DEVELOPMENT, FEASIBILITY TESTING, AND PRELIMINARY OUTCOMES EVALUATION OF THE 3H (HEAD, HEART, HANDS) INTERVENTION FOR SUPPORTING COUPLES IN THEIR LIVING AND RECOVERY POST-STROKE:

AN EMBEDDED MIXED-METHODS STUDY

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Development, Feasibility Testing, and Preliminary Outcomes Evaluation of the 3H (Head, Heart, Hands) Intervention for Supporting Couples in their Living and Recovery Post-Stroke:
An Embedded Mixed-Methods Study

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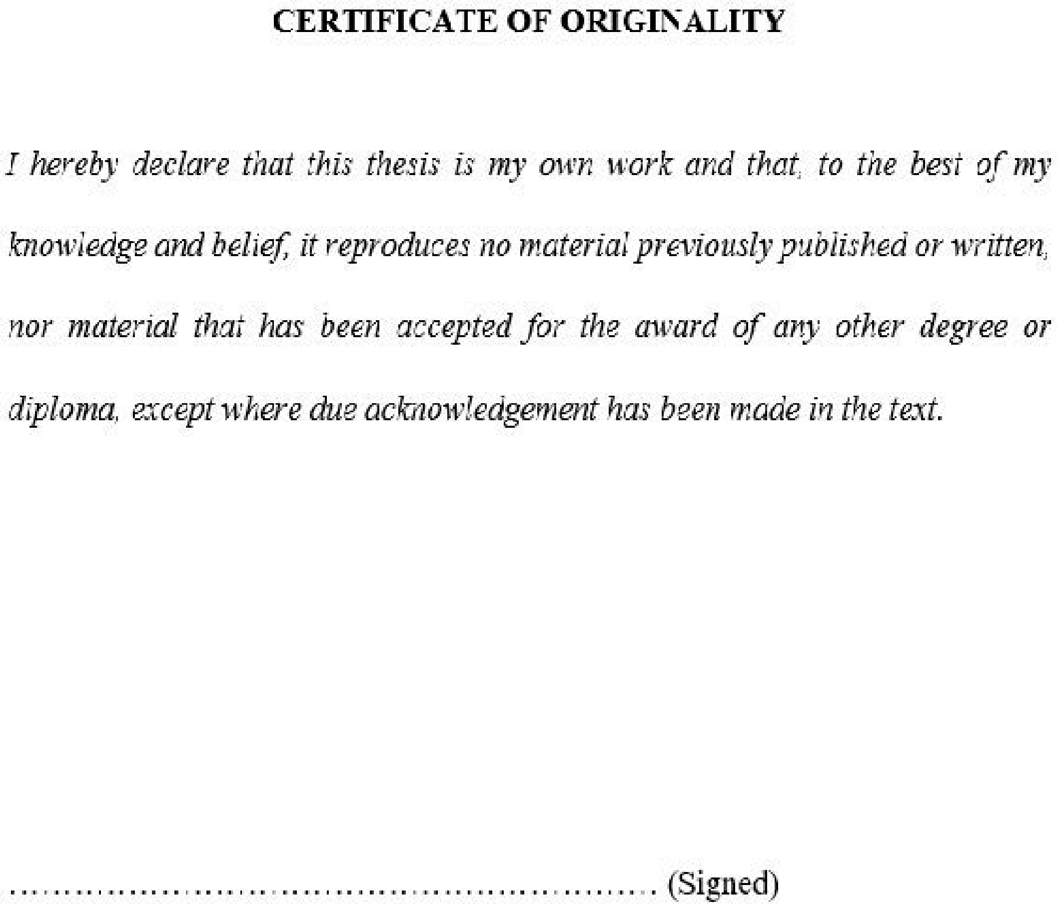

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ABSTRACT

Title

Development, feasibility testing, and preliminary outcomes evaluation of the 3H (Head, Heart, Hands) intervention for supporting couples in their living and recovery post-stroke: An embedded mixed-methods study

Background

Stroke is a chronic and disabling neurological condition that renders persons with stroke dependent on their caregivers. The family caregivers of persons with stroke experience a great burden, due to the sudden onset of a family member’s disabilities resulting from stroke and the uncertain prognosis of recovery. Given family caregivers’ long-term and heavy caregiving responsibilities, their needs are neglected, leading to relationship strains. To address this problem, interventions in supporting persons with stroke and their spousal caregivers to adapt the stroke situation are important and necessary. Little is known about the feasibility and effects of this type of programme on stroke couples.

