although there were no specifications on the qualifications of the stroke nurse who delivered the intervention, the study described the contents of the training for the stroke nurses (Kidd et al., 2015). The training contents included educational sessions, with or without reading materials or the study protocol, which outlined the purposes and procedures of the interventions such as motivational interviewing, and introduced core self-management skills such as goal-setting. The training might also include role-play of the interventions using patient vignettes or face-to-face practice with volunteer stroke survivors.

Consistent with the reports by Kidd et al.’s (2015), the experience obtained from the conduct of the current RCT indicated the importance of a registered nurse in serving as a facilitator of the SSMP. The facilitator of the SSMP examined in the current RCT is the principal investigator of the current study who possesses a Master’s degree in gerontology, and is a registered nurse with over ten years of post-registration experience, and relevant training in stroke care and chronic disease management.

Performing individualised assessment and providing professional support

One of the central roles of the facilitator in delivery of the SSMP was the conduct of comprehensive and individualised assessment for each stroke participant randomly assigned to join the SSMP. The components of the assessment were consistent with previous studies of effectiveness of stroke self-management programs such as current health conditions and adaptability to the home environment after discharge from hospital (Damush et al., 2011; Jones et al., 2015). The current SSMP additionally required the assessment of the participants’ level of self-efficacy, outcome expectation, and performance in stroke self-management behaviours. Based on the assessment results, the facilitator often had to provide appropriate health information related to the care of post-stroke health such as nutrition, exercise, use of assistive devices, or speech or cognitive training, in addition to the concepts of self-management. If necessary, the facilitator needed to refer the stroke participants to appropriate service agencies related to their care for non-stroke related issues. A qualitative study of 27 nurses pointed to the key role of community nurses in providing self-management support. Nurses need to help them to deal with daily challenges consequential to stroke (Been-Dahmen,
Dwarswaard, Hazes, van Staa, & Ista, 2015). The facilitator in the current SSMP devoted most of the time in discussing with the participants, possible approaches that were applicable to their context for managing their daily challenges.

**Facilitating group discussion and interaction**

Another major role of the facilitator in the current SSMP was to facilitate effective group discussion and interaction. It is noted that the facilitator in the current SSMP had three major roles: First, to facilitate the conduct of the group sessions and the dissemination of messages as predetermined in the protocol. Second, to proactively foster an open and facilitating atmosphere to encourage sharing and discussion among group members, so as to enable vicarious experience. Third, to minimise interferences such as over-support by family members or carers, possible negative vicarious experiences, inappropriate health information shared among the members, or offensive conversations among members. Experience is needed by facilitators to control the pace of the group sessions, while ensuring all members have equal opportunities to participate. There has not been much information reported in previous studies about effectiveness of stroke self-management programs in regard to the skills required of the facilitator in leading groups. However, Jones et al. (2016) indicated that the training needed by facilitators included group leading skills in preparing facilitators to deliver stroke self-management programs. The facilitator of the current SSMP was experienced in leading and conducting group sessions in community settings with participants with chronic conditions. The facilitator received continuous education on techniques in facilitating group participation.

**Establishing rapport and promoting effective communication**

The facilitator in the current SSMP played an important role in establishing rapport with the stroke participants. Experience from the current RCT found that participants in general were more receptive and participative in the program if a rapport was established between the two parties. The participants were found more motivated to perform the self-management behaviours. Such behaviours of the participants were consistent with the findings of the review by Hadidi et al., 2012) that rapport facilitated eliciting of comprehensive information during assessment.

Furthermore, the facilitator in the current SSMP played an important role in providing verbal persuasion, feedback on progress, and positive reinforcement to the
stroke participants. There were a few episodes in the SSMP where the stroke participants were concerned about their recovery progress and some cried during the first home visit. It is not uncommon for stroke participants to have emotional upsets during the program. For example, there was a participant who cried when she thought that she was dependent on her maid’s help in ADLs such as bathing. She calmed down when she saw her little grandchildren playing around at home. Consistent with the qualitative systematic review results by Lou et al. (2016) that emotional lability was common among stroke survivors. The facilitator in the current SSMP was required to provide counselling and professional support. The use of wording in conversations needed to be careful. It was consistent with the findings by Lou et al. (2016) that stroke survivors were more sensitive to others’ reactions, behaviours and conversations. They were also easily get frustrated. Effective interpersonal and communication skills are demanded in the facilitator. A meta-review of seven systematic reviews supported the importance of effective communication with healthcare professionals in supporting stroke patients’ self-management (Pearce et al., 2015).

7.8 SUMMARY

The chapter discusses the key issues related to the results of the RCT which aimed at examining the effectiveness of a new SSMP for Chinese community-dwelling stroke survivors. A lesser proportion of participants in the age group of 75 years or above were recruited as they might have been excluded for having severe physical impairment, bilateral hearing loss, or other comorbidities such as dementia that impaired their cognitive or physical functions. Otherwise, the study participants were comparable in age and gender distribution, the type and severity of stroke, and physical independence of participants of previous studies in Western countries. The strategies adopted in the SSMP were deemed effective at enhancing the stroke participants’ self-efficacy and outcome expectation of stroke self-management. Further exploration of effective strategies to address the stroke survivors’ psychological needs and promoting their community reintegration is needed. Moreover, a longer-term measurement time point beyond one month after program completion would be necessary to determine whether the SSMP was able to improve depressive symptoms and community reintegration. Given the mainly positive outcomes of the current study the approaches adopted in this RCT in applying Bandura’s constructs of self-efficacy and outcome
expectation to underpin the SSMP were deemed appropriate. Emphasis by the facilitator on the similarity between the role models in videos and the stroke participants is needed for better association with the role models, and hence effective vicarious experience. Several challenges were encountered in the recruitment of participants and implementation of the SSMP. The current RCT demonstrated appropriate strategies to address the challenges. The role of the nurse in facilitating the SSMP was important. The nurse possessed professional knowledge, skills and experience to perform comprehensive assessment for the stroke participants, and was in the best position to monitor the participants’ progress and advocate for their needs. It would be worthwhile for future studies to consider these issues in their design, implementation and evaluation, for more conclusive evidence on the effectiveness of stroke self-management programs for Chinese community-dwelling stroke survivors.
Chapter 8: Conclusions

8.1 INTRODUCTION

This research project was set out to examine the current research evidence on the effectiveness of theory-based stroke self-management program on promoting recovery of community-dwelling stroke survivors, and to test out the effectiveness of a newly developed self-efficacy enhancing stroke self-management program based on the evidence among Chinese community-dwelling stroke survivors. The limitations and implications of the systematic review conducted in Phase One of the research project have been discussed in Chapter Three. The results of the RCT conducted in Phase Two demonstrated significant improvement in the Chinese stroke participants’ self-efficacy, outcome expectation, and satisfaction with performance in stroke self-management behaviours, HRQoL, and community reintegration at one month after receiving the program. The research project contributes by demonstrating the importance and usefulness of the theoretical framework adopted to underpin a stroke self-management program. However, the results of the research project need to be interpreted with caution. There are several limitations related to the implementation and evaluation of the new stroke self-management program. Despite this, the results of the research project serve as a compass for providing valuable insights and directions for future enactment of policy, practice, education and research related to care of community-dwelling stroke survivors. Furthermore, the research contributes by providing the blueprint on effective strategies taken to recruit stroke participants from acute units for attending a community-based study. The translation of the measuring instruments to assess self-efficacy and HRQoL, and development of two new instruments to assess outcome expectation and satisfaction with performance in stroke self-management programs allow for comprehensive evaluation of the program effectiveness among Chinese stroke survivors in future studies. This chapter first discusses the limitations of the RCT conducted in the second phase of the research project, followed by identifying the key implications in policy, practice, education and research based on the findings of the research project. Each section on the implications closes with a list of recommendations.
8.2 LIMITATIONS OF THE STUDY

The current RCT conducted in the second phase of the research project was limited by the following:

First, the current RCT excluded stroke survivors with severe language and cognitive disabilities. The results of the current RCT were only applicable to stroke participants with the particular characteristics of those recruited into the study. Furthermore, the participants in this RCT were not differentiated in terms of their types of stroke or level of physical or ADL independence when evaluating the program effectiveness. However, the health needs of these participants after returning home might be different (Roberts et al., 2012). Therefore, conclusions about the effectiveness of the SSMP on people with ischaemic or haemorrhagic stroke, or different levels of physical or ADL independence cannot be drawn.

Second, due to the nature of the intervention, blinding of the participants was not possible. The participants in both the intervention and the control groups might be able to identify the group to which they were allocated. It might influence their participation and interest in the study. Contamination among the participants which might also have occurred could have influenced their responses to the outcome measures (Portney & Watkins, 2009). The research assistants who conducted the baseline and follow-up assessments were blinded to treatment allocation. They were reminded not to ask the participants for their group assignment in an attempt to minimise the risk of biased data collection.

Third, this RCT measured stroke participants’ level of satisfaction with their performance in stroke self-management behaviours only. The actual participation of the participants in the target stroke self-management behaviours such as in terms of the frequency or duration of performing the behaviours has not been measured. The information would be helpful to provide more objective interpretation of the change in the behaviours after receiving the SSMP.

Fourth, regarding the types of outcome measures, this study did not measure the participants’ social support and attainment of goals. Social support may be a covariate in determining the effectiveness of stroke self-management programs. Furthermore, the program was designed to ask participants to set goals and implement action plans to achieve those goals. It would be helpful in future studies to measure the attainment
of goals using a validated measurement so that the association of the program with the goal attainment could be quantified.

Fifth, the two new measuring tools on outcome expectation (SSOES) and satisfaction with performance in stroke self-management behaviours (SSBPS) were tested on their reliability and convergent validity among Chinese community-dwelling stroke survivors only. Although both of the measuring instruments had high internal consistency and satisfactory convergent validity based on the results of the validation study and the current RCT, more psychometric testing such as exploratory factor analysis is warranted.

Sixth, the measurement of outcomes was conducted at baseline and at eight weeks after randomisation. The study was not able to capture the changes immediately after completion of the program, as well as the trends in changes in outcomes over a longer period of time and the sustained effects of the program. A longer period of follow-up up to six or 12 months would be valuable to better inform the effectiveness of the program and hence the stakeholders’ decisions of integrating the program into the current stroke care services.

Seventh, the study was not able to recruit the estimated target sample size of 160, which included an attrition rate of 20%, due to the lower rate of recruitment than expected. Although a total of 128 participants were recruited which was equal to the estimated sample size without considering the 20% attrition rate, there were some participants who discontinued the study, leaving 107 participants who completed both baseline and follow-up assessments. The use of GEE models helped accommodate the missing data and the analysis based on the ITT principles were able to show significant effects. However, the analysis in the per-protocol population and the subgroup analysis on effective dose of the program might be limited by the small number of participants in each comparison group, and hence have led to increased difficulty in detecting significant changes in the outcome variables for these two types of analyses.

Eighth, the current RCT conducted quantitative evaluation of the effectiveness of the SSMP on recovery of community-dwelling stroke survivors only. Qualitative evaluation of the participants’ perceptions of usefulness of the program, their perceived barriers to and facilitators of learning and practicing target stroke self-management behaviours, and development of the core self-management skills were
not well known. There is an increasing recognition of conducting process evaluation to better understand the mechanism of change and to identify the possible influencing factors in the delivery of the interventions on the outcomes. However, this study is limited by the lack of conducting process evaluation.

8.3 IMPLICATIONS AND RECOMMENDATIONS FOR POLICY

Given the benefits of the SSMP, the implications of the results of the current RCT for health policies related to the care of community-dwelling stroke survivors after returning home from hospital, include the following:

First, the community-based nurse-led clinics should incorporate the provision of stroke self-management programs for stroke survivors discharged to home as one of the core services. Such programs are important to ensure continued support to stroke survivors during their transition from hospital to home. To support such development, more resources should be allocated to the nurse-led clinics. The resources include the number of staff, both community nurses and administrative or supporting personnel, to accommodate the increased number of people requesting for the stroke self-management training. The resources also include facilities such as computer or DVD players to show the videos, rooms of adequate space to conduct the group sessions, adequate audio-visual facilities to project the related program and health information for the participants. Financial support is also necessary to support the transportation costs to stroke participants travelling to the nurse-led clinics for joining group sessions.

Second, training centres should be established for community nurses in nurse-led clinics to facilitate training in the provision of stroke self-management. Nurse-led clinics should be equipped with the most updated information and resources related to provision of stroke self-management training. All community nurses working in the nurse-led clinics should be trained to provide stroke self-management support and deliver the program competently. Collaboration and exchange opportunities with other Asian countries as well as Western countries should be encouraged to explore approaches to advance the development and provision of stroke self-management support to community-dwelling stroke survivors in Hong Kong.

Third, all stroke survivors who will be discharged home from hospital for continuing rehabilitation and recovery should be offered the opportunity to receive a community-based stroke self-management program. A routine referral to the nurse-led
clinic upon the stroke survivors’ discharge from hospital should be established. Information about the stroke self-management programs offered and the potential benefits should be made available both in the hospitals and in the nurse-led clinics.

Key recommendations on policy:

1. Stroke self-management programs should be routinely offered as one of the core services by the nurse-led clinics.

2. All community nurses working in the nurse-led clinics should receive training locally and internationally to deliver the stroke self-management programs competently.

3. Resources, in terms of nurse staffing, administrative personnel, equipment and financial support should be allocated to the nurse-led clinics to accommodate the stroke survivors’ requests for stroke self-management support.

4. All stroke survivors upon their discharge to home from hospital should be routinely referred to the nurse-led clinic for assessment of eligibility to receive the stroke self-management programs.

5. Information about stroke self-management programs should be provided to the stroke survivors and their family members or carers.

8.4 IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

The implications for practice related to the care of community-dwelling stroke survivors after returning home from hospital, based on the results of the current RCT, include the following:

First, the nurses who care for stroke survivors particularly after their discharge from hospital to home should focus on the concepts and core skills of stroke self-management. Stroke survivors should be provided with specific information related to stroke self-management and given the opportunity to learn and practice the core self-management skills such as problem-solving and decision-making. More importantly, stroke survivors should be supported and encouraged to set goals and action plans related to their stroke recovery.

Second, the nurses should adopt the self-efficacy enhancing strategies in the provision of stroke self-management support to enhance the stroke survivors’ self-
efficacy in and outcome expectation for stroke self-management. Based on the results of the current RCT, effective strategies that could be used include goal-setting and action-planning to promote mastery experience, video viewing and group sessions to promote vicarious experience, verbal persuasion by peers and the nurse, and reinterpretation of physiological and emotional states.

Third, nurses should recognise the importance of using multi-faceted modes of delivery, including individual face-to face consultation, group sessions, and follow-up phone calls in the provision of stroke self-management support. Individualised assessment should be performed for each stroke survivor, not only about their progress in recovery, but also their levels of self-efficacy, outcome expectation, and satisfaction with performance in stroke self-management behaviours. The components of the SSMP include an individual home visit, two community-based group sessions, and three follow-up phone calls. The different components of the SSMP developed in this current study could be incorporated into the routines of the community nurses at different stages to reduce the workload of the nurses, as well as increase their acceptability and adaptation to the change in practice. Individual consultation with specific elements of assessment could be embedded into the current practice first as such approach of consultation is similar to the present care delivery mode of the community nurses. The group sessions and follow-up phone calls could be added gradually as nurses gain more confidence in delivering the sessions. Given the positive outcomes in the current study the components of the SSMP examined in the RCT are important and worth to include in future. The dose of the program was appropriate and emphasis is needed in future to promote stroke participants’ full adherence to the program to attain optimal benefits in developing core self-management skills.

Fourth, nurses should adopt the role of a facilitator in the provision of stroke self-management program. Attention should be paid to the individual needs of stroke participants with careful consideration of the impact of the stroke survivors’ physical and psychosocial well-being, their social support network, and their living environment on their adaptation to post-stroke challenges. Nurses should encourage the stroke survivors to think about their possible solutions and recognise that they can manage to solve their daily self-care challenges. The stroke survivors’ preferences should be respected, in particular their goals and outcome expectations.
Fifth, education can be provided to family members or carers about their roles and responsibilities when their loved ones are receiving the stroke self-management program. Understanding about their roles is important to enable them to be a facilitator, rather than impeding the progress of the stroke survivors and hence become a barrier.

Sixth, the use of the 15 videos developed in the current study could be optimised in the nurse-led clinics. In addition to using it as part of the deliverables of the stroke self-management programs, the videos can be made available in the nurse-led clinics for attendees for convenient access of the helpful resources to stroke survivors. Showing the videos intermittently in the nurse-led clinic is also suggested to increase people’s awareness of importance of stroke self-management, and the practical tips to daily stroke self-management.

Seventh, nurses are in the ideal role to recruit more volunteer stroke survivors to develop the videos on sharing of experience of stroke recovery. This study’s results supported the use of videos with stroke survivors who have successfully managed their stroke to share their experiences and provide positive reinforcement. The positive reinforcement by stroke survivors is a good source of information of self-efficacy (Bandura, 1997). The use of videos to can be enriched in future practice. More volunteer stroke survivors can be invited to produce short videos on their recovery experiences. It would help if more role models were available to increase the possibility of stroke survivors finding “someone just like me” so they could better associate with the stroke participants, and hence provide better quality of vicarious experiences (Bandura, 1997). These videos can be placed in a bank of stroke self-management made available in the nurse-led clinics. Furthermore, different formats of the videos can be produced, including putting the videos on the internet or making them available to be viewed on smartphones, provided that consent is obtained from the volunteer stroke survivors. With the advances in information technology, making the self-management support interventions easily accessible in these applications by wider populations is an emerging trend (Marcano-Belisario, Huckvale, Greenfield, Car, & Gunn, 2013). Attempts in developing these packages would be worthwhile for maximal benefits of the stroke survivors.

Eighth, the nurses providing the SSMP should be sensitive to the stroke participants’ rights to privacy and confidentiality. Sensitive personal issues should be
discussed at times of individual consultation and kept confidential. Furthermore, informed consent about the production and dissemination of the videos should be obtained from the volunteer stroke survivors who participate in the video production. Update of the consent should be made if the purposes and uses of the videos change at later times.

Ninth, nurses should pay more attention to the psychological needs of the stroke survivors. More effective strategies to help stroke survivors to manage their emotions could be added into the stroke self-management programs.

Key recommendations on practice:

1. Nurses are responsible for providing stroke self-management support and training to stroke survivors.

2. Multi-faceted strategies should be used to enhance the stroke survivors’ self-efficacy in and outcome expectation for stroke self-management. The multiple strategies used are to provide mastery experience, vicarious experience, verbal persuasion, and assistance in reinterpretation of negative physiological and emotional states. Key strategies include: goal-setting, action-planning, video viewing on experience sharing, group sessions, verbal persuasion by peers and healthcare professionals, and changing beliefs in particular signs and symptoms.

3. Stroke self-management programs should be delivered in a combination of mode of delivery and dose based on the current evidence, including one individual face-to-face consultation, followed by two community-based group sessions, and three follow-up phone calls. The sessions are delivered weekly.

4. Nurses should conduct an individualised assessment on the stroke survivors receiving the stroke self-management program. The new components include: self-efficacy in and outcome expectation for stroke self-management.

5. Nurses serve as a facilitator during the provision of stroke self-management training and are expected to facilitate the stroke survivors to manage both their physical and psychosocial needs.

6. Family members or carers should be provided with the information their roles and responsibilities in promoting the stroke survivors’ stroke self-management.
7. Stroke survivors’ rights to privacy and confidentiality should be respected throughout the provision of stroke self-management program and support.

8. More videos on sharing of experiences by volunteer stroke survivors who have successfully managed the stroke can be developed.

**8.5 IMPLICATIONS AND RECOMMENDATIONS FOR EDUCATION**

The implications for education related to the care of community-dwelling stroke survivors after returning home from hospital, based on the results of the current RCT, include the following:

First, the nurses who will serve as the facilitator of the SSMP should receive the essential training before delivering the SSMP. The training should equip the nurse with the necessary knowledge and skills to deliver the SSMP. The training should include the following components: concepts of stroke self-management, current research evidence on importance and effectiveness of stroke self-management programs, concept of Bandura’s constructs of self-efficacy and outcome expectation, effective strategies to enhance stroke survivors’ self-efficacy and outcome expectation, skills in setting goals and action plans with stroke survivors, skills in providing verbal persuasion, practical tips in assisting with reinterpretation of negative physiological and emotional states, skills in leading group sessions. Furthermore, it is important for nurses to have continued education on acute and community stroke care, and have an updated information about the community resources available for the stroke survivors to ensure quality health education is provided to stroke survivors during the program.

Second, the training methods of the nurses should base on Bandura’s constructs of self-efficacy and outcome expectation. The strategies adopted should be driven by the constructs to provide the nurses with mastery experience, vicarious experience and verbal persuasion on mastering the skills in providing self-management support for community-dwelling stroke survivors. Furthermore, guidance is needed for nurses to reinterpret the negative physiological or emotional states associated with the learning and practice of skills in providing stroke self-management support. The nurses should be encouraged to think about the positive outcomes likely to attain after successfully mastering the skills. Such training methods provide valuable opportunities for nurses to experience how the self-efficacy enhancing strategies work for them, which in turn
similar approach will be adopted for enhancing stroke survivors’ self-efficacy in stroke self-management.

Third, training package or protocols are need to be further developed to detail the aim and learning objectives, the contents covered, and the mode of delivery. The information is important to ensure consistent delivery of the training across trainers and settings.

Key recommendations on education:

1. Nurses should receive the essential training before serving as a facilitator of the stroke self-management program. The components of the training, while adapting to the needs of local context, should include the following: concepts of and research evidence on effectiveness of stroke self-management program, theoretical framework underpinning the program, effective self-efficacy enhancing strategies and strategies to promote positive outcome expectation for stroke self-management, and skills in leading group sessions.

2. The methods of training of the nurses should base on Bandura’s constructs of self-efficacy and outcome expectation.

3. Standardised training package should be developed to ensure consistent delivery of the training.

8.6 IMPLICATIONS AND RECOMMENDATIONS FOR RESEARCH

The implications for research on effectiveness of stroke self-management for community-dwelling stroke survivors, based on the results of the current RCT, include the following:

First, further examination of the psychometric properties of the two translated Chinese versions of the Stroke Self-Efficacy Questionnaire (SSEQ) and the Stroke Specific Quality of Life Scale (SSQOL), and the two new instruments including the Stroke Self-management Outcome Expectation Scale (SSOES) and the Stroke Self-management Behaviours Performance Scale (SSBPS) is needed. Self-efficacy and outcome expectation for stroke self-management, satisfaction with performance in stroke self-management behaviours, and HRQoL are core outcomes based on Bandura’s constructs of self-efficacy and outcome expectation. More evidence on the
psychometric properties of the translated versions of instruments ensure the reliability and validity of the results.

Second, while the SSBPS measures the stroke survivors’ satisfaction with their performance of stroke self-management, an instrument for measuring the actual performance or a checklist would be worthwhile to quantify the actual participation in self-management behaviours. The SSBPS can still be important to better understand how stroke survivors perceive their performance which may also impact on their actual participation or vice versa.

Third, replication of the current RCT examining the effectiveness of the new SSMP with a larger sample size for subgroup analyses is warranted to provide more conclusive evidence on the effectiveness of the program. Furthermore, measuring the changes in outcomes immediately after completion of the program, as well as in the longer term, such as over one month after completion of the program is needed to better understand the trends in changes in the outcome variables after receiving the SSMP. Psychosocial outcomes such as social support, or outcomes such as goal attainment and duration of participation in the stroke self-management behaviours can be incorporated into the evaluation plan to address the influence of levels of social support, and to enable a comprehensive understanding of the program effectiveness.

Fourth, examination of the characteristics of stroke survivors who would benefit most from the stroke self-management programs would be worthwhile to inform decision-making of the priority of needs of stroke survivors after returning home. Stratification of the stroke participants’ demographic and clinical characteristics such as the type of stroke, level of stroke severity as measured by the NIHSS, ADL independence, or levels of social support would be helpful to better understand the differences in health needs and how the SSMP could benefit their post-stroke recovery.

Fifth, while the current RCT focused on quantitative evaluation of the program effectiveness qualitative evaluation should be performed in future studies to elicit the feedback of the participants, and to explore the facilitators and barriers to the implementation of the SSMP. Furthermore, process evaluation could be performed to better understand the mechanism of changes in the outcomes.

Sixth, the relationships between self-efficacy, outcome expectation and stroke self-management behaviours as postulated in Bandura’s constructs of self-efficacy and
outcome expectation are yet to be determined. Path analyses can be conducted in future studies to provide a clear understanding of the strengths and magnitude of the associations between these variables. The evidence would be helpful to justify the applicability of the theoretical constructs in this phenomenon of promoting stroke self-management among community-dwelling stroke survivors.

Seventh, the current SSMP adopted multiple strategies to enhance the stroke survivors’ self-efficacy in stroke management. Examination of the extent to which the strategy addresses each of the four sources of information of self-efficacy would be helpful to determine the usefulness of the strategies, and to better justify the appropriate use of a combination of the strategies.

Eight, future research opportunities include the following: examining the effectiveness of commencing the SSMP at acute stage after the medical conditions of the stroke survivors have been stabilised; development of more effective strategies to improve depressive symptoms among participants and its integration into the current SSMP to better address their psychological needs; development and examination of the different modes of delivery of the SSMP such as online delivery to facilitate the access of the stroke survivors to the SSMP sessions.

Key recommendations on research:

1. More examination of the psychometric properties of the SSEQ, SSQOL, SSOES and SSBPS in Chinese should be performed.
2. Incorporation of measurement of social support and goal attainment would be worthwhile to better understand the effectiveness of the SSMP.
3. More evidence on the effectiveness of the SSMP on promoting recovery among community-dwelling stroke survivors is needed. RCTs with larger sample size for subgroup analyses and of immediate to longer-term follow-up periods are needed.
4. Examination of the demographic and clinical characteristics of the participants who would benefit most from the program can be performed in future studies.
5. Qualitative evaluation and process evaluation are needed in addition to quantitative outcome evaluation.
6. Path analysis can be conducted in future studies to inform the theory development and applicability of the theoretical constructs to stroke self-management programs.
7. Evaluation of the extent to which each strategy addresses the four sources of information of self-efficacy would be worthwhile to justify the choice of self-efficacy enhancing strategies.

8. Future studies can consider exploring the effectiveness of the SSMP commenced during acute phase, development of effective strategies to improve depressive symptoms and integration into the current SSMP; and development and examination of different modes of delivering the SSMP such as online delivery.

8.7 SUMMARY

To conclude, the results of this RCT showed that the Chinese stroke survivors who received the 4-week nurse-led community-based self-efficacy enhancing stroke self-management program had a significant improvement in self-efficacy, outcome expectation, satisfaction with performance in stroke self-management behaviours, HRQoL, and community reintegration at one month after completion of the program. There were no adverse events reported throughout the conduct of the study. The results provide important contributions to the current evidence base on stroke self-management in a field where the application of stroke self-management programs among Chinese stroke survivors is limited.

While developing complex interventions poses challenges to researchers and clinicians and there has been no consensus on the best approach to underpin the complex interventions with theoretical frameworks, this study demonstrated a promising approach in developing a theory-based complex intervention. This study underpinned the design, implementation, and evaluation of a new stroke self-management program with Bandura’s constructs of self-efficacy and outcome expectation. The results of the study supported the usefulness of the implemented strategies for enhancing stroke survivors’ self-efficacy and outcome expectation. It symbolises a further step taken to advance the development of the program by using a related but not extensively explored construct of outcome expectation. This step is anticipated to stimulate further examination of the role of outcome expectation in effecting stroke self-management behaviours for maximising the effectiveness of the stroke self-management programs.

Furthermore, the study uniquely contributed to the evidence supporting the use goal-setting, action-planning, individualised home visit and assessment, group
sessions, use of videos of experience sharing by stroke survivors who have successfully managed their stroke for provision of vicarious experience, program workbook, and follow-up phone calls. It not only motivated stroke survivors to problem-solve their own post-stroke challenges, provided influential positive reinforcement, but also provided convenient and timely access to other stroke survivors’ experience sharing which indirectly addressed the transportation problems to travel to and from the venue to attend the program.

This study identified the facilitators of and barriers to developing and implementing the stroke self-management program for stroke survivors in a community setting. Transportation problem was one of the major barriers affecting survivors’ interest and rate of participation. Cultural influence of stroke survivors on their interest and participation in group sessions needs to be considered and addressed in future studies. Furthermore, the results highlighted the importance of the role of a therapeutic relationship between the facilitator and stroke survivors in survivors’ participation and receipt of the program.

The study also contributed significantly to the development of four measuring instruments. The translation and testing of equivalence of the SSEQ and the SSQOL in Chinese were performed. The reliabilities and validities of both instruments were satisfactory. Another two measuring instruments, the SSOES and the SSBPS were developed and tested among Chinese community-dwelling stroke survivors with satisfactory internal consistency. The four measuring instruments played a significant role in evaluation of stroke self-management programs for Chinese stroke survivors.

This study provided the groundwork and framework for further refinement of the stroke self-management program applicable for Chinese community-dwelling stroke survivors with different health needs, and examination of effectiveness of integrating the program as a post-discharge support for stroke survivors. It is expected that the provision of comprehensive stroke self-management programs would enhance the recovery of community-dwelling stroke survivors in long run.
References


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Hospital Authority Head Office, Hong Kong. (2012). *Guidelines for specialty nursing services stroke care*. Hong Kong: Hospital Authority Head Office.


Rothman, A. J. (2004). “Is there nothing more practical than a good theory?”: Why innovations and advances in health behavior change will arise if interventions are used to test and refine theory. *International Journal of Behavioural Nutrition and Physical Activity, 1*, 11.


Appendices

Appendix A

Systematic review protocol published in Joanna Briggs Institute Library of Systematic Reviews

Title
Self-management programs for promoting recovery in community-dwelling stroke survivors: A systematic review

Primary reviewer
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This systematic review will be conducted by the Queensland Centre for Evidence Based Nursing and Midwifery.

Expected duration of completion
The systematic review will be undertaken in 2010 and is anticipated to take about ten months to complete.
Title
Self-management programs for promoting recovery in community-dwelling stroke survivors: A systematic review

Background
Stroke is the second leading cause of death globally. In 2005, stroke was estimated as accounting for 5.7 million deaths worldwide and constituting 9.9% of all deaths. The number of people affected by stroke continues to increase as the population worldwide ages. In Hong Kong, stroke was the fourth leading cause of death in 2008. Stroke can have a profound negative impact on survivors’ physical, cognitive, psychological and social functioning leading to compromised quality of life. The recovery post-stroke includes physical, psychological and social aspects. The process of recovery is demanding and long-term. Difficulties and uncertainties often arise in terms of coping with physical disabilities, psychosocial adaptation, community reintegration, adherence to medication and lifestyle changes, especially in the absence of feedback and support by healthcare professionals. Regarding the diverse recovery needs, it is essential for stroke survivors to have adequate knowledge and skills for better self-management of health problems in daily living.

Self-management refers to an individual’s active participation in managing their symptoms, treatment, physical and psychosocial consequences inherent in the chronic illness. To attain effective self-management, learning multiple self-management skills such as goal setting, action planning, problem-solving, decision making, information collection, resources utilization, collaboration, communication skills, or skills to maintain psychosocial well-being are necessary. It is expected that by effectively practicing self-management, clients would have improvement in health status and fewer utilization of health care resources. Warsi et al. conducted a systematic review of 71 trials of self-management education programs for persons with chronic illnesses. The evidence supported that the programs resulted in small to moderate effects in improving clinical outcomes particularly of persons with diabetes mellitus and hypertension.

There have been an increasing number of studies examining the effects of self-management programs for stroke survivors. Some studies also investigated the effectiveness of stroke self-management programs designed on the basis of self-efficacy theory. Positive results were found in terms of enhanced social support, increased locus of control, and participation in exercise and leisure activities among the community-dwelling stroke survivors. A number of Cochrane systematic reviews have been identified assessing evidence of effectiveness of self-management programs for those with chronic diseases such as diabetes mellitus, chronic obstructive pulmonary disease, or self-management education programs led by lay leaders for people with chronic conditions. Recently a new Cochrane systematic review protocol titled ‘Non-pharmacological interventions for caregivers of stroke survivors’ has been published. Despite efforts to investigate the outcomes of stroke self-management programs, no systematic review has been conducted to present and summarize the best available research evidence pertaining to the effects of self-management programs on promoting recovery among community-dwelling stroke survivors. The information gained is important to guide future design, practice and evaluation of effective self-management programs for community-dwelling stroke survivors.

Aim
The aim of the proposed systematic review is to determine the effectiveness of self-management programs for community-dwelling stroke survivors on promoting their post-stroke recovery after discharge from hospitals.

Objectives
The specific objectives of this systematic review are to:
(1) Determine the effectiveness of self-management programs in enhancing quality of life of community-dwelling stroke survivors, as compared with conventional care.
(2) Determine the effectiveness of self-management programs in improving physical outcomes of community-dwelling stroke survivors, as compared with conventional care.
(3) Determine the effectiveness of self-management programs in improving psychological functioning of community-dwelling stroke survivors, as compared with conventional care.
(4) Determine the effectiveness of self-management programs in improving social functioning of community-dwelling stroke survivors, as compared with conventional care.

Inclusion criteria
Types of study
All randomized controlled trials (RCTs) that examine the effects of self-management programs for community-dwelling stroke survivors will be assessed for inclusion. In the absence of RCTs, quasi-experimental studies, uncontrolled pre- and post-studies, cohort studies, case control studies, and case series will be considered.
Types of Participants
Adults aged 18 years or above, clinically diagnosed with a first or recurrent stroke and are residing in the community (either home environments or residential care settings), regardless of gender or ethnicity will be included. The standard WHO stroke definition will be followed, that is ‘a focal neurological impairment of sudden onset, and lasting more than 24 hours, and of presumed vascular origin’ (p.1-4). Stroke can be one of the three major subgroups including ischaemic stroke, intracerebral haemorrhage and subarachnoid haemorrhage. We will exclude studies with participants who have transient ischaemic attack, subdural haemorrhage and epidural haemorrhage.

Types of Interventions
We will consider all structured programs for community-dwelling stroke survivors designed to promote their stroke self-management behaviours. For the purpose of this systematic review, self-management is defined as ‘the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition’ (p.178). The focus of the programs considered will include symptom management, coping with activities of daily living, community reintegration, prevention or management of psychological morbidity, lifestyle modification (e.g. exercise, nutrition), prevention of recurrent stroke (e.g. medication adherence), communication skills, use of community resources, or a combination of these. The programs involving a single or series of sessions, delivered by healthcare professionals or trained lay persons will be included. Studies will also be included whether the programs involve family members, caregivers or volunteers or not. The comparison group considered will include either no intervention, standard or usual care, or another self-management program.

Types of Outcomes
The primary outcome measure will be quality of life of the stroke survivors as assessed using standardized generic or disease-specific quality of life instruments. The secondary outcome measures will include the stroke survivors’
- Physical outcomes: Activities of daily living as assessed using standardized functional outcome measures such as Instrumental Activities of Daily Living Scale; self-management skills including measurement on medication adherence, lifestyle modifications (diet and exercise), and help-seeking behaviours.
- Psychological outcomes: Self-care self-efficacy as measured by general self-efficacy scale or stroke-specific self-efficacy scale; depressive symptoms as measured by standardized depression rating scales such as Geriatric Depression scale.
- Social outcomes: Community reintegration as assessed using questionnaires of community reintegration or participation.

Language
The systematic review will consider studies published in English or Chinese.

Search strategy
The aim of the search strategy is to obtain all published and unpublished studies in English and Chinese relevant to the systematic review. A three-step approach will be adopted. First, the electronic bibliographic databases will be searched to identify relevant key words, index terms and matched subject headings. The search strategies specific to each database will then be developed in consultation with a university librarian. Second an extensive search of the databases will be performed using the developed search strategies to identify potential studies for inclusion. Finally the reference lists of retrieved articles, relevant conference proceedings, postgraduate and doctoral dissertations, journals, online databases and websites will be sought to identify additional studies not located through the search strategies by searching. Authors of relevant studies will be searched online or contacted if necessary to identify additional published, unpublished or ongoing studies.

The following electronic databases will be searched from the first date of database record for primary publications in English: MEDLINE(R), CINAHL Plus, EMBASE, AMED, Cochrane Library, Cochrane Central Register of Controlled Trials, Cochrane Stroke Group Trials Register, British Nursing Index, ProQuest (Dissertations & Theses), ISI Web of Science, ISI Web of Social Science, Biological Abstracts, and BIOSIS Previews. Electronic databases searched for primary publications written in Chinese will include WanFang Data, China Journal Net, Chinese Biomedical Literature Database, Chinese Medical Current Contents, and Hong Kong Index to Chinese Periodical Literature. The resources for searching grey literature or unpublished studies will include Mednar database, Netting the Evidence, Lancashire Care Library and Information Service, Grey Literature Report (via The New York Academy of Medicine), Networked Digital Library of Theses and Dissertations, Academic Archive Online, and Agency for Healthcare Research and Quality.
Initial key words
The initial keywords that will be used for MEDLINE(R) are below:
- exp Stroke/ or exp Cerebrovascular Disorders/
- (stroke or cerebrovascular* or cerebro vascular or cva).mp.
- (self-manag* or self manag* or self care or self-care or self monitor* or self-monitor*).mp.
- (self efficacy or self-efficacy).mp.
- (social cognit* adj3 (theor* or principle* or framework*)).mp.
The keywords will be adapted for the other databases. The Chinese search terms will be based on the terminology used in Taiwan and China.

Study selection
The titles and abstracts of all citations identified from the search strategies will be assessed by two reviewers independently against the inclusion criteria in terms of study design, types of participants, interventions, outcome measures and language. A form for verification of study eligibility will be developed by the reviewers for the assessment (Appendix I). Full text of the articles will be retrieved for further assessment if they are considered relevant to the systematic review, or if there are doubts about their relevance. Inclusion of a publication into the systematic review will be decided independently by the two reviewers. Disagreement will be resolved by discussion according to the inclusion criteria or consultation with a third reviewer.

Assessment of methodological quality
The methodological quality of the included studies will be assessed independently by the two reviewers using the appropriate standardized critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics: Assessment and Review Instrument (JBI-MAStARI) for randomized and pseudo-randomized studies (Appendix II), comparable cohort/case control studies (Appendix III), and descriptive/case series studies (Appendix IV). Disagreements between the two reviewers will be resolved by discussion or consultation with a third reviewer.

Data extraction
Data from the included studies will be extracted independently by the two reviewers using standardized data extraction tools from the JBI-MAStARI (Appendix V). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. If there is data missing or queries about the data, the study authors will be contacted for clarification. Discrepancies between the two reviewers will be resolved by discussion or consultation with the third reviewer.

Data synthesis
The included studies will be categorized according to the focus of the self-management programs. If there is sufficient number of identified studies, they will also be categorized in terms of delivery methods for further subgroup analysis. The data from all studies where possible will be pooled in statistical meta-analysis using the JBI-MAStARI. All data will be entered twice to minimize risks of errors during data entry. Quantitative results of the studies will be summarized statistically if they are of sufficient homogeneity and methodological quality. Heterogeneity of the studies will be tested using I^2 which describes the percentage of total variation across studies that is due to heterogeneity rather than chance. A fixed-effect meta-analysis will be used when there is no evidence of significant heterogeneity across studies ($I^2 \leq 40\%$). A random-effects meta-analysis will be used when there is evidence of heterogeneity across studies ($I^2 > 40\%$). Odd ratios and 95% confidence interval (CI) will be calculated for dichotomous data and used as the summary measure of effect. Mean difference and 95% CI will be calculated for continuous data measured by the same scale and used as the summary measure of effect; while the standardized mean difference and 95% CI will be calculated for continuous data measured by different scales. If statistical pooling of results is not appropriate or feasible, a narrative summary will be undertaken. A funnel plot will be performed to assess publication bias.