Aim

The study aimed to systematically develop a nurse-led intervention programme, and evaluate its feasibility and preliminary outcomes for the daily living and recovery of persons with stroke and their spousal caregivers in Singapore.

Methods

The 3H (head, heart, hands) intervention was developed through a literature review and a qualitative study in Singapore, according to the MRC (Medical Research Council, 2008) framework. The feasibility and preliminary outcomes of this programme were tested using an embedded mixed-methods approach. To supplement the feasibility analysis, qualitative interviews were conducted that explored couples' experiences of participating in the 3H intervention. Acceptability was assessed by the quantitative measurements of participant recruitment, retention, and attrition rates. An evaluation of the preliminary outcomes was performed via a pre- and post-test quasi-experimental design with no control group. As a mixed-methods research reporting standard, the Collins, Onwuegbuzie & Sutton (2006) framework was utilised for this study's report.

Study participants were recruited through convenience sampling at a stroke rehabilitation hospital in Singapore. According to Julious (2005), 12 participants per group are required for conducting pilot or feasibility studies. Considering a study participation refusal rate of approximately 20%, a total of 32 stroke couples was approached and recruited to participate in the study. Of these participants, seven couples were purposively selected to share their post-3H intervention experiences. After the baseline measurement (T_0) of anxiety, depression, dyadic adjustment, and dyadic coping, six sessions of the 3H intervention were conducted in a rehabilitation hospital with stroke patients and their key caregivers over a period of three weeks. The activities were conducted both as face-to-face group sessions with all participants, and individual sessions for the patient and caregiver as a dyad. The post-test measurement was performed at T_1 - the time when participants completed their sixth session of the 3H intervention. Following that, interpretive descriptive qualitative interviews were performed in order to collect data about their experiences to supplement the feasibility analysis.

Results

The 3H intervention, developed from the literature review and qualitative study, comprised three elements: informational support, shared decision making, and practical skills training. From the embedded mixed-methods study that aimed to evaluate the feasibility and preliminary outcomes of 3H intervention, the participants found their involvement in the programme to be acceptable. A total of 64 participants (32 couples) took part in the intervention at T_0. Fifty-four participants (23 spousal caregivers and 31 persons with stroke) remained and completed the intervention at T_1. At the end of the study, an attrition rate of 15.6% of participants (nine spousal caregivers and one person with stroke) was evident.

The qualitative results supplementing the feasibility analysis indicated that the participants were more prepared to face living with stroke as couples. They described the stroke situation as a “storm” in their lives. In the aftermath of a stroke that occurred suddenly, participants felt uncertain and worried about their future. Prior to the 3H intervention implementation, they were struggling with the stroke situation. However, their coping processes improved after taking part in the programme. The coping strategies employed by participants include, *breaking the silence and engaging in conversations, cultivating a sense of*

support, and *conveniently fulfilling their educational needs*. To further strengthen the couples' transitional care support from hospital to home, an extension of the 3H intervention in the community is warranted.

For the preliminary outcomes, spousal caregivers were found to have more significant benefits from the intervention than persons with stroke. In the group by time effect, they scored better in most scales of the dyadic coping inventory (DCI) after their participation in the 3H intervention, i.e., outgoing stress communication (β = -16.88, p = .009), incoming stress coping behaviour (β = -16.96, p = .008), incoming stress communication (β = -17.03, p = .01), outgoing stress coping behaviour (β = -21.81, p = .002), and couples' stress-coping mechanism (β = -19.5, p = .004). Similarly, statistically significant group by time effect interactions were reported for the consensus (β= -14.17, p= .002), satisfaction (β= -20.47, p= .02), and cohesion (β=-12.34, p= .027) of Revised Dyadic Adjustment Scale (RDAS). However, statistically insignificant results were observed for HADS scale using group by time effect interaction. Despite this shortcoming, statistically significant group effects of couples' anxiety ($\beta=5.8, p < .001$) and depression ($\beta=14.89, p < .001$) were observed after their participation in the 3H intervention. Further subgroup analysis with Wilcoxon Test and Mann-Whitney U test reported that spousal caregivers improved significantly in adaptation after their partner suffered a stroke than persons with stroke.

Discussion

The intervention is novel and it is the first to be developed and implemented in a Singaporean context. The development of the 3H intervention included shared decision making as one of its elements, which is an evolving approach to improve care for couples living with stroke (Armstrong, 2017). The 3H intervention is feasible in terms of its acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy (Bowen et al., 2009). The programme allowed persons with stroke and their spousal caregivers to voice their personal concerns related to stroke situation in the family as it comprised group and individual dyadic sessions. The group sessions promoted cross-family alliances, where spousal caregivers interacted with other spouses with similar demanding caregiving roles. Multicomponent interventions, such as the 3H intervention, strengthened a sense of support in persons with stroke and their spousal caregivers by improving family networks, and reducing their feelings of isolation. Unlike the studies of Hatfield and Cacioppo (1994) and Monin and Schulz (2009), it was evident that spousal caregivers who participated in the 3H intervention were able to adapt after the stroke of their spouse. They had learnt self-care strategies that eliminated detrimental effects on their psychological and physical health.

Conclusion

All of the findings add new knowledge in showing that the systematic development of 3H intervention supports persons with stroke and their spousal caregivers during the adaptation process. As a result of participating in the programme, persons with stroke and their spousal caregivers were described as being more prepared to face the storm. As a couple, participants

were able to overcome the struggle of adapting to living with stroke. Effective coping was evident, where the participants engaged in conversations, cultivated a sense of support, and fulfilled their educational needs. The need for the 3H intervention to be extended for community nursing after participants are discharged from hospital was addressed. Primary healthcare professionals should pay more attention to the difficulties and needs of this group of people and provide more resources to support them, to improve their quality of life.

Significance

This study is the first to address an evidence-practice gap in the area of efforts to improve the lives and recovery of couples after a stroke by incorporating shared decision-making in the 3H intervention, in addition to providing information and skills training, prior to the patient's discharge home. The study is important as it improved the post-stroke adaptation of persons with stroke and their spousal caregivers. It added new knowledge and increased the understanding that the 3H intervention is feasible and can be implemented in a clinical context prior to a patient's discharge from hospital. Instead of the current clinical care that focuses predominantly on the individual living with stroke, the 3H intervention helped nursing administrators recognise the value of evidence-based development and support interventions for stroke couples.

Key words

stroke, embedded mixed-methods, spousal caregivers, adaptation, recovery

LIST OF PRESENTED AND PUBLISHED WORK

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LIST OF ABBREVIATIONS

(In alphabetical order)

ADL	Activities of Daily Living
AMT	Abbreviated Mental Test
CES-D	Center for Epidemiological Studies- Depression
CHEERS	Consolidated Health Economic Evaluation Reporting Standards
DCI	Dyadic Coping Inventory
EBCD	Experience-Based Co-Design
FAD	Family Assessment Device
GDS	Geriatric Depression Scale
GEE	Generalised Estimating Equations
HADS	Hospital Anxiety and Depression Scale
JBI	Joanna Briggs Institute
MRC	Medical Research Council
NIHSS	National Institutes of Health Stroke Scale
PSS	Perceived Stress Scale
RCT	Randomised Controlled Trial
RDAS	Revised Dyadic Adjustment Scale
SNSA	Singapore National Stroke Association
UNICEF	United Nations Children’s Fund
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

1.0 Introduction

The World Health Organization (2018) has found that stroke is a chronic disease of global concern. Every year, stroke affects approximately 15 million people worldwide, causing significant chronic disabilities (National Institute of Neurological Disorders & Stroke, 2018). Comparable with Western populations, the burden of stroke is serious in Asia, with higher rates of stroke mortality (Kim, 2014). Specifically, in Taiwan, Korea, Japan, and in some urbanised parts of China, stroke incidence is observed to be high, attributable to the rapidly aging population (Mehndiratta et al., 2014). In Asia, stroke incidence is strongly associated with vascular risk factors, such as hypertension, diabetes, hypercholesterolemia, and high tobacco consumption (Kim et al., 2016; Venketasubramanian et al., 2017).