Conflicts of interest
There is no conflict of interest associated with this review.
References


Appendix I

Study eligibility verification form

Verification of Study Eligibility

Reviewer ___________________  Date _____________ Record No. ___________

Article ______________________________________________________________

Types of Studies
- Randomized controlled trials □
- Quasi-randomized controlled trials □
- Uncontrolled pre- and post-studies □
- Cohort studies □
- Case control studies □
- Case series □

Types of Participants
Adults aged 18 years or above, clinically diagnosed with a first or recurrent stroke and are residing in the community. □

Types of Interventions
All structured programs for community-dwelling stroke survivors designed to promote their stroke self-management behaviours. □

Types of Outcome Measures
Primary outcomes: quality of life □

Secondary outcomes:
- Physical outcomes: Activities of daily living, self-management skills □
- Psychological outcomes: Self-care self-efficacy, depressive symptoms □
- Social outcomes: Community reintegration □

Language
Studies written in English or Chinese □

If you have not ticked at least one box in each category, please do not proceed with the rest of JBI Critical Appraisal Checklist and Data Extraction Form.
## Appendix II

### JBI Critical Appraisal Checklist for Randomized and Pseudo-randomized Studies

Reviewer _______________  Date _____________  Record No. _______________

Article _______________________________________________________________

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<thead>
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<th>Criteria</th>
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<th>No</th>
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<tr>
<td>1. Was the assignment to treatment groups truly random?</td>
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<td></td>
<td></td>
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<tr>
<td>2. Were participants blinded to treatment allocation?</td>
<td></td>
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<tr>
<td>3. Was allocation to treatment groups concealed from the allocator?</td>
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<tr>
<td>4. Were the outcomes of people who withdrew described and included in the analysis?</td>
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<tr>
<td>5. Were those assessing outcomes blind to the treatment allocation?</td>
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<tr>
<td>6. Were the control and treatment groups comparable at entry?</td>
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<tr>
<td>7. Were groups treated identically other than for the named interventions?</td>
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<tr>
<td>8. Were outcomes measured in the same way for all groups?</td>
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<tr>
<td>9. Were outcomes measured in a reliable way?</td>
<td></td>
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<tr>
<td>10. Was appropriate statistical analysis used?</td>
<td></td>
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</tbody>
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Overall appraisal: Include □  Exclude □  Seek further information □

Comments (including reasons for exclusion)

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## Appendix III

**JBI Critical Appraisal Checklist for Comparable Cohort/Case Control Studies**

<table>
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<th>Criteria</th>
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<tr>
<td>1. Is sample representative of patients in the population as a whole?</td>
<td>□</td>
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<tr>
<td>2. Are the patients at a similar point in the course of their condition/illness?</td>
<td>□</td>
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<tr>
<td>3. Has bias been minimised in relation to selection of cases and controls?</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>4. Are confounding factors identified and strategies to deal with them stated?</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>5. Are outcomes assessed using objective criteria?</td>
<td>□</td>
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<tr>
<td>6. Was follow up carried out over a sufficient time period?</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. Were the outcomes of people who withdrew described and included in the analysis?</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. Were outcomes measured in a reliable way?</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. Was appropriate statistical analysis used?</td>
<td>□</td>
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<td>□</td>
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</table>

Overall appraisal:  
Include □  
Exclude □  
Seek further information □

Comments (including reasons for exclusion)

__________________________________________________________________________________

__________________________________________________________________________________

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### Appendix IV

#### JBI Critical Appraisal Checklist for Descriptive/Case Series Studies

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<th>Criteria</th>
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<td>2. Were the criteria for inclusion in the sample clearly defined?</td>
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<tr>
<td>3. Were confounding factors identified and strategies to deal with them stated?</td>
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</tr>
<tr>
<td>4. Were outcomes assessed using objective criteria?</td>
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<tr>
<td>5. If comparisons were being made, were there sufficient descriptions of the groups?</td>
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<tr>
<td>6. Was follow up carried out over a sufficient time period?</td>
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<tr>
<td>7. Were the outcomes of people who withdrew described and included in the analysis?</td>
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<tr>
<td>8. Were outcomes measured in a reliable way?</td>
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<tr>
<td>9. Was appropriate statistical analysis used?</td>
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**Overall appraisal:** Include □ Exclude □ Seek further information □

**Comments (including reasons for exclusion)**

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Appendix V

Data Extraction Form

Reference No.: ____________________ Reviewer ____________________

Authors

Article Title

Journal Title

Year __________________ Volume (Issue) ___________ Page No. ____________

Method

Setting

Participants

Number of Participants

<table>
<thead>
<tr>
<th>Group A</th>
<th>Group B</th>
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Interventions

<table>
<thead>
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<th>Intervention A</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Intervention B</td>
<td></td>
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</tbody>
</table>

Outcome Measures

<table>
<thead>
<tr>
<th>Outcome descriptions</th>
<th>Scales/ Measures</th>
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</table>

Results

Dichotomous data

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Group A (Odd ratio/ Relative risk/ 95% CI)</th>
<th>Group B (Odd ratio/ Relative risk/ 95% CI)</th>
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<tbody>
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</table>

Continuous data

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Group A (Mean differences/ Standardized mean differences/ 95% CI)</th>
<th>Group B (Mean differences/ Standardized mean differences/ 95% CI)</th>
</tr>
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<tbody>
<tr>
<td></td>
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</table>

Authors Conclusion

__________________________________________________________________________________

__________________________________________________________________________________

Reviewers Comments

__________________________________________________________________________________

__________________________________________________________________________________
Appendix B

Systematic review published in Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (executive summary, references and appendices)

Theory-based self-management programs for promoting recovery in community-dwelling stroke survivors: a systematic review

Suzanne H S Lo, RN, BN, MSc1
Anne M Chang, RN, Dip NEd BEdSt(Hons), MEdSt, PhD, FRCNA1
Janita P C Chau, RN, BN, MPhil, PhD, FHKCERN2
Glenn E Gardner, RN, BAppSci, MEdStudies, PhD3

1. School of Nursing, Faculty of Health, Queensland University of Technology; Queensland Centre for Evidence Based Nursing and Midwifery: A Collaborating Centre of the Joanna Briggs Institute, Brisbane, Australia
2. The Nethersole School of Nursing, The Chinese University of Hong Kong; Hong Kong Centre for Evidence Based Nursing: A Collaborating Centre of the Joanna Briggs Institute, Hong Kong
3. School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia

Corresponding author
Ms Suzanne Hoi-Shan Lo, The Nethersole School of Nursing, The Chinese University of Hong Kong, Shatin, NT, Hong Kong, suzannelo@cuhk.edu.hk

Executive summary

Background
Post-stroke recovery is demanding. Increasing studies have examined the effectiveness of self-management programs underpinned by a theoretical framework for stroke survivors. Such theoretical understanding is important in developing the intervention systematically and informing the outcome measures. No systematic review has been conducted previously to summarize the effectiveness of these programs.

Objectives
The aim is to present the best available research evidence about effectiveness of theory-based self-management programs (TSSMP) on community-dwelling stroke survivors' recovery.

Inclusion criteria

Types of participants
All community-residing adults aged 18 years or over, and who have had a clinical diagnosis of stroke.

Types of interventions
Studies which examined effectiveness of a self-management program underpinned by a theoretical framework for stroke survivors.

Types of studies
Randomized controlled trials only.

Types of outcomes
Primary outcomes included health-related quality of life and self-management behaviors measured by generic or disease-specific instruments. Secondary outcomes included physical (activities of daily living), psychological (self-efficacy, depressive symptoms), and social (community reintegration, perceived social support) outcomes.

Search strategy
A three-step approach was adopted to identify all relevant published and unpublished studies in English or Chinese.

Methodological quality
The methodological quality of the included studies was assessed using the JBI critical appraisal checklist for experimental studies.
Data collection
A standardized JBI data extraction form was used. There was no disagreement between the two reviewers on the data extraction results.

Data synthesis
Findings were presented in a narrative form as there were incomplete details about the number of participants and the results in two of the three included studies made it impossible to perform a meta-analysis.

Results
The key issues of concern in methodological quality of the three studies were insufficient information about random assignment, allocation concealment, reliability and validity of the measuring instruments, absence of intention-to-treat analysis, and small sample sizes. Each program in the three studies was designed based on the Stanford Chronic Disease Self-management program (CDSMP) and was underpinned by the principles of self-efficacy. One study showed improvement in the intervention group in family and social roles three months post-program, and work productivity at six months as measured by the Stroke Specific Quality of Life Scale (SSQOL). The intervention group had an increased mean self-efficacy score in communicating with physicians six months post-program. Mean changes from baseline in these variables were significantly different from the control. No significant difference was found in time spent in aerobic exercise between the intervention and control groups at three and six months post-program. Another study, using SSQOL, showed a significant interaction effect by treatment and time on family roles, fine motor tasks, self-care, and work productivity. There was no significant interaction by treatment and time on self-efficacy. The third study showed improvement in quality of life, community participation, and depressive symptoms among participants receiving the TSSMP, CDSMP, or usual care six months post-program; however, there was no significant difference between the groups.

Conclusions
There is inconclusive evidence about the effectiveness of TSSMP on community-dwelling stroke survivors’ recovery. However, the preliminary evidence suggests potential benefits in improving stroke survivors’ quality of life and self-efficacy.

Keywords: disease management, self-care, self-efficacy, stroke, review, systematic review.

References

References of the included studies

Cadilhac et al. 2011

Damush et al. 2011

Kendall et al. 2007

Appendix I: Search strategy

Ovid MEDLINE(R) 1948 to Present with Daily Update
Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations November 23, 2011

1. exp Stroke/
2. Cerebrovascular Disorders/
3. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke or SAH).tw.
4. (((cerebrovascular* or cerebrovascular* or brain vascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*))).tw.
5. (((cerebral* or brain* or cerebell* or vertebrobasilar* or intracerebral* or intra cerebral* or intracran* or intracran*) adj3 (isch?em* or infarct* or thrombo* or embol* or occlus*)).tw.
6. ((cerebral* or brain* or cerebell* or intracerebral* or intra cerebral* or intracran* or intra cran* or subarachnoid*) adj3 (h?emorrhag* or bleed* or h?ematoma*)).tw.
7. or/1-6
8. exp Self Care/
9. exp Disease Management/
10. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*)).tw.
11. (risk factor* adj5 manage*).tw.
12. or/8-11
13. exp Patient Education as Topic/
14. exp Health Education/
15. exp Behavior Therapy/
16. exp Counseling/
17. exp Exercise Therapy/
18. exp Medication Adherence/
19. exp Self-Help Groups/
20. ((stroke* or manage* or education* or workbook* or information* or web* or online* or tele* or computer* or video* or behavio?r* or psychologic* or psychosocial* or biopsychosocial* or medication* or prevent* or rehabilitat* or exercise* or training or counsel* or nursing) adj3 (program* or intervention* or strateg* or session* or therap* or course* or class*)).tw.
21. (self help* or support group* or social support*).tw.
22. or/13-21
23. exp Problem Solving/
24. exp Decision Making/
25. exp Patient Participation/
26. exp Adaptation, Psychological/
27. (problem solv* or decision mak* or informed decision*).tw.
28. (goal* adj3 (set* or attain*)).tw.
29. (action* adj3 plan*).tw.
30. (cope* or coping* or adapt* or adjust* or independen* or empower*).tw.
31. (stroke* adj5 (recover* or knowledge*)).tw.
32. ((communit* or societ* or social* or role* or activit* or life*) adj4 (participat* or integrat* or reintegrat* or reintegrat* or engag* or relation*)).tw.
33. ((resource* or service*) adj3 (utilis* or utiliz* or find* or search*)).tw.
34. or/23-33
35. 22 and 34
36. exp Community Health Services/
37. (communit* or outpatient* or out patient* or home*).tw.
38. (discharg* adj3 hospital*).tw.
39. (stroke* adj5 (live* or living or survivor* or recover*)).tw.
40. or/36-39
41. 12 or 35
42. 7 and 40 and 41

Embase 1980 to 2011 November 23
Embase Classic 1947 to 1979
1. exp Stroke/
2. Cerebrovascular Disease/
3. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke).tw.
4. ((cerebrovascular* or cerebro vascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*)).tw.
5. ((cerebral* or brain* or cerebell* or vertebrobasilar* or intracerebral* or intra cerebral* or intracran* or intra cran*) adj3 (isch?em* or infarct* or thrombo* or embol* or occlus*)).tw.
6. ((cerebral* or brain* or cerebell* or intracerebral* or intra cerebral* or intracran* or intra cran* or subarachnoid*) adj3 (h?emorrhag* or bleed* or h?ematoma*)).tw.
7. or/1-6
8. exp Self Care/
9. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*)).tw.
10. (risk factor* adj5 manage*).tw.
11. or/8-10
12. exp Patient Education/
13. exp Health Education/
14. exp Behavior Therapy/
15. exp Counseling/
16. exp Kinesiotherapy/
17. exp Patient Compliance/
18. ((stroke* or manage* or education* or workbook* or information* or web* or online* or tele* or computer* or video* or behavio?r* or psychologic* or psychosocial* or biopsychosocial* or medication* or prevent* or rehabilitat* or exercise* or training or counsel* or nursing) adj3 (program* or intervention* or strateg* or session* or therap* or course* or class*)).tw.
19. (self help* or support group* or social support*).tw.
20. or/12-19
21. exp Problem Solving/
22. exp Decision Making/
23. exp Patient Participation/
24. exp Adaptive Behavior/
25. (problem solv* or decision mak* or informed decision*).tw.
26. (goal* adj3 (set* or attain*)).tw.
27. (action* adj3 plan*).tw.
28. (cope* or coping* or adapt* or adjust* or independen* or empower*).tw.
29. (stroke* adj5 (recover* or knowledge*)).tw.
30. ((communit* or societ* or social* or role* or activit* or life*) adj4 (participat* or integrat* or reintegrat* or re integrat* or engag* or relation*)).tw.
31. ((resource* or service*) adj3 (utilis * or uliliz* or find* or search*)).tw.
32. or/21-31
33. 20 and 32
34. exp Community Care/
35. (communit* or outpatient* or out patient* or home*).tw.
36. (discharg* adj3 hospital*).tw.
37. (stroke* adj5 (live* or living or survivor* or recover*)).tw.
38. or/34-37
39. 11 or 33
40. 7 and 38 and 39

All EBM Reviews:
Cochrane Central Register of Controlled Trials 4th Quarter 2011
1. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke).tw.
2. ((cerebrovascular* or cerebro vascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*)).tw.
3. ((cerebral* or brain* or cerebell* or vertebrobasilar* or intracerebral* or intra cerebral* or intracran* or intra cran*) adj3 (isch?em* or infarct* or thrombo* or embol* or occlus*)).tw.
4. ((cerebral* or brain* or cerebell*or intracerebr al* or intra cerebral* or intracran* or subarachnoid*) adj3 (h?emorrhag* or bleed* or h?ematoma*)).tw.
5. or/1-4
6. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*)).tw.
7. (risk factor* adj5 manage*).tw.
8. 6 or 7
9. 5 and 8

AMED (Allied and Complementary Medicine) 1985 to November 2011
1. exp Stroke/
2. Cerebrovascular Disorders/
3. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke or SAH).tw.
4. ((cerebrovascular* or cerebro vascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*)).tw.
5. ((cerebral* or brain* or cerebell* or vertebrobasilar* or intracerebral* or intra cerebral* or intracran* or intra cran*) adj3 (isch?em* or infarct* or thrombo* or embol* or occlus*)).tw.
6. ((cerebral* or brain* or cerebell*or intracerebr al* or intra cerebral* or intracran* or intra cran* or subarachnoid*) adj3 (h?emorrhag* or bleed* or h?ematoma*)).tw.
7. or/1-6
8. exp Self Care/
9. exp Disease Management/
10. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*)).tw.
11. (risk factor* adj5 manage*).tw.
12. or/8-11
13. exp Patient Education/
14. exp Health Education/
15. exp Behavior Therapy/
16. exp Counseling/
17. exp Exercise Therapy/
18. exp Patient Compliance/
19. exp Self Help Groups/
20. ((stroke* or manage* or education* or workbook* or information* or web* or online* or tele* or computer* or video* or behavior* or psychologic* or psychosocial* or biopsychosocial* or medication* or prevent* or rehabilitation* or exercise* or training or counsel* or nursing) adj3 (program* or intervention* or strategy* or session* or therapy* or course* or class*)).tw.
21. (self help* or support group* or social support*).tw.
22. or/13-21
23. exp Problem Solving/
24. exp Decision Making/
25. exp Patient Participation/
26. exp Adaptation Psychological/
27. (problem solve* or decision make* or informed decision*).tw.
28. (goal* adj3 set* or attain*).tw.
29. (action* adj3 plan*).tw.
30. (cope* or coping* or adapt* or adjust* or independen* or empower*).tw.
31. (stroke* adj5 recover* or knowledge*).tw.
32. ((community* or societal* or social* or role* or activity* or life*) adj4 (participate* or integrate* or reintegrate* or re-integrate* or engage* or relation*)).tw.
33. ((resource* or service*) adj3 (utilize* or utilize* or find* or search*)).tw.
34. or/23-33
35. 22 and 34
36. exp Community Health Services/
37. (community* or outpatient* or outpatient* or home*).tw.
38. (discharge* adj3 hospital*).tw.
39. (stroke* adj5 (love* or living or survivor* or recover*).tw.
40. or/36-39
41. 12 or 35
42. 7 and 40 and 41

PsycINFO 1967 to November Week 4 2011
1. exp Cerebrovascular Accidents/
2. Cerebrovascular Disorders/
3. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke or SAH).tw.
4. ((cerebrovascular* or cerebrovascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*).tw.
5. ((cerebral* or brain* or cerebell* or vertebrobasilar* or intracerebral* or intra cerebral* or intracran* or intra cran*) adj3 (ischem* or infarct* or thrombo* or embol* or occlus*).tw.
6. ((cerebral* or brain* or cerebell* or intracerebral* or intra cerebral* or intracran* or intra cran* or subarachnoid*) adj3 (hemorrhag* or bleed* or hematoma*)).tw.
7. or/1-6
8. exp Self Management/
9. exp Disease Management/
10. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*)).tw.
11. (risk factor* adj5 manage*).tw.
12. or/8-11
13. exp Client Education/
14. exp Health Education/
15. exp Behavior Therapy/
16. exp Treatment Compliance/
17. exp Counseling/
18. exp Self Help Techniques/  
19. exp Support Groups/  
20. ((stroke* or manage* or education* or workbook* or information* or web* or online* or tele* or computer* or video* or behavior?* or psychologic* or psychosocial* or biopsychosocial* or medication* or prevent* or rehabilitat* or exercise* or training or counsel* or nursing) adj3 (program* or intervention* or strateg* or session* or therap* or course* or class*)).tw.  
21. (self help* or support group* or social support*).tw.  
22. or/13-21  
23. exp Problem Solving/  
24. exp Decision Making/  
25. exp Client Participation/  
26. exp Emotional Adjustment/  
27. (problem solv* or decision mak* or informed decision*).tw.  
28. (goal* adj3 (set* or attain*)).tw.  
29. (action* adj3 plan*).tw.  
30. (cope* or coping* or adapt* or adjust* or independent or empower*).tw.  
31. (stroke* adj5 (recover* or knowledge*)).tw.  
32. ((communit* or societ* or social* or role* or activit* or life*) adj4 (participat* or integrat* or reintegrat* or re integrat* or engag* or relation*)).tw.  
33. ((resource* or service*) adj3 (utilis * or utilis* or find* or search*)).tw.  
34. or/23-33  
35. 22 and 34  
36. exp Community Services/  
37. (communit* or outpatient* or out patient* or home*).tw.  
38. (discharg* adj3 hospital*).tw.  
39. (stroke* adj5 (live* or living or survivor* or recover*).tw.  
40. or/36-39  
41. 12 or 35  
42. 7 and 40 and 41  

British Nursing Index and Archive 1985 to November 2011  
1. exp Stroke/  
2. exp Stroke: Rehabilitation/  
3. (stroke* or cva* or apoplex* or cerebral vascular* or post stroke or poststroke or SAH).tw.  
4. ((cerebrovascular* or cerebro vascular* or brain vascular*) adj3 (disease* or accident* or disorder* or attack* or event*)).tw.  
5. ((cerebral* or brain* or cerebell* or intracerebral* or intracran* or intra cran*) adj3 (isch?em* or infarct* or thrombo* or embol* or occlus*).tw.  
6. ((cerebral* or brain* or cerebell*or intracerebr al* or intracran* or intracran* or intra cran* or subarachnoid*) adj3 (h?emorrhag* or bleed* or h?ematoma*).tw.  
7. or/1-6  
8. exp Self Care/  
9. (self adj4 (manage* or care* or treat* or monitor* or administ* or control*).tw.  
10. (risk factor* adj5 manage*).tw.  
11. or/8-10  
12. exp Patients: Education/  
13. exp Health Promotion/  
14. exp Behaviour Therapy/  
15. exp Patients: Compliance/  
16. exp Counselling/  
17. exp Self Help Groups/  
18. ((stroke* or manage* or education* or workbook* or information* or web* or online* or tele* or computer* or video* or behavior?* or psychologic* or psychosocial* or biopsychosocial* or medication* or prevent* or rehabilitat* or exercise* or training or counsel* or nursing) adj3 (program* or intervention* or strateg* or session* or therap* or course* or class*).tw.  
19. (self help* or support group* or social support*).tw.  
20. or/12-19  
21. exp Decision Making Process/  
22. (problem solv* or decision mak* or informed decision*).tw.  
23. (goal* adj3 (set* or attain*).tw.
24. (action* adj3 plan*).tw.
25. (cope* or coping* or adapt* or adjust* or independen* or empower*).tw.
26. (stroke* adj5 (recover* or knowledge*)).tw.
27. ((communit* or societ* or social* or role* or activit* or life*) adj4 (participat* or integrat* or reintegrat* or re integrat* or engag* or relation*)).tw.
28. ((resource* or service*) adj3 (utilis* or utiliz* or find* or search*)).tw.
29. or/21-28
30. 20 and 29
31. exp Community Health Services/
32. (communit* or outpatient* or out patient* or home*).tw.
33. (discharg* adj3 hospital*).tw.
34. (stroke* adj5 (live* or living or survivor* or recover*)).tw.
35. or/31-34
36. 11 or 30
37. 7 and 35 and 36

Science Citation Index Expanded (SCI-EXPANDED) --1945-present
Social Sciences Citation Index (SSCI) --1956-present
Conference Proceedings Citation Index- Science (CPCI-S) --1990-present
Conference Proceedings Citation Index- Social Science & Humanities (CPCI-SSH) --1990-present
#1   TS=(stroke* OR cva* OR apoplex* OR cerebral vascular* OR post stroke OR poststroke OR SAH)
#2   TS=((cerebrovascular* OR cerebro* OR brain*) NEAR/3 (disease* OR accident* OR disorder* OR attack* OR event*))
#3   TS=((cerebral* OR brain* OR cerebell* OR vertebrobasilar* OR intracerebral* OR intracran*) NEAR/3 (ischSem* OR infarct* OR thrombo* OR embol* OR occlus*))
#4   TS=((cerebral* OR brain* OR cerebell* OR intracerebral* OR intracran* OR subarachnoid*) NEAR/3 (hSmmorrhag* OR bleed* OR hSmatoma*))
#5   #1 OR #2 OR #3 OR #4
#6   TS=(self NEAR/4 (manage* OR care* OR treat* OR monitor* OR administ* OR control*))
#7   TS=(risk* NEAR/5 manage*)
#8   #6 OR #7
#9   TS=(communit* OR outpatient* OR "out patient*" OR home*)
#10  TS=(discharg* NEAR/3 hospital*)
#11  TS=(stroke* NEAR/5 (live* OR living OR survivor* OR recover*))
#12  #9 OR #10 OR #11
#13  #5 AND #8 AND #12

CINAHL PLUS 1937 – present
S1   MH Stroke
S2   MH Cerebrovascular Disorders
S3   TX stroke* OR cva* OR apoplex* OR cerebral vascular* OR post stroke OR poststroke OR SAH
S4   TX (cerebrovascular* OR cerebrovascular* OR brain vascular*) N3 (disease* OR accident* OR disorder* OR attack* OR event*)
S5   TX (cerebral* OR brain* OR cerebell* OR vertebrobasilar* OR intracerebral* OR intra cerebral* OR intracran* OR intra cran*) N3 (ischSem* OR infarct* OR thrombo* OR embol* OR occlus*)
S6   TX (cerebral* OR brain* OR cerebell* OR intracerebral* OR intra cerebral* OR intracran* OR subarachnoid*) N3 (hSmmorrhag* OR bleed* OR hSmatoma*)
S7   S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8   MH Self Care
S9   MH Disease Management
S10  TX self N4 (manage* OR care* OR treat* OR monitor* OR administ* OR control*)
S11  TX risk factor* N5 manage*
S12  S8 OR S9 OR S10 OR S11
S13  MH Community Health Services
S14  TX communit* OR outpatient* OR out patient* OR home*
S15  TX discharg* N3 hospital*
S16  TX stroke* N5 (live* OR living OR survivor* OR recover*)
SCOPUS
1. ABS(stroke* OR cva* OR apoplex* OR "cerebral vascular*" OR "post stroke" OR poststroke OR sah)
2. ABS((cerebrovascular* OR "cerebro vascular*" OR "brain vascular*") AND (disease* OR accident* OR disorder* OR attack* OR event*))
3. ABS((cerebral* OR brain* OR cerebell* OR vertebrobasilar* OR intracerebral* OR "intra cerebral*" OR intracran* OR "intra cran*" OR "intra cranial*" OR "intra cranial" OR "intra cranial"") AND (isch*em* OR infarct* OR thrombo* OR embol* OR occlus*))
4. ABS((cerebral* OR brain* OR cerebell* OR intracerebral* OR "intra cerebral*" OR intracran* OR "intra cran*" OR subarachnoid*) AND (h*emorrhag* OR bleed* OR h*ematoma*))
5. 1 OR 2 OR 3 OR 4
6. ABS(self AND (manage* OR care* OR treat* OR monitor* OR administr* OR control*))
7. ABS("risk factor*" AND manage*)
8. 6 OR 7
9. ABS(communit* OR outpatient* OR "out patient*" OR home*)
10. ABS(dischagr* W/3 hospital*)
11. ABS(stroke* AND (live* OR living OR survivor* OR recover*))
12. 9 OR 10 OR 11
13. 5 AND 8 AND 12

ProQuest Dissertations and Theses (Web version of Dissertation Abstracts)
Dissertations & Theses @ Chinese University of Hong Kong
1. ab(stroke* OR cva* OR apoplex* OR cerebral vascular* OR post stroke OR poststroke OR SAH)
2. self NEAR/4 (manage* OR care* OR treat* OR monitor* OR administr* OR control*)
3. risk* NEAR/5 manage*
4. ((risk* NEAR/5 manage*) OR (self NEAR/4 (manage* OR care* OR treat* OR monitor* OR administr* OR control*)))
5. ((risk* NEAR/5 manage*) OR (self NEAR/4 (manage* OR care* OR treat* OR monitor* OR administr* OR control*))) AND ab(stroke* OR cva* OR apoplex* OR cerebral vascular* OR post stroke OR poststroke OR SAH)
Appendix II: Study eligibility verification form

Study Eligibility Verification Form

Verification of Study Eligibility

Reviewer ___________________  Date _____________ Record No. ___________

Article ______________________________________________________________

Types of Studies
Randomized controlled trials

Types of Participants
Adults aged 18 years or above, diagnosed with a first or recurrent stroke, and are residing in the community.

Types of Interventions
All structured theory-based programs for community-dwelling stroke survivors designed to promote their stroke self-management behaviors.

Types of Outcome Measures
Primary outcomes: Health-related quality of life, self-management behaviors

Secondary outcomes:
Physical outcomes: Activities of daily living
Psychological outcomes: Self-efficacy, depressive symptoms
Social outcomes: Community reintegration, perceived social support

Language
Studies written in English or Chinese

If you have not ticked at least one box in each category, please do not proceed with the rest of JBI-MAStARI Critical Appraisal Instrument and Data Extraction Form.
Appendix III: JBI-MAStARI critical appraisal instrument

JBI-MAStARI Critical Appraisal Instrument
Experimental Studies

Reviewer _________________  Date _____________  Record No. _______________

Article  _______________________________________________________________
_____________________________________________________________

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Yes</th>
<th>No</th>
<th>Unclear</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was the assignment to treatment groups truly random?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Were participants blinded to treatment allocation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Was allocation to treatment groups concealed from the allocator?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Were the outcomes of people who withdrew described and included in the analysis?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Were those assessing outcomes blind to the treatment allocation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Were the control and treatment groups comparable at entry?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Were groups treated identically other than for the named interventions?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Were outcomes measured in the same way for all groups?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Were outcomes measured in a reliable way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Was appropriate statistical analysis used?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall appraisal: Include □  Exclude □  Seek further information □

Comments (including reasons for exclusion)
__________________________________________________________________
__________________________________________________________________
Appendix IV: Data extraction form

Data Extraction Form

<table>
<thead>
<tr>
<th>Ref No.:</th>
<th>Reviewer __________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors</td>
<td></td>
</tr>
<tr>
<td>Article Title</td>
<td></td>
</tr>
<tr>
<td>Journal Title</td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Volume (Issue)</td>
</tr>
<tr>
<td>Page No.</td>
<td></td>
</tr>
<tr>
<td>Study Design</td>
<td></td>
</tr>
<tr>
<td>Setting</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td></td>
</tr>
</tbody>
</table>

Number of Participants

<table>
<thead>
<tr>
<th>Group A</th>
<th>Group B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Interventions

<table>
<thead>
<tr>
<th>Intervention A</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention B</td>
<td></td>
</tr>
</tbody>
</table>

Outcome Measures

<table>
<thead>
<tr>
<th>Outcome descriptions</th>
<th>Scales/ Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Results

**Dichotomous data**

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Intervention ()</th>
<th>Intervention ()</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Number/ total number)</td>
<td>(Number/ total number)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Continuous data**

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Intervention ()</th>
<th>Intervention ()</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(Mean and Standard deviation)</td>
<td>(Mean and Standard deviation)</td>
</tr>
<tr>
<td></td>
<td>(number)</td>
<td>(number)</td>
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</tbody>
</table>

**Authors’ Conclusion**

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

**Reviewers’ Comments**

__________________________________________________________________________________
__________________________________________________________________________________
Appendix V: List of excluded studies and the reasons for exclusion

Studies published in English (n=168)

Reason for exclusion: The content of the program/intervention/course was not related to self-management. (n=84)

- Galvin R, Cusack T, Stokes E. A randomised controlled trial evaluating family mediated exercise (FAME) therapy following stroke. BMC Neurol 2008; 8: 22.


Reason for exclusion: The program examined in the study was not a stroke-specific self-management program. (n=8)


Reason for exclusion: The intervention was commenced while the stroke patients were in the hospitals. (n=3)

Reason for exclusion: Ineligible participants. (n=7)

Reason for exclusion: The topic of the study was not related to the systematic review. (n=34)


**Reason for exclusion:** There was insufficient information about the underlying theoretical or conceptual framework of the program. (n=11)


Graven C, Brock K, Hill K, Ames D, Cotton S, Joubert L. From rehabilitation to recovery: protocol for a randomised controlled trial evaluating a goal-based intervention to reduce depression and facilitate participation post-stroke. BMC Neurol 2011; 11: 73.


Reason for exclusion: A non-randomized cohort study/editorial/a multiple-participant two-phase single subject design/case series/a descriptive study (n=7)


Reason for exclusion: No further details could be obtained from the authors to assess the relevance of the study to the systematic review. (n=6)


**Reason for exclusion: Conference abstracts/presentations.** (n=6)


Nasr N. Supporting the self management of stroke by applying a user-centred design approach [Internet]; 2011 [cited 2012 Feb 16]. Available from: http://shura.shu.ac.uk/3415.

**Reason for exclusion: Study protocols.** (n=2)


**Studies published in Chinese (n=18)**

**Reason for exclusion: The content of the intervention was not related to self-management.** (n=5)


**Reason for exclusion: Ineligible participants.** (n=2)


Reason for exclusion: The topic of this study was not related to the systematic review. (n=5)


Reason for exclusion: There was insufficient information about the underlying theoretical or conceptual framework of the program. (n=4)


Reason for exclusion: Non-randomized controlled trial. (n=1)


Reason for exclusion: A Chinese version of an included study in English. (n=1)

Appendix VI: Summary of quality assessment of the included studies (n=3)

Joanna Briggs Institute Meta Analysis of Statistics: Assessment and Review Instrument (JBI-MAStARI) for Experimental Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Was the assignment to treatment groups truly random?</th>
<th>Were participants blinded to treatment allocation?</th>
<th>Was allocation to treatment groups concealed from the allocator?</th>
<th>Were the outcomes of people who withdrew described and included in the analysis?</th>
<th>Were those assessing outcomes blind to the treatment allocation?</th>
<th>Were the control and treatment groups comparable at entry?</th>
<th>Were groups treated identically other than for the named interventions?</th>
<th>Were outcomes measured in the same way for all groups?</th>
<th>Were outcomes measured in a reliable way?</th>
<th>Was appropriate statistical analysis used?</th>
<th>Total score (possible score out of 9-10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadilhac et al.33</td>
<td>1</td>
<td>NA</td>
<td>U</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>U</td>
<td>1</td>
<td>7.9</td>
</tr>
<tr>
<td>Damush et al.34</td>
<td>U</td>
<td>NA</td>
<td>U</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>6.9</td>
</tr>
<tr>
<td>Kendall et al.11</td>
<td>1</td>
<td>NA</td>
<td>U</td>
<td>U</td>
<td>U</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>5.9</td>
</tr>
</tbody>
</table>

(NA: Not applicable; U: Unclear)

(The total score of the studies is not equivalent to 10 due to that the items which was determined as ‘Not applicable’ was excluded.)
Appendix VII: Summary of the characteristics of the included studies (n=3)

<table>
<thead>
<tr>
<th>Authors/year/country/ study setting/type of study</th>
<th>Participants</th>
<th>Interventions</th>
<th>Comparison</th>
<th>Outcome measures</th>
<th>Follow-up period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadilhac et al.33</td>
<td>143 people with stroke</td>
<td>Stroke self-management program (SSMP)</td>
<td>Stanford Chronic Disease Self-management program (CDSMP) 6-week, co-facilitated program and covers topics e.g. appropriate use of medicines, communicating effectively with family and friends, and nutrition. Usual care Access only to the information and education provided by the hospital team or their local general practitioner.</td>
<td>Primary outcomes: Participation Recruitment methods Adverse events (participant safety) Secondary outcomes: Health Education Impact Questionnaire (Positive and active engagement in life) Assessment of Quality of Life tool Irritability, depression, and anxiety scale</td>
<td>SSMP and CDSMP: Baseline, 2 to 4 weeks, and 6 months after program completion. Usual care: Baseline, 1 month after baseline, and 6 months after program completion.</td>
</tr>
<tr>
<td>South Australia</td>
<td>143 people with stroke</td>
<td>Stroke self-management program (SSMP) Key characteristics: Provided targeted stroke-specific information each week. Revisited information provided in other weeks to ensure retention of learning and skills.</td>
<td>Stanford Chronic Disease Self-management program (CDSMP) 6-week, co-facilitated program and covers topics e.g. appropriate use of medicines, communicating effectively with family and friends, and nutrition. Usual care Access only to the information and education provided by the hospital team or their local general practitioner.</td>
<td>Primary outcomes: Participation Recruitment methods Adverse events (participant safety) Secondary outcomes: Health Education Impact Questionnaire (Positive and active engagement in life) Assessment of Quality of Life tool Irritability, depression, and anxiety scale</td>
<td>SSMP and CDSMP: Baseline, 2 to 4 weeks, and 6 months after program completion. Usual care: Baseline, 1 month after baseline, and 6 months after program completion.</td>
</tr>
<tr>
<td>Damush et al.34</td>
<td>63 participants with ischemic stroke</td>
<td>Stroke self-management program Key characteristics: Topics: e.g. overview of stroke, recovery from stroke, rehabilitation services, creating a daily schedule, adapting/ coping with stroke related disability, community resources. Each session targeted building self-efficacy using goal setting and behavioral contracting. Each patient was coached to choose at least one specific goal to work on in each session. Patients received individualized feedback about their progress towards their selected goal(s).</td>
<td>Attention placebo control Received stroke education pamphlets and a general stroke education session at enrolment, and phone calls to assess stroke symptoms (with no self-management training) at identical time points as intervention patients.</td>
<td>Primary outcomes: Stroke Specific Quality of Life Scale Secondary outcomes: Self-management behavior frequency (exercise, social and recreation activities, cognitive/mental relaxation) Self-efficacy Patient Health Questionnaire</td>
<td>Baseline (prior to hospital discharge or within 4 weeks of discharge), and 3 and 6 months post-enrolment.</td>
</tr>
<tr>
<td>2011</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>US</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two Veterans Administration hospital sites</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RCT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authors/year/country/study setting/type of study</td>
<td>Participants</td>
<td>Interventions</td>
<td>Comparison</td>
<td>Outcome measures</td>
<td>Follow-up period</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>--------------</td>
<td>---------------</td>
<td>------------</td>
<td>-----------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Kendall et al.11</td>
<td>100 people with first stroke</td>
<td>Stanford Chronic Disease Self-management program plus a stroke-specific information session at the end of the program. Key characteristics: Topics were related to health and well-being (e.g. healthy eating, exercise, relaxation). Emphasizes group interaction and support, and reinforces solution-focused behaviors (e.g. problem solving, goal setting, communication with health care team and family). Aimed at assisting individuals to actively manage the impact of chronic conditions on their life (e.g. emotional, physical and social well-being).</td>
<td>Standard post-discharge rehabilitation offered by the health system.</td>
<td>Stroke Specific Quality of Life Scale Self-efficacy Scale</td>
<td>Baseline, and 1, 4 and 7 months after program completion. (corresponds to 3, 6, 9 and 12 months post-stroke)</td>
</tr>
</tbody>
</table>

(C: Control group; S: Stroke-specific self-management program; G: Group receiving a generic Stanford Chronic Disease Self-management program)
## Appendix VIII: Summary of the demographic and clinical characteristics of the participants in the included studies (n=3)

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Sample size</th>
<th>Mean age (SD)</th>
<th>Gender N (%) (Female vs. Male)</th>
<th>Types of stroke N (%)</th>
<th>Time since stroke onset</th>
<th>Severity of stroke</th>
<th>First-ever stroke N (%)</th>
<th>Living condition/cognitive status N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadilhac et al. 33 2011</td>
<td>All: 143 S: 48 G: 47 C: 48</td>
<td>All: 69 (11) G: 71 (12) C: 69 (11)</td>
<td>All: 85 (59%) vs.58 (41%) S: 27 (56%) vs. 21 (44%) G: 29 (62%) vs. 18 (38%) C: 29 (60%) vs. 19 (40%)</td>
<td>Ischemic vs. hemorrhage:* All: 89 (62%) vs. 31 (22%) S: 35 (73%) vs.9 (19%) G: 33 (70%) vs. 7 (15%) C: 21 (44%) vs. 15 (31%)</td>
<td>All: ≥3 months ≥12 months (N (%)):^ All: 78 (70%) S: 29 (76%) G: 23 (62%) C: 26 (70%)</td>
<td>Modified Rankin Scale score (0-1) (Baseline) (N (%)): All: 51 (36%) S: 19 (40%) G: 20 (43%) C: 12 (25%)</td>
<td>All: 106 (74%) S: 35 (73%) G: 36 (77%) C: 35 (73%)</td>
<td>Live alone#: All: 48 (34%) S: 18 (38%) G: 14 (30%) C: 16 (34%) Severe cognitive impairment: 59 (41%)</td>
</tr>
<tr>
<td>Damush et al. 34 2011</td>
<td>All: 63 S: 30 C: 33</td>
<td>All: 67.3 (12.4) (median: 67.5; range: 40.1-86.9) C: 64.0 (8.4) (median: 64.9; range: 42.1-83.7)</td>
<td>All: 1 vs. 62 (98%) S: 0 vs. 30 (100%) G: 0 (0%) C: 1 (3%) vs. 32 (97%)</td>
<td>Ischemic: 63 (100%)</td>
<td>Within the past month.</td>
<td>NIHSS score (Mean (SD); median; range): S: 3.27 (2.72); 3: 0-11 G: 3.33 (3.37); 2: 0-11</td>
<td>No information was available.</td>
<td>Live alone: All: 18 (28.6%) S: 7 (23.3%) G: 11 (33.3%) No information about participants’ cognitive status was available.</td>
</tr>
<tr>
<td>Kendall et al. 11 2007</td>
<td>All: 100 S: 58 C: 42</td>
<td>All: 65.96 (10.67) (range: 25-82) S: 66.38 (10.90) C: 66.36 (10.40)</td>
<td>All: 33 (33%) vs. 67 (67%) S: 17 (29.3%) vs. 41 (70.7%) G: 16 (28.1%) vs. 26 (61.9%)</td>
<td>No information was available.</td>
<td>Within the past three months.</td>
<td>No information was available.</td>
<td>100 (100%)</td>
<td>No information was available.</td>
</tr>
</tbody>
</table>

(C: Control group; S: Stroke-specific self-management program; G: Group receiving a generic Stanford Chronic Disease Self-management program; N: Number; NIHSS: National Institute of Health Stroke Scale; %: Percentage; SD: Standard deviation)

(*The sum of the percentages was not equal to 100% due to that the type of stroke in some participants was unsure.)

(^31 out of 143 cases were missing.)

(#1 out of 143 cases was missing.)
## Appendix IX: Summary of the characteristics of the stroke self-management programs of the included studies (n=3)

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Type of program</th>
<th>Setting</th>
<th>Underlying theoretical/conceptual framework</th>
<th>Frequency</th>
<th>Total number of sessions</th>
<th>Personnel to deliver the intervention</th>
<th>Delivery format</th>
<th>Presence of families/carer/friend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cadilhac et al.33 2011</td>
<td>Stroke-specific self-management program</td>
<td>Community-based organizations</td>
<td>Chronic Disease Self-management model (CDSM) Self-efficacy</td>
<td>8 weeks Once per week</td>
<td>8 sessions Each 2.5 hours</td>
<td>Health care professionals and peer leaders skilled in stroke and trained by the National Stroke Foundation</td>
<td>Group sessions In person</td>
<td>Stroke survivors can attend with a friend or caregiver, such as a spouse.</td>
</tr>
<tr>
<td>Damush et al.34 2011</td>
<td>Stroke self-management program</td>
<td>Two Veterans Administration hospital sites</td>
<td>CDSM Self-efficacy</td>
<td>6 months Biweekly</td>
<td>6 sessions over the first 3 months Each 20 minutes</td>
<td>A nurse, a physician assistant, and a master’s level social scientist</td>
<td>Both in person (3 sessions) and by telephone (3 sessions) over the first 3 months, and additional telephone contacts (biweekly calls) over the following 3 months A written standardized manual</td>
<td>No information was available.</td>
</tr>
<tr>
<td>Kendall et al.11 2007</td>
<td>Stanford Chronic Disease Self-management program plus a stroke-specific information session at the end of the program</td>
<td>Community settings</td>
<td>CDSM Self-efficacy</td>
<td>7 weeks Once per week</td>
<td>7 sessions Each 2 hours</td>
<td>Two trained health care professionals</td>
<td>Group sessions (10-15 participants) Face to face</td>
<td>Most participants invited a spouse to participate in the study (n= 69), and the remaining participants invited an adult child (n=25), a friend (n=4) or a sibling (n=2).</td>
</tr>
</tbody>
</table>
Appendix C

Article on translation and testing of equivalence of Stroke Self-Efficacy Questionnaire published in Topics in Stroke Rehabilitation

Title of article
Translation and validation of a Chinese version of the Stroke Self-Efficacy Questionnaire in community-dwelling stroke survivors

ABSTRACT
BACKGROUND
Self-efficacy is a significant factor influencing stroke survivors’ participation in self-care and outcomes. The Stroke Self-Efficacy Questionnaire (SSEQ) is a stroke-specific measure of stroke survivors’ self-efficacy in performing daily functional activities and self-management. However, there has been no Chinese version of the questionnaire.