Stroke incurs approximately 2%-4% of total healthcare expenditure costs worldwide (Ng et al., 2015). Studies from 2005 to 2015 reported that the total estimated annual cost of stroke care are as follows in these countries: the United States (US$40 billion), Australia (AUS$ 1.3 billion), and the United Kingdom (£8·9 billion) (Ng et al., 2015; Palmer et al., 2005; Saka et al., 2009). In 2011, the cost of stroke care per patient was found to be higher in Singapore (S$12,473.70) than in other Asian countries such as Korea (KRW$8 million per patient) (Hu et al., 2013).

The American Stroke Association (2019) asserted that persons with stroke will require significant assistance from caregivers to function in their daily lives as a result of post-stroke disabilities. Consequently, caregiver burden has also been found to be higher among caregivers of persons with stroke (Rigby et al., 2009). For persons with stroke and their spousal caregivers, it was observed that stroke is a significant life-changing event that threatened marital relationships (Coombs, 2007). Two systematic reviews from the Cochrane Database (Legg et al., 2011; Forster et al., 2012) also reported that persons with stroke and their caregivers lacked knowledge of existing community providers, programs, resources, and the necessary tools to manage post-acute stroke care in the community. Given that there is evidence of stroke affecting marital relationships, it is of paramount importance for healthcare professionals to avert the emotional suffering of both persons with stroke as well as their spousal caregivers (McCarthy & Bauer, 2015).

1.1 Background

1.1.1 Stroke significance

The two most common types of stroke are haemorrhagic and ischaemic strokes. Haemorrhagic stroke disrupts blood supply to the brain by bursting blood vessels, while ischaemic stroke occurs as a result of vessel occlusion by a clot (WHO, 2019). Stroke is also commonly known as cerebral infarction (National Stroke Association, 2018). From 24% to 49% persons with stroke suffer from disabilities that include: hemiplegia, sensory loss, swallowing impairments, bladder and bowel incontinence, aphasia, cognitive deficits, and weakened mobility and self-care abilities (Carmo et al., 2015).

An estimated figure of 15 million stroke cases occur annually worldwide (Thrift et al., 2017). Stroke incidence ranges from 76 to 119 per 100,000 (people per year) depending on the country (Feigin et al., 2017). In the United States, stroke is the third leading cause of death, with 140,000 people dying as a result of stroke each year (UT Southwestern Medical Center, 2020). As for the United Kingdom, stroke is the fourth biggest killer, with more than 100,000 deaths in the UK annually (Stroke Association, UK, 2018). Similarly, stroke is the fourth leading cause of death in Singapore, accounting for 10%-12% of all deaths annually. The Singapore public hospital system observed an average of 20 stroke cases daily and admitted a total of 7,413 persons with stroke in 2016 (National Registry of Diseases Office, 2018). Of these, 58.2% of persons with stroke were men, while another 41.8% were women.

Internationally, 80% of persons with stroke had suffered an ischaemic stroke, while the other 20% had a haemorrhagic stroke (Donkor, 2018). Similar to international statistics (Donkor, 2018), most persons with stroke in Singapore suffered an ischemic stroke (81.1%) followed by hemorrhagic stroke (18.7%). Around the world, the prevalence of stroke is expected to increase (Gorelick, 2019). A forecast in the United States indicated that by the year 2050, the number of stroke cases would double, occurring mostly in people aged 75 years or older and in minority racial ethnic groups (Gorelick, 2019). Comparatively, since 2007, increasing numbers of stroke episodes among Singaporean Chinese, Malay, and Indian ethnic populations have been evident (SingHealth Group, 2014). From a public health perspective, the global burden of stroke is expected to rise in developed countries, imposing challenges to many healthcare systems, including in Singapore.

1.1.2 Role of spousal caregivers for persons living with stroke

Persons with stroke are often cared for by their spouse, who renders psychosocial support and physical care in assisting with the activities of daily living (ADL) (Adriaansen et al., 2011). To ensure optimal recovery of persons with stroke, the care and support of their spousal caregiver is essential (Persson et al., 2012). Approximately 4.6 hours per day is needed to provide care for a person living with stroke of poor physical status and mental health, more than six months post-stroke (Tooth et al., 2005). However, caregiving hours are expected to escalate up to 14.2 hours per day whenever additional caregiving is provided (van Exel et al., 2005).