OBJECTIVE
The current study aims to examine the reliability and validity of a translated Chinese version of SSEQ (SSEQ-C).

METHODS
The English version of SSEQ has been translated into Chinese. A descriptive study was conducted. A convenience sample of 135 Chinese stroke survivors (mean age 58.9, SD 9.75) was recruited from three community centres and a stroke support group. Eligible participants completed the SSEQ-C, and the Chinese versions of General Self-Efficacy Questionnaire (GSES), Frenchay Activities Index (FAI), and Stroke Specific Quality of Life Scale (SSQOL). Thirty of the participants completed the questionnaires at baseline and four weeks afterwards.

RESULTS
SSEQ-C had a high internal consistency (Cronbach’s alpha 0.92). Test-retest reliability was satisfactory with the intraclass correlation coefficient of the total scale 0.52. Positive correlations were found between the total scores of SSEQ-C, GSES, FAI and SSQOL (Spearman’s rho: 0.48-0.68, p<0.01), suggesting acceptable convergent validity. Principal component analysis suggested a two-factor model, namely “Live with new challenges” and “Activity and exercise engagement” in contrast to the single factor model for the original questionnaire.

CONCLUSION
The results suggest SSEQ-C is a reliable and valid tool for measuring Chinese community-dwelling stroke survivors’ self-efficacy in managing post-stroke condition. More studies are warranted to confirm the two-factor model of the questionnaire.

Keywords: Stroke, Self-efficacy, Psychometrics, Questionnaires, Translations

Introduction
Stroke is a leading cause of long-term disability with survivors often having to adapt to different degrees of physical, functional or cognitive consequences after discharge from hospital. Previous studies showed that stroke survivors had a higher risk for depression or participation restriction in the first year after stroke.

Self-efficacy refers to a person’s confidence to perform a particular behavior required to reach a desired goal. Stroke survivors with a higher self-efficacy were found to have fewer depressive symptoms, improved functional abilities, mobility, activities of daily living, and quality of life. Self-efficacy is developed via four sources of information namely mastery experience, vicarious experience, verbal persuasion, and reinterpretation of emotional or physiological arousals. The stronger the self-efficacy beliefs, the more likely one will initiate and adhere to the behavior.

Recent systematic reviews reported that community-based stroke self-management programs underpinned by Bandura’s self-efficacy theory were associated with significant improvement in stroke survivors’ self-efficacy in managing post-stroke health conditions. Common strategies to enhance stroke survivors’ self-efficacy in stroke care included dividing a self-care task into simple steps, use of role models, and offering positive reinforcement. To determine the effectiveness of self-efficacy enhancing interventions, a reliable and valid measuring instrument is crucial.

The 13-item Stroke Self-Efficacy Questionnaire (SSEQ) is a stroke-specific measure of stroke survivors’ self-efficacy in performing daily functional activities and self-management developed by Jones et al. Principal component analysis in the original study suggested a two-factor structure explaining 54% of the total variance of self-efficacy. However the scree plot confirmed the single factor structure of the data. SSEQ had a high internal consistency with a Cronbach’s alpha of 0.90. Further testing among 57 stroke survivors, who were about two weeks after the first stroke, showed SSEQ had high criterion validity and was able to differentiate between those stroke survivor participants who were able to walk with or without others’ assistance. However SSEQ was developed in English and there has been no validated Chinese version. It limits the evaluation of effectiveness of self-efficacy enhancing interventions for Chinese stroke survivors.

The aim of this study was to examine the reliability and validity of a translated Chinese version of SSEQ among Chinese stroke survivors.

**Methods**

The original English version of SSEQ was translated into Chinese by two independent bilingual senior baccalaureate nursing students. Two bilingual members of the research team examined the differences in the translated versions and made consensus on a draft Chinese version (SSEQ-C). Another two independent bilingual senior baccalaureate nursing students who did not know the original English version back translated the SSEQ-C into English to ensure semantic equivalence. The two bilingual members of the research team examined the differences between the back translated and the original versions. Some terms were modified including “persevere to make progress from your stroke”, “keep getting faster”, and “get yourself comfortable in bed” to improve the translation. The resulting SSEQ-C and the original English version were administered to 60 bilingual baccalaureate nursing students. They were asked to rate the appropriateness of the translation on a 4-point Likert scale (1=“very inappropriate” to 4=“very appropriate”). Two respondents rated two items as “inappropriate”. Minor amendments were made to these items to improve clarity.

Content validity was conducted by an expert panel of two physicians, one nurse academic, one nurse manager, one advanced practice nurse and two registered nurses. Panel members rated the relevance of each item of SSEQ-C to stroke self-management.
on a 4-point Likert scale (1 = “not relevant” to 4 = “very relevant and succinct”). Content validity index (CVI) was calculated as the percentage of items with a rating of three or above. CVI of SSEQ-C was 0.97. Values greater than or equal to 0.80 are considered acceptable for content validity. No modifications were made. SSEQ-C was tested on a convenience sample of five Chinese community-dwelling stroke survivors (age 35-60 years) to determine the readability of the language used. Three of them attained primary education and two attained secondary education. The participants completed the questionnaire without further clarification. No modifications were made. The first version of SSEQ-C was ready for validation.

A cross-sectional, descriptive study was conducted. A convenience sample of stroke survivors was recruited from three community centers and a stroke support group in Hong Kong. Inclusion criteria of the participants included: 1) aged 18 years or above; 2) clinically diagnosed with stroke; 3) live at home; 4) have a Mini Mental State Examination score >18; 5) capable of giving informed consent; and 6) can speak in Cantonese. Participants were excluded if they had 1) transient ischemic attack, subdural or epidural hemorrhage; 2) significant dysphasia or aphasia; or 3) cognitive impairment or mental illnesses. It is recommended that a subject-to-item ratio should be at least 10:1 for principal component analysis. A minimum of 130 participants was required for the study.

Self-efficacy is the main measure of interest of the study. The 13-item SSEQ-C was used to measure participants’ level of self-efficacy in performing daily functional activities and self-management. Each item was scored on an 11-point scale (0 “not at all confident” to 10 “very confident”). The total score is calculated by summing up the score of all items (range 0-130). A higher score indicates a higher perceived self-efficacy in performing daily functional activities and self-management. The original English version of SSEQ has high internal consistency (Cronbach’s alpha 0.90) and significant positive correlations with the Falls Efficacy Scale (Spearman’s rho \( r_s = 0.803, P < 0.001 \)), and the Modified Rivermead Mobility Index \( r_s = 0.464, P < 0.001 \), suggesting acceptable convergent validity.

The following three tools were used to measure the convergent validity of SSEQ-C. The 10-item Chinese version of the General Self-Efficacy Scale (GSES) was adopted to measure participants’ confidence in dealing with stressful situations. Each item was rated on a 4-point Likert scale (1 “not at all true” to 4 “exactly true”). The total score is derived by summing up the response of all items (range 10-40). A higher score indicates higher self-efficacy in managing demands in life. Reliability of the scale is high (Cronbach’s alpha 0.91). Good convergent validity was indicated by the positive correlation with items assessing self-efficacy to deal with stressful political transition \( r = 0.44-0.48 \).
The 49-item Stroke Specific Quality of Life Scale was adopted to measure participants’ health-related quality of life.\textsuperscript{19} It consists of 12 domains namely self-care, vision, language, mobility, work/productivity, upper extremity function, critical-thinking, personality, mood, family roles, social roles, and energy. Each item was rated on a 5-point Likert scale (1=“strongly agree” to 5=“strongly disagree”; or 1=“couldn’t do it at all” to 5=“no trouble at all”). All item scores are summed to yield the total score (range 49-245). A higher score indicates a higher level of health-related quality of life. The authors back-translated the scale into Chinese (SSQOL-C) and validated it in a convenience sample of 135 Chinese community-dwelling stroke survivors (the results are to be discussed in another paper). Internal consistency of the scale was high (Cronbach’s alpha of the total and domain scores=0.65-0.94). There was significant positive correlations between the total and subscales scores of the scale with the Frenchay Activities Index ($r_s=0.56-0.60$), suggesting acceptable convergent validity.

The 15-item Chinese version of the Frenchay Activities Index (FAI) was adopted to measure participants’ level of participation in daily chores and social activities.\textsuperscript{20} Each item was rated on four response options from “1”(lowest level of activity) to “4” (highest level of activity). The total score is calculated by summing up all item scores (range 15-60). A higher score indicates a higher level of participation. The scale shows high internal consistency (intraclass correlation coefficient (ICC) of the total sample=0.86). Positive correlation was found between the scores of FAI and Reintegration to Normal Living Index ($r_s=0.61$).\textsuperscript{20}

Participants’ demographic and clinical information including age, gender, marital status, educational level, occupation, financial assistance, living condition, accommodation, type of stroke, years after diagnosis of stroke, medical history, activities of daily living, change in health status and mobility were recorded. Statistical analyses were performed using IBM SPSS Statistics 22. Descriptive statistics were conducted to summarize participants’ demographic and clinical characteristics, and scores of SSEQ-C. Normality of the data was checked using Shapiro-Wilk tests. The internal consistency of SSEQ-C was assessed by Cronbach’s alpha. Values exceeding 0.70 were considered acceptable. Corrected item-total and item-subscale correlations were performed to assess the contribution of each item to the internal consistency. The test-retest reliability of SSEQ-C was examined using ICC of the scale at the two time points. ICC of >0.7 indicates high reliability correlation and ICC of 0.4-0.7 were considered acceptable.\textsuperscript{21} A confidence interval of 95% was adopted as the level of significance.\textsuperscript{21} The convergent validity of SSEQ-C was assessed by determining the bivariate correlations among the total score of SSEQ-C with GSES, FAI, SSQOL-C total scores using Pearson product moment correlation coefficient for parametric data and Spearman’s rho correlation coefficient for non-parametric data. The GSES was chosen as it is a generic measure of self-efficacy which has previously been found correlated with specific measures of self-efficacy.\textsuperscript{18} FAI and SSQOL-C were chosen as it has been found that stroke survivors’ self-efficacy is a factor influencing participation in daily or social activities, and health-related quality of life during post-stroke recovery.\textsuperscript{12,20} A correlation of 0 to 0.25 was considered as weak, 0.26 to 0.50 as moderate, 0.51 to 0.70 as strong, and above 0.71 as very strong.\textsuperscript{22} Principal component analysis was performed to reduce the observed variables to a smaller set of independent composite variables.\textsuperscript{22} The significance level was set at $P<0.05$. 

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Appendices 303
Results

A total of 143 community-dwelling stroke survivors were approached and 135 of them (mean age 58.9 years, SD 9.75) consented to participate (response rate 94.4%). The main reasons for their refusal to participate was lack of interest or they had no time. Among the 135 stroke survivors recruited, 49 were females (36.3%) and 86 were males (63.7%). Majority of them had an ischemic stroke (55.6%). The average years after diagnosis of the first stroke were 6.08 (SD 5.24) (Table 1). A total of 30 of the 135 stroke survivors (mean age 59.1 years, SD 10.89) completed the SSEQ-C at baseline and four weeks afterwards (response rate 22.2%). Among them, 10 were females (33.3%) and 20 were males (66.7%). Over 80% had a first-ever stroke. The average years after diagnosis of the first stroke were 5.89 (SD 5.83). There was no significant change in health conditions or readmission to hospitals reported by the participants.

SSEQ-C had a high internal consistency (Cronbach alpha = 0.92). The inter-item correlation matrix showed the bivariate correlations among items ranged from 0.27 to 0.70. The ICC of SSEQ-C total score after the two assessments for 30 participants among individual raters was 0.52, indicating acceptable test-retest reliability of SSEQ-C after four weeks.

The total score of SSEQ-C had a significantly positive association with the total scores of GSES ($r_s=0.48$, $P<0.01$) and FAI ($r_s=0.51$, $P<0.01$). There were significantly moderate correlations between the total score of SSEQ-C and the total SSQOL-C score ($r_s=0.68$, $P<0.001$). The results showed that SSEQ-C has acceptable convergent validity.

The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.89, which is greater than the minimal acceptable level of 0.5. The Bartlett’s test of sphericity was acceptable at $P<0.0001$ (Chi-square=1066.11, df=78). These results showed that the sample was appropriate and adequately correlated to conduct principal component analysis. Two factors with eigenvalues over 1.0 emerged. The loadings of the first factor ranged from 0.57 to 0.80. The loadings of the second factor ranged from 0.52 to 0.91. The two-factor model accounted for 61.7% of the total variance with Eigenvalues of 6.92 and 1.10 respectively (Table 2).

The seven items loaded on the first factor reflect stroke survivors’ capabilities to manage the common challenges in daily living after stroke. Therefore this factor is designated as the “Live with new challenges” subscale. The remaining six items loaded on the second factor reflect stroke survivors’ capabilities in engaging in indoor and outdoor activities, and exercise. This factor is designated as the “Activity and exercise engagement” subscale. Cronbach’s alpha for the subscales “Live with new challenges” and “Activity and exercise engagement” were 0.88 and 0.87 respectively. Both factors were positively associated with the total scores of GSES ($r_s=0.36-0.51$, $P<0.01$) and FAI ($r_s=0.36-0.56$, $P<0.01$). The two factors were also significantly associated with the total and domain scores of SSQOL-C (Table 3).

Discussion

This study aims to examine the reliability and validity of a translated Chinese version of SSEQ-C. The results showed SSEQ-C has high internal consistency and acceptable convergent validity. Principal component analysis yielded a two-factor model namely “Live with new challenges” and “Activity and exercise engagement”, which is different from the single factor structure of the original SEQ suggested by Jones et al. Further analysis showed that the two factors had high internal consistencies. There were significant positive correlations between the total scores of SSEQ-C, GSES, FAI and SSQOL-C, suggesting acceptable convergent validity.
The first factor “Live with new challenges” suggested in this study included seven items, for example, preparing favorite meals, managing frustrations, or keeping increasing the pace of performing activities. These items reflect stroke survivors’ capabilities to manage challenges consequential to post-stroke physical limitations, or increased predisposition to psychosocial problems such as one sided weakness, fatigue, or depression, for attaining an optimal level of independence. Consistent with a recent emphasis in international guidelines on enhancing stroke survivors’ capabilities in self-management, stroke survivors learn to exercise core self-management skills namely problem-solving, decision-making, goal-setting, resources utilization, and communication with healthcare professionals to manage their physical or psychosocial challenges for assuming pre-stroke or new roles. Measurement of this factor would enable healthcare professionals to assess stroke survivors’ confidence in managing common post-stroke challenges and hence individualized interventions could be provided.

The second factor “Activity and exercise engagement” consists of six items which reflect stroke survivors’ level of physical independence in satisfying their basic physical or social needs, such as getting in bed comfortably, and walking safely outdoors to participate in social activities, and exercising regularly. Previous literature reported that older Chinese adults with chronic illness worried about losing the ability to maintain independence. They believe that one’s capabilities to manage to walk, sleep, and exercise for keeping oneself normal and self-balance without relying on others such as children is one of the priorities in managing their health. This study found that these six items clustered to form one factor to reflect stroke survivors’ confidence in maintaining physical independence for engaging in daily activities and exercise.

A recent study suggested a two-factor structure namely “Self-management” and “Activities” for the original SSEQ. However the grouping of the items was slightly different from that suggested in this study. Three items about eating with both hands, dressing and undressing, and preparing meals in the first factor “Live with new challenges” in this study were combined with items such as getting in and out of bed, or walking indoors or outdoors of the factor “Activities” in Riazi et al.’s study. The item about exercising regularly in the first factor “Live with new challenges” in this study was suggested in the “Self-management” factor in Riazi et al.’s study along with other items such as managing emotions, and doing tasks at a faster rate. The differences may be related to the emphasis in traditional Chinese culture of one’s capabilities in adapting or solving challenges consequential to sudden disruption in life such as a stroke event, and the importance of maintaining one’s self-independence. Furthermore the concept of chronic disease self-management has not been very well known by Chinese stroke survivors. The stroke survivors in the current study might not be able to associate readily activities such as exercising regularly or managing emotions with the concept of stroke self-management.

Self-efficacy has been found to be an important factor influencing stroke survivors’ stroke recovery. However there has been inconclusive evidence about the best approach to enhance stroke survivors’ level of self-efficacy. The SSEQ-C could be used to compare the effectiveness of different self-efficacy enhancing interventions for Chinese community-dwelling stroke survivors such as stroke self-management programs. The two-factor structure of SSEQ-C suggested in this study would enable a more culturally specific assessment and interpretation of Chinese community-dwelling stroke survivors’ self-efficacy in managing their stroke, particularly managing daily challenges, and maintaining independence in engaging in...
activities and exercise. Further studies of larger sample sizes of Chinese stroke survivors are warranted to confirm the two-factor structure of SSEQ-C. Furthermore examining the administration of the questionnaire among stroke survivors during the acute or rehabilitation stage in clinical settings would be worthwhile to examine its application to stroke survivors with different health needs.

Limitations of the study include the use of convenience sampling of community-dwelling stroke survivors recruited from community centers and a stroke support group. Second stroke survivors recruited in the study had a mean duration of six years after onset of the first stroke. The results may not be generalizable to stroke survivors in the acute or early rehabilitation stage.

**Conclusion**

The results of this study found that the translated Chinese version of the SSEQ-C is a valid and reliable tool for measuring the level of self-efficacy among Chinese community-dwelling stroke survivors. The study suggested a two-factor model of SSEQ-C. The two factors are “Live with new challenges” and “Activity and exercise engagement”. Further studies are worthwhile to confirm the two-factor model of SSEQ-C among Chinese stroke survivors.

**References**


Table 1 Demographic and clinical characteristics of the participants (n=135)

<table>
<thead>
<tr>
<th></th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD), range</td>
<td>58.9 (9.75), 30-85</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>8 (5.9)</td>
</tr>
<tr>
<td>Married</td>
<td>110 (81.5)</td>
</tr>
<tr>
<td>Divorced/ Separated</td>
<td>13 (9.6)</td>
</tr>
<tr>
<td>Widow/ Widowed</td>
<td>4 (3.0)</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
</tr>
<tr>
<td>No schooling</td>
<td>5 (3.7)</td>
</tr>
<tr>
<td>Informal school</td>
<td>5 (3.7)</td>
</tr>
<tr>
<td>Primary</td>
<td>49 (36.3)</td>
</tr>
<tr>
<td>Secondary</td>
<td>65 (48.1)</td>
</tr>
<tr>
<td>Tertiary</td>
<td>11 (8.1)</td>
</tr>
<tr>
<td><strong>Type of stroke</strong></td>
<td></td>
</tr>
<tr>
<td>Ischemic</td>
<td>75 (55.6)</td>
</tr>
<tr>
<td>Hemorrhagic</td>
<td>46 (34.1)</td>
</tr>
<tr>
<td>Both</td>
<td>2 (1.5)</td>
</tr>
<tr>
<td>Unknown</td>
<td>12 (8.9)</td>
</tr>
<tr>
<td><strong>Number of strokes</strong></td>
<td></td>
</tr>
<tr>
<td>First-ever</td>
<td>120 (88.9)</td>
</tr>
<tr>
<td>Recurrent</td>
<td>15 (11.1)</td>
</tr>
<tr>
<td><strong>Accommodation</strong></td>
<td></td>
</tr>
<tr>
<td>Private housing</td>
<td>55 (40.7)</td>
</tr>
<tr>
<td>Public housing</td>
<td>79 (58.5)</td>
</tr>
<tr>
<td>Staff quarters</td>
<td>1 (0.7)</td>
</tr>
<tr>
<td><strong>Living condition</strong></td>
<td></td>
</tr>
<tr>
<td>Live alone</td>
<td>15 (11.1)</td>
</tr>
<tr>
<td>Live with family</td>
<td>113 (83.7)</td>
</tr>
<tr>
<td>Live with maid/ friends</td>
<td>7 (5.2)</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
</tr>
<tr>
<td>Walk unaided</td>
<td>28 (20.7)</td>
</tr>
<tr>
<td>Walk with stick</td>
<td>92 (68.1)</td>
</tr>
<tr>
<td>Walk with frame</td>
<td>7 (5.2)</td>
</tr>
<tr>
<td>Use wheelchair</td>
<td>8 (5.9)</td>
</tr>
<tr>
<td><strong>Slurred speech/ dysphasia</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46 (34.1)</td>
</tr>
<tr>
<td>No</td>
<td>89 (65.9)</td>
</tr>
<tr>
<td><strong>Smoking habit</strong></td>
<td></td>
</tr>
<tr>
<td>Non-smoker</td>
<td>98 (72.6)</td>
</tr>
<tr>
<td>Chronic smoker</td>
<td>5 (3.7)</td>
</tr>
<tr>
<td>Ex-smoker</td>
<td>32 (23.7)</td>
</tr>
<tr>
<td><strong>Use of alcohol</strong></td>
<td></td>
</tr>
<tr>
<td>Non-drinker</td>
<td>117 (86.7)</td>
</tr>
<tr>
<td>Social drinker</td>
<td>18 (13.3)</td>
</tr>
<tr>
<td><strong>Financial assistance</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>117 (86.7)</td>
</tr>
<tr>
<td>No</td>
<td>18 (13.3)</td>
</tr>
</tbody>
</table>

**Note:** SD=Standard deviation.
Table 2 Items and factor loadings from the exploratory two factor solution of SSEQ-C (n=135)

<table>
<thead>
<tr>
<th>Items</th>
<th>Factor 1 loadings</th>
<th>Factor 2 loading</th>
<th>Communality coefficients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Get in bed.</td>
<td>0.556</td>
<td>0.436</td>
<td></td>
</tr>
<tr>
<td>2. Get out of bed.</td>
<td>0.851</td>
<td>0.759</td>
<td></td>
</tr>
<tr>
<td>3. Walk inside the house.</td>
<td>0.914</td>
<td>0.788</td>
<td></td>
</tr>
<tr>
<td>4. Walk around the house to do things.</td>
<td>0.698</td>
<td>0.685</td>
<td></td>
</tr>
<tr>
<td>5. Walk outside.</td>
<td>0.568</td>
<td>0.548</td>
<td></td>
</tr>
<tr>
<td>6. Use both hands to eat.</td>
<td>0.685</td>
<td></td>
<td>0.465</td>
</tr>
<tr>
<td>7. Dress and undress.</td>
<td>0.579</td>
<td></td>
<td>0.667</td>
</tr>
<tr>
<td>8. Prepare meals.</td>
<td>0.753</td>
<td></td>
<td>0.615</td>
</tr>
<tr>
<td>9. Continue to improve after stroke.</td>
<td>0.531</td>
<td></td>
<td>0.535</td>
</tr>
<tr>
<td>10. Exercise daily.</td>
<td></td>
<td>0.516</td>
<td>0.543</td>
</tr>
<tr>
<td>11. Manage frustrations.</td>
<td>0.569</td>
<td></td>
<td>0.574</td>
</tr>
<tr>
<td>12. Continue with pre-stroke activities.</td>
<td>0.792</td>
<td></td>
<td>0.672</td>
</tr>
<tr>
<td>13. Doing things faster.</td>
<td>0.703</td>
<td></td>
<td>0.736</td>
</tr>
<tr>
<td>Eigenvalue</td>
<td>6.918</td>
<td>1.104</td>
<td></td>
</tr>
<tr>
<td>Percentage of variance explained</td>
<td>53.216</td>
<td>8.490</td>
<td></td>
</tr>
</tbody>
</table>

Extraction method: principal component analysis; rotation method: promax. Coefficients greater than 0.40 are retained for that factor.

Table 3 Spearman’s rho correlation coefficients between the subscale scores of SSEQ-C and the total scores of GSES and FAI, and the total and domain scores of SSQOL-C (n=135)

<table>
<thead>
<tr>
<th>SSEQ-C</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>GSES total score</td>
<td>0.513**</td>
<td>0.358**</td>
</tr>
<tr>
<td>FAI total score</td>
<td>0.556**</td>
<td>0.356**</td>
</tr>
<tr>
<td>SSQOL-C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td>0.680**</td>
<td>0.566**</td>
</tr>
<tr>
<td>Domain: Self-care</td>
<td>0.590**</td>
<td>0.466**</td>
</tr>
<tr>
<td>Domain: Vision</td>
<td>0.350**</td>
<td>0.285**</td>
</tr>
<tr>
<td>Domain: Language</td>
<td>0.280**</td>
<td>0.185*</td>
</tr>
<tr>
<td>Domain: Mobility</td>
<td>0.444**</td>
<td>0.403**</td>
</tr>
<tr>
<td>Domain: Work/ productivity</td>
<td>0.518**</td>
<td>0.438**</td>
</tr>
<tr>
<td>Domain: Upper extremity function</td>
<td>0.537**</td>
<td>0.376**</td>
</tr>
<tr>
<td>Domain: Critical-thinking</td>
<td>0.192*</td>
<td>0.236**</td>
</tr>
<tr>
<td>Domain: Personality</td>
<td>0.252**</td>
<td>0.303**</td>
</tr>
<tr>
<td>Domain: Mood</td>
<td>0.519**</td>
<td>0.428**</td>
</tr>
<tr>
<td>Domain: Family roles</td>
<td>0.464**</td>
<td>0.368**</td>
</tr>
<tr>
<td>Domain: Social roles</td>
<td>0.431**</td>
<td>0.278**</td>
</tr>
<tr>
<td>Domain: Energy</td>
<td>0.472**</td>
<td>0.385**</td>
</tr>
</tbody>
</table>

**Note:** FAI=Chinese version of the Frenchay Activities Index; GSES=Chinese version of the General Self-Efficacy Scale; SSEQ-C=Chinese version of the Stroke Self-Efficacy Questionnaire; SSQOL-C=Chinese version of the Stroke Specific Quality of Life Scale

**Correlation is significant at the 0.01 level (two-tailed).**

*Correlation is significant at the 0.05 level (two-tailed).
Appendix D

Article on translation and testing of equivalence of
Stroke Specific Quality of Life Scale published in Disability and Rehabilitation

Title
Establishing equivalence of a Chinese version of the Stroke Specific Quality of Life measure for stroke survivors

Abstract
Introduction: The Stroke Specific Quality of Life Scale is a stroke-specific measure of health-related quality of life. However there has been no Chinese (Hong Kong) version of the scale.

Methods: A descriptive study was conducted to examine the reliability, validity and factor structure of the translated version (SSQOL-C) among stroke survivors. Participants completed SSQOL-C, and the Chinese versions of the Medical Outcomes Study Short-Form Health Survey (SF-36), Stroke Self-Efficacy Questionnaire (SEQ-C), and Frenchay Activities Index (FAI). Thirty of these participants completed the same questionnaires after four weeks.

Results: A total of 135 stroke survivors (mean age 58.90±9.75) was recruited. SSQOL-C had good internal consistency with Cronbach’s alphas for each domain ranging from 0.63-0.90. Most domains had moderate to high correlations with similar dimensions of SF-36, SEQ-C, FAI and Barthel ADL Index total scores (Spearman’s rho: 0.40-0.77, p<0.01), suggesting acceptable convergent validity. Principal component analyses suggested an 11-factor model in contrast to the 12-factor model for the original scale with six new factors emerging and five original factors retained.

Discussion: The results suggest SSQOL-C is a reliable and valid tool for measuring Chinese stroke survivors’ health-related quality of life. More studies are needed to confirm the 11-factor model of the scale.

Introduction
Stroke is a debilitating neurological disease and has significant negative impact on the survivors’ physical and psychosocial functioning. The global prevalence of people with stroke was projected to increase from 62 million in 2005 to 77 million in 2030 [1]. Stroke remains a leading cause of mortality and disability. It accounted for approximately 6.7 million (11.9%) global deaths in 2012 and is the second leading cause of death worldwide [2]. Annually stroke is associated with 43.7 million lost disability-adjusted life years (DALYs) around the world (about 3.2% of all lost DALYs) [1]. People surviving a stroke often live with different degrees of physical or psychosocial challenges such as limbs weakness, visual or cognitive impairment, low self-esteem, or depression. They may find difficulties in activity participation, or reintegration into previous family or social roles, and hence impairing their health-related quality of life (HRQOL) [3,4]. Continued support in stroke rehabilitation and recovery is important to enable stroke survivors to manage their difficulties and promote HRQOL.
HRQOL is an important outcome after stroke [5]. International guidelines have been stressing the importance of stroke rehabilitation services to enhance survivors’ HRQOL [6,7]. Selecting a stroke-specific, reliable and valid HRQOL tool is important to assess the impact of stroke on survivors’ life, their satisfaction with particular aspects of life that are important to them, as well as to evaluate the effectiveness of stroke rehabilitation services [7]. Studies examining HRQOL after stroke have mainly adopted generic tools such as Medical Outcomes Study Short-Form Health Survey (SF-36) or Sickness Impact Profile [8-10]. However these tools were often criticised for their inadequacy in capturing all domains of concern among stroke survivors such as vision, language, cognition, and upper extremity function [8]. The Stroke Impact Scale and the HRQOL in stroke patients (HRQOLISP) questionnaire are two commonly used stroke-specific tools. However the former measures eight subscales only and only four of the subscales can be summed up to generate a combined score [11]. The later consists of 102 items that its administration adds burden to stroke survivors [12].

The Stroke Specific Quality of Life Scale (SSQOL) developed by Williams et al. [13] is a stroke-specific measure of HRQOL. The scale was developed based on the findings of focused interviews with 32 stroke survivors with mild to moderate ischaemic stroke at one to six months post-stroke. It contains 49 items in 12 commonly affected domains after stroke. SSQOL is reported to have high internal consistency and convergent validity [13]. Since then, there has been no retesting of the factor structure of the original English version. However the equivalence of different language versions of the SSQOL has been tested in patients with ischaemic and haemorrhagic stroke, as well as subarachnoid haemorrhage [14,15]. Some studies reported different factor structures for the scale. Ewert and Stucki [11] reported an 8-factor model of the German version of SSQOL; while Hakverdioglu Yont and Khorshid [16] suggested another 8-factor model of the Turkish version. Another study evaluating the Danish version of SSQOL suggested that the 12 domains could be categorised into two major components, namely physical and psychosocial [17].

There has been no report of the translation and testing of equivalence of SSQOL among Hong Kong Chinese stroke survivors. In Hong Kong, the majority are Chinese who speak in Cantonese and write Traditional Chinese. The cultural context among Hong Kong Chinese is different from the Chinese people living in Mainland China or Taiwan. The original SSQOL is developed in English from stroke survivors in Western countries. The stroke care practice and culture are distinct from that in the Asian countries. A specific version for Hong Kong Chinese stroke survivors would be helpful for appropriate selection of tools to assess HRQOL and to evaluate the effectiveness of stroke rehabilitation services for this population.

Aim
The aim of this study was to examine the reliability and validity of a translated Chinese (Hong Kong) version of SSQOL among Chinese stroke survivors.

Methods
Translation of SSQOL into Chinese

Two independent bilingual senior baccalaureate nursing students translated the original English version of SSQOL into Chinese. Two bilingual members of the research team came to a consensus on the discrepancies between the two translated versions and prepared the first draft Chinese version (SSQOL-C). Another two independent bilingual senior baccalaureate nursing students, who were blind to the original SSQOL, translated the draft SSQOL-C into English to ensure semantic equivalence [18]. The two bilingual research team members reviewed the back-
translated and the original versions. Minor modifications were made for some colloquial English terms including “seeing things off to one side”, “finishing jobs”, and “to enjoy a show” to improve the translation. The second draft SSQOL-C was administered to 60 bilingual baccalaureate nursing students who then rated the appropriateness of the translation on a 4-point Likert scale (1=“very inappropriate” to 4=“very appropriate”). All items were rated at either appropriate or very appropriate. No further modifications were made.

**Content validity**

An expert panel of two physicians, one nurse academic, one nurse manager, one advanced practice nurse and two registered nurses conducted the content validity test of the second draft SSQOL-C. The panel rated each item on its relevance to stroke survivors’ HRQOL using a 4-point Likert scale (1=“not relevant” to 4=“very relevant and succinct”). The content validity index (CVI) was computed as the percentage of items with a score of three or above. CVI of SSQOL-C was 0.99. CVI of at least 0.80 is considered acceptable for content validity [19]. No further modifications were made. SSQOL-C was then piloted on a convenience sample of five Chinese community-dwelling stroke survivors (age 35-60 years) to determine its readability and to ask for their feedback on comprehensiveness of items to reflect their HRQOL. Three stroke survivors had attained primary education and two attained secondary education. The participants completed the questionnaire without requests for clarification and they did not suggest the need to include additional items to reflect their HRQOL. Therefore the second draft SSQOL-C was ready for testing equivalence.

**Validation of SSQOL-C**

**Design**

A cross-sectional descriptive study was conducted.

**Participants and settings**

A convenience sample of stroke survivors was recruited from three community centres and a support group in Hong Kong. Inclusion criteria for participants included 1) 18 years or above; 2) clinically diagnosed with ischaemic or haemorrhagic stroke; 3) had a Mini Mental State Examination score of 18 or above [20]; and 4) speak Cantonese. Exclusion criteria included having 1) transient ischaemic attack, subdural or epidural haemorrhage; 2) significant dysphasia or aphasia; or 3) mental illnesses.

**Data collection procedure**

A research assistant approached the stroke survivors while they were attending the community centres and explained in detail the study purposes, procedures, rights to confidentiality and voluntary participation to potential participants. Informed written consent was obtained from eligible participants before commencing data collection. Individual face-to-face interviews which were used to administer the questionnaires were conducted in a private room. Each interview took about 45 minutes. Thirty of the participants were again interviewed face-to-face at the same community centre after four weeks. The participants returned to the community centre when they had activities at the centre. An interval of four weeks enabled greater flexibility in scheduling with the participants. Participants recruited in this study had chronic stroke with stable medical conditions, hence changes in their health condition which might affect their responses to the questionnaire was considered minimal.

**Ethical considerations**

Ethical approval to conduct the study was obtained from the Survey and Behavioural Research Ethics Committee of The Chinese University of Hong Kong. Approvals were also obtained from the three community centres and the support group to conduct the study before commencing data collection. Informed written consent was
obtained from participants by the research assistant before collecting data. The federal and institutional ethical standards, Hong Kong Personal Data (Privacy) Ordinance, Declaration of Helsinki, and ICH-GCP were upheld.

Data collection tools

Health-related quality of life is the main outcome of interest of the study. The 49-item SSQOL-C was adopted to measure participants’ HRQOL. It consists of 12 domains including self-care, vision, language, mobility, work/ productivity, upper extremity function, critical-thinking, personality, mood, family roles, social roles, and energy. The first 27 items were rated on a 5-point Likert scale from 1 “couldn’t do it at all” to 5 “no trouble at all”, and the remaining 22 items were rated on a 5-point Likert scale from 1 “strongly agree” to 5 “strongly disagree”. Summing the item scores yielded the total scale (range 49-245) and domain scores. A higher score indicates a higher level of HRQOL. The scale had high internal reliability (Cronbach’s alpha for all domains ≥0.73). Most domains were moderately correlated with similar domains of established outcome measures (Pearson correlation coefficient=0.3-0.5) [13].

Convergent and discriminant validity of SSQOL-C were tested using the following three tools: the Chinese versions of the Medical Outcomes Study Short-Form Health Survey (SF-36), Stroke Self-Efficacy Questionnaire (SSEQ) and Frenchay Activities Index (FAI-C). SF-36 is a generic measure of HRQOL with high reliability and validity [21,22]. It consists of eight dimensions: physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health. Each item was rated on either a three- or five-point response set. SF-36 provides two component scores including physical component score and mental component score. The total scale, component and dimension scores were calculated by summing the item scores and normalised to 100 (range 0-100). A higher score indicates a high level of HRQOL [22]. The Chinese (Hong Kong) version of SF-36 was adopted and the scale showed high internal consistency (Cronbach’s alpha for all dimensions=0.65-0.87) [23].

The 13-item Stroke Self-Efficacy Questionnaire (SSEQ) is a stroke-specific measure of participants’ perceived self-efficacy in performing functional activities and self-management [24]. SSEQ was chosen as previous systematic reviews found that self-efficacy enhancing interventions was positively associated with HRQOL during post-stroke recovery [4,25]. Each item was rated on an 11-point scale (0=“not at all confident”; 10=“very confident”). The total score ranged from 0 to 130 and is yielded by summing all item scores. A higher score indicates a higher level of self-efficacy [24]. The authors of this paper used the back-translation process of the original English version into Chinese (SSEQ-C). SSEQ-C tested on a convenience sample of 135 Chinese community-dwelling stroke survivors had high internal consistency (Cronbach’s alpha=0.92). The testing also showed significant positive correlations between the total scores of SSEQ-C, and the General Self-Efficacy Scale and Frenchay Activities Index (Spearman’s rho (rs)=0.36-0.56).

The 15-item Chinese version of Frenchay Activities Index (FAI) is a measure of participation in daily and social activities [26]. It is chosen as previous studies found stroke survivors’ participation in community was associated with HRQOL [27]. FAI asks about the frequency of performing daily chores and activities such as preparing meals over the past three months, and frequency of performing activities such as travelling over the past six months. Each of the 15 items was rated on four response options from 0 (“never”) to 3 (“Most of the time”, “At least once a week”, “One or two times a week”, “At least 30 hours every week”, “Once every two weeks”, or “All the necessary work”). Summing up all item scores yielded the total score (range 0-45).
A higher score indicates a higher level of participation. FAI had high internal consistency (intraclass correlation coefficient (ICC) of the total sample=0.86). The total score of FAI was significantly correlated with that of Reintegration to Normal Living Index (rs=0.61) [26].

Demographic and clinical information

Participants’ demographic and clinical information including age, gender, marital status, educational level, occupation, financial assistance, living condition, accommodation, type of stroke, duration after stroke onset, current and past medical history, mobility, activities of daily living as measured by Barthel ADL Index (range 0-20, a higher score indicates better physical function) [28], change in health status, and utilisation of medical services were recorded.

Statistical analyses

Statistical analyses were performed using IBM SPSS Statistics 22. Descriptive statistics were conducted to summarise the participants’ demographic and clinical characteristics, and scores of SSQOL-C. Normality of data was checked using Shapiro-Wilk tests. Parametric tests were used for analysis when a non-significant test result was found; while non-parametric tests were used when a significant test result was found. Factor analyses by principal component analyses (PCA) were used to explore possible groupings of SSQOL-C into a limited number of components. The Kaiser-Meyer-Olkin (KMO) index and the Bartlett’s test of sphericity were performed to determine the appropriateness of data for performing factor analysis [29]. An eigenvalue >1.0 was used to identify separate factors and a cutoff of ≥0.37 was used for factor loadings for each item. Rotations of the data were performed by Varimax method. The internal consistency of SSQOL-C was assessed by Cronbach’s alpha statistics for the total and domain scores. Values exceeding 0.70 were considered acceptable. Test-retest reliability of SSQOL-C was examined using ICC of the scale at the two time points. ICC of >0.7 indicates high reliability correlation and ICC of 0.4-0.7 were considered acceptable. A confidence interval of 95% was adopted [30]. Floor and ceiling effects were assessed by calculating the percentage of participants who scored the highest and lowest possible total and subscale scores of SSQOL-C. Floor or ceiling effect was considered present when greater than 15% of participants scored these values [31]. Convergent and discriminant validity of SSQOL-C were assessed by determining the bivariate correlations among the total and domain scores of SSQOL-C with the total scores of SSEQ-C, FAI, and Barthel ADL Index; and the total, summary, and dimension scores of SF-36 using Pearson product moment correlations or Spearman’s rank order correlations where appropriate. A correlation of 0 to 0.25 was considered as weak, 0.26 to 0.50 as moderate, 0.51 to 0.70 as strong, and above 0.71 as very strong. Convergent validity was supported when two domains were moderately correlated (r≥0.40). Discriminant validity was supported when two domains were weakly correlated (r<0.40) [29]. The significance level was set at p<0.05.

Results

Participants

A total of 135 Chinese community-dwelling stroke survivors consented to participate (response rate 94.41%). The major reasons for refusal to participate in the study included unavailability to be interviewed and no interest. The participants’ mean age was 58.90±9.75 years (range 30-85 years). Majority of them were men (63.70%) and had a first-ever stroke (88.89%). The mean duration after first stroke was 6.08±5.24 years. Majority of the participants were independent in activities of daily living (mean Barthel ADL Index score 17.50, SD 3.86). Nearly 90% of them walked
unaided or walked with stick. Among the participants, 71.11% had hypertension, 32.59% had diabetes, 16.30% had heart diseases, and 33.33% had other chronic medical conditions such as hyperlipidaemia, gout, or arthritis. Table 1 presents the participants’ demographic and clinical information at baseline. Thirty of the 135 participants (mean age 59.10±10.89 years) were available to complete SSQOL-C after four weeks. Majority of them were men (66.67%) and had a first-ever stroke (83.33%). The mean duration after first stroke was 5.89±5.83 years.

**Insert table 1 about here**

**Principal component analysis**

The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.82. The Bartlett’s test of sphericity was significant ($p<0.0001$). These results showed that the sample was appropriate and adequately correlated to conduct PCA [32,33]. Twelve factors with eigenvalues over 1.0 emerged. However since only one item, interested in food (MD8), loaded on the last factor only, this factor and this item were removed. One item, doing work you used to do (W3), did not clearly load onto any factor (factor loadings <0.30). This item was also deleted. One item finishing jobs started (W2), with a factor loading close to 0.4 (0.37), was included in the factor “Leisure and Work”. Therefore from a total of 47 items of SSQOL-C there were 11 factors (factor loadings 0.37-0.84). The 11-factor model accounted for 67.25% of the total variance with eigenvalues ranged from 1.13 to 12.76 (Table 2).

The 11-factor model found in this study contrasted with the 12-factor model for the original questionnaire, with six new factors emerging and five original factors retained. The new factors that emerged were Activities, Mood, Energy and Family Role, Relationships, Basic Needs, Leisure and Work, and Transfer. Five factors including Language, Upper Extremity Function, Thinking, Vision, and Personality of the original SSQOL were reproduced (Table 2).