1.1.3 Service systems for persons with stroke

Stroke care takes place in a connected system of care for persons with stroke (Magdon-Ismail et al., 2017). Several countries, such as the United States, adopted a network approach to stroke systems of care (Zachrison et al., 2019). In the provision of a stroke service system, hospitals do not exist as silos, instead serving as interconnected networks between multiple services (Zachrison et al., 2019). Likewise, there are four levels of interconnected stroke services, comprised of primary care, acute care, rehabilitation care, and home care services in the Singapore public healthcare system (Ministry of Health, Singapore, 2018). At each level of health system service, different types of treatment and care are delivered by healthcare professionals.

Primary care services focus on health promotion, detection of risk factors, prevention, and control of chronic medical conditions such as stroke (National Healthcare Group Polyclinics, Singapore, 2017). The burden of chronic disease poses a significant challenge to the primary healthcare system in the United States (Poghosyan et al., 2018). Similarly, chronic disease is a growing problem in Singapore, where one in four persons aged 40 years and above are expected to be diagnosed with at least one chronic disease condition (Health Promotion Board, Singapore, 2018). There are 18 government funded polyclinics in Singapore that provide long-term follow up care for persons with chronic disease conditions (Venketasubramanian & Chen, 2008). Globally, the goals of acute stroke management are to eliminate the worsening of neurological conditions, treat stroke-related complications, optimise recovery, and develop strategies to minimise the risk of recurrent stroke occurrence (Katzan, 2017). Both in the United Kingdom and Singapore, acute stroke management services have been reorganised into multidisciplinary acute stroke units. Furthermore, the change in the stroke management policy has been initiated to enhance the timely admission of persons with stroke to acute stroke care and facilitate prompt utilisation of medical services such as thrombolysis (Suddick et al., 2019; SingHealth Group, 2014).

The World Health Organization (WHO) encourages access to rehabilitation services to meet the needs of disabled persons and their family members by ensuring social inclusion and participation (World Health Organization, 2018). Rehabilitation services coordinate intermediate levels of care to facilitate the reintegration of a person living with stroke from hospital to the home environment (Ministry of Health, Singapore, 2017). Stroke rehabilitation programmes are found in acute care hospitals and rehabilitation centres in the community. From an international perspective, common features of a comprehensive stroke rehabilitation programme include, the establishment of care plans and rehabilitation goals, an emphasis on patient and family education, and the facilitation of early home discharge planning with a smooth transition into the community (Foley et al., 2010). Singapore's five government funded hospitals, where acute rehabilitation services are available, are further supported by four community hospitals that provide slow-stream rehabilitation services for persons with stroke (Venketasubramanian & Chen, 2008). Community hospitals serve as a continuation of rehabilitative services that encourage persons with stroke to achieve an optimal level of functional recovery prior to discharge from hospital and returning home (Ministry of Health, Singapore, 2017).

In addition to rehabilitation programmes in an acute care hospital, community rehabilitation day care centres are designed to provide either active or maintenance rehabilitation therapy sessions for persons with stroke (Singapore Silver Pages, 2018). A non-profitable charitable organisation known as the Singapore National Stroke Association (SNSA) also supports persons with stroke in coping after a stroke. An example of an early initiative includes befriending services, where volunteers visit persons with stroke and listen to their concerns about living with stroke in the community (Singapore National Stroke Association, 2018). As far we as know, stroke management in most countries, including India and Singapore, is highly focused on meeting the needs of individuals living with stroke (Prasad at al., 2011). There is a dearth of emphasis on supporting persons with stroke and their spousal caregivers as a couple or dyad in stroke recovery.

1.1.4 Post-stroke coping experiences of couples in the community

Ramazanu and colleagues (2020a) conducted a scoping review revealing the coping experiences of persons with stroke and their spousal caregivers living at home in the community post-stroke. The aims of the review were to find out, (1) what is known from the existing literature about the coping experiences of couples in the community after the stroke of a spouse?, (2) what is the impact on the spousal relationship after a stroke?.The review identified key post-stroke challenges faced by couples. They included (a) emotional challenges, (b) role conflicts, (c) lack of coping strategies, (d) reduced life satisfaction for the couples, and (e) marital relationships being at a point of change. The review identified various emotional challenges encountered by couples coping with stroke such as feeling emotionally overwhelmed, stressed, depressed, lonely, irritable, and in an intolerable situation. Interestingly, unavoidable role conflicts between persons with stroke as a 'recipient of care' and spousal caregivers as the 'protector' further strained couples' relationships (Ramazanu et al., 2020a). It was also evident that spousal caregivers lacked effective coping strategies to deal with their spouse's stroke. Visser Meily et al. (2009) reported spousal caregivers' engagement in passive and avoidance coping at three years post-stroke. For instance, some spouses coped by 'walking away' from their caregiving responsibilities for their spouse living with stroke. Spousal caregivers tend to have lower levels of life satisfaction than persons with stroke. One study revealed that at three years post-stroke, more spousal caregivers (50%) were found to be dissatisfied with their lives than persons with stroke (28%) when assessed using the LiSat-9 scale. Unfortunately, some couples who had been married for 11-15 years divorced after one of the spouses experienced a stroke (Anderson et al., 2017).

From the perspective of persons with stroke and their spousal caregivers at home in the community, Ramazanu et al. (2020a) reiterated that couples require more support to cope and manage living with stroke at home. It is also of utmost priority for hospital management to develop policies to address the inadequate coping and preparation of couples after a stroke. The Stroke Foundation of Australia (2019) highlighted the fact that persons with stroke and their caregivers often grieve due to the "loss" of life as usual, functional abilities, and independence after a stroke. Thus, it is crucial to reduce psychological stressors by adequately supporting the needs and concerns of both persons with stroke and their spousal caregivers during their care transition from hospital to home.

CHAPTER TWO

LITERATURE REVIEW

2.1 Interventions facilitating care transition of couples from hospital to home after a stroke

Recently, a systematic review and meta-analysis (Minshall et al., 2019) was conducted examining psychosocial interventions for persons with stroke and their family caregivers. The review reported that psychosocial interventions minimised depressive symptoms in both persons with stroke and their family caregivers. However, the focus of ‘carers’ was not specific to spousal caregivers. As such, the review included family caregivers, such as siblings of persons with stroke. Another meta-analysis (Lee et al., 2007) of four studies was conducted to examine the effectiveness of interventions aimed at promoting mental health and well-being amongst elderly informal caregivers of persons with stroke. However, little attention has been given to empirical work on specific support interventions for persons with stroke and their spousal caregivers. Similarly, Bakas and colleagues (2017) updated evidence on stroke-related interventions. In that review, caregiver-specific interventions mainly focused on caregiver health outcomes. Whereas, dyadic interventions developed for both persons with stroke and their family caregivers generally targeted measuring the health outcomes of the person living with stroke. Hence, this current review was conducted to update and extend the three reviews carried out previously by: (i) identifying the extent and nature of existing support interventions available for persons with stroke and their spousal caregivers, and (ii) exploring participant experiences after they had taken part in a support intervention (Ramazanu & Chiang, 2019). The literature review covered all types of studies: quantitative, qualitative, and mixed-methods. Relevant articles on interventional studies on stroke care strategies were systematically searched using five electronic databases (PsychInfo, CINAHL, Pubmed, Embase, and MEDLINE via OvidSP). The following keywords were employed for the search strategy: stroke, cerebrovascular disease, intervention, therapy, support, couple, dyad, hospital and home. “AND” and “OR” Boolean operators were used to combine search terms This mixed-methods systematic review was conducted from the inception of databases to 1 June 2020, so as to update the evidence on interventions that enables couples in their coping following a stroke. Reference lists of the included articles were carefully scrutinized for any potentially additional eligible articles. End Note X7 software was used to search, download, organize and cite the articles. After the searches and screening, four studies were identified for the review. It was reported based on the Joanna Briggs Institute (JBI) methodology for mixed-methods systematic review guidelines (The Joanna Briggs Institute, 2014).

JBI critical appraisal tools (randomised controlled trials, quasi-experimental studies, and qualitative research) were used to appraise the quality of articles included in this mixed-methods systematic review (Lockwood et al., 2015; Tufanaru et al, 2017). All four articles included in the review were of moderate to high in quality after appraisal with JBI tools.