The 11-factor model consisted of one major factor which explained 26.03% of the total variance. This factor was designated as Activities and it contained two items from the original Self-Care domain, four items from Mobility, and one item from Work/ Productivity. The original domains Family Role and Energy, and three items from Mood merged to form one factor designated as Mood, Energy and Family Role. Three items from the original Social Role domain and one item feel withdrawn (MD6) merged to form one factor named as Relationships. Three items from the original Self-Care domain formed one factor named as Basic Needs. Furthermore two factors, were emerged, namely Leisure and Work (two items from the original Social Role domain (SR1 and SR4) and W2), and Transfer (standing (M8) and getting out of a chair (M9)) (Table 2).

**Insert table 2 about here**

**Convergent and discriminant validity**

The convergent and discriminant validity of the SSQOL-C was established. Table 3 shows the associations between the scores of SSQOL-C with SF-36, SSEQ-C, FAI and Barthel ADL Index. The total score of SSQOL-C was significantly and positively associated with the total scores of the physical and mental components of SF-36 ($r_s=0.52-0.56$, $p<0.05$).

The scores of four domains of SSQOL-C, including Activities, Upper Extremity Function, Basic Needs, and Leisure and Work, were significantly and moderately associated with the physical component score of SF-36 ($r_s=0.43-0.61$, $p<0.01$). The scores of Activities and Basic Needs domains of SSQOL-C had moderate to strong associations with the Physical Functioning dimension score of SF-36 and the total Barthel ADL Index score ($r_s=0.51-0.77$, $p<0.01$). The Mood, Energy and Family
Role domain score of SSQOL-C had moderate associations with the Vitality, Physical Role, Emotional Role and Mental Health dimension scores of SF-36 and the total SSEQ-C score ($rs=0.46-0.52$, $p<0.01$). The Upper Extremity Function domain score of SSQOL-C was moderately associated with the Physical Functioning dimension score of SF-36, and the total FAI score ($rs=0.51-0.53$, $p<0.01$). The Relationships domain score of SSQOL-C was moderately associated with the Social Functioning dimension score of SF-36 ($rs=0.49$, $p<0.01$). The Leisure and Work domain score of SSQOL-C was moderately associated with the Physical Role dimension score of SF-36 and the total SSEQ-C and FAI scores ($rs=0.43-0.52$, $p<0.01$). The Transfer domain score of SSQOL-C was moderately associated with the Physical Functioning dimension score of SF-36 ($rs=0.45$, $p<0.01$). The scores of the domains, Language, Vision and Personality, of SSQOL-C had weak associations with the total score of SSEQ-C ($rs=0.26-0.35$, $p<0.01$) (Table 3).

Insert table 3 about here

Reliability, ceiling and floor effects

The internal consistency of SSQL-C was high. Cronbach’s alpha for the total scale was 0.93 and Cronbach’s alpha for all 11 domains ranged from 0.63 to 0.90 (Table 4). Two domains had a Cronbach’s alpha below 0.70, including Thinking (0.65) and Leisure and Work (0.63). The test-retest reliability of SSQOL-C after four weeks was high with ICC of the total score of 0.57 (95% confidence interval: 0.27 to 0.77). The results showed that fewer than 15% of the participants scored the lowest possible score of one in each domain of SSQOL-C. There were fewer than 15% of the participants who scored the highest possible score in all except four domains. The domain with the highest ceiling effect was vision (66.67%), followed by transfer (51.85%), basic needs (45.93%) and language (31.85%).

Insert table 4 about here

Discussion

The aim of this study was to examine the validity and reliability of a translated Chinese (Cantonese) version of SSQOL. This study suggested that a total of 47 items were retained in SSQOL-C. SSQOL-C has an 11-factor structure with six new factors emerging and five domains of the original SSQOL suggested by Williams et al. [13] retained. The results showed that SSQOL-C has high internal consistency for the total scale and the 11 domains. There were significant positive correlations between the total and domain scores of SSQOL-C, and the total scores of SSEQ-C, FAI, and BI, and the total, summary, and dimension scores of SF-36, suggesting acceptable convergent validity.

PCA conducted in this study suggests an 11-factor model of SSQOL-C which is different from the 12-factor model of the original SSQOL suggested by Williams et al. [13]. This 11-factor model explains 67.25% of the total variance. The results are comparable with previous studies. The percentage of total variance explained ranged from 69.7% by a 12-factor model of a Danish version [17], 69.8% by an 8-factor model of a German version [11], to 77.47% by an 8-factor model (48 items) of a Turkish version [16]. This study suggests SSQOL-C contains 47 items with two items excluded due to only one item (interested in food (MD8)) loading for a factor or carrying factor loading $<0.3$ (doing work you used to do (W3)). Different items were removed in other language versions of SSQOL. The item W2 were removed from the German version of SSQOL in addition to felt as a burden (FR7), for not being loaded clearly to any
An item (jotting things down (T4)) was removed from the Turkish version of SSQOL for not culturally adaptable [16]. Although the 11-factor model suggested in this study did not coincide with the 12-factor model suggested by Williams et al. [13], five factors including Language, Upper Extremity Function, Thinking, Vision, and Personality suggested by Williams et al. [13] were reproduced. Previous studies also reported the reproduction of the Thinking, Vision, and Personality factors in the German version [11]; or the Language and Personality factors in the Turkish version [16]. Language problems such as aphasia or dysphasia, cognitive or visual disturbances, and personality change are common post-stroke challenges [34-37]. The successful reproduction of factors particularly Language, Vision, Personality and Thinking in the Chinese translated version (SSQOL-C) supports the ability of this scale version in capturing domains of distinct concerns after stroke in Chinese stroke survivors.

This study suggests that the Activities factor accounts for the greatest percentage (26.03%) of the total variance. It encompasses seven items with two (SC1, SC5) from the original Self-Care domain, four (M1, M4, M6, M7) from Mobility, and one (W1) from Work/ Productivity. Similar results were obtained in the study examining the Turkish version of SSQOL [16]. In this version, an 8-factor structure was reported with the Activities factor explaining the greatest percentage (13.74%) of total variance. This factor contained 19 items including all items of the original Self-Care, Mobility, Work/ Productivity, and Upper Extremity Function domains. Another study examining the German version of SSQOL also reported an Activities factor among the 8-factor structure [11]. This factor encompasses 18 items with all original items of Self-Care, Mobility, and Upper Extremity Function, and two items from Work/ Productivity (W1, W3), and one item (FR8) from Family Role. Though different in the number of items, the original domains suggested by Williams et al. [13] constituting the Activities factor were similar.

It is interesting to note that this current study found that three items from the original Self-Care domain (eating (SC2), getting dressed (SC4), and use the toilet (SC8)) formed a new factor designated as Basic needs. Similarly two items from the original Mobility domain (standing (M8) and getting out of a chair (M9)) formed a new factor designated as Transfer. The differences may be related to Chinese people’s cultural beliefs that eating, dressing, and using toilets are the fundamental needs to be satisfied for living. Furthermore training in regaining adequate postural control and balance during standing and transfer are critical components in stroke rehabilitation to enhance survivors’ stability in walking after stroke [38]. It may explain the formation of the new domain Mobility.

The items in the original Social Role domain were separated into two new factors in this study. Three items (SR5, SR6, SR7) were combined with one item from Mood (Feel withdrawn (MD6)) forming a new Relationship factor; while the remaining two items (SR1, SR4) were combined the item (W2) to form a new Leisure and Work factor. The introduction of these two factors highlights the importance of maintaining relationships with friends and partners, and pursuing leisure activities by the Chinese stroke survivors. Chinese people emphasise the maintenance of harmonious relationships between people and a sense of belonging within the groups. Furthermore emergence of the Leisure and Work factor is in line with the increasing emphasis on enhancing stroke survivors’ capability in self-management and social participation, which encourage survivors’ participation in previous or new social roles or leisure activities [39].
The high internal consistency of SSQOL-C total scale and nine of the domains had a Cronbach’s alpha of 0.70 or above, indicating that the items in each domain measure the same concept [29]. The results were comparable with that of previous studies [11,13,16]. However the domains of Thinking and Leisure and Work had Cronbach’s alphas below 0.70. It is lower than that of similar domains reported by Muss et al. [14] (Thinking: 0.88, Work/Productivity: 0.84). Muus et al. [14] had a sample size of 152 participants which was greater than the present study. The influence of sample size on Cronbach’s alpha may be possible as discussed in the previous study.[14] In this study, ceiling effects were present in the domains of vision, transfer, basic needs and language. The results were comparable with previous studies that Mahmoodi et al. [40] and Muus et al. [14], examining the Persian and Danish versions respectively, reported a ceiling effect in domains of vision, language, self-care and mobility. The participants in these two studies had a mean duration of two to three years after stroke while the present study was about six years. The time elapsed since stroke onset might contribute to the findings that the participants might have achieved adequate recovery in these aspects. The moderate to strong associations among the SSQOL-C domain scores and the total score of SSEQ-C, FAI and Barthel ADL Index are plausible.

Including this study, the total number of items contained within each of the different language versions of SSQOL ranges from 47 to 49. The length of this scale may be too long for stroke survivors to complete especially when this scale is used as part of a study measuring several outcomes. Post et al. [41] developed a 12-item short version of SSQOL by selecting one item with the highest item total correlation from each of the 12 domains of SSQOL. A high internal consistency and convergent validity were reported for this short version. Since then, other language versions such as Chinese (Taiwan) [42], Chinese (Hong Kong) [43], and Spanish [44] were developed. A short version is advantageous in reducing the time and hence the burden on people with stroke to complete the questionnaire. However the long version of SSQOL would still be valuable in providing more comprehensive understanding of HRQOL after stroke.

This study is limited by the use of convenience sampling. Second the stroke survivors recruited in the study had an average of six years after onset of the first stroke. The results may not be generalizable to survivors during the period of acute stroke or early rehabilitation.

**Conclusion**
Assessing HRQOL among stroke survivors is integral to evaluate the effectiveness of interventions for stroke rehabilitation and recovery. SSQOL, originally developed in English, is a valid and reliable tool for measuring HRQOL among stroke survivors. Compared with other stroke-specific HRQOL tools, SSQOL embraces a comprehensive battery of stroke-related domains. The number of items included are also reasonably workable for stroke survivors. However there has been no Chinese version for adoption among Chinese stroke survivors. This study found the translated Chinese (Hong Kong) version of SSQOL a valid and reliable tool for measuring HRQOL among Chinese community-dwelling stroke survivors. The study suggested an 11-factor model of the 47-item SSQOL-C. Further studies are needed to confirm the factor structure of SSQOL-C among Chinese stroke survivors.

**Declaration of interest**
The authors report no declarations of interest.
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References
Table 1. Participants’ demographic and clinical information at baseline (n=135).

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<th>Frequency</th>
<th>Percentage (%)</th>
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<td><strong>Marital status</strong></td>
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<td>Single</td>
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<tr>
<td>Married</td>
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<tr>
<td>Divorced/ Separated</td>
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<tr>
<td>Widow/ Widowed</td>
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<tr>
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<td>Primary</td>
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<td>Live with maid/ friends</td>
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<td>Walk unaided</td>
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<td>Walk with stick</td>
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<tr>
<td>Walk with frame</td>
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<td>5.18</td>
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<tr>
<td>Use wheelchair</td>
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<td>5.93</td>
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<td><strong>Slurred speech/dysphasia</strong></td>
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<td><strong>Smoking habit</strong></td>
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<td>Ex-smoker</td>
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<td><strong>Use of alcohol</strong></td>
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<td>18</td>
<td>13.33</td>
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Table 2. Factor structure of the SSQOL-C (n=135).

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<tr>
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<th>F1</th>
<th>F2</th>
<th>F3</th>
<th>F4</th>
<th>F5</th>
<th>F6</th>
<th>F7</th>
<th>F8</th>
<th>F9</th>
<th>F10</th>
<th>F11</th>
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<td>SC1. Prepare food</td>
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<td>SC5. Bathing/Showering</td>
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<tr>
<td>M1. Walking</td>
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<td>0.82</td>
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<tr>
<td>M4. Balancing</td>
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<td>0.73</td>
<td></td>
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<td>M6. Climbing stairs</td>
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<td></td>
<td></td>
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<td>0.80</td>
<td></td>
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<td>M7. Need to rest when walking</td>
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<td>W1. Do daily work around the house</td>
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<td><strong>Mood, energy and family role</strong></td>
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<td>MD2. Discouraged about future</td>
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<td>MD3. Not interested in people or activities</td>
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<td>FR5. Not join activities with family</td>
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<td></td>
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<tr>
<td>FR7. Burden to family</td>
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<td>FR8. Physical condition interfered with family life</td>
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<td>E3. Rest often</td>
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<td>E4. Too tired to do what I want</td>
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<td>L5. People cannot understand what you said</td>
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<td>L7. Need to repeat what you said</td>
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<td>UE1. Writing</td>
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<td>UE3. Buttoning buttons</td>
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<td>UE6. Opening a jar</td>
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<td>0.61</td>
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<td>SR5. Meet friends</td>
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<td>Factor Value</td>
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<td>Have sex</td>
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<td>Feel withdrawn</td>
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<td>T2.</td>
<td>Concentrate</td>
<td>0.41</td>
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<td>T3.</td>
<td>Remember things</td>
<td>0.80</td>
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<td>T4.</td>
<td>Write things down to remember</td>
<td>0.81</td>
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<td><strong>Vision</strong></td>
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<td></td>
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<tr>
<td>V1.</td>
<td>See television</td>
<td>0.82</td>
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<td>V2.</td>
<td>Difficult reaching things due to poor eyesight</td>
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<td>V3.</td>
<td>See things off to one side</td>
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<td></td>
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<tr>
<td><strong>Basic needs</strong></td>
<td></td>
<td></td>
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<td>SC2.</td>
<td>Eating</td>
<td>0.83</td>
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<td>SC4.</td>
<td>Getting dressed</td>
<td>0.48</td>
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<tr>
<td>SC8.</td>
<td>Use the toilet</td>
<td>0.52 (0.55)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Personality</strong></td>
<td></td>
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<tr>
<td>P1.</td>
<td>Irritable</td>
<td>0.63</td>
<td></td>
<td></td>
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<td>P2.</td>
<td>Impatient</td>
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<tr>
<td>P3.</td>
<td>Personality has changed</td>
<td>0.83</td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Leisure and work</strong></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>W2.</td>
<td>Finishing work you started</td>
<td>0.37</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>SR1.</td>
<td>Go out often</td>
<td>0.67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>SR4.</td>
<td>Do hobbies/recreation for shorter periods</td>
<td>0.54</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Transfer</strong></td>
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<td></td>
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<tr>
<td>M8.</td>
<td>Standing</td>
<td>0.56</td>
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<td>M9.</td>
<td>Getting out of a chair</td>
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<tr>
<td></td>
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<td>12.76</td>
<td>4.41</td>
<td>3.80</td>
<td>2.04</td>
<td>1.74</td>
<td>1.67</td>
<td>1.54</td>
<td>1.39</td>
<td>1.28</td>
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<td><strong>Percentage of variance explained</strong></td>
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<td>26.03</td>
<td>9.00</td>
<td>7.76</td>
<td>4.16</td>
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<td>3.14</td>
<td>2.84</td>
<td>2.61</td>
<td>2.44</td>
</tr>
</tbody>
</table>

E: Energy; FR: Family Roles; L: Language; M: Mobility; MD: Mood; P: Personality; SC: Self-Care; SR: Social Roles; T: Critical-thinking; UE: Upper Extremity Function; V: Vision; W: Work/ Productivity.

F1: Factor 1; F2: Factor 2; F3: Factor 3; F4: Factor 4; F5: Factor 5; F6: Factor 6; F7: Factor 7; F8: Factor 8; F9: Factor 9; F10: Factor 10; F11: Factor 11.

Extraction method: principal component analysis; rotation method: promax. Coefficients greater than or equal to 0.37 are retained for that factor. Coefficients below 0.37 were suppressed.
Table 3. Spearman’s rho correlation coefficients between the total and domain scores of SSQOL-C and the total and subscale scores of SF-36, and the total scores of SSEQ-C, FAI, and BI (n=135).

<table>
<thead>
<tr>
<th>SSQOL-C domains</th>
<th>PF</th>
<th>PR</th>
<th>BP</th>
<th>GH</th>
<th>VT</th>
<th>SF</th>
<th>ER</th>
<th>MH</th>
<th>PCS</th>
<th>MCS</th>
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</thead>
<tbody>
<tr>
<td>Activities</td>
<td>0.77**</td>
<td>0.60**</td>
<td>0.18*</td>
<td>0.23**</td>
<td>0.32**</td>
<td>0.51**</td>
<td>0.44**</td>
<td>0.33**</td>
<td>0.61**</td>
<td>0.32**</td>
</tr>
<tr>
<td>MEFR</td>
<td>0.40**</td>
<td>0.47**</td>
<td>0.17</td>
<td>0.45**</td>
<td>0.50**</td>
<td>0.45**</td>
<td>0.46**</td>
<td>0.48**</td>
<td>0.39**</td>
<td>0.48**</td>
</tr>
<tr>
<td>Language</td>
<td>0.18*</td>
<td>0.19*</td>
<td>0.08</td>
<td>0.16</td>
<td>0.15</td>
<td>0.39**</td>
<td>0.26**</td>
<td>0.23**</td>
<td>0.14</td>
<td>0.29**</td>
</tr>
<tr>
<td>UEF</td>
<td>0.53**</td>
<td>0.53**</td>
<td>0.14</td>
<td>0.22*</td>
<td>0.34**</td>
<td>0.47**</td>
<td>0.48**</td>
<td>0.31**</td>
<td>0.43**</td>
<td>0.40**</td>
</tr>
<tr>
<td>Relationships</td>
<td>0.42**</td>
<td>0.31**</td>
<td>0.02</td>
<td>0.36**</td>
<td>0.37**</td>
<td>0.40**</td>
<td>0.21*</td>
<td>0.31**</td>
<td>0.34**</td>
<td>0.28**</td>
</tr>
<tr>
<td>Thinking</td>
<td>0.21*</td>
<td>0.23**</td>
<td>0.14</td>
<td>0.24**</td>
<td>0.31**</td>
<td>0.22*</td>
<td>0.37**</td>
<td>0.49**</td>
<td>0.17</td>
<td>0.40**</td>
</tr>
<tr>
<td>Vision</td>
<td>0.28**</td>
<td>0.27**</td>
<td>0.11</td>
<td>0.14</td>
<td>0.09</td>
<td>0.26**</td>
<td>0.27**</td>
<td>0.14</td>
<td>0.24**</td>
<td>0.19*</td>
</tr>
<tr>
<td>Basic needs</td>
<td>0.54**</td>
<td>0.53**</td>
<td>0.19*</td>
<td>0.24**</td>
<td>0.28**</td>
<td>0.48**</td>
<td>0.47**</td>
<td>0.32**</td>
<td>0.46**</td>
<td>0.38**</td>
</tr>
<tr>
<td>Personality</td>
<td>0.19*</td>
<td>0.24**</td>
<td>0.09</td>
<td>0.22*</td>
<td>0.27**</td>
<td>0.27**</td>
<td>0.33**</td>
<td>0.37**</td>
<td>0.14</td>
<td>0.37**</td>
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<tr>
<td>LW</td>
<td>0.59**</td>
<td>0.43**</td>
<td>0.20*</td>
<td>0.33**</td>
<td>0.47**</td>
<td>0.42**</td>
<td>0.38**</td>
<td>0.36**</td>
<td>0.49**</td>
<td>0.37**</td>
</tr>
<tr>
<td>Transfer</td>
<td>0.45**</td>
<td>0.31**</td>
<td>0.14</td>
<td>0.08</td>
<td>0.20*</td>
<td>0.32**</td>
<td>0.27**</td>
<td>0.12</td>
<td>0.36**</td>
<td>0.15</td>
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<tr>
<td>Total score</td>
<td>0.68**</td>
<td>0.62**</td>
<td>0.20*</td>
<td>0.38**</td>
<td>0.49**</td>
<td>0.62**</td>
<td>0.56**</td>
<td>0.51**</td>
<td>0.56**</td>
<td>0.52**</td>
</tr>
</tbody>
</table>

BI: Barthel Index; BP: Bodily pain; ER: Emotional role; FAI: Chinese version of the Frenchay Activities Index; GH: General health; LW: Leisure and work; MCS: Mental component score; MEFR: Mood, energy, and family role; MH: Mental health; PCS: Physical component score; PF: Physical functioning; PR: Physical role; SF: Social functioning; SF-36: Medical Outcomes Study Short-Form Health Survey; SSEQ: Chinese version of the Stroke Self-Efficacy Questionnaire; SSQOL-C: Chinese version of the Stroke Specific Quality of Life Scale; UEF: Upper extremity function; VT: Vitality.

**Correlation is significant at the 0.01 level (two-tailed).
*Correlation is significant at the 0.05 level (two-tailed).
^Indicates a modified domain.
Table 4. Reliability statistics, ceiling and floor effects for the subscales of the SSQOL-C (n=135)

<table>
<thead>
<tr>
<th>SSQOL-C domains</th>
<th>No. of Items</th>
<th>Cronbach’s alpha</th>
<th>Floor effects (%)</th>
<th>Ceiling effects (%)</th>
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</thead>
<tbody>
<tr>
<td>Activities^</td>
<td>7</td>
<td>0.89</td>
<td>0</td>
<td>13.33</td>
</tr>
<tr>
<td>Mood, energy and family role^</td>
<td>9</td>
<td>0.86</td>
<td>0.74</td>
<td>0.74</td>
</tr>
<tr>
<td>Language</td>
<td>5</td>
<td>0.90</td>
<td>0.74</td>
<td>31.85</td>
</tr>
<tr>
<td>Upper extremity function</td>
<td>5</td>
<td>0.81</td>
<td>1.48</td>
<td>14.81</td>
</tr>
<tr>
<td>Relationships^</td>
<td>4</td>
<td>0.75</td>
<td>10.37</td>
<td>0.74</td>
</tr>
<tr>
<td>Thinking</td>
<td>3</td>
<td>0.65</td>
<td>3.70</td>
<td>5.93</td>
</tr>
<tr>
<td>Vision</td>
<td>3</td>
<td>0.70</td>
<td>0</td>
<td>66.67</td>
</tr>
<tr>
<td>Basic needs^</td>
<td>3</td>
<td>0.72</td>
<td>0.74</td>
<td>45.93</td>
</tr>
<tr>
<td>Personality</td>
<td>3</td>
<td>0.74</td>
<td>1.48</td>
<td>8.89</td>
</tr>
<tr>
<td>Leisure and Work^</td>
<td>3</td>
<td>0.63</td>
<td>0</td>
<td>3.70</td>
</tr>
<tr>
<td>Transfer^</td>
<td>2</td>
<td>0.79</td>
<td>0.74</td>
<td>51.85</td>
</tr>
<tr>
<td>Total score</td>
<td>47</td>
<td>0.93</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

^Indicates a modified domain
Appendix E

Trial record at the ClinicalTrials.gov.

ClinicalTrials.gov
A service of the U.S. National Institutes of Health

A Self-efficacy Enhancing Stroke Self-management Program for Community-dwelling Stroke Survivors (SESSMP)

This study is currently recruiting participants. (see Contacts and Locations)
Verified April 2015 by Queensland University of Technology

Sponsor:
Queensland University of Technology

Information provided by (Responsible Party):
Suzanne Hoi Shan Lo, Queensland University of Technology

Full Text View Tabular View No Study Results Posted

<table>
<thead>
<tr>
<th>Condition</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>Behavioral: Stroke self-management program</td>
</tr>
<tr>
<td></td>
<td>Behavioral: Usual care</td>
</tr>
</tbody>
</table>

Study Type: Interventional
Study Design: Allocation: Randomized
Endpoint Classification: Efficacy Study
Intervention Model: Parallel Assignment
Masking: Single Blind (Outcomes Assessor)
Primary Purpose: Treatment

Official Title: A Randomized Controlled Trial of the Effectiveness of a Nurse-led Self-efficacy Enhancing Stroke Self-management Program for Community-dwelling Stroke Survivors

Further study details as provided by Queensland University of Technology:

Primary Outcome Measures:
- Self-efficacy in performing stroke self-management behaviors [ Time Frame: One month after the program ] [ Designated as safety issue: No ]
  Stroke Self-Efficacy Questionnaire

Secondary Outcome Measures:
- Stroke self-management behaviors [ Time Frame: One month after the program ] [ Designated as safety issue: No ]
  Stroke Self-management Behaviors Performance Scale
- Health-related quality of life [ Time Frame: One month after the program ] [ Designated as safety issue: No ]
  Stroke Specific Quality of Life Scale
- Depressive symptoms [ Time Frame: One month after the program ] [ Designated as safety issue: No ]
  Geriatric Depression Scale
- Community reintegration [ Time Frame: One month after the program ] [ Designated as safety issue: No ]
  Reintegration to Normal Living Index

https://clinicaltrials.gov/ct2/show/study/NCT02112955
Outcome expectation: Time Frame: One month after the program [ Designated as safety issue: No ]

Stroke Self-management Outcome Expectation Scale

Other Outcome Measures:
- Usefulness of the program [ Time Frame: Within one week after the completion of the program ] [ Designated as safety issue: No ]
- Extent of overall program participation, and other qualitative comments.

Estimated Enrollment: 100
Study Start Date: May 2014
Estimated Study Completion Date: May 2016
Estimated Primary Completion Date: October 2015 (Final data collection date for primary outcome measure)

<table>
<thead>
<tr>
<th>Arms</th>
<th>Assigned Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experimental: Stroke self-management program</td>
<td>Behavioral: Stroke self-management program</td>
</tr>
<tr>
<td>The program is aimed at enhancing community-dwelling stroke survivors' post-stroke recovery.</td>
<td>A nurse-led community-based self-efficacy enhancing stroke self-management program.</td>
</tr>
<tr>
<td>Active Comparator: Usual care</td>
<td>Behavioral: Usual care</td>
</tr>
<tr>
<td>Usual care provided to stroke survivors discharged to their home.</td>
<td>Usual care such as hospital-based or community-based health education or services.</td>
</tr>
</tbody>
</table>

Detailed Description:
Previous systematic reviews showed that theory-based stroke self-management programs had potential benefits in improving stroke survivors' quality of life and self-efficacy. However, there is a lack of evidence evaluating the effectiveness of a nurse-led theory-based stroke self-management program among community-dwelling Chinese stroke survivors.

This is a parallel group, single-blinded, randomized controlled trial to be held in a community center. All participants will be assessed at two time-points (baseline before randomization, and one month after program completion). Eligible participants will be randomly allocated to either the control group (receiving usual care) or the intervention group (receiving the self-efficacy enhancing stroke self-management program). Participants in the intervention group will receive an additional assessment on usefulness of the program immediately after program completion.

Eligibility

Ages Eligible for Study: 18 Years and older
Genders Eligible for Study: Both
Accepts Healthy Volunteers: No

Criteria

Inclusion Criteria:
- aged 18 years or above
- have a clinical diagnosis of stroke
- currently live at home or will be discharged from hospital to home within one week
- have a Mini Mental State Examination score > 18
- speak Cantonese
- capable of giving informed consent
- can attend sessions of the self-efficacy enhancing stroke self-management program
- can use a phone

Exclusion Criteria:
- diagnosed with transient ischemic attack, subdural or epidural hemorrhage
- have cerebrovascular events due to presence of malignancy or head trauma
- have limited comprehension and receptive aphasia
- have been diagnosed with schizophrenia, bipolar disorder, or dementia
- have received a stroke self-management program in the past 12 months as reported by the participants

https://clinicaltrials.gov/ct2/show/study/NCT021112555
Contacts and Locations

Choosing to participate in a study is an important personal decision. Talk with your doctor and family members or friends about deciding to join a study. To learn more about this study, you or your doctor may contact the study research staff using the Contacts provided below. For general information, see Learn About Clinical Studies.

Please refer to this study by its ClinicalTrials.gov identifier: NCT02112955

Contacts
Contact: Suzanne Lo  hoishanlo@gmail.com

Locations
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  Contact: Suzanne Lo  hoishanlo@gmail.com
- Acute public hospital 2  Recruiting
  Contact: Suzanne Lo  hoishanlo@gmail.com
- Acute public hospital 3  Recruiting
  Contact: Suzanne Lo  hoishanlo@gmail.com

Sponsors and Collaborators
Queensland University of Technology

Investigators
Principal Investigator: Suzanne Lo  Queensland University of Technology

More Information
No publications provided

Responsible Party: Suzanne Hoi-Shan Lo, PhD candidate, Queensland University of Technology
ClinicalTrials.gov identifier: NCT02112955  History of Changes
Other Study ID Numbers: SESS1MP01
Study First Received: April 9, 2014
Last Updated: April 20, 2015
Health Authority: Hong Kong: Ethics Committee
  Australia: Human Research Ethics Committee

Keywords provided by Queensland University of Technology:
Stroke
Disease management
Self-efficacy
Quality of life
Community integration

Additional relevant MeSH terms:
Cerebral Infarction
Stroke
Brain Diseases
Brain Infarction
Brain Ischemias
Cardiovascular Diseases
Central Nervous System Diseases
Cerebrovascular Disorders
Nervous System Diseases
Vascular Diseases

ClinicalTrials.gov processed this record on September 09, 2015

https://clinicaltrials.gov/ct2/show/study/NCT02112955
Appendix F

Study protocol published in BMC Health Services Research

Full title
Study Protocol: A Randomised Controlled Trial of a Nurse-led Community-based Self-management Programme for Improving Recovery among Community-residing Stroke Survivors

Background
Stroke is the second leading cause of global death with the death toll amounting to 6.7 million (11.9% of all deaths) in 2012 [1]. In Hong Kong, stroke was the fourth leading cause of death in 2014 [2]. Stroke is a significant cause of disability with survivors having a higher risk of depressive symptoms and a lowered quality of life [3]. Indeed stroke recovery is long-term and demanding, encompassing not only physical rehabilitation, but also coping with cyclic frustrations and adapting to new life roles [4,5]. Previous studies found poorer functional ability, more depressive symptoms, and lower self-esteem were significantly associated with participation restriction 12 months post-stroke [6]. The period for optimal recovery inevitably extended far beyond in-patient rehabilitation. The level of complexity in managing physical and psychosocial needs after stroke is intensified when stroke survivors return home and healthcare professionals are not immediately available to provide support. Furthermore when at home support from family may decrease as they return to their normal life [7]. Provision of effective community-based interventions to optimise stroke survivors’ capability to manage their post-stroke challenges is important to foster independence and early reintegration to pre-stroke life.

Self-management refers to an individual’s active participation in managing the symptoms, treatment, physical and psychosocial consequences of a chronic illness. There are three main components of chronic disease self-management including medical, emotional and role management [8]. To attain effective self-management, practicing core self-management skills including goal-setting, problem-solving, decision-making, resources utilisation and communication with healthcare professionals is crucial [4]. A recent systematic review of nine randomised and six non-randomised studies reported benefits of stroke self-management programmes in physical outcomes, quality of life, and confidence in recovery among stroke survivors. However the essential contents and the best approach to deliver the programmes for stroke survivors are yet to be determined [9].

Stroke self-management programmes are complex interventions given the interaction of multiple components of interventions with varying strengths, doses, or contents. According to the Medical Research Council guidance [10], designing complex interventions with an underlying theoretical premise enables its systematic development and implementation, and informs selection of appropriate outcome indicators. Furthermore it helps predict and explain the mechanism of change in target behaviours or the relationship between interventions and outcomes. A recent systematic review was conducted to examine the effectiveness of theory-based stroke self-management programmes [11]. The review included three randomised controlled trials examining three community-based programmes based on the Stanford Chronic Disease Self-management programme underpinned by Bandura’s construct of self-efficacy. The results showed potential benefits of the programmes in improving stroke
survivors’ self-efficacy and health-related quality of life. However only two of the three included studies explicitly described how the theory informed programme design and implementation, and measured stroke survivors’ changes in self-efficacy. The other study neither linked the programme to Bandura’s four sources of self-efficacy nor measured self-efficacy [11]. There is also insufficient evidence on effectiveness of different strategies to enhance community-residing stroke survivors’ self-efficacy in managing their health conditions. All studies were conducted in Western countries and were delivered by healthcare professionals or trained peer leaders [11]. There has been no study which assessed the effectiveness of stroke self-management programmes delivered by nurses for Chinese stroke survivors.

In Hong Kong, stroke patients, after having their acute medical conditions stabilised, are either transferred to rehabilitation hospitals for continued rehabilitation, or discharged directly to their homes, old aged homes or other residential care homes depending on their progress. Community-based support for stroke survivors, particularly for those after returning home, often includes stroke support groups, private physiotherapy or occupational therapy, and social services offered by non-government organisations such as vocational training. However, support programmes for community-residing stroke survivors to promote their psychological and social well-being, as well as to enhance their knowledge and skills for better reintegration into the community and assumption of post-stroke social and life roles are relatively insufficient. Given the potential programme benefits, it would be worthwhile to determine the effectiveness of a community-based nurse-led stroke self-management programme underpinned by a theoretical framework for Chinese stroke survivors. The findings of such a study would inform future identification and evaluation of best strategies to deliver effective stroke self-management programmes.

**Research aim**

To examine the effectiveness of a nurse-led community-based self-management programme for improving recovery among Chinese community-residing stroke survivors.

**Research objectives**

To determine the effectiveness of the programme on improving community-residing stroke survivors’

- self-efficacy, outcome expectation, and satisfaction with performance of self-management behaviours;
- health-related quality of life;
- depressive symptoms; and
- community reintegration.

**Methods/Design**

**Study design and setting**

A two-arm, single-blinded randomised controlled will be conducted (Figure 1). Participants will be recruited from acute stroke units of three public hospitals in Hong Kong. The nurse-led community-based self-management programme will be conducted at both the participants’ homes and a community centre after the participants have been discharged home from the hospital.

**Ethics consideration**

Ethical approvals have been obtained from the Kowloon West Cluster Research Ethics Committee, Hospital Authority, Hong Kong (Ethical Approval No.: KW/EX-14-021(71-21)), the Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee, Hong Kong (CREC Ref. No.: 2014.375-T), and the Human Research Ethics Committee of the Queensland University of
Technology (Approval No.: 1400000333). Informed written consent will be collected from participants before commencing data collection. All potential participants will receive a full explanation by the research assistant about the purpose and data collection process of the study, their rights to voluntarily participate, refuse, or withdraw from the study without any negative consequences to them. The questionnaires will be anonymous and will be used for research purposes only. All the information collected will be kept strictly confidential and will be destroyed six years after completion of the study. The federal and institutional ethical standards, Hong Kong Personal Data (Privacy) Ordinance, Declaration of Helsinki, and ICH-GCP will be upheld.

Participants

All stroke survivors admitted to the acute stroke units will be recruited if they 1) are aged 18 years or above; 2) have a clinical diagnosis of a first or recurrent ischaemic or haemorrhagic stroke (inclusive of intracerebral haemorrhage and subarachnoid haemorrhage); 3) will be discharged from hospital to home in the next seven days; 4) have a Mini Mental State Examination (MMSE) score >18 measured at the time of consenting to participate in the study [12]; 5) can speak Cantonese; and 6) can attend sessions of the self-management programme.

Participants will be excluded if they 1) are diagnosed with transient ischaemic attack, subdural or epidural haemorrhage [13]; 2) have cerebrovascular events due to malignancy or head trauma; 3) have limited comprehension and receptive aphasia; 4) have been diagnosed with schizophrenia, bipolar disorder, or dementia; or 5) have received a stroke self-management programme in the past 12 months.

Sample size estimation

Primary outcome of this trial is stroke survivors’ self-efficacy in performing self-management behaviours measured by the Stroke Self-Efficacy Questionnaire at eight weeks after randomisation. A sample size of 64 per group (128 for two groups) is required to detect a significant mean difference in self-efficacy between groups for a medium effect size of 0.5 [14] with significance set at 0.05 and a power of 0.8 [15]. Taking into consideration an attrition rate of 19% over six months among stroke survivors [14], the final sample size is 160 (80 participants per group). Recruitment of participants is anticipated to take 12 months.

Randomisation

Eligible participants, immediately after providing baseline assessment data, will be randomly assigned in a 1:1 ratio to the intervention or the control group according to a computer-generated random schedule in permuted blocks of six with no stratification. A statistician who is not involved in recruitment, treatment allocation, and outcome assessment will generate the randomisation numbers. The statistician will put the randomly sequenced numbers indicating group assignment into sealed, opaque, containing a carbon paper inside, and sequentially numbered, otherwise identical, envelopes. Upon enrolling each participant, a research assistant who is not involved in recruitment and outcome assessment will take an envelope consecutively, write the participant’s study identifier on the envelope, open it and inform the principal investigator about the treatment allocation.

Blinding

Due to the nature of the intervention, the participants and the principal investigator who delivers the self-management programme will not be blinded to treatment allocation. However the research assistants who will administer the outcome assessment, data entry and analysis will remain blinded to the treatment allocation. The research assistants will not be involved in implementing the programme or
treatment of the participants at any stage. The participants will be asked not to tell the research assistants about their treatment allocation. However, the research assistants who will collect the participants’ feedback on usefulness of the programme will not be blinded to treatment allocation as they need to know this information for conducting the assessment.

**Intervention**

**Intervention group: A nurse-led community-based self-management programme**

Participants assigned to the intervention group will receive a 4-week nurse-led community-based self-management programme in addition to usual care. The programme is aimed at enhancing community-residing stroke survivors’ capabilities in self-managing their post-stroke health conditions. It includes one 1.5-hour individual home visit, two 1.5-hour group sessions held in a community centre, and three follow-up phone-calls (Table 1). The programme is underpinned by Bandura’s constructs of self-efficacy and outcome expectation [16]. The programme will be delivered by the principal investigator who is a registered nurse experienced in stroke care and chronic disease management. Each participant will receive a programme booklet and two DVDs specifically designed for this programme. The booklet provides information about stroke recovery and self-management, and records participants’ goals and action plans. The DVDs contain video clips of experience sharing by 15 stroke survivors who have successfully managed their stroke. A panel of experts including two nurse academics, two advanced practice nurses, one nurse manager and one physician who are experienced in stroke care has reviewed the programme contents and the booklet. A protocol detailing the programme contents and delivery methods have been developed to ensure consistent delivery of the programme. The programme will commence when six participants have been assigned to the intervention group and repeated to accommodate all participants assigned to this band. Family members or informal carers of each participant who are interested may join the programme as an accompanying person.

**Theoretical framework of the self-management programme**

Bandura’s construct of self-efficacy [16] will be adopted to guide the proposed programme design and implementation. Self-efficacy refers to an individual’s confidence to perform an action to reach a desired goal [16]. Judgment of one’s self-efficacy determines the course of action required, degree of effort, and perseverance to continue an action even in face of obstacles. Self-efficacy is developed through four sources of information namely mastery experience, vicarious experience, verbal persuasion, and minimising physiological or emotional arousal [16]. Substantial literature reported increased self-efficacy leads to modification of health behaviours, and better patient outcomes such as quality of life or perceived health status [9,11]. Outcome expectation, another central construct of Bandura’s social cognitive theory, refers to an individual’s judgement of the likelihood that performance of a particular action will produce a certain outcome. It takes three major forms including physical, social and self-evaluative effects. Within each form, positive expectations serve as incentives while negative expectations serve as disincentives to one’s performance of an activity [16]. Bandura suggests that the initiation and continuation of a particular activity or behaviour would be best predicted by the combined influence of self-efficacy beliefs and types of outcome expectation. The stronger one believes in own ability to perform a specific activity and the outcome of that activity, the more likely that one will initiate and maintain the behaviour [16,17]. In this study, the influences of self-efficacy and outcome expectancy beliefs on stroke survivors’ performance in stroke self-management behaviours will be addressed when designing the programme.
Figure 2 outlines the theoretical framework of the programme. Table 2 summarises the strategies adopted to enhance participants’ self-efficacy and outcome expectation of performing self-management behaviours.

### Table 1 Overview of the nurse-led community-based self-management programme for community-residing stroke survivors

<table>
<thead>
<tr>
<th>Week</th>
<th>Programme components</th>
<th>Key contents</th>
</tr>
</thead>
</table>
| 1    | Home visit (at participant’s home) | - Perform an individualised assessment.  
- Provide information about stroke self-management.  
- Establish a short-term goal and an action plan.  
- Video viewing.  |
| 2    | Group sessions (in a community centre) | - Discuss the physical and psychosocial consequences of stroke.  
- Discuss the practical tips of managing post-stroke challenges.  
- Facilitate reflection and experience sharing among the group.  
- Explore alternative ways to better implement the action plans.  
- Practice the use of core self-management skills.  
- Video viewing.  |
| 3 & 4| Three follow-up phone calls | - Review progress towards goal attainment.  
- Provide individualised feedback and positive reinforcement.  
- Encourage to continue, revise, or set a new short-term goal.  |

**Programme contents**

The nurse will schedule with the participants for home visit. During home visit, the nurse will assess the participant’s current medical, emotional and role management of their post-stroke conditions [4,8], and their self-efficacy and outcome expectancy beliefs of performing self-management behaviours. Based on the assessment, the nurse will work with the participant to establish a short-term goal of importance to stroke recovery, and develop a realistic action plan to achieve the goal [4]. Information about stroke self-management and core self-management skills such as problem-solving and decision-making will be provided. Furthermore participants will be guided to view one to two video clips on the DVDs to enable them to learn from other stroke survivors’ experiences. Positive reinforcement will be provided to promote their confidence in implementing their action plans [16]. Participants will be encouraged to view the videos, read the programme booklet, and record the implementation of their action plans after the home visit.
<table>
<thead>
<tr>
<th>Sources of information of self-efficacy</th>
<th>Strategies adopted</th>
<th>Programme components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mastery experience</td>
<td>- Establish a short-term goal and a realistic action plan.</td>
<td>HV</td>
</tr>
<tr>
<td></td>
<td>- Assist to break down difficult tasks into simple steps.</td>
<td>HV, GS</td>
</tr>
<tr>
<td></td>
<td>- Practice the use of core self-management skills.</td>
<td>GS</td>
</tr>
<tr>
<td></td>
<td>- Revise the action plan if necessary.</td>
<td>GS, PF</td>
</tr>
<tr>
<td></td>
<td>- Encourage to record the implementation of the action plan.</td>
<td>HV, GS, PF</td>
</tr>
<tr>
<td>Vicarious experience</td>
<td>- Guide the viewing of videos about experience sharing.</td>
<td>HV, GS</td>
</tr>
<tr>
<td></td>
<td>- Facilitate experience sharing among the group.</td>
<td>GS</td>
</tr>
<tr>
<td>Verbal persuasion</td>
<td>- Acknowledge incremental successes.</td>
<td>HV, GS, PF</td>
</tr>
<tr>
<td></td>
<td>- Provide positive reinforcement.</td>
<td>HV, GS, PF</td>
</tr>
<tr>
<td></td>
<td>- Reinforce the importance of ‘taking an active role’.</td>
<td>HV, GS, PF</td>
</tr>
<tr>
<td>Physiological &amp; emotional arousal</td>
<td>- Assist to reinterpret negative physiological and emotional states.</td>
<td>HV, GS, PF</td>
</tr>
<tr>
<td>Outcome expectation</td>
<td>- Assess and reinforce the positive outcomes valued by the participants after performing stroke self-management behaviours.</td>
<td>HV, GS, PF</td>
</tr>
</tbody>
</table>

GS: Group sessions; HV: Home visit; PF: Follow-up phone calls.

In the following week after the home visit, two group sessions will be held on the same day in a community centre. During the group sessions, participants will be provided with information about the physical and psychosocial consequences of stroke, and practical tips for effective stroke self-management. More importantly, the nurse will act as a facilitator to encourage participants to reflect and share their barriers to and facilitators of implementing their action plans. Based on the common problems among the group, video clips of sharing by stroke survivors will be presented. Participants will be facilitated to explore own ways to address their barriers. Examples will be provided to guide their practice of core self-management skills to better implement their plans. If necessary, their action plans will be revised. Positive reinforcement will be provided and participants are encouraged to visualise their expected positive outcomes after performing the self-management behaviours [16]. Participants will be encouraged to continue implement their action plans and record their progress after the sessions.

Three weekly follow-up phone calls by the nurse will be provided after the group sessions to review the participant’s progress, barriers to and facilitators of implementing the action plans. Individualised feedback and positive reinforcement will be provided. Participants’ expected positive outcomes of achieving the goals will be reinforced. At the end of the last follow-up phone call, participants’ extent of goal
attainment will be evaluated. They will be guided to continue, revise, or establish a new short-term goal for the next month.

**Control group: Usual care**

Participants in the control group will receive usual care provided to stroke survivors discharged to their home without any additional interventions. Usual care includes some or all of the following services: hospital- or community-based health education for example talks or leaflets; follow-up appointments in an outpatient clinic or a day hospital; medical consultations with a local general practitioner; referral to or information about local community-based services for people with stroke or disability for example meals on wheels.

**Outcome measures**

**Primary outcomes**

**Self-efficacy**

The 13-item Stroke Self-Efficacy Questionnaire (SSEQ) will be used to measure participants’ self-efficacy in performing daily functional activities and self-management such as getting in or out of bed, preparing meals, or persevering to make progress [18]. Each item is rated on an 11-point Likert scale (0=’not at all confident’; 10=’very confident’). The score of all items is summed to yield the total score (range 0-130). A higher score represents higher self-efficacy in performing daily functional activities and self-management. The authors have back-translated [19] and validated the Chinese version of SSEQ in a convenience sample of 135 Chinese community-residing stroke survivors. The results showed high internal consistency (Cronbach’s alpha=0.92). There were positive correlations between the total scores of the translated Chinese version of SSEQ, and General Self-Efficacy Scale (Spearman’s rho \(r_s=0.48\), \(p<0.01\)) and Frenchay Activities Index (Spearman’s rho \(r_s=0.51\), \(p<0.01\)), suggesting acceptable convergent validity.

**Outcome expectation**

An 11-item Chinese version of the Stroke Self-management Outcome Expectation Scale was developed based on Bandura’s construct of self-efficacy [16], and previous literatures on stroke self-management [4] and outcome expectation [20,21] to measure participants’ current level of confidence that the desired outcomes will be resulted after performing the self-management behaviours. Each item is rated on an 11-point Likert scale (0=’not confident at all’; 10=’very confident’). The total score is summed (range 0-110). A higher score indicates higher confidence in likelihood of the outcomes to occur. An expert panel of two nurse academics, one nurse manager, three advanced practice nurses and two physicians performed assessment of content validity (Content validity index: 0.94). The scale was piloted in a convenience sample of 83 Chinese community-residing stroke survivors and showed high internal consistency (Cronbach’s alpha=0.94).

**Secondary outcomes**

**Stroke self-management behaviours**

An 11-item Chinese version of the Stroke Self-management Behaviours Performance Scale was developed by the authors based on previous literatures about stroke recovery to measure participants’ satisfaction with their current performance in stroke self-management behaviours [4,22,23]. Each item is rated on an 11-point Likert scale (0=’very dissatisfied’; 10=’very satisfied’). The total score is obtained by summing the scores of all items (range 0-110). A higher score indicates higher level of satisfaction with own performance in self-management behaviours. An expert panel of two nurse academics, one nurse manager, three advanced practice nurses and two physicians performed assessment of content validity (Content validity index: 0.98).
The scale was piloted in a convenience sample of 83 Chinese community-residing stroke survivors and showed high internal consistency (Cronbach’s alpha=0.93).

**Health-related quality of life**

The 49-item Stroke Specific Quality of Life Scale (SSQOL) will be used to measure participants’ health-related quality of life [24,25]. It consists of 12 domains including self-care, vision, language, mobility, work/productivity, upper extremity function, critical-thinking, personality, mood, family roles, social roles, and energy. Each item is rated on a 5-point scale (0=’couldn’t do it at all’ to 5=’no trouble at all’; or 0=’strongly agree’ to 5=’strongly disagree’). The scores are summed to yield the total score (range 49-245) and domain scores. A higher total score indicates better health-related quality of life [24]. The authors have back-translated [19] and validated the Chinese version of SSQOL in a convenience sample of 135 Chinese community-residing stroke survivors. The results showed high internal consistency (Cronbach’s alpha of the total and domain scores: 0.63-0.93). The total score of the translated Chinese version of SSQOL was significantly correlated with the Chinese version of SSEQ (Spearman’s rho \( r_s = 0.68, p<0.01 \)) and Frenchay Activities Index (Spearman’s rho \( r_s = 0.60, p<0.01 \)), suggesting acceptable convergent validity. An additional 13 items will be used to measure participants’ changes in each domain and the overall health-related quality of life compared with their pre-stroke condition. Each item is rated on a 4-point scale from 1 ‘same as’ to 4 ‘a lot worse’.

**Depressive symptoms**

The 15-item Chinese version of the Geriatric Depression Scale will be used to measure participants’ presence of depressive symptoms in the past week [26,27]. Each item is rated on a yes/no format. A score will be given to the ‘yes’ items. The total score is calculated by summing each item score (range 0-15). A score of nine or above suggests moderate or severe depression. The scale has high internal consistency (Cronbach’s alpha=0.78) and acceptable convergent validity. Significant correlation was found between the total scores of the scale and the London Handicap Scale (\( r = -0.30, p<0.01 \)) [28].

**Community reintegration**

The 11-item Chinese version of the Reintegration to Normal Living Index will be used to measure participants’ level of community reintegration after stroke [29,30]. Participants will be asked about the extent to which each statement with regards to six domains (mobility, self-care, activities, role within the family, comfort with relationships, and ability to handle life events) describes their current situation. All items are rated on a 4-point scale (1=’does not describe my situation’ to 4=’fully describes my situation’). Two subscale scores ‘daily functioning’ and ‘perception of self’, and a total score will be summed and normalised to 100 (range 25-100). A higher score indicates higher perceived community participation. The index has high internal consistency (Cronbach’s alpha=0.92) and good convergent validity. Significant associations were reported between the Index and Frenchay Activities Index (\( r = 0.44, p<0.001 \)), and Personal Wellbeing Index (\( r = 0.25, p=0.033 \)) [30].

**Usefulness of the programme**

Participants receiving the self-management programme will be assessed about their: 1) extent of overall programme participation by calculating the average of participants’ percentage of attendance at the programme; 2) self-reported frequency of viewing the videos on the DVDs; 3) number of personal goals attained upon programme completion; 4) reasons for not being able to attain the goals; and 5) qualitative comments about usefulness of the DVDs and areas for further improvement of the programme.
Demographic and clinical information

Demographic data of the participants including age, gender, educational level, occupation, marital status, living condition, accommodation, main carer, social history, and financial assistance will be recorded. Clinical information including duration after stroke onset, type and location of stroke, past health history, current medication regimen, medical follow-up, smoking habits, use of alcohol, use of assistive devices and health services utilisation will be recorded. Furthermore, physical examination will be performed by the research assistant using instruments including MMSE, Glasgow Coma Scale, National Institutes of Health Stroke Scale (NIHSS), and the Barthel Activities of Daily Living (ADL) Index.

Data collection procedures

All potential participants will be identified by reviewing their medical records or referrals by stroke nurses at the study venues. The principal investigator or research assistants will screen the participants in a face-to-face interview for their eligibility and willingness to participate in the study. Written informed consent will be obtained from those who are eligible. A card indicating participants’ involvement in the study and means of urgent contact will be provided to each participant after obtaining the consent. The consented participants’ demographic and clinical information will be retrieved from their medical records. Baseline and follow-up assessments will be conducted by two research assistants. The participants will be scheduled via phone by a research assistant for baseline assessment within one month after their discharge from hospital. Immediately after baseline assessment is completed, the participants will be randomly assigned to either the intervention or the control group. At eight weeks after randomisation, the participants will be scheduled via phone by the research assistant again for follow-up assessment. The participants will be scheduled via phone by the research assistant again for follow-up assessment. The research assistants will administer the assessment tools in a face-to-face interview at the participants’ homes. The administration of the questionnaires has been pilot tested among six Chinese community-dwelling stroke survivors (mean age 55 years, SD 10.35, range 35-64 years). It took an average of one hour to complete the six questionnaires. Another research assistant will call the participants in the intervention and control groups at the time immediately after programme completion to collect their feedback on the programme (Table 3). The research assistants will be trained to administer the assessment tools consistently and non-judgmentally; and be reminded of the importance of confidentiality and safe storage of data. Inter-rater reliability between research assistants will be checked using Kappa statistics before data collection.

Non-participant observation

An expert panel member will conduct non-participant observation of the first session of the programme. The purpose is to identify the extent to which the programme was delivered according to the protocol using a Likert scale from 1 ‘A small extent’ to 5 ‘A large extent’, participants’ level of participation, and facilitators of and barriers to their participation.
Table 3 Summary of measurements and study outcomes

<table>
<thead>
<tr>
<th>Measurements</th>
<th>Instruments</th>
<th>Group</th>
<th>Baseline</th>
<th>Follow-up</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Basic</td>
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<tr>
<td>Self-efficacy</td>
<td>SSEQ</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Outcome expectation</td>
<td>SSOES</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Satisfaction with performance</td>
<td>SSBPS</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>of SSMB</td>
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<tr>
<td>Health-related quality of life</td>
<td>SSQOL</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
<td>×</td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>GDS</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
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<tr>
<td>Community reintegration</td>
<td>RNLI</td>
<td>IG, UG</td>
<td>×</td>
<td>×</td>
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</tr>
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</table>

IG: Intervention group; SSEQ: Stroke Self-Efficacy Questionnaire; SSMB: Stroke self-management behaviours; SSOES: Stroke Self-management Outcome Expectation Scale; SSBPS: Stroke Self-management Behaviours Performance Scale; SSQOL: Stroke Specific Quality of Life Scale; GDS: Geriatric Depression Scale; RNLI: Reintegration to Normal Living Index; UG: Usual care group.

1°: Primary outcome; 2°: Secondary outcome.

Statistical analysis

Statistical analyses will be performed using the IBM SPSS Statistics version 22 (SPSS Inc., Chicago, IL, USA). All primary analyses will be conducted on an intention-to-treat basis. No interim analyses will be undertaken. Descriptive statistics will be used to summarise participants’ baseline characteristics and outcome variables. All continuous outcomes will be assessed for normality in distribution. Appropriate transformation of skewed data will be performed before analysis. Chi-square tests and independent t-tests will be used to compare the demographic and clinical characteristics, and mean scores of outcomes between the intervention and control groups at baseline. A generalised estimating equation (GEE) model will be employed to assess differential change of the primary and secondary outcomes across the time points (baseline and eight weeks after randomisation) between the two groups. Adjustment will be made for potential confounding demographic and clinical variables, including gender, age, number of strokes, NIHSS, and the Barthel ADL Index, that were ‘unbalanced’ between the two groups (p<0.25) [31,32]. The longitudinal association of self-efficacy and outcome expectation with secondary outcomes will be examined using GEE model. GEE model can account for intra-correlated repeated measures data and accommodate missing data caused by dropouts, provided the data are missing at random [33], and is particularly suitable for intention-to-treat analysis without imputation for missing data. Significance level will be set at two-sided p<0.05 and all statistical tests will be two-tailed.

Discussion

To the best of the authors’ knowledge, this is the first randomised controlled trial which examines the effectiveness of a nurse-led stroke self-management programme on recovery among Chinese community-residing stroke survivors. This study adopts Bandura’s constructs of self-efficacy and outcome expectation [16] which considers both efficacy and outcome expectancy beliefs and the methods for improving these, as the underlying theoretical premise to guide the programme design, implementation and evaluation. Maintaining hopes for positive outcomes would be important incentives to stroke survivors’ pursuance in stroke self-management behaviours given a certain level of physical functioning [4]. It is expected that stroke
survivors receiving the stroke self-management programme will have improved self-efficacy, outcome expectation, and performance of self-management behaviours. Enhanced health-related quality of life and level of community reintegration, and decreased depressive symptoms are also be expected. The study results will provide valuable evidence to inform future identification and evaluation of best approaches to deliver stroke self-management programmes to enhance community-residing stroke survivors’ recovery.

List of abbreviations used
ADL: Activities of Daily Living; GEE: Generalised Estimating Equation; MMSE: Mini Mental State Examination; NIHSS: National Institutes of Health Stroke Scale; SSEQ: Stroke Self-Efficacy Questionnaire; SSQOL: Stroke Specific Quality of Life Scale.

Consent for publication
Not applicable.

Availability of data and materials
The data supporting the findings of the study has not yet been available. The study is currently at the stage of collecting data.

Competing interests
All authors declare that they have no competing interests.

Authors’ contributions
SHSL, AMC and JPCC contributed to the conception and design of the study. SHSL wrote the first draft manuscript with input from AMC and JPCC on the methods and statistical analysis. AMC and JPCC reviewed and commented on the draft of the manuscript. All authors read and approved the final manuscript.

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References
Appendix G

Interview guide (Sharing of experience about post-stroke recovery)

1. Please tell me more about your stroke and impact of stroke on your daily life.
   (Prompts: stroke history, severity, impact, quality of life)
2. Please share with me your experience during recovery after stroke.
   (Prompts: stroke recovery progress)
3. Tell me more about the things that impressed you most during your recovery journey. (Prompts: Positive/ negative experiences)
4. What were the most difficult parts in your stroke recovery?
   (Prompts: experience, solutions to address the difficulties)
5. What were the facilitators to enhance your stroke recovery?
   (Prompts: experience, how)
6. Share with me some practical tips to manage your life after stroke.
7. What are your goals currently? (Prompts: Goals, action plans)
8. What would you expect to have after attaining these goals?
9. Do you have other experiences that you would like to share, but have not yet mentioned?
10. Share with us some positive tips to encourage the other stroke survivors.
Appendix H

Information sheet and informed consent form for volunteer stroke survivors
(interview and video production)

Image Release: Research Participants

Background: A photographic image (including a video recording) which is sufficiently clear to enable you to be identified as an individual is personal information. Queensland University of Technology seeks to comply with the Information Privacy Principles as set out in the Information Privacy Act 2009. QUT shall, from time to time, endorse a privacy policy to ensure that personal information is used and disclosed only in ways which are consistent with privacy principles and will otherwise comply with QUT’s privacy obligations under statute. In general, personal information is not disclosed or published except where an individual’s consent has been obtained.

- QUT is seeking your consent to use an image of you in a research project titled ‘Effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors’. This project is being undertaken as part of the PhD study for Ms Suzanne Hoi-Shan Lo at the School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia. The purpose of this project is to examine the effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors in Hong Kong.
- Participation in this release is voluntary.
- Your decision to participate or to not participate will in no way impact upon your current or future relationship with Ms Suzanne Hoi-Shan Lo (the principal investigator) or with QUT, or your present or future medical and nursing care at the hospital or in the community.

If you have any questions please ensure you have discussed them and are comfortable with the response before providing consent. You may choose to discuss participation with the following people:
- Ms Suzanne Hoi-Shan Lo (the principal investigator)
- Family or friends.

What is the release about? We are developing videos to showcase experience-sharing by stroke survivors about their stroke recovery for supporting other people with stroke during their post-stroke journey. The videos which will be made into a DVD are being developed for the stroke self-management program for research purposes only and each video will be approximately five to eight minutes in length.

Why do you want to include me? The video will feature stroke survivors. You are invited to be featured in one of the videos because you had a stroke before and are willing to share your experience of stroke recovery with other stroke survivors.

What will you ask me to do? Your participation will involve an interview where you will be asked to share your experience of stroke recovery including your stroke history, impact of stroke on your life, positive and negative experiences that you had after your stroke, difficulties encountered and strategies that you adopted to overcome the difficulties and manage your condition, and other experiences that you would like to share with other stroke survivors. The answers you provide to these questions will form the basis of the video content. The length of each filming session may vary; it is estimated that your involvement would require a time commitment of between two to three hours.
The questions asked of video participants will relate to your experience of managing your health condition. The following questions are provided as indicative samples:

- Tell us about the difficulties that you have in your daily life after your stroke.
- Share with us how you have managed your condition.
- What would you like to share with other stroke survivors to support them during their recovery?

Are there any benefits for me in taking part? While the filming and publication of this video is not expected to provide direct benefits to participants, the video is not expected to be of detriment to participants either. The research team seeks to benefit from this video by providing valuable resources to support stroke survivors during their recovery journey post-stroke.

Are there any risks for me in taking part? We believe there are minimal risks with your participation in this video, which you should consider:

- Revealing your identity which will mean that family members, friends and others will be aware of health issues that you have or had;
- The questions asked of video participants, recalling your health problems, may cause you some discomfort. If you become emotional, filming will be stopped. It is not the intention of the video to portray any emotional discomfort.
- You do not have to talk about any issue(s) you are uncomfortable sharing.

Confidentiality The faces and speech of all video participants will be included in the video. Your face in the video and/or photo will be concealed and your voice in the video will be altered upon your request to protect your identity. QUT understands that video participants may not wish to be named in this video. As a result the names of all video participants will be excluded from this video. QUT will only identify you in the video on the basis of your association with the researcher, i.e. participant in the research study.

Who will see the video? The videos will first be shown to an expert panel of health care professionals of the research team. The videos will then be put onto a DVD which will be distributed to participants enrolled in the study. Copies of the DVD may be released to you if you would like to keep one.

Can I change my mind? You will have the opportunity to view the images/footage as we plan to use them, and can decide to withdraw at that stage. However, once the video is produced it will not be possible to withdraw.

I am interested – what should I do next? All persons appearing in this video will be required to sign the attached Consent Form, acknowledging that they have read and understood the Image Release Information Sheet, and agree to allow the use of their image and voice in the video for QUT research purposes.

If you have any questions about this video, please do not hesitate to contact:
Ms Suzanne Hoi-Shan LO, PhD student, School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia
Phone: (852) 9016 1573 Email: h1.lo@student.qut.edu.au

Thank you for helping with this research project. Please keep this sheet for your information.
PLEASE RETURN THIS COMPLETED FORM TO Ms Suzanne Hoi-Shan LO
A COPY WILL BE PROVIDED FOR YOUR RECORDS

If you agree to give consent regarding the use of your image in the research study titled ‘Effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors’, please read and complete the consent below.

CONSENT

- I agree to the University using, reproducing and disclosing photographic or video images of me as explained in this Image Release: Research Participants Information Sheet and Consent Form.

- I agree that I will make no claim against QUT for any payment or fee for appearing in promotional material or advertisements and that the video materials will not be used by QUT for any other purpose than for the research project.

- I understand that the anonymity afforded me as a participant in the research project titled ‘Effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors’ will be rescinded if I appear in the videos.

Name

Signature

Date

Please return this sheet to the investigator.
Appendix I

The original Chinese and English translation of subtitles of the 15 videos

Video 01 Setting goals • Confidence enhancing (Duration: 16 min)

於這段短片中跟大家分享的是一位年青男士，年輕的他勇於面對中風。雖然左邊身體活動能力受到影響，但他每星期會為自己訂立目標，做運動鍛鍊自己，慢慢地看着自己進步，增加自信心。這段短片中他會跟大家分享他中風的經歷，中風後他如何改善自己的活動能力，如何為自己訂立目標。他亦會談及中風後，做義工的所見所感。現在讓我們一同聽聽他的分享！

This is a story of a young male stroke survivor. Having suffered from stroke at such a young age, he still faced it with bravery. Despite limited left-side mobility, he still insists to set goals for himself weekly. With regular exercise, his conditions gradually improved. His self-confidence also builds up. In this video, he is telling us his experience after getting stroke, the ways to improve his mobility and how he set personal goals. He also shares his voluntary experience after stroke. It is time for us to get into his world.

大家好，我中風已兩年多。中風前我任職公關的，中風後便沒有工作了，今年三十五歲。

Hello, everyone! I have had stroke for about two years. Before stroke, I had a job in the public relation industry. After stroke, I became unemployed. I am currently thirty-five years old.

中風經過，當時是二零一一年八月二十日，當晚我正在睡覺，突然覺得右腦有點痛，像是針刺的，慢慢地痛至左腦。我覺得有些問題，但仍可思考。想去取止痛藥，但當站起來，想走出房門時，左手左腳已開始無力了。感覺快要暈倒時，因當時工作關係，我住在宿舍的，隔鄰有位同事，我就在暈倒前，叫醒我的同事。請他打電話，送我去醫院。說罷我便暈倒了，然後被送入醫院。才知道原來是爆血管，中風了。

The stroke process, I got stroke on 20th August, 2010. I was sleeping at that time. Suddenly, I experienced sharp pain on my right brain, just like getting pinched. The pain radiated to the left brain. Although I noticed something wrong, I could still make my decision. I wanted to get some pain killer. Unfortunately, soon after I got up, my left-side started getting flaccid. I was about to faint! Luckily, my colleague was right beside me at the hostel. I woke him up and asked him to send me to the hospital before losing my consciousness. I was then hospitalised and knew that I suffered from a haemorrhagic stroke afterwards.

中風後的活動能力，那時我不能坐，我左邊身體無力，好像一下子由天堂跌進地獄。甚麼也做不到，以前是靠自己的，工作等都是靠自己的，但現在不行了。現在有些事情真的做不到，需要別人幫助或要想想用其他方法做。出院時，我覺得我要多瞭解這個病，當時我不太認識這個病，於是我參加了這個會和一些課程。見到其他病人，其實努力，只要努力就會有某程度的復康，有些甚至可以復康得很好，年紀也比我大很多。

My physical mobility after stroke, with left-sided weakness, I could not sit up. It seemed that my splendid world was ended abruptly. I could not do anything at all. In the past, I did all the things on my own. Now, I required the assistance from the others or needed to think of alternatives. By the time I got stroke, I was unfamiliar with it. After discharge, I thought I had to get to know more about stroke. Therefore, I joined this association and attended courses. Through these activities, I noticed that the conditions could get better by paying enough effort, regardless of the age.

腳部運動，這個動作是踏前、踏左、踏後。這個動作可令你走路時更敏捷，但你要先練習。因為當你想揚開雙腿時，你要先想再做這個動作，便會慢了，所以你要先練習。這個動作很好，可以令你更敏捷。我每天會練習三次，每次約十分鐘。

Lower limb exercise, this exercise requires stroke survivors to step forward, to the left and backward. It helps build up your agility in walking. Sufficient practice is crucial. When you spread your legs apart before thinking how the action continued, you will slow down. This exercise really works for increasing the agility in walking. I practise it for three times a day in a 10-minute session each.

手部運動，我通常會多拉筋，因為通常這隻手會縮起。我會慢慢地把每隻手指攤開，然後拉筋，這樣拉筋，然後停約十至十五秒。一、二、三、四、五、六、七、八、九、一零，當你不斷做，慢慢地可伸出手，並攤開手指，那隻手便不會太緊。你也可用較好的手扶着另一隻手，
多做這些動作，膊頭不會太緊。如關節太緊，當你想活動時，便會很痛，所以閒時多做這動作。

Upper limb exercise, I always do stretching exercise because my hand often contracts. I spread my fingers apart and then stretch. Just like this and hold for ten to fifteen seconds. One, two, three, four, five, six, seven, eight, nine, ten. When you keep practising, you can gradually spread your fingers apart with your arm extended. This can prevent contracture of your affected limb. Also, you can use the unaffected limb to hold the affected one. When you practice more, you will not get frozen shoulder. This prevents a painful sensation when you move about. Therefore, stroke survivors should practise these exercise more. Stretching and raising hands are simpler and easier for beginners. Undoubtedly, you feel painful initially. However, the pain subsides day by day. I do not feel painful at all when extending my hands now. With enough practice, we can all manage it.

拉筋的重要，如你運動或走路後不拉筋，你會覺得隻腳不屬於自己。你回家後便睡覺，更覺不

The importance of stretching, if you do not stretch a bit after exercising or walking, you will not feel like using the legs of your own. The conditions get worse if you do nothing after exercise. Therefore, it is extremely important to do stretching after exercise. If you stretch your legs daily, you will gradually adapt to it and feel nothing at all. Stretching exercise does induce a positive effect on walking. Do not give up! Never give up! If you tend to hold back your ability, you never know how far you can go. I will not acknowledge defeat. Only by doing so, you will be on the road to improvement. At that time, you can tell the others confidently that you are able to make it!

怎樣訂立目標? 我初時會為自己訂一星期的目標，例如走十五分鐘，三十分鐘，然後慢慢地增

How to set personal goals? Initially, I set goals for the whole week. For instance, walking for 15 minutes or thirty minutes. Then, I gradually, increase the time. If I cannot make it, I will not let my disappointment flourish. Setting short-term goals is a strategy to build up self-confidence through the mastery experience.

現在的目標，我現時的目標是希望不用拐杖，把耐力鍛鍊得更好，能走較長的時間。使用拐杖

Current aim, currently, I want to abandon the use of stick and build up my perseverance so that I could walk for a longer time. The advantage of using a stick is that it conserves part of your energy. It takes your own energy to walk with stick. Therefore, you will feel tired easily. It can be dangerous sometimes. The others may bump into you if you do not use a stick, due to their fast walking pace. It is hard to blame them because they do not know our physical limitations.

如何達到目標? 初時我會訂一星期的目標，即先每一天的目標，然後一星期的目標，例如每日

How to achieve the goals? As what I have mentioned, I will set goals for the whole week. That is setting smaller goals for each day, then stepping up to set goals for the whole week. For example, to raise my legs fifty to hundred times a day and stretch for fifteen minutes. It takes time to acknowledge the progress. However, it is worthwhile. See, I can now walk with a stable gait for half an hour on my own!

堅持我比較看重朋友多於自己。我不想令關心我的人不開心，所以我要努力。我亦不想令他們

Determination, I take my friends as more important than myself. I do not want to let ones down, particularly those who care about me. Therefore, I have to strive hard. I also want to prove that I am tough and strong. Before the day of diagnosis, I have long been my friends’ focus. Although I am
diseased, I believe in my own ability to stay persevered. Success does not only bring me strength to carry on, but also encourages others to give things a try.

My feelings in doing voluntary work, despite living with stroke, I still have the ability to get things done. Then why not try to help others? Staying with other stroke survivors, I chat and visit them. It is very common that our family may not show enough understanding sometimes. I am not an exception. It took me so much effort and energy to walk step by step. Yet, some of my friends see it as a relaxing task. It did not seem to be so hard while the fact is just vice versa. Walking indeed can be a difficult task due to hemiplegia. As a volunteer, I gained a lot from it. The others can get the help they look for while I can enjoy a sense of success. This also serves as a reminder to keep me going and be a good role model.

Encouragement and support, regular exercise is inevitable. Our value and belief determine our fate. Therefore, we should never give up! Our effort will bear fruit. Different stroke survivors have their own pace of recovery, but each of us can definitely see improvement bit by bit. We may not notice it at first when you perform rehabilitative exercise. However, when we keep going, we can acknowledge the progress obviously. Therefore, never give up when facing obstacles!

**Video 02 My life in my hands (Duration: 15 min)**

於這段短片中跟大家分享的是一位男士。他中風時剛剛退休，幸得到太太的悉心照顧，他慢慢康復過來。在康復的過程中，他從不間斷地運動。因為他相信，健康是掌握在自己的手裏。這段短片中他會跟大家分享他中風的經歷、剛出院時的情況、他練習用拐杖的經驗。他亦會談及中風後他在工作家庭、朋友和消閒活動方面的改變。更更重要的是他會於片尾，跟大家分享他在復康過程的心得。現在讓我們一同聽聽他的分享。以前香港還有工業時，我從事織布的，我是三年前的聖誕節中風的。

由于这期间的健康状况，他慢慢地康復過。他從不間斷地運動。因為他相信，健康是掌握在自己的手裏。這段短片中他會跟大家分享他中風的經歷、剛出院時的情況、他練習用拐杖的經驗。他亦會談及中風後他在工作家庭、朋友和消閒活動方面的改變。更重要的是他會於片尾，跟大家分享他在復康過程的心得。現在讓我們一同聽聽他的分享。以前香港還有工業時，我從事織布的，我是三年前的聖誕節中風的。

This is a story of a male stroke survivor. He got stroke soon after his retirement. Fortunately, with the love and care from his wife, his conditions gradually improved. In his rehabilitative process, he never stops exercising. What he believes is our health is in our control. In this video, he is telling us his experience after getting stroke, his conditions immediately after discharge, and his experience in practicing the use of a stick. He also talks about how his work, the relationship with his family and friends, and changes in the type of leisure activities after stroke. More importantly, he will share with us his precious experience in his rehabilitation journey. It is time for us to get into his world! I used to work in the textile industry and got stroke at Christmas three years ago.

中風經過，當時在廁所裏，正想站起來，但要很辛苦地站起來，結果都可以站起來。第二天如廁後突然跌倒，幸好沒有傷及頭部，醫生都說我很幸運。我的左手和左腳受到影響，即右腦中風。醫生說我是因塞血管而中風，如是爆血管更難救治。The stroke process, it was the time when I tried to get up after toileting. It took me so much effort to get up from the toilet seat although I could make it. On the next day when I did the same thing, I suddenly collapsed. Fortunately, my head did not get hurt. My physician also said so. My left side was affected which meant my right hemisphere was affected. Mine was an ischemic stroke. The physician said the survival rate would be a lot lower for a haemorrhagic stroke.

中風後活動能力，我躺在病床上，完全不能動，幸好我太太每天放工後，幫我不斷屈我的腿，當然不是很殘忍地屈。我知她是為我好的，想我能儘快活動，令我不會長出那些褥瘡。中風後我做不到精細的事情，要用體力的，又怕自己負擔不來。

My physical mobility after stroke, I was completely immobile at that time. Luckily, my wife came to me and helped stretch my legs. Of course, doing it gently. I knew what she did was for my own good,
hoping to minimise the risk of pressure ulcers. After stroke, I could not manage the tasks with the use of fine motor skills. For those physically-demanding one, I could not handle.

Fall incident after stroke, with the permission to stay out of my bed, I was excited and overjoyed. I could eventually get out of my bed to do what I wanted. The first thing popped up in mind was to use the computer at my bedside. I had not been using it for a long time! With a desire to reach that single step, I thought I could make it. Such a tiny single step should not be a problem to me. However, the fact is just vice versa. Even the objects were just placed at a single-stepped distance, I was unable to pick them up. Thus, I fell. Protecting my head is of paramount importance to avoid a strong collision to my head.

Using a stick to replace a wheelchair, I had to sit on a wheelchair for a few months. With the presence of a stick, my wife revealed her belief that if I relied on a wheelchair for mobilisation, it would be very likely that I had to use it for the rest of my life. It would be hard to return to normal. Of course, I had to explore other methods to abandon the use of a wheelchair. Whether we can manage the change merely depends on ourselves. For example, how to grasp a stick with sufficient force and what should be done to prevent falls. All these are done by trials and errors. I believe that our health is in our control. Getting rid of wheelchairs should be a good thing.

Exercising, there are some poles in the sports stadiums. I hold on these poles to practise squatting and standing. This helps strengthen my thigh and calf muscle. Determination, to be frank, how much you gained reveals the effort paid.

Exercising, there are some poles in the sports stadiums. I hold on these poles to practise squatting and standing. This helps strengthen my thigh and calf muscle. Determination, to be frank, how much you gained reveals the effort paid.

Working, I tried to help my family members pay the bills. At that time, I held the money and bills in my hands. However, I lost them on my way. I could not even hold a piece of paper tightly. How could I manage to work?

Family and friends, due to limited mobility, I lacked financial income. My relatives keep me at a distance since they did not want to me to borrow money from them. Some even stayed away from me because they did not want to offer me financial support. Getting stroke is a torture to both stroke survivors and our families. Though we may place a burden on our families, we can actually make some contributions. We should not rely on our families always. For example, buying things or paying the bills are some of the simple things that we can manage. These are good ways to contribute to our families.

Leisure activities, I love going to concerts and participating in activities organised by the district council. As long as there are tickets available, I will go and get one. Music is what I enjoy. By attending concerts, time passes by quickly. I would not have to confine myself at home doing nothing as well. These are all discovered after stepping out of my comfort zone to join various activities.
Encouragement • Support, no matter how difficult the time is, we should never lose the hope. As a stroke survivor, we need to work hard in doing exercise to return to our premorbid state.

Video 03 Take care of myself (Duration: 13 min)

於這段短片中跟大家分享的是一位男士。他是潮洲人。中風後他在兩名兒子的鼓勵下，由初中風時不能照顧自己，到現在可以自己用拐杖走路。他說就是要拼命地鍛鍊，能自己照顧自己就得了。這段短片中他會跟大家分享他中風的經歷、中風後對他的活動能力、說話能力、日常生活和心情的影響。他亦會分享一下他自己做運動的心得。最後他更會同大家分享於復康的過程裡他認為最重要的事。現在讓我們一同聽聽他的分享！

This is a story of a male stroke survivor who is from Chaozhou. The encouragement of his two sons meant a lot to him. Initially, he completely lost the ability to self-care. Now, he can walk with a stick.

Training with perseverance is his motto. As long as he can care for himself, that’s enough. In this video, he is going to tell us his experience after getting stroke, his physical mobility, speaking ability, daily life and mood in post-stroke phase. He will also tell us some tips in doing exercise. At last, he brings out the most important message along his rehabilitation journey. It is time for us to get into his world!

The stroke process, I was in coma after stroke. When I regained my consciousness, I was already in the hospital. I was very confused at that time and was hospitalised for more than three months.

活動能力, 我右邊的手腳不能動, 手腳不能動。幸好我兩名兒子輪流來照顧我, 今天其中一名兒子來, 明天另一名兒子來, 兩名兒子真的很好。我就想, 既然兩名兒子這麼好, 不要負累他們。我一定要再次走路! 現在的日常生活, 我練習到可以自己照顧自己, 不要依賴別人照顧, 自己照顧自己就得了。

My physical mobility after stroke, my right limbs could not move at all due to right-sided weakness. Fortunately, my sons came to care for me alternatively. If my elder son came today, tomorrow would be my younger son’s turn. I am so blessed to have them in my life. With my two splendid sons, I ought not to be their burden. I must walk again! Now, I am trained to take care of myself and not to rely on the others. To me, the ability to self-care is of paramount importance!

日常生活, 初時由工人幫我洗澡, 很多事情都由工人幫我做。不斷鍛鍊後, 現在不需要工人了,都可以做到。不能洗臉, 只有一隻手做不來, 非常不自然。等其他人照顧都是麻煩, 要等其他人照顧的心情都是不好。如果中風的時間較長, 沒有辦法。如果你不靠自己, 子女都沒有辦法幫你, 唯有靠自己, 靠自己去鍛鍊。

My daily life, initially, my domestic helper assisted me in bathing and relied on my domestic helper for most of the time. After undergoing lots of training in activities of daily living, I did not require my domestic helper anymore. I can do many things on my own now. Due to right-sided weakness, it is hard to squeeze the towel before washing your face. It is also unnatural to use a single hand to wash face. At the same time, it is very troublesome to wait for assistance. This explains why relying on the others for help makes stroke survivors feel upset. If you suffer from stroke for a longer period of time, you have no choice but to rely on the others. However, if you have lost the concept of self-care, no one can help you. You must work on your own with perseverance.
說話能力，現在說話時有些會忘記了。中風初期我說話時，在家中說話，我一向都不說潮洲話。我是潮洲人，我來香港後沒有再說潮洲話。中風後常說潮洲話，當我說潮洲話，但我的兒子和媳婦聽不懂。她說，老爺，我聽不懂你在說甚麼，慢慢地說話便可以了。現在已兩年半，這一年多我講話便漸講得好。

My speaking ability, sometimes, I forgot what to say suddenly. Before I got stroke, I never spoke in Chaozhou language at home although Chaozhou is my hometown. I did not speak it after coming to Hong Kong. After getting stroke, I often spoke in Chaozhou language. My son and daughter-in-law could not understand even for a single word. She told me that she was not familiar with the language I spoke and encouraged me to speak slowly. It has been two and a half years since then. In recent months, I improved a lot in my speaking.

心情，初時別人來探望我時，我仍然躺在床上，不能活動。他們來探望我時，我就流淚。時間沖淡一切，不可能改變了，已經是這樣了。

My mood, at the initial stage of stroke, my friends and relatives came to visit me. Due to limited mobility, I had to lie in bed. When they came, tears rolled down on my face. Times passes by and fades things out. This was something that I could not change.

不用輪椅，我沒有想困難，就是要拼命地鍛鍊，都要自己練習，練習站立。站立、再蹲下、不需要扶手，再站起來，很多曾中風的人都不能做這個動作。初時坐在椅上練習，後來練習蹲下，練習了很久。我沒有灰心，灰心與否都要鍛鍊。如你不鍛鍊，要依賴坐輪椅。若不鍛鍊，便只會繼續坐輪椅。我不斷鍛鍊，現時可以慢慢地走路。雖然走得不太快，只一步一步地走，但都可以了，不用其他人照顧便行了。

Abandoning the use of a wheelchair, ignoring the difficulties, I had loads of self-practice in the rehabilitative phase. Stand up, then squat, and stand up again without holding the handles. Many stroke survivors were unable to make it. I sat on the chair for practice initially. Then I try to squat. I had been practising it for a long time. Even though it takes time to view the progress, I never thought of giving up or feeling hopeless. If we do not practise, we need to use the wheelchair to move around. If we do not practise, we will be sitting on the wheelchair for the rest of our life. With continuous practice, I can walk slowly. Although I am walking step by step in a slow pace, I can still make it! I need not require the assistance from others anymore!

做運動，我現在每朝四時多便起床，早上四至五時許，我便出外做運動。我會做八段錦、伸展運動等，自己想練習甚麼便去練了，例如活動手腳。以前學過的運動經常忘記了，所以自己想起哪樣運動便做了。

Doing exercise, I wake up at around 4 a.m. in the morning and go for exercise for an hour. I do some stretching exercise and “Qigong Baduanjin” I do not have restrictions on the types of exercise done. For example, to swing my legs and arms. I always forget what exercise I had learnt before. Therefore, I just do it randomly.

鼓勵。支節，總之中風後不會完全康復，只要練習至能自己照顧自己便行了。不鍛鍊當然不行！鍛鍊後未必一定有幫助，但多少都有幫助！再見！

Encouragement. support, we cannot get fully recovered after stroke, but at least we should train up ourselves until we have self-care ability. We cannot stop practising. Although our work may not help much, it will be nice if it helps a bit. Thank you and goodbye!

Video 04 Be confident. All is possible (Duration: 16 min)
於這段短片中跟大家分享的是一位女士。中風後她說話不通，活動能力大受影響。有一次因為一煲水，她下定決心要努力練習，不再倚賴其他人。此後她還學習陶瓷藝術，用左手完成一件件精美的陶瓷作品。於這段短片中她會跟大家分享她中風的經歷、中風後對她的活動和說話能力的影響。她亦會分享一下出院後令她印象最深刻的事和介紹她的陶瓷作品。最後她會以過來人的身份，鼓勵大家要對自己有信心。現在讓我們一同聽聽她的分享！

This is a story of a female stroke survivor. After stroke, her speaking ability and physical mobility are severely affected. Interestingly, a pot of water has changed her attitude towards her post-stroke life. She had decided to pay more effort in practice and not to rely on others since then. She even devoted her time in learning pottery. With a stronger left hand, she finished the delicate pottery products. In this video, she is telling us about her experience after getting stroke, and the impacts on her physical mobility and speaking ability after stroke. She will also share with us the most memorable incident after discharge.
and her pottery products. She encourages all stroke survivors to have confidence in oneself. It is time for us to get into her world!

At that time, I babysat for the children of my neighbour because my children had grown up already. Babysitting was an activity for me to do in my leisure time. One night, the baby cried. However, I was unable to speak before finishing the whole sentence. In the hospital, the physician informed me that I suffered from stroke. I lost my consciousness for three days. By the time I regained my consciousness, I could not speak nor move. I could just open my eyes widely with minimal ability to move my unaffected arm. Some blood clots flowed to my brain, causing aphasia and right-sided weakness. My eyes could only move to one side. To be honest, I knew nothing about my situation. I had stayed at the hospital for two to three months. I was only forty years old at that time.