2.1.1 Review study characteristics

A total of four studies was included in the review for synthesis after the process that followed PRISMA (2015). Two authors independently reviewed and appraised the articles. Any disagreements in the assessment were resolved through discussion until a consensus was reached. Two quantitative studies, one mix-methods study, and one qualitative study were included in the literature review (Ramazanu & Chiang, 2019).Two quantitative studies were randomised control trials (RCTs) (Clark et al., 2003; Ostwald et al., 2014), while the other was a mixed-methods pilot study (Robinson-Smith et al., 2015). The qualitative study employed a case study design (Hodson et al., 2019). Two countries were represented in the included studies (U.S., n=2; Australia, n=2). No studies targeting couples-based stroke interventions were conducted in Asia. In all studies, stroke interventions were conducted at couples' homes after discharge from hospital. The mean age of persons with stroke was 68.1 years, while for spousal caregivers it was 65.2 years.

2.1.2 Intervention type

Three out of four studies carried out psychoeducational interventions for persons with stroke and their spousal caregivers (Clark et al., 2003; Ostwald et al. 2014; Robinson-Smith et al., 2015). They incorporated the multicomponent strategies of education, social support, and counselling techniques. These studies focused on educational elements comprised of general information on stroke condition and stroke recovery, measures for healthy lifestyle promotion, and ways to minimise the risk of a recurrent stroke. Additionally, in one study, couples received mailed information on stroke management (Ostwald et al. 2014). All interventions were delivered by healthcare professionals, such as allied health workers and nurses, with relevant clinical training and expertise in stroke care.

2.1.3 Quantitative results synthesis: Impact of stroke intervention on couples

The effect of stroke interventions on couples' stress appraisal, coping, depression, and family functioning was evaluated. With reference to Cohen (1992), an intervention effect size of 0.20 was classified as small, 0.50 as medium, and 0.80 as large.

Stressor appraisal

One study reported on the stressor appraisal of persons with stroke and their spousal caregivers (Ostwald et al. 2014). Stressor appraisal was measured using the Perceived Stress Scale (PSS). The study found that after a home-based psychoeducational intervention, PSS scores for persons with stroke were much lower in the intervention group than in the control group at 12 months, with a small effect size (*d* = 0.33). Similarly, there was a slight improvement in the PSS scores of spousal caregivers at 12 months after the intervention with a very small effect size (*d* = 0.02). It is worth noting that in both persons with stroke and spousal caregiver groups, there was a reduction in stress appraisal scores after participating in the intervention.

Coping

The effect of a nurse-led psychoeducational intervention on couples coping together after a stroke was measured using the Dyadic Coping Instrument (DCI) (Robinson-Smith et al., 2015). The study reported a significant difference in dyadic coping between persons with stroke in the intervention group compared to the control group, with a large effect size (*d* = 1.26). As for spousal caregivers, a significant improvement was also found in dyadic coping, sustained for four to five months after study completion, with a large effect size (*d* = 1.10).

Depression

Two studies measured the effects of respective interventions on couples' depression scores (Ostwald et al. 2014; Robinson-Smith et al., 2015). In one study, depression was measured using the Geriatric Depression Scale (GDS) (Short Form) (Ostwald et al. 2014). The other study utilised the Center for Epidemiological Studies-Depression (CES-D) self-report scale (Robinson-Smith et al., 2015). Home-based psychoeducational intervention showed a small effect in reducing the depression scores of couples at 12 months after the intervention (*d* = 0.38) (Ostwald et al. 2014). Robinson-Smith et al. (2015) reported that the nurse-led psychoeducational intervention showed a statistically significant decrease in the depression scores of persons with stroke in the intervention group compared to the control group, with a large effect size (*d* = 1.93). Unfortunately, there was no statistically significant difference observed in the depression scores of spousal caregivers in the intervention group compared to the control group.

Family functioning

One study examined the family functioning of couples using the McMaster Family Assessment Device (FAD) (Clark et al., 2003). Persons with stroke in the intervention group showed statistically improved family functioning, compared to those in the control group, with a medium effect size (*d* = 0.67). Spousal caregivers in the intervention group also reflected a significant improvement in family functioning after participating in the intervention, with a medium effect size (d = 0.46).

2.1.4 Qualitative results synthesis

Themes of ‘being flexible and adapting to life post-stroke’ and ‘supporting spouse through communication’ were extracted from two studies (Hodson et al., 2019; Robinson-Smith et al., 2015). Similarities and differences between the findings were critically analysed using JBI techniques (The Joanna Briggs Institute, 2014).