The situation after stroke, having passed the critical period, I started to regain my feelings. Why was I like this? I was unable to speak nor sit on the chair. If I sat on this type of chair at that time, I would fall. The physiotherapist knew my gloom about own situation. They had tried their very best to teach me rehabilitative exercise. At that time, I did nothing but cry. My tears rolled down on my face without making any sound. They then comforted me by saying “No matter you are happy or not, time flies. You had to think about how to keep yourself moving on and the activities you used to do in the past. If you want to lead a joyful life as before, you must learn how to exercise your arm.”

After stroke, I insisted on doing exercise. The healthcare professionals let me exercise three times a week in a two-hour session each. It really worked for me. At the very beginning, I was incapable to raise my hand. I could gradually touch my fingers and raise my hands as time passed by. I was told that it was a good sign. Therefore, stroke survivors must work hard to exercise ourselves. If we let go, our physical conditions got worse. The healthcare professionals gradually reduced the time for me to do the exercise until no one was required to assist with my walking. Now, I can walk with a stick. When I no longer had to go to the hospital for rehabilitative exercise, I took the initiative by myself. Remember, we need to exercise at home!

Practising the use of my left hand to write, and practice speak, regardless how tired I was, I insisted in doing exercise. Even I suffered from pain, it showed a good sign. This showed that I still had sensation. Without sensation, you would have no idea about how to move. Now, I am trained to write using my left hand. As I have mentioned before, I could not speak after stroke. However, how can I speak now? This was the result of a combination of traditional Chinese medicine and physiotherapy. There are many
acupoints around the tongue. They teach me to eat apples or pears at a big bite instead of cutting them into small pieces. I had to chew while eating them in order to stimulate the acupoints around my tongue.

出院後印象最深刻的事, 因為有一次令我一定要振作的。當時我先生去剪頭髮, 我的子女去補習, 剩下我一人在家。我心想, 我不可能一世都靠別人, 那我便去煲水, 我可將煲水放上去。左手可以活動, 右手就不能。我用左手, 但非常沒有力, 不夠力去拿起水煲, 但我仍拼命地用雙手拿着水煲, 放在爐頭上煲水。後來因我不能久站, 我放一張椅於廚房前, 邊看邊等着水滾。水滾了, 我怎樣倒水呢？拿上去已很辛苦, 怎樣放在地上呢？我先打開暖壺的蓋, 然後放在地上, 然後雙手拿着那煲滾水, 將滾水倒進暖壺, 但我不懂控制左手, 因左手要重新學習。我要用左手將熱水倒進暖壺, 但倒不準。怎料整個水煲坐在地上, 同時我稱為後退, 怕會濺到自己, 水煲跌在地上, 沒有倒溝。我自己亦跌在地上, 我的腿錯點踢倒水煲, 我只坐在地上, 同時我哭了。當時我在想為甚麼我不能自己煲一煲水呢?

The most memorable incident after stroke, this incident is my trigger point to brace up. One day, my husband went for a hair cut while my children went for tutorial classes. I was the only one left at home. By that time, I was determined not to rely on anyone again and again. Then I went to boil a pot of water. My left hand could still function, but not for my right hand. Therefore, I tried to take that pot of water and put it on the stove. Even though I did not have enough force to take the pot, I still strived hard to take it with my both hands and put it on the stove. I sat in front of the kitchen and waited for the water to reach the boiling point. The water eventually boiled. Another challenge was to pour the water from the pot. It took me so much energy to get the pot on the stove already. I took away the lid of the bottle and put the bottle on the ground. I then held that pot of hot water in both of my hands, trying to pour the water into the bottle. However, I did not have a good control of my left hand and I missed it. The whole pot of hot water was dropped on the ground. I stepped backward a bit to avoid getting scalds. Luckily, the hot water did not splash out. I fell at the same time with my legs almost hitting the pot. I cried immediately while sitting on the floor. A sentence popped up in my mind. “Why couldn’t I even boil a pot of water?”

開始學習陶瓷, 那時有一個為傷健人士舉辦的展覽, 去到只是四處望, 覺得那些陶瓷很美。我沒有走開, 因我不能說話。我只指着那些陶瓷, 覺得很美, 不斷點頭, 但不懂說話。我的女兒鼓勵我去學, 看看需要多少錢, 你在家中也沒事做, 如跌倒更麻煩。就這樣我在中風後學習陶瓷, 直至現在。可能當年我專注學陶瓷, 年三月我第一次中風, 同年九月第二次中風, 共兩次, 但我第二次中風後, 我不太害怕。

Learning pottery, there was an exhibition held for the disabled. I looked around and discovered some beautiful pottery products. I was stuck to it. I kept pointing at those amazing works and nodding my head due to impaired communication. My daughter encouraged me to attend pottery classes so that I needed not stay at home always. My pottery journey had begun since then. Perhaps I put most of my focus on pottery. I got stroke in March for the first time. Another episode of stroke happened in September last year. However, fear subsided accordingly.

我的陶瓷作品, 這兩個都是拉杯。拉杯就如電影「人鬼情未了」中的那種。一定要有一部機器和泥, 才可以拉。我製作拉杯是這樣做的, 將泥放在此, 一定要用一隻手按着, 這隻手在旁邊伴着, 用這隻手去做其他所有工作, 慢慢地握緊, 這隻手伴着。這隻手雖不能動, 但可以擦着泥, 好讓它轉動。一隻手都可以做到, 不是只有一隻手便做不到, 但一定要用較長的時間, 就是這樣。

My pottery products, these two are made by wheel-throwing. It was like what we saw in the movie “Ghost”. A machine and clay are essential tool for wheel-throwing. This is the way I performed wheel-throwing. I used one of my hands to press the clay firmly. My right hand (affected side) served as a support. The rest of the job was done by my left hand (unaffected side). With the support from my right hand, I practised pottery slowly. Although I suffer from right-sided weakness, my right hand let the clay follow the way as the wheel moves. Pottery can be done even you have one-side weakness. We can make it even though it takes a longer time.

鼓勵。支持，其實我們曾中風的人士，最重要有恒心！有恆心和用心去做運動，對自己要有信心，千萬別想着我做不到，我永遠都做不到，不是永遠都做不到！我們只是暫時病了，跌在地上，我們要再次站起來，要靠自己的！但我只有一隻手，怎能做到？就是用另一隻手幫助完成餘下部份，要對自己有信心，最重要有信心，沒有信心便甚麼也做不到！
Encouragement • support, perseverance is inevitable to stroke survivors. We can demonstrate it by continuing regular exercise. We have to stay confident in ourselves. If you believe that you cannot make it, you can never taste the glory of success. Everything is possible. Stroke is just part of the challenges faced in life. Life must go on and it all depends on wills. Some may wonder how I get things done with one-sided weakness. The answer is straight-forward: to use the unaffected side to complete tasks! If we lose confidence and faith, we can do nothing!

Video 05 Continuous practice • Memory and mobility (Duration; 15 min)

於這段短片中跟大家分享的是一位男士，笑容滿面的他，細訴自己的一套訓練記憶和活動能力的方法和他如何跟太太轉換角色，分擔家庭裏的生活瑣事。這段短片中，他會跟大家分享他中風的經歷，中風後的活動能力、平時鍛鍊左手活動能力、記憶力和穿衣的方法。他亦會提及中風後找工作的經驗，跟太太轉換角色，分擔家庭裏的生活瑣事。最後他亦會分享他在中風復康路上堅持的心得。現在讓我們一同聽聽他的分享！我今年六十歲。我在四十七歲那年中風，中風後已十三年了。我在一九九八年十一月五日中風的，我記得很清楚，塞血管。

This is a story about a male stroke survivor. This cheerful man is sharing with us ways to train up his memory and mobility. He will also tell us how the role change between his wife and him so that they could manage their family life better. In this video, he is telling us his experience after getting stroke, his level of mobility after stroke, the ways he trains up the mobility of his left hand, the methods used to improve memory and ability to put on clothes. He will also share with us his job searching experience after stroke and how he exchanges social roles with his wife to lead a better family life. At the end, he is telling us what makes him stay strong along the rehabilitative journey. It is time for us to get into his world. I am sixty years old now. I got stroke when I was forty-five years old. It has been thirteen years since then. I had stroke on 5th November, 1998. I remembered it very clearly. It was an ischaemic stroke.

The stroke process, I was a driver working between Hong Kong and Mainland China. I could only go home for a sleep for a few days in a month. Luckily, my workload was not that heavy on the day when I got stroke. Therefore, I went back home earlier. After getting back, I suffered from a headache. My wife therefore accompanied me to the accident and emergency department. At that time, I could still walk to the accident and emergency department. Soon after I got into the accident and emergency department, I fainted. The physician informed me that I got stroke. I could not see anything when I was awake. That was what my wife told me. I had completely lost my memory about that incident. Therefore, my wife told me afterwards. She said I could see nothing until a month later. I eventually regained my vision and saw things.

My mood after stroke, at the beginning, I thought it was disastrous with hemiplegia. I may require the assistance from others for the rest of my life. Whenever I had this thought, my mood turned bad. I even thought of ending my life as an alternative so that I would not bother the others. Eventually, I regained my mobility through rehabilitative exercise with obvious improvement. I thereby had the motivation to exercise. I walked for three to four hours a day and gradually improved my situation. It became less painful when doing stretching exercise. With my perseverance, I regained the mobility. That relieves me a lot!

中風後的活動能力，當時左手只能舉至此，後來才越來越好。初時左腳只是拖着走，拖着走。初時我有用拐杖，後來不需要用了，都用了拐杖幾個月。

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My physical mobility after stroke, initially, I could just move my left upper limb up to here. Worse still, I had to drag my left leg on ground when walking. I had to use a stick to aid my walking. After my conditions got improved, I abandoned the use of a stick which I had been using for a few months.

左手的活動能力, 中風後的兩至三年, 肢頭都有痛的, 隻手舉至某個位置便痛了。後來做健身時, 教練教我們拉架, 單是拉架都用了一年, 才開始不覺痛, 鬆至這兒都痛了。剛開始拉那個架時, 真的痛至流眼淚。自己忍著痛, 拿著那條柱, 稍微蹲下便覺痛了。但自己強忍著痛, 不理會它, 不斷忍著痛, 經常可以再蹲下些, 非常痛時便不蹲下太多。就這樣忍著痛, 直至不覺得痛, 直至能整個人蹲下都不覺痛, 便知自己開始不用拉了, 可以自然地活動。

My physical mobility of my left hand, my shoulders hurt after two to three years post-stroke. I felt painful when raising my arm to a certain level. Later, a coach I met in the gym room advised me to do stretching exercise. It took a year so that I would not be in pain when doing stretching and raising arm up to here. My tears rolled down due to great pain experienced initially. I told myself to bear the pain. Holding the rod, I practiced squatting. Despite of the pain, I just tolerate it. Bearing the pain, I could move down a bit day by day. However, it was not advised to continue when the pain exceeded your limit. I carried on with the stretching exercise until I was not in pain after squatting successfully. At that moment, I knew that I needed not stretch my legs anymore. I am able to move freely!

穿衣, 當穿上衣服後, 後面這些部份, 因當時自己的活動能力不太好, 衣服後的部份又不能滑下, 手又不能拉下衣服, 唯有自己扭動身體。慢慢地像在做運動, 同時讓衣服慢慢地滑下, 當滑下後便可用手把衣服拉下。初時都很氣憤的, 請他們替我拉下衣服都不願, 硬要我辛苦地扭動身體, 好等衣服滑下。初時都很忿怒, 但後來手腳的活動能力漸好, 不用靠家人的協助, 都要靠自己活動, 所有事都要靠自己。

Putting on clothes, after putting on the clothes, with limited mobility, the clothes often slipped down. I could not raise my arm to pull the clothes down, so I had to twist my body. It was very much like doing exercise. I had to let the clothes slipped down until I could pull it off. Initially, I felt furious because my family members were not offering me any help. I really had to twist my body with difficulty to put off my clothes. It was very annoying at the very first beginning. However, my physical mobility gradually improved. I did not require the assistance from my family members. Now, I could do most of the things on my own.

記憶力, 我現在一定要自己寫下才記得。我要把第二天要做的事寫在紙上。如我約了你, 我要寫在紙上並貼於廁所門外。我也有鍛鍊記憶力, 因自己的記性不好。我有時會到超級市場看價錢牌, 有哪些貨品便宜了。超級市場有否出古惑說貨品已便宜了, 但其實沒有的, 經常講大話, 我去看看有否這樣。

Memory, after stroke, my memory got poorer. I have to write a “To-do” list now. I have to write a memo and stick on the door of my bathroom whenever I have appointments. I have taken measures to train up my memory. Sometimes, I go to the supermarkets to take a look at the price tags to see which products are getting more economical. I will see if the supermarkets really offer consumer discounts without cheating.

工作, 現在不能工作了。現在最麻煩的是沒有記性和雙眼視力模糊, 不能工作了。我試過到勞工處, 他們介紹我做那些展能訓練的工作, 介紹我做速遞員。我單是找公司的地址, 已經頭昏腦脹, 即是找公司的工場。我去到後又叫我去收件, 再去找, 去找那些公司的地址, 更加找不到。怎可能做得到！後來與勞工處的職員再談, 那職員說我連最簡單的工作都做不來, 他也幫不了我, 請我康復好些後, 再來找工作。於是我留在家中, 跟太太調轉角色。

My work, I have lost my ability to work. The biggest trouble is the poor memory and blurred vision. This deters me from getting a job. I had asked for help from the Labour Department. They advised me to work as a courier. Nevertheless, I had trouble in finding the address of the companies where I had to deliver the parcels to. When I arrived, they asked me to collect the documents. I was told to find out the locations on my own again! How could I do it? I could not finish the tasks at all. Facing the difficulties, I raised my concern to the staff working in Labour Department. They said that was already the simplest task. He had no idea on how to help me. He then advised me to take care of my own body before getting a job. Then, I stayed at home and exchanged the social roles with my wife.

家庭角色, 我現時在家負責買餸煮飯, 我太太會替鄰居的孩子補習。我有時間還會負責晾衫和洗衫, 打理家中瑣事。我太太一樣會幫手做家務, 見到便做。大家一起分擔, 見到有事要做便去做。
My family role, I am now responsible for cooking meals and buying daily necessities. My wife works as a tutor of my neighbour’s children. Sometimes, I wash clothes and dry them up as well. I do more housework than the past. My wife also takes up the responsibility to share the household chores. We share our work at home to lessen the burden on each other.

Encouragement • support, not to give up is the most important motto! As stroke survivors, we need to take all possible measures to ameliorate the situation! If we choose to do nothing, our physical health will get worse. Therefore, we must work hard to maintain a physically fit body!

Video 06 Live in the present (Duration: 16 min)

This is a story of a female stroke survivor. This year, she enters her eighty. She is very passionate in arts, sketching and drawing. Although stroke came to her for twice, she still holds on drawing. At the same time, she keeps learning new things and continues exercising to train herself up. “Embracing the present” is her life motto. In this video, she is telling us her experience after stroke, her conditions after discharge, and how she upholds her interest in drawing. She will also share her point of view on “Embracing the present” and how she could make it. At last, she encourages all stroke survivors to take the initiatives to join the activities that are fit for them. It is time for us to get into her world.

I have three daughters in total. After my daughters start working, I start to live alone. My husband passed away thirty years ago. I used to be an accountant. However, due to the attractive wage in textiles industry, I became a seamstress. I continued my work. Starting from a worker, then I became a supervisor. At last, I was responsible for quality control. Therefore, I had to go to Mainland China to ensure the quality of the products. I love arts, that is drawing. Sometimes, I attended drawing classes.

The stroke process, it has been three years since 2010. I remembered it was in April. I dropped a pair of chopsticks when having lunch. The chopsticks dropped again after picking them up. I knew it was a sign of stroke. Due to the blockage of blood flow in brain, I had stayed at the hospital for a month. I still had the rehabilitative power. The condition was not too bad. I continued with drawing and doing voluntary work sometimes. However, stroke came to me again in September 2013. After going for sketching outdoors, I was sitting to read the newspaper at that time. I had a brief conversation with my daughter. However, she discovered my slurred speech. At that moment, she knew that I was getting stroke again. Things did not go smooth in the second episode. I drooled with my mouth deviated to one side. Then I received acupuncture for a month. I then noticed that I could start doing exercise. My course on acupuncture ceased while my exercise regimen began.
The conditions after discharge, my mood and physical mobility was greatly affected in the first episode of stroke. That made my family feel troublesome too. My daughter and son-in-law were still working. Due to my impaired self-care ability, I had to live with my daughter in a small compartment. Most of the household chores were done by my daughter and son-in-law. After getting stroke again, I was in a low mood. I felt really helpless. Stroke came to me all of a sudden without any noticeable pattern. Unstable gait and a lack of a sense of direction distressed me a lot too. However, I still carried on with my interest. Due to a lack of ability to focus, I drew really bad one time. I asked my physician why it was like this. My physician made a joke by saying “Why don’t you take it as drawing with Picasso?”. How to keep my passion in drawing burning? After stroke, there is a limitation in doing all activities. This was due to insufficient strength and force. For example, if you want to go to distant places, you cannot take heavy objects. I could just take a pen and a piece of paper with me when sketching outdoors. I could not do the colouring promptly. I used to go alone, so I will not go in extreme weathers. If the places are too remote, I will not go too.

The importance of having interests, I am already eighty years old. Time is running short. I want to know more, experience more and learn more! I thought I had to give up drawing at once. Yet, I am really glad that I can continue with it. That means I can still enjoy what I love to do. Although the situation may not be as good as before, I can still make it. Before getting stroke, I drew these portrait paintings. I drew as long as there was a model. I did it by self-learning. I borrowed books from the library. This is also a portrait painting that I drew before stroke. These are done after getting stroke. The use of perspective and symmetry is not so sophisticated as before. After stroke, my drawing skills are getting poorer. This is a portrait painting drawn lately. Engaging into the activities you enjoy such as reading newspaper or books is a way to keep yourself going. You will find yourselves more competent in making decisions. If you do not work hard at all, you can never see the progress. In other words, you have to keep moving and learning. As long as we do not have too high expectation, all of us should be able to make it.

How I see “Embracing the present”, the meaning of “Embracing the present” is to treasure the people around you and do whatever you can in the present. The execution of “Embracing the present”, you may wonder how I manage to do it. That is to continue exercising! In my meals, I avoid food that is high in fat or difficult to digest. I take all possible measures to improve my physical health. Joining more activities is another way to stay healthy. From my point of view, I am a burden to my family members. Now, my limbs are dexterous. Therefore, I wash clothes or do some cleaning despite the disagreement from my family. I insist on washing the clothes even though my daughter do not let me finish it. I just cannot let myself stay at home doing nothing. I really want to make some contributions. To a certain extent, I would describe myself as a greedy person. I want to read more books and accomplish more in my life. Therefore, when I am invited to be the volunteer, I am very willing to take...
up the role. Participating in voluntary work also widens my horizons. My post-stroke life changes my attitude in doing voluntary work. I want to know how the outside world is like. As a stroke survivor, I feel really glad to lend the others a helping hand.

鼓励，支持，我知道社會上有很多復康活動的。只要你找尋自己喜歡的活動，但你不能光坐着。
你也可問同路人，我想學習和得到甚麼，便去找尋和問其他人。只要你肯問，你會找到你需要的。人生雖然苦短，但還有很多事的。總之透過唱歌、閱讀報紙或其他能令你變得更開朗和認識更多事物！

Encouragement • support, there are loads of rehabilitative activities in our society for stroke survivors to pursue their dreams and interests. However, you cannot gain anything by just sitting here. You can ask your companions. If you have decided what to learn and gain, you should go to check it out. As long as you are willing to take the first step, you must be able to find what you need. Remember, there is a limit in our life. Therefore, we should spend more time to get to know our world and stay positive by actively participating in all sorts of activities that arouse your interest!

Video 07 Help others and self-help (Duration: 17 min)

於這段短片中，跟大家分享的是一位女士在三十多歲時中風，中風後，她曾想過放棄。幾經掙扎，她終於熬過了。現在，她視中風為她生命的其中一個階段。近年，她更積極投入義工服務，用自己的經歷勉勵其他有相同經歷的人。這段短片中，她會跟大家分享她中風的經歷，中風後令她感到難受的事情，和如何渡過這個階段。她亦會談及在復康的過程中她常做的活動，現時的生活和她做義工服務的分享。最後，她更鼓勵大家在復康的路上要加油、努力。現在讓我們一同聽聽她的分享。

This is a story of a lady who suffered from stroke in her 30s. She has never thought of giving up. Overcoming lots of struggles, she eventually managed to lead her new life. Now, she takes stroke as just a tiny part of her life journey. In recent years, she participates actively in voluntary service. Sharing her own experience, she motivates other companions. In this video, she is telling us what she experienced as a stroke client, what made her feel sad after having stroke, and how she went through the hard times. She also mentions about the rehabilitation process, her usual activities, her present life as well as her voluntary experience. In the end, she encourages all stroke survivors to endeavour along the rehabilitation journey. It’s time for us to get into her world.

我於一九九二年十一月十三日星期五當天中風的。當天早上我起床後，準備去取機票。當時我已向公司申請大假，準備去旅行。原想着會很開心，已經預訂並準備去取機票，但當天早上起床後不知為何，我自己不察覺有任何問題。我起身洗臉刷牙。梳洗後，並更換好衣服，我準備出門口。當我出門口時，那時我跟我二哥一家人一起住的，我二嫂在門口看見我，覺得我不太對勁，但我本人並不覺得有問題。她便背起我下樓，然後坐的士去醫院。原來我在醫院昏迷了幾天！當我醒來時，醫生來見我。我因此問醫生我發生了甚麼事。醫生說我中風了。我當時不知中風是甚麼回事，因我對這方面不太認識。我當時以為是傷風，我想我可能在醫院休息幾天便沒事了。後來才知道原來中風令我左邊身，半邊不遂，完全不能動。我不能自己去廁所，要請護士給我取便盆在床上如廁。後來我才知道是這麼嚴重！中風原來是這樣。當時我都很害怕，因為那年我只有三十多歲。

My story begins on 13th November, 1992. It was a Friday, when I got stroke. It was the time when I woke up and got ready for taking my flight ticket. At that time, I had already applied for an annual leave so that I could go for a trip. I was so happy and excited that I had booked and prepared to take my flight ticket. After getting out of my bed, I wasn’t aware that there was anything special yet. I got my face washed and teeth brushed as usual. After that, I got dressed and decided to go out. When I stepped out of the door, saying goodbye to my elder brother’s family, his wife stared at me. She thought something had changed though I still insisted that nothing went wrong. She then carried me on her back and went to the hospital by taxi. In the end, I found myself in coma for a few days. When I regained my consciousness in the hospital, the physician came. I therefore asked the physician what had ever happened. He said I had suffered from stroke. I did not have much idea on what stroke was because I was unfamiliar with the medical term. I thought it was something like common colds which I could get well after resting in the hospitals for a few days. Later on, I discovered that my left side was paralysed due to stroke. I could not move. I could not go to the washroom on my own. The nurse gave me a bedpan for me to urinate and pass out stools in bed. Stroke was such a serious thing. I would be leading the rest of my life like this. I was terrified since I was just a middle-aged lady at that moment.
出院後的情況，出院後回到家中，真的任何事都做不到。自己倒水都會倒瀉，要家人幫我抹。當時覺得自己就如一個廢人，每一天都很不開心，在家中只會哭。我覺得現在只有三十多歲，還有一條很長的路。如上帝給我六七十年壽命，我還有三四十年要這樣生活，所以我當時很不開心。亦覺得會帶給我的家人很大的負擔，他們要經常照顧我。我是非常不開心的！我覺得既然這樣，我有想過結束生命，我已寫下遺書。After discharge, after getting discharged and being back home, I could not do anything. Water spilled when I tried to fill up a cup. That bothered my family members. I felt like being a useless person, feeling depressed every day. The only thing that I would do was to cry. As a thirty-something lady, I still had a long way to go. If I could stay up to sixties or seventies, I would still have to live with my disability for further thirty to forty years. That was why I was always in low mood. I also thought that I was a burden to my family members. They had to sacrifice their time to take care of me. I felt really sorry and upset towards them. If that was the case, ending my life could be an option. I had drafted a posthumous statement at that time.

中風初期最難受的事情，我感到很難受和想結束生命，因為我初中風時不能夠自己洗澡。連洗澡也要家人幫助我，我覺得自己完全沒有尊嚴。其他事情做不來，他們幫我做我可以接受。雖然很難過，但我都可以接受。但洗澡這麼私隱的事都要他們幫我，我真的受不了！每天洗澡時，我便會哭，因為我覺得很難過。其他人覺得我已很好，因有嫂子幫我洗澡。已經是很好的！他們不覺得自己完全沒有尊嚴時，難有其他人幫助，但我也想這樣！The hardest time in the initial stage of stroke, I felt bad and hoped to end my life. I could not take a shower by myself at the very beginning, so my family members had to assist me. I had lost my dignity completely. If they do me a favour other than taking a shower, I would still be willing to receive their help. Although I felt miserable deep inside my heart, I could still accept it. However, back to bathing, I could not bear them to participate in such a personal issue. I cried everyday when I got bathed. Clearly, I felt sad. The others thought I was a lucky one because my sister-in-law could assist me. That was good enough. However, they would not understand that it was hard to live without dignity even if you received the help from others.

如何渡過這個階段？後來我的家人幫助我，陪我上街走動。在屋企附近走動，每天都如是。慢慢地，我覺得自己開始有少少進步，便沒有再想着要死了。我是基督徒，我信耶穌基督。我平時有返教會，有時在教會裏的弟兄姊妹會跟我傾談。他們會安慰和幫助我。當他們幫助我時，便稍為減輕了我家人的負擔。How to overcome the hurdles? Family support played a critical role in the rehabilitation process. My family members accompanied me to go for a walk daily. Sooner or later, I realised that my condition was getting better. Then, I stopped having suicidal ideation. I am a Christian, who believes in Jesus Christ. I went to the church where friends of mine chatted with me. They comforted and helped me. When they lent me a helping hand, the burden on my family members lessened.

現時的生活，我最近於一間補習社工作，我已開始做一些兼職的工作。我不會做全職工作了。第一因為太長時間，雖然我可以應付，但因我現在參加了復康會舉辦的義工服務，我會去醫院做探訪。基本上，我現在的生不開心。因為我現在參加了復康會舉辦的義工服務，我會去醫院做探訪。基本上，我現在的生活都很開心。中風雖然令我很不開心，但對我來說就如我人生的另一個經歷，所以有時我想雖然中風，但都要多投入自己以前的生活圈子。My present life, I start working in a tutorial centre which offers me a part-time job. I cannot work as a full-time staff whose working hours are too long for me. Although I can handle it, I need to join the voluntary service. I will go for visits in the hospitals. Basically, I lead a relaxing life. Despite the
unhappiness that stroke brought by, it is just another experience in my life journey. Therefore, I tell myself not to isolate from my past social networks.

分享参加義工服務的經歷，其實，每一位中風的人士都希望康復。我想沒有人不想康復，但需要時間和一定要努力。至於家人不明白，有時中風的人士儘量要體諒，因為他們沒有中風。他們怎知道原來很簡單的事都做不來。他們真的不知道！大家要彼此溝通，一起相處時便不會有太多爭拗，至少不會有太多誤會。

Sharing voluntary experience, indeed, every stroke survivor wants to get well. I think no one would love to let his/her conditions remain the same or deteriorate. However, time and effort must be paid. Sometimes, our family members may be less aware that we require more considerations. Our family members have not suffered from stroke. We cannot expect them to understand our incapability in doing simple things. They do not really know! Communication is essential to us. Only by initiating frequent communication, we will come across fewer conflicts, at least not to have too much misunderstanding.

Video 08 Stay strong (Duration: 8 min)

於這段短片中跟大家分享的是一位男士。他於二十多年前患出血性中風。當時他正在家中，收看世界盃球賽，突然感到十分不舒服，然後就不省人事，被送進醫院。當然在醫院昏迷了多久？昏迷了三日才甦醒。醒來後的活動能力右邊身、說話及寫字都不行，用輪椅，手腳都不能動。

This is a story of a male stroke survivor who had suffered from a haemorragic stroke twenty years ago. At that time, he was at home, watching the World Cup. Suddenly, he was in great discomfort. Then, he even lost his consciousness and was sent to the hospital. How long did he take to regain consciousness? He regained consciousness three days after coma. His physical mobility after regaining consciousness. He could not write nor speak with right-sided weakness. He could not move his limbs and had to sit on a wheelchair.

中風後的心情頹喪，想尋死，總之很驚。雖然中風後心情低落，但他仍堅持每日做運動。當活動能力稍為改善時，他開始重拾自己的興趣。每日練習書法和畫畫。他特別愛練習寫「心經」，因他覺得「心經」的內容讓他感到平靜。

His mood after stroke. He felt hopeless and depressed. He even thought of ending his life. He was in great panic. Although he was in low mood, he insisted doing exercise every day. When his mobility got improved, he then picked up his interest again. He practised calligraphy and drawing every day. “Heart Sutra” is his favourite piece of work for practice. The contents of “Heart Sutra” makes him feel peaceful.

於中風的復康路上，他有一句說話想跟大家分享的，大家猜到是哪一句嗎？無錯，就是自強不息！短片拍攝當日，他除即席寫了「自強不息」外，他更寫了宋代詩人蘇軾的千古名篇——「水調歌頭」。現在讓我們欣賞他的書法！蘇軾 「水調歌頭」，他開時亦愛畫山水畫，這些就是他的畫作。唔記得他的介紹！這幅是牡丹。這幅是蝦。這幾幅都畫得很美麗。他亦愛用畫來製作書籤，這些是他親手製作的書籤。是否很漂亮呢？他說希望可以鼓勵大家，做到自強不息！

Along the rehabilitation journey, he would like to share a single sentence that keeps him moving. Can you make a guess? Yes, that’s right! To stay strong and not to be discouraged easily. On the day of recording this video, he did not only write the mentioned quote in Chinese characters, but also showed us his pieces of work on “Shui diao ge tao” from the famous poet – Su Shi. “Shui diao ge tao”. Let us now take a look at his beautiful calligraphy! "Shui diao ge tao" – Su Shi. He also loves to do landscape painting. All these amazing work are done by him. Let us now listen to his introduction! This is peony. This is shrimp. These are painted nicely without doubt. Besides, he likes making bookmarks with his paintings. These are all done by him. Don’t you think they are beautiful? At last, he hopes to bring out the message that all stroke survivors should stay strong and not to be discouraged easily!
Video 09 Meet new friends • Integrate into the community (Duration: 15 min)

於這段短片中，跟大家分享的是一位中年男士。中風後，他的世界像是突然變灰了，活動能力和日常生活都大受影響。出院後，有好幾個月未能出外走動。後來，他踏出第一步，走到樓下公園，慢慢地認識了很多新朋友，重投他的社交生活。這段短片中，他會跟大家分享中風的經歷，中風後對他的活動能力、日常生活、心理及社交方面的影響。他亦會談及自己如何面對這些轉變和認識一班新朋友後的好處。現在讓我們一同聽聽他的分享！

This is a story of a middle-aged man. Getting stroke seems to destroy his pre-existing world. He suffered greatly from performing his activities of daily living. After discharge, he was incompetent to go for a walk outdoors for months. Subsequent, he took the first step with bravery, made numerous friends in the park, and got back into his community. In this video, he is going to share with us his past experience of having stroke, his limitations in terms of physical mobility, his usual life, as well as the psychological and social impacts brought by. He will also tell us how he faced these changes and the benefits of meeting new friends. Let us now get into his world!

我今年五十四歲，我於二零一二年七月二十七日中風，至今約一年多。中風後，很多活動都改變了。我也不知為甚麼會中風。因自我出生至中風前一天，我很少感到不舒服、發燒或感冒，一年裏頭都不用看醫生，所以突然中風實令我不能接受。

I am fifty-four years old now. I got stroke on 27th July, 2012. This disease accompanied me for more than a year. After getting stroke, I encountered loads of changes. Up till now, I still do not understand why I got this. Since I was born, I seldom suffered from any discomfort, fever or influenza. I needed not consult the physicians frequently, so I felt really unbearable when suffering from stroke.

中風過程，那天凌晨三時許，突然感到胸口痛，大約痛了二十多秒。第二天起來，以為前一晚的痛沒有大問題，沒有立即去看醫生。如常地上班、品茗、食飯、開工，都沒有問題的。直至第二天七月二十六日早上，亦如常地品茗，然後上班。怎料品茗後結帳，如廁後出來，便站着不能動。原來是爆血管了！原來這麼嚴重！

The process I suffered from a sudden chest pain at 3 a.m. The pain lasted for around twenty seconds. I thought the pain was not a big deal since it subsided. Thus, I did not consult a physician. On the next day, I worked, yum cha and had meals as usual. Nothing had happened until 27th July. I went to the Chinese restaurant before going to work like I did yesterday. After settling the bill and going to the washroom, I found myself not being able to move. Then, I realised that I got stroke, the haemorrhagic one. It was that serious!

出院後的活動能力，爆血管後，首幾個月的活動能力很差。不能活動，洗滌，甚麼也不能做。後來慢慢地學習走路，用拐杖慢慢地一步一步走路。後來，物理治療師和醫護人員說不能太急的，要一步一步地走。我便開始慢慢地走，不時停下，但一定要每天做運動。千萬不要停下來！一旦停下來，我們的關節和血液循環會不通，所以每天都要做運動！我想已有半年了。至少有半年，我才有信心不用拐杖，慢慢地走路。

My mobility after discharge, after getting haemorrhagic stroke, my mobility was seriously affected in the first few months. I could not carry out activities of daily living such as walking and bathing as I did before. I learnt to walk as if I was a child. The stick was my best assistant during that period of time. According to the physiotherapist and healthcare professionals, I should not walk in hurry. Instead, I needed to do it step by step. I took their advice and walked more slowly with some rest periods in between. I insisted on doing exercise every day, even on rainy days. If not, we will suffer from impaired circulation and joint movement. Therefore regular exercise means a lot to stroke survivors. It takes time to note the progress. I took at least six months to build up my confidence, and not to use a stick for assistance, and walk independently in a slow pace.

日常生活最大的困難，首先是飲食方面，怕自己洗東西和煮食。不能夠自己洗東西和煮食，害怕會出現問題，自己不敢做。從此做，現在嘗試自己煮菜和麵。現在漸漸沒有大問題，只是手腳的活動能力還不太好。如何克服？我會請太太在旁邊看着我洗東西，她也在旁邊看我切東西或做其他事。一至兩次後，覺得可以了便自己做。現在大致可以了，只要要拿着鍋炒食物時比較麻煩，但其他煮食都沒有問題了。只是任何事都要靠自己，不可以終日待在家中，待在家中只不過是在等罷了。

The biggest issue in carrying out activities of daily living, my first concern is making meals. I was afraid of washing and cooking dishes. I was unable to do them on my own because I worried that things would
go wrong. Starting off with something easy first, I cooked noodles and vegetables. Gradually, I feel more comfortable with cooking despite my limited fine motor and gross motor movement. How to conquer the difficulties? I would ask my wife to stay with me when I was washing dishes, cutting meat or doing any other things. After trying one to two times, I would decide to do it myself when I felt confident. I can do most of the things on my own now. Although I find stir-frying things in the wok is quite troublesome, I feel good with the other cooking methods. We have to get things done using our own strengths. We cannot stay at home all the time, waiting for miracles to happen.

My feelings after stroke, soon after I was informed that I had stroke, it was just like the end of the world. I totally cannot accept it. Even though we might feel desperate, we got to face the whole world. So, never confine yourself to your own comfort zone! We cannot change the past, but we can alter our attitude towards it. I understand that it must be an unpleasant thing. Even after a year or more, my mood still fluctuates. Yet, we are still alive. Then, why not spend our time and enjoy life with our family and friends? Take it easy! Meeting new friends, and joining more activities or organisations if it is possible. Participating in various functions and activities enables us to relax and not to be glued to mournful things. Taking part in more outdoor activities and avoid staying at home always can prevent us from getting into a blind alley.

自己單獨出街，我想都有四至五個月，我才敢自己拿着拐杖上街走動。我才敢上街，嘗試踏出第一步，是十分困難的。害怕自己單獨外出，去到公園後，我會坐在一旁，四處看看其他事物。當沒有人時，便動身走走，走到有椅子時便坐下。第一天上街時都很害怕，害怕再次中風、跌倒和沒有人照顧。我最大的問題是一個人很悶的，像是很孤獨的。

Going out alone, I thought it took around four to five months until I mustered up the courage to walk with a stick. Taking the first step out of my comfort zone is obviously difficult. I was afraid of going out alone. When I arrived at the park, I sat down and looked around. When nobody was nearby, I walked for a while. I sat down again when there were chairs. I felt horrified on the first day of stepping out of my door. I was afraid of getting recurrent stroke, falling down and not being taken care of. The biggest problem is that I felt bored and lonely when not being accompanied.

認識新朋友，當你踏出第一步，日子一天天地過，慢慢地開始有自信心。後來越來越大膽，逢人打招呼。現時我在公園裏認識了很多朋友，有很多人鼓勵我和相約我去吃喝玩樂，就是這樣我開始有信心。是不同的，所以不可整天待在家中！

Meeting new friends, when you take the first step, day after day, you start building up your self-confidence and getting even braver to greet everyone you meet. Now, I have many good friends whom I met in the park. Many of them encourage me and arrange gatherings for me. That makes me feel confident in meeting people. Getting back into the community enables me to lead a new life!

堅持，感到不忿，覺得自己無故有這個病，難道就這樣過一世？上天再給我生命，又開始恢復活動能力，就自己去克服這個病！每個人都這樣，有病的人都會較負面。儘可能不要想太多，有時間中會想，但有誰不會想，每個人都會的。總之大部份時間儘量不要想太多！靜下來時，我知每個病人都會向壞方面想，因為自己也是這樣。儘量多出外去不同的地方，認識多些朋友，那便會好些。最重要的是堅持！雖然說很容易，我自己也知道，但如你不堅持，便會比以前更差。因已有了這個病，你一定要堅持！

Persistence, at first, I felt resentful to have suffered from this disease. Am I going to lead the rest of my life like this? As a stroke survivor, I could live again and regained some mobility. Therefore, I should strive hard to live with it! It is common for the diseased to have negative thoughts. However, we should try to think more positively. Initially, it is hard. However, we should cherish what we possess instead of grieving all the time! Every single client tends to consider the worst thing, especially when staying alone. I am not an exception either. Things will be getting better when we go out and make friends with the others. Determination is of paramount importance! Though it seems to be an easy thing, things would not go smoothly unless you are persistent enough. Persistence would be inevitable as a stroke survivor!

Appendices
Video 10 I wish I can continue (Duration: 13 min)

於這段短片中跟大家分享的一位男士。在短片中不難發現他常說「我希望可以繼續！」正因為他對未來抱有希望，現在他重新投入工作，為自己、女兒和家庭努力。這段短片中他會跟大家分享他的經歷、中風後對他的活動、說話、記憶力、工作和駕車的影響。他亦會分享一下他做運動的心得，現時的工作、對朋友的看法和將來自己希望做到的事！最後他衷心鼓勵大家，要努力和堅持！現在讓我們一同聽聽他的分享！

This is a story of a male stroke survivor. It is not difficult to find a common quote from our conversation “I hope to continue.” This reveals his possession of hope in the future. Now, he re-enters the workforce and works hard for his family and himself. In this video, he is telling us about his experience of getting stroke, the impacts on his mobility, speaking, memory, work and driving after stroke. He also shares his tips of doing exercise, his perception on the present work and friends, and his bucket list in the future.

At last, he encourages all stroke survivors to hold on to our beliefs and strive hard. It is time for us to get into his world!

我記得我應該是第二次中風的。我第一次中風是在二零零九年。我今年五十二歲，塞血管。我记得那時的記憶力不好。我中風前的記憶力很好的，直至二零一三年九月我再次中風。中風的原因，我都不知道，第二次中風較緊張。那次之後，我說話時就像現在不太好。中風前我從事保險工作，說話十分流暢，但現在不太好。自去年十二月一日，我重投工作。我的女兒剛出世，她現年一歲三個月，希望可以多賺點錢幫到她。

As far as I remembered, it was the second time I suffered from stroke. The first time that stroke came to me was 2009. I was fifty-two years old now. Mine is an ischaemic stroke. My memory became really poor at that time. I used to be proud of my excellent memory in the past. Until September 2012, I got stroke again. The reason for it was unknown to me. The recurrent stroke stimulated my nerves. My speaking ability deteriorated since the second episode of stroke. I worked in an insurance company and used to speak frequently in premorbid state. Since 1st December of last year, I returned to work. My daughter is a year and three months old. I hope to earn more to provide a better environment for her to grow.

活動能力，那時我手腳的活動能力不太好，右邊手腳的活動能力和行動不太好。打籃球時需用雙手，那時候右手不能使出很大力。中風前我右手的力量很大的，但現在不行了，舉起手都有些問題，但現在已好了點。

My mobility was not as good as my premorbid state, this is especially prominent to my right side. Playing basketball requires the use of both hands. However, due to right-sided weakness, my right hand could not generate forces as much as before. That disappointed me a lot. Raising my arms also troubled me a lot although it gets better now.

工作，中風後，即二零零九年後，最緊要的是，我有很多保單不能再跟進。因我的記性不好，所以不能跟隨。我以前從事保險時，幹得很出色的，曾獲多個獎項，但現在唯有放棄。因為我記性不好，不能跟進保單的問題。

Working, after stroke, that is 2009 onwards, I could not follow up most of my policy. Owing to poor memory, I could not carry on with my work. I used to be proud of my performance in the insurance company. I had to give it up now despite receiving a lot of prizes acknowledging my effort. Now, my poor memory becomes my biggest hurdle in continuing my work.

駕車，中風前我駕私家車已有十多年，現在仍然不夠膽，所以不能靠駕車維生。如能練習一下，應該可以的。

Driving, I have more than ten years of experience in driving. However, I do not dare to drive. Thus, I cannot earn a living by being a driver. With enough practice, I think I could make it.

持續運動，在二零一三年九月至今年的狀況，我繼續在大陸跑步，在香港游泳，有清潔的泳池讓我游泳。游泳、打球，做一切康復的運動，能有今天的狀況不是必然的，但都要繼續做。

Continuous exercise, starting from September, 2013, I insisted on running in Mainland China and swimming in Hong Kong. There are hygienic swimming pools provided in Hong Kong. Swimming, playing basketball and doing rehabilitative exercise become my routine. My hard work paid off. Yet, I should keep going.
重投工作，我於去年十二月找到工作，十二月一日至現在二月中，約兩個多月。希望能把這份工作幹好。我在機場找到一份負責派餐和雜務的工作，但一般，工作尚算可以，希望可以儘快康復。因為在機場工作，當時說話不太好，現在已好了點，但希望儘快把說話講得更好。說話時不用像現在有點窒，不用這樣，我儘量做好些。

Returning to work, I eventually got a job in December last year. I started working on 1st December. It has been around two months until now. I want to get this job well done! I am currently working at the airport for meal delivery and some sundry works. Although I am still able to manage the workload, I really want to get well soon. Due to my poor speaking ability, I often encounter problems at work. The situation gets better now. I really desire to speak more fluently, unlike the present condition. I am sure I can make it with more practice.

認識新朋友，中風後我身邊的朋友越來越少，之前我有很多朋友的，如果有朋友，沒有見面便算了。沒有所謂的，所以現在我會認識一班新朋友。朋友是一班又一班的，沒有見面便算了。如朋友找我，我便一起傾談。如朋友不找我，便算了。我不會特地去找朋友。

Meeting new friends, after stroke, I have fewer and fewer friends. This situation is exactly opposite to my premorbid state. If I have friends whom I do not always meet with, I will just let go and meet a group of new ones. Therefore, my friends come and go. I will not care much if we are not meeting one another regularly. If my friends come to me for a talk, I will welcome them. But if they do not, I’ll just leave it. I will not take the initiative to find friends.

將來希望做到的事，我希望可以繼續，這三個字，希望可以繼續，說話能力好些，活動能力好些，繼續工作，繼續做一切事情，都希望繼續。

Bucket list for my future, I want to continue to have improvements in my life! I hope to enhance my speaking ability, my mobility, my work and just everything! I hope to keep up such a belief!

鼓勵。支持，堅持做物理治療！希望做好這部份！希望儘快可以行動自如！

Encouragement, support, I persist in doing physiotherapy with an urge to get it done and a desire to move freely.

Video 11 Walk down the roads (Duration: 13 min)

於這段短片中跟大家分享的是一位女士，中風後她有過正面的也有負面的經歷。對她來說，最重要的是好好的為自己打算，安排好自己的生活。這段短片中她會跟大家分享她中風的經歷、如何改善自己的活動能力，如何安排自己的生活，繼續上班，沒有上班後她怎樣消磨時間。她亦會分享她有過的正面和負面的經歷。最後她鼓勵大家不用想太多，有路就走。現在讓我們一同聽聽她的分享！

This is a story of a female stroke survivor. Stroke brings her both positive and negative experience. To her, the most important thing is to plan for herself and make the right arrangement on her own life. In this short video, she is telling us her experience after getting stroke, the ways to improve her mobility and manage her life. She decides to continue her work. How she spends her leisure time will also be discussed. Besides, she also shares the positive side and negative side of her stroke experience. She ends up encouraging all stroke survivors to keep things simple and there must be a way out! It is time for us to get into her world!

我於二零零六年四月中風，相隔現在約八年了。我以前在寫字樓工作的，我負責安排時間表，以文職工作為主。中風後，我所有的計劃都給打亂了。我當時正計劃於幾年內退休，中風時我是五十六歲，打算在六十歲退休，於這幾年安排好退休後的生活，怎料給打亂了，硬從頭再來。

I suffered from stroke in April of 2006. It has been eight years since then. I used to work as an office lady who was responsible for making timetables, mainly in clerical work. After stroke, all my plans were interrupted. Indeed, I was planning for retirement in a few years afterwards. I got stroke when I was fifty-six years old. Intending to retire in my sixty. Therefore, I had begun arranging my life after retirement. However, the plan was interrupted and had to begin all over again.

中風經過，中風初期我都唔懂得驚，只希望自己千萬別不能走，不能動。但入院後，中風當晚我係自己行入醫院的，睡至半夜才發覺自己的手不能動，雙腿話能動，但慢慢地開始無力，那時開始慌張，不知怎算好。檢查後發覺我的血管阻塞，在醫院住了數星期，及後轉至另一間醫
The stroke process, initially, I did not feel scared. I just hoped that I could still walk and move. However, after getting hospitalised, I changed my perception. I remembered that I walked to the hospital at night. I discovered that my hands could not move at midnight. My legs were still movable although the strength was getting weaker. I started to panic with a blank mind. After some investigations, I noticed that my blood vessels got blocked. I have been staying in the hospital for a few weeks. Then, I was transferred to another hospital to receive three courses on acupuncture, thirty times in total. After discharge, I went to a day hospital for exercise. I was not fully recovered yet by that time. I did the exercise three days per week for the whole day and my conditions gradually improved. Later, I hired a domestic helper for cleansing. She came to my home from 9 a.m. to 5 p.m. six days a week. She is kind and helpful. She accompanied me for exercise after breakfast every time.

Improving my mobility, after stroke, we are all very nervous. Our hands tend to place at our chest level when crossing roads. This behaviour is very common among stroke survivors. It was shiny at 3 p.m. every day. My domestic helper held an umbrella and guided me. She accompanied me to cross the roads every day. We practised how to cross the road, go up and down the escalator. Due to nervousness, I walked very slowly. I stopped for a while before I continued. I needed to relax before crossing the roads. I had to practise crossing the roads before traffic lights turned red. Therefore, I chose some narrower roads for practice. I have practiced for a few months. I have started the practice before the commencement of my job for almost three to four months.

Hand exercise, my thumb can move now. Index finger and thumb are the most important. The functional use of these two fingers determines whether I can work or not. These fingers can spread apart, showing a good sign. After clenching objects, they could not spread apart in the past. After clenching, they can spread apart a bit now. What type of exercises did I do? Pulling the barbed wire. This helps exercise my hands.

After suffering from stroke, I continued to work. During the initial stage of stroke, I still got a paid job. However, I did not receive any salary four months afterwards. At that time, I had no idea what to do. The financial problem worried me a lot. After getting the proposal done, I had a discussion with the boss who came to Hong Kong to have a meeting with me. He allowed me to work three days per week. At that time, I lived in Tin Shui Wai. It took a long time for me to travel between Sham Shui Po and Tin Shui Wai. My helper accompanied me to go for work. She waited at the bus station at 7:45 a.m. every morning and sent me to my company. She then picked me up after work at night. A lunch box and a dinner box were also prepared every day. Then, I continued to work for around three months. Later, I moved to Mong Kok and lived alone. My helper who lived in Tuen Mun, so she could not take care of me anymore. I had to go to work by myself. At first, I went to work by taxi every day. Two to three months later, I started to take MTR by myself. It was fine for me to take MTR alone so I continued...
with my job. From Tuen Mun to Mei Foo, I came out from the West Rail exit. I always felt happy. Although taking the stairs was tired, I could keep working. Since the commencement of my job, I had ceased the worry about my disease. My disease did not provoke my anxiety again. I just took myself as a normal individual and worked until fifty-nine years old. I still had a half year to go before my retirement. Due to great pressure from work, I did not work anymore.

Period without a job, I always stayed at home after my unemployment. It was not good to my health. I wanted to step out of my home to have fun. I heard that transportations would be arranged after participating in those associations, and I need not prepare meals and other things by myself. Other people would make arrangements for us. I thought it was convenient so I joined the association together with some of my companions. After joining the association, I did not have to stay at home always. I went out with others with well-structured arrangement. We participated and played together whenever possible until now. When people confine themselves to a small place, s/he would get into a blind alley. Staying outdoors can energise us. It really helps improve our mood. Despite the limited flexibility of hands and feet, we can equip ourselves with a better mind. I also participate in some research studies, seminars or sports classes. As long as I can walk, I will participate in those activities. If I cannot move or with knee pain, I will not join those activities. I will stay at home and take a rest until I am physically fit for the activities.

Positive experience, when I lived in Tin Shui Wai, I went to work with my helper. I arrived at Mei Foo station where I had to go up and down the stairs. Some people gave me a nice eye contact and seemed to praise me deep down from their hearts. "You are doing very well! It is very encouraging to see you walk on your own!" A foreigner even thumbed up, saying that I did really well. That is very comforting to see someone acknowledge your effort paid.

Negative experience, I went to take a cruise for a trip. When I was queuing to ashore, I was staying with some companions and holding sticks in hand. Some people were really offensive, by saying "I will never come again!" At that time, caregivers and we were all very upset about it. I told them to ignore the words of that person. People are not always sensible and understandable. Thus, we do not have to stick to their words. Others’ comments are no more significant than ours. We must stand out bravely. If we look down on ourselves, no one will ever be proud of us. More importantly, we are not alone! We walk and support each other.

Encouragement • Support, opening up your mind is the most important. If you do not even take the first step, it will be very difficult to carry on. Holding back yourself all day helps nothing. It is useless to stick to our disease always! Keep things simple! There must be a way out!
Video 12 Be positive (Duration: 16 min)

於這段短片中跟大家分享的是一位女士，她曾有過三次中風，令她身心俱疲，但她仍很努力邁過這階段。現在她可以自己去覆診。這段短片中，她會跟大家分享她中風的經歷、平時鍛鍊活動能力的方法、中風後如何調整自己在跳舞事業上的角色，和她中風後的心情。她亦會分享她在復康過程裏的經驗和感受。最後她肯定地跟大家說，要自己幫自己，步步向前望。現在讓我我們一同聽聽她的分享！

This is a story of a female stroke survivor who has suffered from stroke for three times. Such an experience tortures her both physically and psychologically. However, she strives hard to overcome this difficult period. Now, she can go for follow-up appointments on her own. In this video, she is going to share with us her experience after getting stroke, the ways to train up her physical mobility, the adjustment made after stroke as a dance teacher, and her feelings after stroke. She also tells us her experience and feelings in the rehabilitative process. At the end of this video, she tells us confidently that self-management is crucial To keep us on the right track and move on. It is time for us to get into her world!

我和我丈夫都是跳舞老師。我在一九九八年第一次中風。中風後，我覺得自己仍很頑強，我的活動能力已訓練至跟正常人一樣。但十五年後，我第二次中風是在去年一月三日，下午一時十五分。我的左腦有血管爆了，我這次中風是很嚴重的。我右邊身體完全不能動，不能進食，不能說話。我第三次中風是在去年七月二十一日，也是因爆血管，但這次不是太嚴重，只是右手和右腳有點麻痺。我在入醫院後，才知道是第三次中風。因為我感覺到腳腳麻痺，入院後做電腦掃描，發現我腦內又出血，我才找到又中風。我在醫院的日間護理中心做運動，共三個月。

每星期做兩天運動，當時我的血壓正常。所以我覺得算吧，只好日日向前望，儘量做我應該做的事。可以幫助別人的話，便去幫助別人。可以的話便去鼓勵其他人。可以做的便去做，都不想想太多。即使我要想，也想不通。為甚麼？你不會知道會怎樣，所以要步步向前望。這是我的口號！

My husband and I are both dance teachers. The first time that I got stroke was in 1998. After getting stroke, I still found myself tough and strong. My mobility was trained to be as good as normal individuals. However, fifteen years later, I had stroke for the second time on 3rd January last year. It was at 1:15 p.m. Blood vessels on my left brain burst. It was a serious episode. My right side could not move at all. I could not eat nor speak. I got stroke again for the third time on 21st July last year. It was again a haemorrhagic one though with a lesser severity. I just felt numb on my right upper and lower limbs. I was noticed to have a recurrent stroke after getting hospitalised. Since numbness was the only symptom presented, I went for a computed tomography scan. The physician noted a haemorrhage in my brain. Then, I knew that stroke came to me again! I went to a day care centre to do rehabilitative exercise for three months. I did it twice a week with normal blood pressure. Therefore, I take the best way to move on and do what I should do. If I am able to offer help, I will lend the others a helping hand. I give encouragement to others whenever possible. To me, it is essential to do as much as I can in order to leave no regret. We cannot predict our future. Therefore, moving on with a positive mind is what I hold on tight.

重新定位，我其實不能再跳舞，因為我沒有能力再參加比賽。我也在去年十二月在老師的比賽中，宣佈我比賽退休了，所以我不會再跳比賽了。對我有影響的，因為不會再在比賽場地裏，見到我在比賽，但這會是另一個階段。雖然我不再比賽，不代表我不會教學生。將來我的學生可能跳得比我更好，這決定是我、我丈夫和我的老師一起做的。我的老師覺得這樣比較適合我們，一方面令自己的壓力不會太大，當你放棄一些事情後，會開心些，不會因為自己的能力做不到而令自己感到不舒服。

Reallocation of my job, indeed, I cannot dance anymore because I has lost my ability to join the competitions. I also announced that I would withdraw from competitions in December last year. Therefore, I am not joining competitions anymore. This was a major issue to me. I am not appearing in any of the competitions to win a place. However, I will enter another stage of my career. Although I do not act as a competitor, I can still teach students. Perhaps my students can do better than I do. This was a decision made together with my husband and teacher. My teacher thought this was a more suitable option for us. On one hand, I could refrain from great pressure due to reduced workload. I would not feel uneasy in the way that I lost the capability to complete tasks.
Keep your passion burning! I am not a superwoman, so I have thought of giving up too. Sometimes, I also feel like being a useless dummy. Whenever I want to give up, I talk to my husband or my son. They serve as my booster to give me the greatest support. My husband always encourages me to stay positive. No matter how bad the situation is, we should not give up and must carry on. Holding on to your belief is super important! Without value or belief, it is hard to stay passionate towards life. I want to continue my teaching, thus I have the passion.

The experience and feelings in rehabilitative phase, when I was having acupuncture, I saw a lot of stroke survivors with limited mobility. I therefore encouraged them to do more upper limb and hand exercise. He told me that it was very hard. I advised him to stretch his arms a bit when watching television so as not to feel difficult. He said he would rather die if he had to do in this way. I was very upset about it. I said you were here to receive treatment was all because of your children. They did not only settle the bills, their time was also devoted to bring you here. Therefore, we must strive hard! This is what I always tell. My Chinese medicine practitioner always used me as an example to encourage the others. At the very beginning, I came here on a wheelchair and was accompanied by my son. Both of them had to transfer me to the bed. Now, I can come on my own. I am able to come for follow-up appointments and go back home after getting the medication. I can go shopping as well. My Chinese medicine practitioner acknowledges my effort paid in the rehabilitative phase. Therefore, I always tell that your future is in your hands. No one can offer you help at any moment.

Encouragement – support, there is a Chinese song I like very much. One of the lyrics is (our spirit grows even brighter in sunny days). The name of this song is “A prosperous future”. I always have this song in mind, hoping to encourage others to strive hard and face the obstacles with bravery. No matter how difficult the situation is, we should never stop seizing the day.

Video 13 Talk more ● Feeling good (Duration: 13 min)

This is a story of a male stroke survivor who lives alone. After suffering from stroke, he has once isolated himself from the community. Later, he has participated in some activities especially designed for stroke patients with more interaction with others, his mood gets better. In this video, he is telling us his experience after getting stroke, his physical mobility after stroke, the impacts on his psychological and social aspects of life. He also talks about how he could overcome and adapt to the changes before and after suffering from stroke. Finally, he tells us the tips of managing his life after suffering from stroke. It is time to get into his world.
大家好！我於二零零三年中風。因為血管阻塞，我那时已沒有工作了。因為自己年齡雖然不大，但自小的身體都較孱弱，一直是獨居。中風後的活動能力，中風令我的活動能力有些障礙，行動等各方面都很不方便。

Hello, everyone! I suffered from stroke since 2003. Due to vascular occlusion, I had lost my job at that time. Although I did not have advanced age, my body has been weak since birth. I am used to live alone.

中風後的心情，初有這個病時，自己的情緒曾經很低落，自己的生活習慣完全改變了。初時真的不能接受這個情況，突然的一個大改變。平時我很活躍的，游泳、行山、四處走，突然變成今天這樣。

My mood after stroke, during the initial stage of stroke, I had low mood almost every day. My lifestyle was changed completely. At first, I really could not accept the situation. It was a sudden and huge change to me. In the past, I was a very active and sporty person who swam, went hiking and enjoyed outdoor activities. All of a sudden, I was turned to be like this.

不想與外界接觸，躲在家中不想出外見朋友，像是自閉的，都有約兩至三年。中風前我有一些朋友的，會大家在一起的。中風後沒有跟他們一起了。放開心情，後來參加了一些機構的活動，多了出外，認識新朋友。大家互吐心聲，講講自己日常生活中的不好或不方便，有哪些事情需要其他人幫助，解決日常生活的困難。我自參加了這些服務中風人士的組織，我有很多活動。我自己比較活躍的，喜歡運動，去旅行。中心會舉辦很多興趣班等，對改進自己的日常生活都有些裨益的。

Not interacting with anybody, I stayed at home all the time and avoid all gatherings with friends as if I was autistic. It lasted for about two to three years. Before suffering from stroke, I had some friends whom I stayed together with. After suffering from stroke, we did not contact one another again. Opening up my mind, later, I have participated in activities organised by some institutions. I had more chances to go outside and met new friends. We shared together. We talked about the hard time or inconvenience in our daily lives and things that required others’ assistance. This facilitated the sharing of information and experience among stroke survivors. The participation of these activities energised me a lot. I became more active as before. I did exercise and went traveling. The institution have organised various classes to elicit our potential. These induced a great improvement in my daily life.

中風前後的改變，至於改進方面，要完全改進是不可能的。因為好像現在要寫字時，以前我用手工寫字是很流暢的。但現在寫字時的力度跟以前有很大分別，力度少了。現在我的字體較以前不太端正。現在用筷子挾起較大或重的食物時，都有些困難。現在要慢慢地挾起較輕或細小的食物。

Changes before and after suffering from stroke, as for the improvement, it is impossible to look for full recovery. Taking writing as an example. I used to write very smoothly in the past. However, there is a huge difference in the exertion of force in writing I now write with less exerted force. My penmanship now is less beautiful than before. When I use chopsticks to hold large or heavy food, I also encounter difficulty. I have to hold small or light food slowly now.

怎樣面對？只有處之泰然！不會鑽牛角尖！因為現在做事最緊要實際，不可能做的事，不會不可能而為之的。自己做不來的便無謂費精神去做，一是對自己無益，二是浪費了時間。不如向好的方面想，對自己更有益，其餘的都是不設實際的。

How to overcome? Just take it easy! Never stick yourself in a blind alley! I now focus on the feasibility of tasks. If the tasks are not feasible at all, I will not waste my time on that. It is unwise to put your time and energy on impossible missions. That does no good to us and time will be wasted as well. If I think positively, it is more beneficial to me. The rest are impractical to me.

中風後的自我管理，如自己的能力和精神許可，便參加。如果做不來或需要長時間活動，便不會勉強去做了，最重要的是要靠自己管理！因為我是自住的，沒有其他人管束自己，而且得出的後果都是自己負責，是否願意去改就由自己決定！

Self management after stroke, if I have ability and energy, I will participate. For impossible missions or activity taking a long time to complete, I will not force myself to do it. Good self-management is essential! I live alone, so no one can control and influence my decision. I solely bear the responsibility. Therefore, making changes all depends on me!
於這段短片中跟大家分享的是一位女士。中風後她經歷了一次大手術，手術後因為孫女的一句話，她努力做運動，希望可儘快回復中風前的生活，照顧她的家庭。現在她做到了，不但做義工，還積極教其他中風朋友做運動，生活充實。這段短片中和她會跟大家分享她中風的經歷和中風後的活動能力。亦會談及她由初時一步步地學習做運動，到後來教其他中風朋友做運動的經驗和感受，對她的來說，於復康路上最重要的事。短片結尾還節錄了一段由她親自示範的一套坐在椅子上做的運動。現在讓我們一同聽聽她的分享！

This is a story of a female stroke survivor. After getting stroke, she had undergone a major surgery. Owing to a word from her granddaughter, she works hard in doing exercise post-operatively. It is hoped to get back to her premorbid state and take care of her family. She succeeds at last. Now, she works as a volunteer to teach other stroke survivors to exercise, leading a fruitful life. In this video, she is telling up about her experience after getting stroke and and her physical mobility after stroke. She also shares with us the transition from learning to exercise step by step to teaching other stroke survivors. Besides, she tells us her feeling and experience in doing exercise, and the most important thing along her rehabilitation journey. At the end of this video, she demonstrates a set of exercise that can be done when sitting on a chair in person. It is time for us to get into her world!

我是一名家庭主婦，我有三名孩子。我平時在家中照顧他們的早餐和飲食，還有負責清潔和車衣。中風經過，直至二零零零年二月初，我突然在晚上又嘔又頭痛。醫生說我中風了，說要幫我做手術。那是一項頗大的手術。手術中要先打開頭蓋骨，再在頭骨裏鑽一個洞，再在頸項取一條血管補上去，手術共進行了九小時。可能時間較短，對我的影響不大。出院後住進一間做物理治療的中心，住了一個多月。

I am a housewife with three children in total. I am responsible for their meals, cleaning and sewing. The stroke process, it was early February in 2000. Suddenly, I felt headache and started to vomit at night. The physician said I got stroke, claiming to start an operation for me. This is a major surgery. First, the physician had to remove part of the skull bone. Then, a hole was drilled so that a blood vessel from neck could be connected. This operation lasted for nine hours. Perhaps the operation was done for a rather short time, there were just little impacts on me. After discharge, I got into a centre for physiotherapy and stayed there for a month more.

中風後的活動能力，最印象深刻的是我的孫女來醫院探我時，孫女告訴我。「婆婆，我每晚都會為你祈禱的！我跟天父說你一定要康復，如你不康復，便沒有人照顧我了。我每晚都這樣同天父說的。婆婆，你會沒事的，你一定會出院的！」可能這些鼓勵說話影響我，我的身體真的沒有太大問題，而我當然很心急，家中有老有嫩要照顧，我很想出院的，但物理治療師說我暫未能出院。你試走幾步，我告訴你為什麼不能出院。你試走幾步，我給你解釋，你便會明白。當我走路時，他說我的身體會飄向一邊，你暫未能一步一步地走，你會跌倒的，所以暫未能讓你出院，他解釋給我知。我很心急，想快些出院，但物理治療師不讓我出院，要我能走路才讓我出院，我唯有自己努力做運動。

My physical mobility after stroke, my granddaughter came to visit me in the hospital. She told me that "Grandma, I pray for you every single night. I ask Lord to heal you up. If you do not get well, no one will be taking care of me. This is what I tell the Lord. Grandma, you will be alright and get discharged!" All these encouraged me a lot. It is not a big problem to my physical health. Of course, I longed for getting discharged since I still had to care for a lot of family members. Yet, physiotherapists told me that it was not time for discharge. He asked me to walk for a few steps before telling me the reason. He promised to explain everything to me. When I walked, my body just deviated to one side. I was incapable of walking step by step at that time. He worried that I would fall on the ground after discharge. This is what he told me. Despite my desire to get discharged, physiotherapists insisted on their decisions. He would allow me to get discharged only when I could walk with a stable gait. Therefore, I stay persevered to do exercise.

教學其他中風康復者做運動，我屋企附近有一個政府舉辦的活動，是給予六十歲以上人士參加的康體活動。我參加後發覺原來可以坐着做運動，全身都可以活動。於是我學習並將這套運動，然後在小組活動時跟大家說，我們可以坐着做運動，我們可否一起坐着做這套運動呢？就這樣開始教其他中風朋友做運動，他們大部份跟做運動的都很開心。

Teaching other stroke survivors to exercise, at that period of time, a government-funded activity was held nearby. It was a creative and sports activity specially for people in sixty or above. From that activity,
I learnt to do exercise while sitting on a chair. It was an exercise that moves all your body parts. Therefore, I learnt this set of exercise by heart and invited other stroke survivors to practise this set of exercise with me. I encouraged each other to learn it. That started my teaching on rehabilitative exercise. Most of them learn it with joy.

The greatest difficulty in exercising, the biggest problem is forgetfulness. When I went back home, I often forgot the action taught in lesson. Indeed, I learnt the set of exercise from a master who has been teaching the same set of exercise each year. Even though I had done it for two years, I could not remember all actions not until the third year. My memory was getting poorer, maybe advanced age matters. The reason for remembering every single action is to understand the meanings behind. I require my master to explain each action to me. In the past, I acted as a follower. However, I could not grasp the main point of that action. Getting the main point helps me remember the actions better. For example, in Qigong Ba Duan Jin, I can remember the actions as long as I know to get the manoeuvre. There are some pithy formula in each manoeuvre. This is how I strengthened my memory on exercise. For example, “both hands push towards the sky and do it in three parts”. You will then remember to push your hands forward, upward and then downward. “Your kidneys and waist get strengthened when your hands are able to touch your feet”. Remembering the clues really helps.

Does doing exercise really work? You can experience the progress for sure. We might not experience the improvement immediately. The same situation applies to me too. Even though I learnt the exercise, it takes around an hour or more to complete all the actions.

Sharing of exercise and feeling, I would teach the companions to exercise our limbs and joints. I would encourage them not to use a stick and step out with stability. Then, try to take another step and walk gradually. As long as we have confidence, we can make it! The greatest hurdle is a lack of confidence among stroke survivors. They would think that they could not move freely. I am a normal, healthy person to their perception. I said it was not the case. Then, I showed them the scores. They ended the conversation with a surprise. Therefore, I told them not to give up and stay confident. If you decide to give up, You really cannot do anything. Although we have to live with stroke, we can still lead a joyful life. Taking the initiatives to give things a try is already a good sign. The most important thing is not to stay at home always. We tend to think negatively when staying alone at home. Stepping out of your door to meet friends can be a better option. Chatting with family and friends can help us relax a bit. If we conserve all the unhappiness, our life will get worse. Therefore, let’s take the first step bravely! We are companions. Your conditions may not be the worst among all! Meeting new friends and sharing our life experience can really make a difference. Thus, I encourage all stroke survivors to go for visits.

在復康路上最重要是甚麼？豁出去，即使現時不能動，都要活動，若不活動，關節便會變硬。再活動那些關節時，你便覺痛，你覺痛便更加不想活動，就是這樣鼓勵大家多活動。千萬別想著我不能動，便不去活動，那便糟糕了。
The most significant thing in rehabilitation journey, moving around as much as possible can prevent frozen joints. You will find more painful if you do not move at all. If you feel hurt, I can assure that you will lose your desire to exercise. This is what I tell the others. Do not give yourself excuses not to do exercise. That is the most important!

Video 15 After volunteering (Duration: 5 min)

This is a story of a female stroke survivor. She has suffered from stroke for twice. Her motion slows down after stroke. However, her conditions improve day by day. She even devotes herself in doing voluntary service and initiating visits. She thereby becomes more and more cheerful. In this video, she is telling us her experience after getting stroke and her feelings after stroke. She also shares with us the reason why she loves doing voluntary work. As an experienced person, she encourages all stroke survivors. It is time for us to get into her world.

I got stroke in 1993 and lost my consciousness for two days. I regained my consciousness on the third day. Fortunately, I was given another chance to survive and stay awake. However, my motions slow down a lot after stroke. Indeed, I worked for the government in the past. Yet, I quitted my job after stroke and took up the responsibility for cooking meals. I had hired a domestic helper before. Later, I found her unnecessary to me anymore. I started to take up all the things on my own, including taking care of my children. I have two daughters who were in primary one and three respectively. I took care of them and cook for my family members. Nothing had gone wrong so far. Ten years later, I suffered from a haemorrhagic stroke again and was hospitalised. The surgeon was exactly the one who treated me before. After discharge, I went to a rehabilitation centre. Not only do I joined the activities organised by the centre, I also went for visits sometimes. That improved my mood a lot. I need not stay at home always! Until now, I have been living with stroke for twenty one to twenty two years. My daughters are grown-ups who have completed their undergraduate study and entered the workforce. Now, I can have time to do what I want.
中風後的心情，第一次中風後我做起事來很慢，我很急躁的。第二次中風時我做起事來較容易，所以我覺得可能現在我不用顧及那麼多的事，所以比較好些。即是有時不要催促我煮好飯菜或完成某些事情，我會很煩燥的。這樣做不到，那樣又做不到，我便會很煩燥。第二次中風後一切都較順暢，我可以去做義工，比較好些。

My feelings after stroke, I did things really slowly after the first episode of stroke. I was very impatient about it. Things get better when I suffered from a recurrent stroke. Therefore, when I do not have to be a multi-tasker, things go more smoothly. If I am forced to cook the meals or finish certain things quickly, I will become very impatient about it. If I cannot finish the tasks desired, I will become very annoyed and impatient too. Perhaps everything went smoothly at the second episode of stroke. I can go to do voluntary work. That seemed to be better for me.

現時的活動能力，右手是不太好的。右手不太自然，左手很自然。右手不是舉得很高，右腳的感覺比較差，左腳的感覺較好。

My physical mobility after stroke, my right hand was weaker than the left one. My left upper limb is more flexible and natural in making movements. I could not raise my right hand high. The sensation of my right lower limb is poorer compared with the left one.

做義工，參加義工服務！我很喜歡做義工服務的！有時會學習其他新事物，例如有關中風後如何管理自己的生活。

Being a volunteer, joining voluntary service is my favourite thing to do on my list. Sometimes, I get to learn new things. For example, the self-care management in post-stroke life.

鼓勵支支持，儘量多跟其他人傾談，就會好些！如終日一個人待在家中，便不好了！

Encouragement, support, opening up yourself to talk to others is a good way to ventilate your emotions! Staying at home always is no good to your psychological and social health!
Appendix J

Video content page and design of the DVD cover
Appendix K

Cover page of the program workbook in Chinese and an English translation of the workbook contents

A confidence enhancing stroke self-management program
Program Workbook
Version 1 2014

“Effectiveness of a confidence enhancing stroke self-management program for community-dwelling stroke survivors”
This program workbook is specifically designed for the program examined in this study.
Author / Editor Suzanne Hoi-Shan LO

School of Nursing, Faculty of Health, Queensland University of Technology
Enclosed 2 DVDs
Cantonese
Effectiveness of a confidence enhancing stroke self-management program for community-dwelling stroke survivors

This study is aimed at assessing the effectiveness of a confidence enhancing stroke self-management program on promoting recovery among community-dwelling stroke survivors.

A confidence enhancing stroke self-management program

This program is aimed at enhancing community-dwelling stroke survivors’ confidence and outcome expectation of performing stroke self-management behaviours, and enhancing their level of performance of stroke self-management behaviours, improving their depressive symptoms and community reintegration. This program is designed based on the self-efficacy theory postulated by the famous U.S. psychologist Bandura A.

What is stroke self-management?

In general, it is about active participation in managing your own health condition. Including:

1. medical management
2. emotional management
3. role management

To attain effective stroke self-management, it is important to practice the five core self-management skills.
- Problem-solving skills
- Decision-making skills
- Goal setting and action planning
- Communication with healthcare professionals
- Community resources utilisation

(Lo et al., 2013; Lorig et al., 2007)

What are stroke self-management behaviours?

Examples:
- Regular exercise
- Attend medical follow-up appointment
- Nutrition
- Manage your own emotions
- Participate in social activities
- Continue to participate in or adapt to own family or social roles

Apart from the above examples, what other stroke self-management behaviours can you think of?

I am the manager of myself
Recovery journey after stroke
Goal setting, action planning
Confidence
Positive outcome expectation
Self-management behaviours
Continuous learning
Be good to yourself and people around you

Accomplishing stroke self-management behaviours
I can do it!

1. Enhancing confidence
   Ways:
   Having mastery experience
   Observing others’ behaviours
   Providing verbal persuasion
   Reinterpreting the influence of physical and psychological symptoms

2. Having positive outcome expectation
   You will have attained your expected outcomes after having performed the stroke self-management behaviour.
   “I can be … after I have performed …”
3. Goal setting
Smart goals with the following five elements:
Specific, measurable, achievable, relevant, time-based

4. Action planning
Tips for good action planning

Sharing / Interaction
15 stroke survivors who have successfully managed their stroke shared with you their experience and tips via video clips.

Video 01  Stay strong
He strives to continue his interest – calligraphy after stroke. He also practices calligraphy and drawing using his left hand. In the video, he uses his calligraphy to demonstrate to others that we need to ‘Stay strong’. (07:20)

Video 02  Setting goals. Confidence enhancing
‘How you perceive things will determine the level of performance that you can attain’, ‘Never give up’, he had a stroke when he was young, he faces his stroke positively. He sets goals for himself every week, he sees his improvement gradually, and his confidence is enhanced. (15:16)

Video 03  Live in the present
She likes arts, and drawings. Her passion about drawing does not decrease after having stroke for two times. Now she is over 80 years old, she keeps learning new things, exercise regularly, and believes in the life philosophy ‘Live in the present’. (15:49)

Video 04  Take care of myself
A traditional Chinese man, motivated by his two sons, recovers from his stroke. He was not able to take care of his activities of daily living after stroke. Now he can walk independently with a stick. He said, ‘Work hard to practice, take care of myself, it’s ok!’ (12:46)

Video 05  I wish I can continue
It’s not difficult to note that he always say, ‘I wish I can continue …’ in the video. It is because that he has hope and expectation about the future, he doesn’t stop after stroke. Now he returns to work. He works hard for himself, his little girl and his family. (12:10)

Video 06  Help others and self-help
She thought of giving up several times. Now she has passed through the hard times. She perceives the stroke as one of the chapters in her life. She learns many new things after stroke. She participates actively in volunteer services in recent years. She uses her own experience to help others with similar experiences. She helps other and helps herself. (16:17)

Video 07  Be positive
Having a stroke for three times made her tired. However she tells you firmly that she is a good example. From not being able to walk to now that she can attend medical follow-up herself … as long as you work hard, there will be returns. (14:59)

After viewing these videos,

Video 08  My life in my hands
He had a stroke after he had retired. He gradually recovered with the care of his wife. He has never stopped exercising and training himself. It is because he believes that ‘his life is in his hands’. (14:37)

Video 09  Be confident. All is possible
She could not talk and her mobility was severely restricted. On one occasion, because of one kettle of water, she determined that she had to work hard to train herself. She did not want to require assistance from others any more. From then, she learns ceramics. She made each pieces of ceramics with her left hand. (15:18)

Video 10  Continuous practice • Memory and mobility
He smiles and tells you his own ways of training his memory and mobility, how he changes roles with her wife to manage the household issues. Everything has passed. Now he faces the pain during the journey after stroke at ease. (14:59)

Video 11  Meet new friends • Integrate into the community
He had a stroke at his middle age. The world turned grey. He had several months when he was not able to walk outdoors. Later he took his first step to go to the park near his home. He knew many new friends gradually and reintegrated to his social life. (14:26)

Video 12  Walk down the roads
She had both positive and negative experiences after stroke. For her, the most important thing is to have a better planning for herself, arrange well in advance her life. She said, ‘there is no need to think too much. Wherever there are roads, just walk down the roads.’ (12:37)
Video 13  Talk more. Feeling good
He lives alone. He have had a time of isolating himself from the outside world. Later he joined
activities organised for the stroke survivors. After having talked more with others, he feels better.
(12:43)
Video 14  Exercise tips
She had a major surgery after her stroke. Motivated by her grand daughter, she worked hard to
exercise. She hopes to return to her pre-stroke life soon and took care of her family. She can do it
now. She also participates actively in teaching other stroke survivors to exercise and do volunteer
services. (13:09)
Video 15  After volunteering
She had stroke for two times. She did tasks at a much slower rate than before. She recovered
gradually. She actively participates in volunteer services and other visits. She feels happier. (04:55)

Sharing / Talks
“Stay strong.”
“I work very hard to do exercise, practice standing, practicing sitting, practicing walking. We have to
keep practicing!”
“Work hard to do exercise. Never give up!”
“Keep doing it! Must be confident in ourselves!”
“Participate in more activities. Keep contact with more people. It makes me feel happier!”
“Regardless of you are happy or not, time still goes on. I choose to lead my days happily!”
“Walk around outdoors, and know more people. You will feel better!”
“I can do it and so you can do it too.”
“All people who have stroke need to work it out themselves!”
“I like drawing, so I continue to draw pictures. Being able to find a thing that you like to do makes me
feel that my life is meaningful.”
“After stroke, I swapped the roles with my life. We shared to look after the households ourselves.”
“Live in the present!”
“I think that a persons has to work continuously. Therefore I keep doing exercise. I read books when I
have time, or practicing speaking. It enables me to learn more new things.”
“There are groups and groups of friends. I knew another new group of friends after stroke.”
“I will set a goal for myself each week. When I see that I have improvement, I will be more confident
in doing it. Then I will make more steps of progress.”
“Now I have found a job. I hope that I can do it better.”
“I have only one hand. How can I do ceramics? I used the other hand to help this hand to do it. It
works.”
After viewing of the 15 videos, do you have any sharing words that impressed you most?”

Stroke self-management behaviours
My Goals
Upon completion of this program, I will be

Which goal is the one that you want to achieve it first?
What is the level of your confidence in performing the target self-management behavior?
What do you expect to be after you have performed the target self-management behavior?
Not confident at all  0 1 2 3 4 5 6 7 8 9 10 Very confident

My action plan
In this week, I will
Good planning
My record of goal planning
You goal: completed  not completed

After the program has finished, my goal has
Been completed
Been partially completed
Not been completed

Can I achieve the outcome expectation?
After the program has completed, I will
1. Set a new goal and an action plan
2. Continue to work on the action plan
3. Review the goal and the action planning

My thoughts / My feelings
I think that I have performed the stroke self-management behaviours …
I am confident in …
My goal in this week …
I have planned …

References

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If you would like to have further information about this study, please do not hesitate to contact us.

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Appendix L

The original English version of Stroke Self-Efficacy Questionnaire

These questions are about your confidence that you can do some tasks that have been difficult for you since your stroke. For each of the following tasks, please circle a point on the scale that shows how confident you are that you can do the tasks now in spite of your stroke.

Where 0 = not at all confident and 10 = very confident

1. Get yourself comfortable in bed every night

2. Get yourself out of bed on your own even when you feel tired

3. Walk a few steps on your own on any surface inside your house.

4. Walk about your house to do most things you want.

5. Walk safely outside on your own on any surface.

6. Use both your hands for eating your food.

7. Dress and undress yourself even when you feel tired.
9. Prepare a meal you would like for yourself.

10. Persevere to make progress from your stroke after discharge from therapy.
   
   Savanna

11. Do your own exercise programme every day.

12. Cope with the frustration of not being able to do some things because of your stroke.

13. Continue to do most of the things you liked to do before your stroke.

14. Keep getting faster at the tasks that have been slow since your stroke.

Reference
Appendix M

The Chinese version of Stroke Self-Efficacy Questionnaire translated by the Ph.D. candidate

中風自我效能問卷

這些問題是關於你有多大信心做一些自你中風後對你來說可能有困難的事情。就以下各項，請在量表上圈出一個數字以表示儘管你已中風，你對自己現時能夠做到這些事情的信心有多大。

0 代表完全沒有信心 及 10 代表非常有信心

你現時對自己能夠做到以下事情的信心有多大

<table>
<thead>
<tr>
<th>完全沒有信心</th>
<th>非常有信心</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

1. 每晚讓自己舒適地睡在牀上。
2. 雖然你感到疲倦，仍可自行下牀。
3. 在你家中的任何地面上自行步行數步。
4. 在你家中走動去做大部份你想做的事情。
5. 自行在室外的任何地面上安全地走路。
6. 用你的雙手進食。
7. 雖然你感到疲倦，仍能自行穿上及脫下衣服。
8. 為自己準備一頓喜愛的膳食。
9. 在完成治療後，仍堅持不斷要從中風中康復過來。
10. 每天進行你自己的運動計劃。
11. 克服中風而無法做到某些事情的挫敗感。
12. 繼續做大部份你中風前喜歡做的事情。
13. 不斷將自從你中風後做得緩慢的事情做得越來越快。
Appendix N

The English version of Stroke Self-management Outcome Expectation Scale

The following sentences are some stroke specific self-management behaviours and the corresponding outcomes that the behaviors will produce. For each item, please indicate how confident you are that doing the following activities will lead to the stated outcomes.

0 – Not confident at all       10 – Very confident

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If I exercise regularly, I will <strong>be more physically independent to do what I want.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>2. If I adopt a healthy lifestyle, I will <strong>have improved physical functioning.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>3. If I attend follow-up appointment, I will <strong>understand my health condition better.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>4. If I deal with my emotional reactions to my stroke and daily events, I will <strong>feel more at ease.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>5. If I participate in social activities regularly, I will <strong>feel happier and supported.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>6. If I keep regular contact with my family, I will <strong>have a closer relationship with them.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>7. If I keep regular contact with my friends, I will <strong>have a closer relationship with them.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>8. If I continue to take up or adjust my family roles after stroke, I will <strong>have a family life that I am comfortable with.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>9. If I continue to take up or adjust my social roles after stroke, I will <strong>have a social life that I am comfortable with.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>10. If I develop my plan of care with my health care providers, I will <strong>be more involved in my recovery process.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td>11. If I continuously practice strategies to self-manage my life after stroke, <strong>my quality of life will be enhanced.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>
Appendix O

The Chinese version of Stroke Self-management Outcome Expectation Scale translated by the Ph.D. candidate

以下是有关中风后自我管理的行为及完成该项行为后期望可以达到的结果。就以下每一项，请指出你觉得自己完成该项中风后自我管理行为后，有多大信心可以达到该项所指的结果预期。

0 代表完全没有信心 及 10 代表非常有信心

<table>
<thead>
<tr>
<th>你觉得自己完成以下中风自我管理行为后，有多大信心可以达到所指的结果预期呢？</th>
<th>完全没有信心</th>
<th>非常有信心</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 如果我定期做运动，我就可以更活动自如地去做自己想做的事</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>2. 如果我保持健康的生活习惯，我的身体状况就会得到改善</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>3. 如果我按时复诊，我就会更了解自己的健康状况</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>4. 如果我处理好自己面对中风和生活中各种事情的情绪，我就会感觉更自在</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>5. 如果我定期参与社交活动，我就会觉得更开心和感受到其他人的支持</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>6. 如果我同家人保持联系，我和他们的关系就会更亲密</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>7. 如果我同朋友保持联系，我和他们的关系就会更亲密</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>8. 如果我在中风后做回自己在家庭里原有或新的角色，我就有一个令自己觉得舒适的家庭生活</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>9. 如果我在中风后做回自己在社交圈里原有或新的角色，我就有一个令自己觉得舒适的社交生活</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>10. 如果我和医护人员一起去订立自己的照护计划，我就会更投入参与自己的康复活动</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>11. 如果我持续实践不同的方法，去管理好自己中风后的生活，我的生活质量就会提高</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix P

The English version of Stroke Self-management Behaviours Performance Scale

Please indicate your level of satisfaction with your performance of each of the following stroke self-management behaviours.

0 – Very dissatisfied  10 – Very satisfied

<table>
<thead>
<tr>
<th>Stroke self-management behaviours</th>
<th>Very dissatisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Exercise regularly.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>2. Adopt a healthy lifestyle.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>3. Attend follow-up appointment.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>4. Deal with my emotional reactions to my stroke and daily events.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>5. Participate in social activities regularly.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>6. Keep regular contact with my family.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>7. Keep regular contact with my friends.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>8. Continue to take up or adjust my family roles after stroke.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>9. Continue to take up or adjust my social roles after stroke.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>10. Develop my plan of care with my health care providers.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>11. Continuously practice strategies to self-manage my life after stroke.</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix Q

The Chinese version of Stroke Self-management Behaviours Performance Scale translated by the Ph.D. candidate

就以下各項中風後自我管理行為，請表示你對自己完成該項行為的表現的滿意程度。

0 代表非常不滿意 及 10 代表非常滿意

<table>
<thead>
<tr>
<th>中風自我管理行為</th>
<th>非常不滿意</th>
<th>非常滿意</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 定時做運動</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>2. 保持健康的生活習慣</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>3. 依時覆診</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>4. 處理好自己面對中風和生活各種事情的情緒</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>5. 定期參與社交活動</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>6. 同家人保持聯繫</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>7. 同朋友保持聯繫</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>8. 中風後做回自己在家庭裏原有或新的角色</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>9. 中風後做回自己在社交圈裏面原有或新的角色</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>10. 同醫護人員一齊去訂立自己的照護計劃</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
<tr>
<td>11. 持續實踐不同的方法，去管理好自己中風後的生活</td>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix R

The original English version of Stroke Specific Quality of Life Scale

We would like to know how you’re doing with activities or feelings that can sometimes be affected by stroke. Each question will ask about a specific activity or feeling. For each question, think about how that activity or that feeling has been in the past week.

The first group of questions asks about how much trouble you have with a specific activity. Each question deals with problems that some people have after their stroke. Circle the number in the box that best describes how much trouble you have had with that activity in the past week.

DURING THE PAST WEEK:

<table>
<thead>
<tr>
<th></th>
<th>Couldn’t do it all</th>
<th>A lot of trouble</th>
<th>Some trouble</th>
<th>A little trouble</th>
<th>No trouble at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did you have trouble preparing food?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Did you have trouble eating, for example, cutting food or swallowing?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Did you have trouble getting dressed, for example, putting on socks or shoes, buttoning buttons, or zipping?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Did you have trouble taking a bath or shower?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Did you have trouble using the toilet?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Did you have trouble seeing the television well enough to enjoy a show?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Did you have trouble reaching for things because of poor eyesight?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Did you have trouble seeing things off to one side?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Did you have trouble speaking, for example, get stuck, stutter, stammer, or slur your words?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Did you have trouble speaking clearly enough to use the telephone?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Did other people have trouble understanding what you said?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Did you have trouble finding the word you wanted to say?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Did you need to repeat yourself so others could understand you?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
The next set of questions asks about how much you agree or disagree with each statement. Each question deals with a problem or feeling that some people have after their stroke. Circle the number in the box that best says how you felt about each statement during the past week.

<table>
<thead>
<tr>
<th>Question</th>
<th>Couldn’t do it at all</th>
<th>A lot of trouble</th>
<th>Some trouble</th>
<th>A little trouble</th>
<th>No trouble at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Did you have trouble walking? (If you can’t walk, circle 1 and go to question M7)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Did you lose your balance when bending over or reaching for something?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. Did you have trouble climbing stairs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. Did you have trouble with needing to stop and rest when walking or using a wheelchair?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. Did you have trouble with standing?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. Did you have trouble getting out of a chair?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. Did you have trouble doing daily work around the house?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. Did you have trouble finishing jobs that you started?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. Did you have trouble doing the work you used to do?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. Did you have trouble writing or typing?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. Did you have trouble putting on socks?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. Did you have trouble buttoning buttons?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Did you have trouble zipping a zipper?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. Did you have trouble opening a jar?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
**DURING THE PAST WEEK:**

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Moderately agree</th>
<th>Neither agree nor disagree</th>
<th>Moderately disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>28.</td>
<td>It was hard for me to concentrate.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29.</td>
<td>I had trouble remembering things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30.</td>
<td>I had to write things down to remember them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31.</td>
<td>I was irritable.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32.</td>
<td>I was impatient with others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33.</td>
<td>My personality has changed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34.</td>
<td>I was discouraged about my future.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35.</td>
<td>I wasn’t interested in other people or activities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36.</td>
<td>I didn’t join in activities just for fun with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37.</td>
<td>I felt I was a burden to my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38.</td>
<td>My physical condition interfered with my family life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39.</td>
<td>I didn’t go out as often as I would like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40.</td>
<td>I did my hobbies and recreation for shorter periods of time than I would like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41.</td>
<td>I didn’t see as many of my friends as I would like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42.</td>
<td>I had sex less often than I would like.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43.</td>
<td>My physical condition interfered with my social life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44.</td>
<td>I felt withdrawn from other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45.</td>
<td>I had little confidence in myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46.</td>
<td>I was not interested in food.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>47.</td>
<td>I felt tired most of the time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48.</td>
<td>I had to stop and rest often during the day.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49.</td>
<td>I was too tired to do what I wanted to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Reference**


Appendix S

The Chinese version of Stroke Specific Quality of Life Scale translated by the Ph.D. candidate

中風生活質素量表

我們希望了解一下你在進行一些有時會因中風而受影響的活動時的情形或感受。每一條問題會問關於一項指定的活動或感受。就每一條問題，想想你在過去一星期中進行這些活動時的情形或感受。第一組問題會問有關你進行一項指定的活動時有多大困難。每一條問題均關於一些人在中風後會有的問題，請在空格上圈出一個數字，而這數字是最能表示你在過去一星期中，進行該活動時的困難有多大。

在過去一星期中，

<table>
<thead>
<tr>
<th>項目</th>
<th>完全無法做到</th>
<th>有許多困難</th>
<th>有少許困難</th>
<th>完全沒有困難</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. 食物有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. 進食有沒有困難？例如將食物切塊或吞嚥？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. 穿衣服有沒有困難？例如穿襪、穿鞋、扣鈕，或拉鍊？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. 浴或淋浴時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. 如廁時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. 你有沒有因為看不清楚電視畫面，以致影響去享受該電視節目？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. 你有沒有因視力不佳，以致拿取東西時感到困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. 你看偏側一方的東西時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. 說話時有沒有困難？例如語塞、口吃、結巴，或含糊不清？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. 你有沒有困難清晰地講電話？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. 別人有沒有困難去明白你說的話？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. 你有沒有困難尋找合適的字詞以表達你想說的話？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. 你需要重覆你說的話時，其他人能明白你？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. 走路有沒有困難？（如受訪者不能走路，請將第14至16題評為1分，及跳到第17題）</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. 你彎腰或伸手取物件時有沒有失平衡？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. 上樓梯時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. 走路或使用輪椅時，會否因感到困難，而需要停下來休息？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. 站立時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. 你從椅子起來有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. 做日常活動時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. 你要完成你已開始的工作時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. 當你做你以往常做的工作時有沒有困難？</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
下一組問題會問有關你對每一句句子有幾同意或不同意。每一條問題均關於一些人在中風後有的問題或感受。請在空格上圈出一個數字，而這數字是最能表示你在過去一星期中對每一句句子的感受。

在過去一星期中，

| 23. 你書寫或打字有沒有困難？ | 完全無法做到 | 有很多困難 | 有些困難 | 有少許困難 | 完全沒有困難 |
| 24. 你穿襪子有沒有困難？ | 1 | 2 | 3 | 4 | 5 |
| 25. 你扣鈕有沒有困難？ | 1 | 2 | 3 | 4 | 5 |
| 26. 你拉拉鍊有沒有困難？ | 1 | 2 | 3 | 4 | 5 |
| 27. 你開瓶蓋有沒有困難？ | 1 | 2 | 3 | 4 | 5 |

| 28. 我難以集中精神。 | 非常同意 | 頗同意 | 中立 | 頗不同意 | 非常不同意 |
| 29. 我記事情時有困難。 | 1 | 2 | 3 | 4 | 5 |
| 30. 我需要將事情寫下才能把它們記住。 | 1 | 2 | 3 | 4 | 5 |
| 31. 我很急躁。 | 1 | 2 | 3 | 4 | 5 |
| 32. 我對其他人沒有耐性。 | 1 | 2 | 3 | 4 | 5 |
| 33. 我的性格已改變了。 | 1 | 2 | 3 | 4 | 5 |
| 34. 我對自己的將來感到氣餒。 | 1 | 2 | 3 | 4 | 5 |
| 35. 我對其他人或活動不感興趣。 | 1 | 2 | 3 | 4 | 5 |
| 36. 我沒有參與與家人玩樂的活動。 | 1 | 2 | 3 | 4 | 5 |
| 37. 我覺得自己是家人的負擔。 | 1 | 2 | 3 | 4 | 5 |
| 38. 我的身體狀況擾亂了我的家庭生活。 | 1 | 2 | 3 | 4 | 5 |
| 39. 我外出的次數沒有如我想要的多。 | 1 | 2 | 3 | 4 | 5 |
| 40. 我進行我的嗜好和康樂活動的時間較我想要的短。 | 1 | 2 | 3 | 4 | 5 |
| 41. 我見朋友的數量沒有如我想見的多。 | 1 | 2 | 3 | 4 | 5 |
| 42. 我進行性行為的次數較我想要的少。 | 1 | 2 | 3 | 4 | 5 |
| 43. 我的身體狀況擾亂了我的社交生活。 | 1 | 2 | 3 | 4 | 5 |
| 44. 我感到跟其他人很疏離。 | 1 | 2 | 3 | 4 | 5 |
| 45. 我對自己沒有信心。 | 1 | 2 | 3 | 4 | 5 |
| 46. 我對食物不感興趣。 | 1 | 2 | 3 | 4 | 5 |
| 47. 我大部分時間均感到疲倦。 | 1 | 2 | 3 | 4 | 5 |
| 48. 我在日間經常需要停下來休息。 | 1 | 2 | 3 | 4 | 5 |
| 49. 我太疲倦去做我想做的事情。 | 1 | 2 | 3 | 4 | 5 |
### Appendix T

**The original English version of Geriatric Depression Scale**

Choose the best answer for how you have felt over the past week:

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Are you basically satisfied with your life?</td>
<td>Yes</td>
</tr>
<tr>
<td>2.</td>
<td>Have you dropped many of your activities and interests?</td>
<td>Yes</td>
</tr>
<tr>
<td>3.</td>
<td>Do you feel that your life is empty?</td>
<td>Yes</td>
</tr>
<tr>
<td>4.</td>
<td>Do you often get bored?</td>
<td>Yes</td>
</tr>
<tr>
<td>5.</td>
<td>Are you in good spirits most of the time?</td>
<td>Yes</td>
</tr>
<tr>
<td>6.</td>
<td>Are you afraid that something bad is going to happen to you?</td>
<td>Yes</td>
</tr>
<tr>
<td>7.</td>
<td>Do you feel happy most of the time?</td>
<td>Yes</td>
</tr>
<tr>
<td>8.</td>
<td>Do you often feel helpless?</td>
<td>Yes</td>
</tr>
<tr>
<td>9.</td>
<td>Do you prefer to stay at home, rather than going out and doing new things?</td>
<td>Yes</td>
</tr>
<tr>
<td>10.</td>
<td>Do you feel you have more problems with memory than most?</td>
<td>Yes</td>
</tr>
<tr>
<td>11.</td>
<td>Do you think it is wonderful to be alive now?</td>
<td>Yes</td>
</tr>
<tr>
<td>12.</td>
<td>Do you feel pretty worthless the way you are now?</td>
<td>Yes</td>
</tr>
<tr>
<td>13.</td>
<td>Do you feel full of energy?</td>
<td>Yes</td>
</tr>
<tr>
<td>14.</td>
<td>Do you feel that your situation is hopeless?</td>
<td>Yes</td>
</tr>
<tr>
<td>15.</td>
<td>Do you think that most people are better off than you are?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Reference**

Appendix U

The translated Chinese version of Geriatric Depression Scale

中風之後，好多時自己個心情都會受到影響，我想了解多少少你嘅感受。頭先
我地問你同唔同意，而家就只係答係同唔係就可以啦。
我會講一啲句子，係一般人對某啲事情嘅感受。我想睇下你係過去一星期內，
有無呢啲感受，只係答係同唔係就可以啦。一樣，你嘅答案係無啱同錯，係你
嘅感受就可以啦。

| 1. 你基本上對自己的生活感到滿意嗎？ | 是 | 否 |
| 2. 你是否已放棄了很多以往的活動和嗜好？ | 是 | 否 |
| 3. 你是否覺得生活空虛？ | 是 | 否 |
| 4. 你是否常常感到煩悶？ | 是 | 否 |
| 5. 你是否很多時感到心情愉快呢？ | 是 | 否 |
| 6. 你是否害怕將會有不好的事情發生在你身上呢？ | 是 | 否 |
| 7. 你是否大部份時間感到快樂呢？ | 是 | 否 |
| 8. 你是否常常感到無助？ | 是 | 否 |
| 9. 你是否寧願留在家中，而不出外做些有新意的事情？ | 是 | 否 |
| 10. 你是否覺得你比大多數人有多些記憶的問題呢？ | 是 | 否 |
| 11. 你認為現在活著是一件好事嗎？ | 是 | 否 |
| 12. 你是否覺得自己現在一無是處呢？ | 是 | 否 |
| 13. 你是否感到精力充足？ | 是 | 否 |
| 14. 你是否覺得自己的處境無望？ | 是 | 否 |
| 15. 你覺得大部份人的境況比自己好嗎？ | 是 | 否 |

Reference
Appendix V

The original English version of Reintegration to Normal Living Index

The Reintegration to Normal Living Index
1 = does not describe my situation
2 = describes my situation a little
3 = describes my situation a lot
4 = fully describes my situation

Items

1. I move around my living quarters as I feel necessary. 1 2 3 4
2. I move around my community as I feel necessary. 1 2 3 4
3. I am able to take trips out of town as I feel are necessary. 1 2 3 4
4. I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met. 1 2 3 4
5. I spend most of my days occupied in work activity that is necessary or important to me. 1 2 3 4
6. I am able to participate in recreational activities (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to. 1 2 3 4
7. I participate in social activities with family, friends and/or business acquaintances as is necessary or desirable to me. 1 2 3 4
8. I assume a role in my family which meets my needs and those of other family members. 1 2 3 4
9. In general, I am comfortable with my personal relationships. 1 2 3 4
10. In general, I am comfortable with myself when I am in the company of others. 1 2 3 4
11. I feel that I can deal with life events as they happen. 1 2 3 4

Reference
Appendix W

The translated Chinese version of Reintegration to Normal Living Index

其實如果我話「你係家中，當你覺得有需要時，你能夠随意走動」，你覺得係
完全講中你嘅情況，定係講中左大部份呀，講中左少部份，又或係講唔中你嘅
情況呢？

<table>
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<tr>
<th>不能描述我的情況</th>
<th>描述我少部份的情況</th>
<th>描述我大部份的情況</th>
<th>完全描述我的情況</th>
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<td>1</td>
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<td>4</td>
</tr>
</tbody>
</table>

1. 在家中，當你覺得有需要時，你能夠随意走動。
2. 在社區中，當你覺得有需要時，你能夠随意走動。
3. 當你覺得有需要時，你能夠随意出境外遊。
4. 對於點樣去應付自我照顧嘅需要，你都覺得自在。
5. 你大部分的日子都用係你覺得有需要或重要嘅工作上。
6. 當你想嘅時候，你能夠參與康樂活動。
7. 當你覺得有需要或者你希望嘅時候，你會同家人、朋友及/或工作上有往來嘅人一齊
   參與社交／羣體活動。
8. 你認為你現時所擔當嘅角色，可以切合自己同其他屋企人嘅需要。
9. 整體而言，你對你嘅個人關係（家人、親戚、朋友）感到自在。
10. 整體而言，當你同其他人共處嘅時候，你感到自在。
11. 你覺得你能夠應付得到人生中會發生嘅各種事情。

Reference
Appendix X

Confidentiality pledge for research assistants

Research Assistant Confidentiality Agreement

Research title: Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors

Principal Investigator: Ms Suzinne Hoi-Shan LO

I, __________________________, agree to assist the principal investigator of this study by recruiting study participants, and conducting baseline and follow-up assessment. I agree to maintain full confidentiality when performing these tasks.

Specifically, I agree to:

1. keep all research information shared with me confidential by not discussing or sharing the information in any form or format (e.g., papers, disks, tapes, transcripts) with anyone other than the primary investigator;

2. hold in strictest confidence the identification of any individual that may be revealed during the course of performing the research tasks;

3. not make copies of any raw data in any form or format (e.g., papers, disks, tapes, transcripts), unless specifically requested to do so by the primary investigator;

4. keep all raw data that contains identifying information in any form or format (e.g., papers, disks, tapes, transcripts) secure while it is in my possession. This includes:
   • keeping all digitised raw data in computer password-protected files and other raw data in a locked file;
   • closing any computer programs and documents of the raw data when temporarily away from the computer; and
   • permanently deleting any e-mail communication containing the data;

5. give, all raw data in any form or format (e.g., papers, disks, tapes, transcripts) to the primary investigator when I have completed the research tasks;

6. destroy all research information in any form or format that is not returnable to the primary investigator (e.g., information stored on my computer hard drive) upon completion of the research tasks.

Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

Print name of research assistant          Research assistant’s signature          Date of signature

Print name of principal investigator     Principal investigator’s signature      Date of signature
Appendix Y

Ethical approval by the Kowloon West Cluster Research Ethics Committee, Hospital Authority, Hong Kong

Miss LO Ho-Nam, Suzanne, Professional Coordinator
The Netherland School of Nursing,
The Chinese University of Hong Kong

Dear Miss LO,

KWC-REC Reference: KWC/EX-14-021(78-21)

Title: Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors

The Kowloon West Cluster Research Ethics Committee (KWC-REC) is authorised by the Cluster Chief Executive to review and monitor clinical research. It serves to ensure that research complies with the Declaration of Helsinki, ICH GCP Guidelines, local regulations and HA policy. It has the authority to approve, register modifications to (its) studies, and assure ethical conduct. The Committee has no power to terminate or suspend any research at any time if there is evidence to indicate that the above principles and requirements have been violated.

KWC-REC has approved your research application on 12 March 2014 by expedited review process, and reached the following decision on the documents submitted as shown below. You are required to adhere to the attached conditions.

<table>
<thead>
<tr>
<th>Study sites(s) approved</th>
<th>Document(s)</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Clinical Research Ethics Review Application Form (received on 13 December 2013)</td>
<td>I.</td>
<td>KWC/EX-14-021(78-21)</td>
</tr>
<tr>
<td>II. One-Page Summary Form (received on 13 December 2013)</td>
<td>II.</td>
<td></td>
</tr>
<tr>
<td>III. Protocol, Version 2 / Version date: 01 January 2014</td>
<td>III.</td>
<td></td>
</tr>
<tr>
<td>V. The Stroke Self-management Outcome Expectation Scale, Chinese Version 2 / Version date: 30 January 2014</td>
<td>V.</td>
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<tr>
<td>VI. The Stroke Self-management Behavior Scale, Chinese Version 2 / Version date: 30 January 2014</td>
<td>VI.</td>
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<tr>
<td>VII. Stroke Specific Quality of Life Scale, Chinese Version 2 / Version date: 30 January 2014</td>
<td>VII.</td>
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<tr>
<td>VIII. The Barred ADL Index, English Version 2 / Version date: 30 January 2014</td>
<td>VIII.</td>
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<tr>
<td>IX. Geriatric Depression Scale, Chinese Version 2 / Version date: 30 January 2014</td>
<td>IX.</td>
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<tr>
<td>X. Reintegration of Normal Living Index, Chinese Version 2 / Version date: 30 January 2014</td>
<td>X.</td>
<td></td>
</tr>
<tr>
<td>XI. Demographic and clinical information sheet, Chinese Version 2 / Version date: 30 January 2014</td>
<td>XI.</td>
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<tr>
<td>XII. Participation Card, Chinese Version 2 / Version date: 30 January 2014</td>
<td>XII.</td>
<td></td>
</tr>
<tr>
<td>XIII. Information Sheet and Informed Consent Form, Chinese and English Version 2 / Version date: 30 January 2014</td>
<td>XIII.</td>
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</table>

Conditions:

1. Do not deviate from, or make changes to the study protocol without prior written REC approval, except when it is necessary to eliminate immediate hazards to research subjects or when the change is not an only logistical or administrative issue.

2. Apply a clinical trial certificate from Department of Health if indicated.

3. Report the following to KWC-REC:
   - (1) study protocol or consent document changes,
   - (2) serious adverse events,
   - (3) study progress (6) new information that may be relevant to a subject’s willingness to continue participation in the study.

4. Report first study program to KWC-REC at 12 monthly intervals until study closure.

Please quote the REC Reference KWC/EX-14-021(78-21) in all your future correspondence with the KWC-REC, including submission of progress reports and requesting for amendments to the research protocol.

If you have any inquiry, please feel free to consult Ms Catherine CHENG, Secretary to the KWC-REC, at 2990 3719.

Thank you for your attention.

Yours sincerely,

[Signature]

(Dr. Angela CHENG)

[Title]

Kowloon West Cluster Research Ethics Committee

400 Appendices
Appendix Z

Ethical approval by the Human Research Ethics Committee of the Queensland University of Technology

From: QUT Research Ethics Unit
Sent: Tuesday, 17 June 2014 10:27 AM
To: Anne Chang; Glenn Gardner; Hoi Shan Lo
Cc: Janette Lamb
Subject: Ethics Application Approval -- 1400000333

Dear Prof Anne Chang and Miss Hoi Shan (Suzanne) Lo

Project Title: Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors

Ethics category: Human - Human Negligible-Low Risk
QUT approval number: 1400000333 (Approval number: )
QUT clearance until: 2/06/2017

We are pleased to advise that your application has been reviewed and administratively approved by the Chair, University Human Research Ethics Committee (UHREC) based on the approval gained from the responsible HREC.
We note this HREC has awarded the project ethical clearance until 2/06/2017.

CONDITIONS OF APPROVAL
Please ensure you and all other team members read through and understand all UHREC conditions of approval prior to commencing any data collection:
- Standard: Please see attached or www.research.qut.edu.au/ethics/humans/stdconditions.jsp
- Specific: None apply

Projects approved through an external organisation may be subject to that organisation’s review arrangements. Researchers must immediately notify the QUT Research Ethics Unit if their project is selected for investigation / review by an external organisation.

VARIATIONS
All variations must first be approved by the responsible HREC before submission to QUT for ratification.
Once approval has been obtained please submit this to QUT using our online variation form:
www.research.qut.edu.au/ethics/humans/var/

MONITORING
Please ensure you also provide QUT with a copy of each adverse event report and progress report submitted to the responsible HREC.

Administrative review decisions are subject to ratification at the next available UHREC meeting. You will only be contacted again in relation to this matter if UHREC raises additional questions or concerns.
Ethics Variation-- 1400000333

Research Ethics <ethicscontact@qut.edu.au>

Thu 27/11/2014 3:27 PM

Inbox

To: Anne Chang <am.chang@qut.edu.au>; Hoi Shan Lo <h1.lo@hdr.qut.edu.au>
Cc: Janette Lamb <jd.lamb@qut.edu.au>

Dear Prof Anne Chang and Miss Hoi Shan Lo

Approval #: 1400000333
End Date: 2/06/2017
Project Title: Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors

This email is to advise that your variation has been considered by the Chair, University Human Research Ethics Committee. This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007).

Approval has been provided for:

< Addition of hospital site in HK (Joint CUHK-NTEC).
< Two group sessions to be combined into one session to cut travelling time.
< Reimbursement of taxi fares to attend community centre.

PLEASE NOTE:
RESEARCH SAFETY -- Ensure any health and safety risks relating to this variation have been appropriately considered, particularly if your project required a Health and Safety Risk Assessment.

CONFLICTS OF INTEREST -- If this variation will introduce any additional perceived or actual conflicts of interest please advise the Research Ethics Unit by return email.

Please don't hesitate to contact us if you have any questions.

Regards

Janette Lamb on behalf of Chair UHREC
Office of Research Ethics & Integrity
Level 4  |  88 Musgrave Avenue  |  Kelvin Grove
p: +61 7 3138 5123
e: ethicscontact@qut.edu.au
https://poed51034.outlook.com/owa/presentation.aspx
Ethics Variation-- 1400000333

Research Ethics <ethicscontact@qut.edu.au>

Thu 18/12/2014 12:15 PM
Inbox

To: Anne Chang <am.chang@qut.edu.au>; Hoi Shan Lo <h1.lo@hdr.qut.edu.au>
Cc: Janette Lamb <jd.lamb@qut.edu.au>

Dear Prof Anne Chang and Miss Hoi Shan Lo

Approval #: 1400000333
End Date: 2/06/2017
Project Title: Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors

This email is to advise that your variation has been considered by the Chair, University Human Research Ethics Committee. This HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007).

Approval has been provided for reimbursement of participants with HK$100 (AUD 15).

PLEASE NOTE:
RESEARCH SAFETY -- Ensure any health and safety risks relating to this variation have been appropriately considered, particularly if your project required a Health and Safety Risk Assessment.

CONFLICTS OF INTEREST -- If this variation will introduce any additional perceived or actual conflicts of interest please advise the Research Ethics Unit by return email.

Please don't hesitate to contact us if you have any questions.

Regards

Janette Lamb on behalf of Chair UHREC
Office of Research Ethics & Integrity
Level 4 | 88 Musk Avenue | Kelvin Grove
p: +61 7 3138 5123
e: ethicscontact@qut.edu.au
w: http://www.oer.e.qut.edu.au
Appendix AA

Ethical approval by the Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee, Hong Kong

Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee
香港中文大學-新界東醫院聯網臨床研究倫理聯席委員會

8/F, Lui Che Woo Clinical Sciences Building, Prince of Wales Hospital, Shatin, HK
Tel: (852) 2632 3935 / 2144 5926 Fax: (852) 2646 6653 Website: http://www.crec.cuhk.edu.hk

The Joint CUHK-NTEC CREC is an independent committee established by CUHK/NTEC and authorized to perform ethics and scientific review and oversight of clinical studies within the jurisdiction of CUHK/NTEC in accordance with its standard operating procedure and the principles of the Declaration of Helsinki and ICH Good Clinical Practice.

CREC Ref. No.: 2014.375-T

To: [Redacted]

This notice is issued by the Joint CUHK-NTEC CREC with respect to the application/submission by you, being the principal investigator of the following study at your study site:

- **Study Protocol Title:** Effectiveness of a self-efficacy enhancing stroke self-management program on promoting recovery of community-dwelling stroke survivors
- **Investigator(s):** Sharon Wai Man PANG, Suzanne Hoi Shian LO, Anne Marie CHANG, Janita Pak Chun CHAU and Glenn Elizabeth GARDNER

In accordance with our standard operating procedure, we have duly performed ethics and scientific review of your application/submission as detailed below:

- **Nature of Your Application/Submission:** ☒ Initial application  ☐ Amendments/changes  ☐ Others:  ☐ Renewal
- **Mode of Review:** ☒ Full review  ☐ Expedited review
- **Date of Initial/Renewal Approval:** 13 August 2014
- **Document(s) Reviewed:** See Schedule 1
- **Reviewer(s):** See Schedule 2

After due review by our reviewer(s), we hereby write to inform you of our decision on your application/submission as follows:

- **Decision:** ☒ Application/Submission approved  ☐ Application/Submission approved with condition(s) (see condition(s) below)
  ☐ Application/Submission approved with remark(s) (see remark(s) below)
  ☐ Application/Submission approved with condition(s) and remark(s) (see condition(s) and remark(s) below)

- **Regular Progress Report(s) Required:** Every 12 months from the date of initial/renewal approval and during the period of the study if required
You, being the principal investigator of the study at your study site, are reminded to comply with our requirements and to maintain communication with us during the period of the study by undertaking the principal investigator’s responsibilities including (but not limited to):

- if the study is an industry-sponsored clinical study, submitting to us a copy of the fully executed indemnity agreement satisfying the Hospital Authority’s requirement prior to commencement of the study (if it has not been submitted yet);
- observing and complying with all applicable requirements under our standard operating procedure (“IRB/REC SOP”), the Declaration of Helsinki and the ICH GCP (if applicable);
- submitting regular progress report(s) at the required intervals (as specified above) in accordance with the requirements in the IRB/REC SOP;
- not implementing any amendment/change to any approved study document/material without our written approval, except where necessary to eliminate any immediate hazard to the subjects or if an amendment/change is only of an administrative or logistical nature;
- notifying us of any new information that may adversely affect the rights, safety or well-being of the subjects or the proper conduct of the study;
- reporting any deviation from the study protocol or compliance incident that has occurred during the study and may adversely affect the rights, safety or well-being of any subject in accordance with the requirements in the IRB/REC SOP;
- submitting safety reports on all SAEs observed at your study site or SUSARs reported from outside your study site in accordance with the requirements in the IRB/REC SOP, and
- submitting a final report in accordance with the requirements in the IRB/REC SOP upon completion or termination of the study at your study site.

In addition to the above, you are also reminded to observe and comply with other applicable regulatory and management requirements including (but not limited to):

- if required by Hong Kong laws or regulations, obtaining a certificate for clinical trial through the Hong Kong Department of Health and complying with the associated requirements;
- obtaining the necessary consent from the management of your institution/department in accordance with the requirements of your institution/department;
- if required by local laws or regulations at conducting site out of IRB/REC’s jurisdiction, obtaining an approval and complying with associated requirements;
- not representing to any third party or in any way likely to mislead any third party forming the view that the approval from the IRB/REC has any extraterritorial effect; and
- with due diligence ensuring your teams, staff, agents or whoever connected with you to comply with the preceding requirements.

Yours sincerely,

[Signature]

Envy Lee (Secretary)
for and on behalf of
The Joint CUHK-NTEC CREC

EL/4i

CREC Ref. No.: 2014.375-T
Appendix BB

Information sheet and informed consent form for participants (main study)

Effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors

QUT Ethics Approval Number: 1400000333
KWC REC Reference Number: KW/EX-14-021(71-21)
Joint CUHK-NTEC CREC Reference Number: 2014.375-T

RESEARCH TEAM
Principal Researcher: Suzanne Hoi-Shan LO, PhD student, School of Nursing, Faculty of Health, Queensland University of Technology (QUT), Brisbane, Australia
Associate Researchers: Anne M. CHANG, Professor of Clinical Nursing, School of Nursing, Faculty of Health, QUT, Brisbane, Australia
Glenn E. GARDNER, Professor, School of Nursing, Faculty of Health, QUT, Brisbane, Australia
Janita Pak-Chun CHAU, Professor, The Nethersole School of Nursing, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong

DESCRIPTION
This project is being undertaken as part of the PhD study for Ms Suzanne Hoi-Shan LO at the School of Nursing, Faculty of Health, QUT, Brisbane, Australia.

Stroke recovery is long-term and demanding. The purpose of this project is to examine the effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors in Hong Kong.

You are invited to participate in this project because you have had a stroke in the past year and are planned to continue your stroke recovery in the home setting.

PARTICIPATION
If you agree to participate in this study, you will be randomly assigned to join the intervention group or the usual care group. If you join the usual care group, you will continue to receive any health services, talks, and/or other educational materials arranged for you by your attending hospitals or other health organisations that you have participated in. If you join the intervention group, you will receive the usual care services mentioned above, plus a 4-week stroke self-management program which consists of a home visit of about 2 hours from a registered nurse (the principal researcher), two group sessions (1.5 hours each) to be held consecutively on the same day at a community centre, and three follow-up phone calls. During the program, you will receive education on stroke self-management, and participate in group sharing with other stroke survivors about their experiences after stroke. Individualised assessment and feedback provided by a registered nurse (the principal investigator) will be offered throughout the program. Furthermore you will receive a DVD containing videos about stroke survivors’ experiences in managing their stroke. If you are in the usual care group, a copy of the DVD will be given to you after completion of the study.

You will be invited to complete a questionnaire about your confidence in and expected outcomes of participating in stroke self-management behaviours, your quality of life, and health status. Questions will include, for example, ‘If I exercise regularly, I will be more physically independent to do what I want’, or ‘Did you have trouble walking?’. You will be asked to give your level of agreement for some questions and for other questions your level of satisfaction. You will be asked to complete the questionnaire at the start of the study, and two months afterwards. A research assistant will administer the questionnaire face-to-face with you at your home, scheduled at a time convenient to you. Each interview will take about 45 minutes.
Your participation in this project is entirely voluntary. If you agree to participate, you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with your present or future medical and nursing care at the hospital or in the community. If you do agree to participate, you can withdraw from or discontinue the project at any time without comment or penalty. Any identifiable information already obtained from you will be destroyed. The questionnaire that have been collected from you will be retrieved using the identifying code and will be destroyed.

You will be reimbursed for your time involved in participation in the study. Supermarket coupons with a total value of HK$100 will be given to you upon completion of the study i.e., if you have completed the first and second data collection sessions in the usual care group, or if you have completed the first and second data collection sessions, plus attendance to at least four sessions of the stroke self-management program, if you are assigned to the intervention group.

A maximum amount of travel (up to HK$150) will be provided on request if you encountered difficulties in arranging the transport to the community centre to join the group sessions if you are assigned to during the study.

**EXPECTED BENEFITS**

It is expected that this project will enhance your confidence in participating in stroke self-management behaviours, and improve your quality of life, depressive symptoms, and level of community reintegration. It is expected to promote your positive recovery after stroke in the long run. Furthermore this study will provide valuable data for developing more effective interventions to enhance community-dwelling stroke survivors’ capability in stroke self-management.

**RISKS**

There are no risks, beyond those for normal day-to-day living, associated with your participation in this project. This study will not cause you any pain, discomfort or injuries. However if you are receiving the stroke self-management program, you may experience emotional discomfort such as distress when you recall your health problems during the discussion in the program. Referrals to healthcare professionals will be made if necessary. You may experience inconvenience or discomfort when you visit the community centre for joining the program. Your family members or carers are welcome to accompany you.

**PRIVACY AND CONFIDENTIALITY**

All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. However the questionnaires will be coded to indicate that the questionnaires are completed by the same participant in the first and second data collection. All the collected data will be used for research purposes only. Your name or other identifying particulars will not be disclosed in documents or research publications related to this study without prior approval from you. All the non-identifiable data collected from you will only be used for research purposes related to this research study or other related research studies in future.

Any data collected as part of this project will be stored securely in a locked cabinet as per QUT’s Management of research data policy. Only the research team members (Suzanne Lo, Anne Chang and Janita Chau) will gain access to the stored data. All data collected will be destroyed after completion of the study. A copy of the signed information sheet and consent form will be given to you for your reference.

**QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT**

If you have any questions or require further information, please contact the research team member below.

Ms Suzanne Hoi-Shan LO (852) 9016 1573 h1.lo@hdr.qut.edu.au
Prof Anne CHANG (617) 3138 3842 am.chang@qut.edu.au

A copy of the study brief results will be provided to you upon request.
CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project, you may contact the QUT Research Ethics Unit on (617) 3138 5123 or email: ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Alternatively, if you have questions related to your rights as a research participant, you may contact Research Ethics Committee (Kowloon West Cluster), Hospital Authority, Hong Kong at (852) 2990 3749, or the Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee, Hospital Authority, Hong Kong at (852) 2632 3935.

Thank you for helping with this research project. Please keep this sheet for your information.

CONSENT TO PARTICIPATE

Statement of your consent to participate in this project:
I have read this participant information sheet. I have been given a detailed account of the study aim, the procedures required, and the potential risks and benefits that I may experience. I have had the opportunity to ask questions about the study and any questions that I have asked have been answered to my satisfaction. I understand that I will get a copy of the signed information sheet and consent form. I agree to give my consent to participate as a participant in this research study.

_____________________ _____________________________________ _________________
Print name of the participant  Participant’s signature  Date of signature

_____________________ _____________________________________ _________________
Print name of the witness  Witness’s signature  Date of signature

Statement of individual obtaining consent:
I have explained the research to the study participant, and I have answered all questions about this research study to the best of my ability.

_____________________ _____________________________________ _________________
Print name of the research assistant obtaining the consent  Research assistant’s signature  Date of signature

_____________________ _____________________________________ _________________
Print name of the principal investigator  Principal investigator’s signature  Date of signature
Appendix CC

Information sheet and informed consent form for participants (development of measuring instruments)

PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

Effectiveness of a confidence enhancing stroke self-management program on recovery of community-dwelling stroke survivors

QUT Ethics Approval Number: XXXXXX
KWC REC Reference Number: KW/EX-14-021(71-21)

RESEARCH TEAM

Principal Researcher: Suzanne Hoi-Shan LO, PhD student, School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia
Anne M. CHANG, Professor of Clinical Nursing, School of Nursing, Australia

Associate Researchers: Faculty of Health, Queensland University of Technology, Brisbane, Australia
Janita Pak-Chun CHAU, Professor, The Nethersole School of Nursing, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong
Glenn E. GARDNER, Professor, School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia

DESCRIPTION

This project is being undertaken as part of the PhD study for Ms Suzanne Hoi-Shan LO at the School of Nursing, Faculty of Health, Queensland University of Technology, Brisbane, Australia.

Stroke recovery is long-term and demanding. The purpose of this project is to examine the current performance of stroke self-management behaviours, and expected outcomes after performing the stroke self-management behaviours among community-dwelling stroke survivors in Hong Kong. You are invited to participate in this project because you have had a stroke in the past.

PARTICIPATION

If you agree to participate in this study, you will be invited to complete a questionnaire about the perception of your performance, and expected outcomes of stroke self-management behaviours. Questions will include, for example, ‘If I exercise regularly, I will be more physically independent to do what I want’. You will be asked to give your level of satisfaction for some questions and for other questions your level of confidence. You will be asked to complete the questionnaire yourself. It will take about 10 minutes to complete the questionnaire.

Your participation in this project is entirely voluntary. If you agree to participate, you do not have to complete any question(s) you are uncomfortable answering. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT, or your present or future medical and nursing care at the hospital or in the community. If you do agree to participate, you can withdraw from or discontinue the project at any time without comment or penalty. Any identifiable information already obtained from you will be destroyed. However as the questionnaire is anonymous once it has been submitted it will not be possible to withdraw.

EXPECTED BENEFITS

It is expected that this project will provide valuable data for developing a reliable and valid tool for measuring stroke survivors’ outcome expectation and performance of stroke self-management interventions. The instruments are important to evaluate effectiveness of stroke self-management programs designed to enhance community-dwelling stroke survivors’ ability in participating in stroke self-management.
RISKS
There are no risks, beyond those for normal day-to-day living, associated with your participation in this project. This study will not cause you any pain, discomfort or injuries.

PRIVACY AND CONFIDENTIALITY
All comments and responses will be treated confidentially unless required by law. The names of individual persons are not required in any of the responses. All the collected data will be used for research purposes only. Your name or other identifying particulars will not be disclosed in documents or research publications related to this study without prior approval from you. All the non-identifiable data collected from you will only be used for research purposes related to this research study or other related research studies in future.

Any data collected as part of this project will be stored securely in a locked cabinet as per QUT’s Management of research data policy. Only the research team members (Suzanne Lo, Anne Chang and Janita Chau) will gain access to the stored data. All data collected will be destroyed after completion of the study. A copy of the signed information sheet and consent form will be given to you for your reference.

CONSENT TO PARTICIPATE
Statement of your consent to participate in this project:
I have read this participant information sheet. I have been given a detailed account of the study aim, the procedures required, and the potential risks and benefits that I may experience. I have had the opportunity to ask questions about the study and any questions that I have asked have been answered to my satisfaction. I understand that I will get a copy of the signed information sheet and consent form. I agree to give my consent to participate as a participant in this research study.

Print name of the participant    Participant’s signature    Date of signature

Print name of the witness    Witness’s signature    Date of signature

Statement of individual obtaining consent:
I have explained the research to the study participant, and I have answered all questions about this research study to the best of my ability.

Print name of the research assistant obtaining the consent    Research assistant’s signature    Date of signature

Print name of the principal investigator    Principal investigator’s signature    Date of signature
QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT
If you have any questions or require further information, please contact the research team member below.

Ms Suzanne Hoi-Shan LO
PhD student, School of Nursing, Faculty of Health, Queensland University of Technology,
Brisbane, Australia
Phone: (852) 9016 1573     Email: h1.lo@student.qut.edu.au

A copy of the study brief results will be provided to you upon request.

CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT
QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project, you may contact the QUT Research Ethics Unit on (617) 3138 5123 or email: ethicscontact@qut.edu.au. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner. Alternatively, if you have questions related to your rights as a research participant, you may contact Research Ethics Committee (Kowloon West Cluster), Hospital Authority, Hong Kong at (852) 2990 3749.

Thank you for helping with this research project. Please keep this sheet for your information.