Being flexible and adapting to life post-stroke

The first theme synthesised the ways in which couples cope by being flexible and adapting to life after stroke. Rather than worrying, these couples were encouraged to take one step at a time, focus on the present moment, and set reasonable goals to anticipate success in their everyday tasks (Robinson-Smith et al., 2015). In contrast, during the first month after a stroke, participants in the Hodson and colleagues (2019) study felt shocked and confused about how to deal with the aftermath of a stroke. Over time, as the couples adapted, they felt thankful for the supportive social environment and the intervention they had received from healthcare professionals.

Supporting spouse through communication

The second theme synthesised the need to support spousal caregivers through communication. In the first month following discharge home, a number of persons with stroke experienced difficulties carrying out their daily living activities, due to stroke-related disability. This contributed to a heightened feeling of frustration in their spousal caregiver, whose daily life was disrupted (Hodson et al., 2019). The spousal caregiver also felt suffocated when she had to prioritise her spouse’s needs over her own. In a Robinson-Smith et al. (2015) study, nurses facilitated communication between persons with stroke and their spousal caregiver. The steps for communication included slowing down and taking the time to listen to one another, without the need to offer solutions. Despite the support service that was available, some spousal caregivers were hesitant about seeking assistance from healthcare professionals (Robinson-Smith et al., 2015).

2.1.5 Mixed-methods synthesis

When integrating findings from the study by Robinson-Smith et al. (2015), it was noted that the interventions improved couples’ ability to cope with living with stroke. This was evident as improvements in the outcome measures of stressor appraisal, coping, depression, and family functioning were reported. Similarly, qualitative findings reported that couples generally adapted well after a stroke. However, some spousal caregivers required more support, as they contemplated seeking help from healthcare professionals whenever necessary. As a result, these spousal caregivers suffered from the caregiving demands of caring for their spouse living with stroke. Furthermore, amongst spousal caregivers, there was no significant improvement in depression scores after participating in the psychoeducation.

2.1.6 Research gaps

This review provided updated information on the interventions available to support couples in coping after a stroke (Ramazanu & Chiang, 2019). Although limited research has been conducted on interventions targeting persons with stroke and their spousal caregivers, the review found that it is necessary to support stroke couples as a dyadic unit of care.

It is understood that some spousal caregivers suffer from the demands of daily caregiving at home. Unfortunately, some of them contemplate seeking timely support from healthcare professionals. Similarly, a recent study conducted in Sweden reported that spouses had experienced several challenges in their daily lives when providing informal care for their spouses, who had been diagnosed with a chronic disease (Eriksson et al., 2019). Spousal caregivers' physical and psychological health was increasingly affected due to the limited time they had for themselves. It is therefore of paramount importance to develop support initiatives that strengthen spousal caregivers' resilience and their efficacy at home in the community (Roberts & Struckmeyer, 2018). The term 'caregiver resilience' refers to the utilisation of successful coping strategies by caregivers that shifts the caregiver burden perspective to a resilience perspective (Ross et al., 2003).

In addition to caregiving burden and depressive symptoms, another study identified that spousal caregivers of persons with Alzheimer disease and Parkinson's disease experienced difficulties around caregiving (Davis et al., 2011). Spousal caregivers felt disappointed and tense within their marital relationship, and care decision conflicts within the relationship were apparent. Significant relationship stress from caring for a spouse with chronic disease necessitates the need to develop couples-based interventions that allow spousal caregivers to deal with the tensions related to caregiving, and care decision making conflicts (Davis et al., 2011).

Couples-based interventions for persons with chronic disease and their spousal caregivers are deemed promising, enabling them to cope effectively as a couple. The results of a randomised pilot trial on self-management intervention for head and neck cancer patients and their spousal caregivers also indicated that such an intervention empowered couples with the essential skills to coordinate and overcome the challenges of a cancer diagnosis together (Badr et al., 2019). This pilot intervention holds great promise for improving couples' psychological functioning after cancer. In another study, a couples-based mind-body (CBMB) intervention was developed to minimise psychological and spiritual distress in persons with metastatic lung cancer and their spouses (Milbury et al., 2018). Likewise, preliminary evidence of CBMB intervention suggested that the couples-based intervention enhanced the quality of life in both persons with cancer and their spouses (Milbury et al., 2018).

Interestingly, overall there have been no stroke interventions developed in the Asian context in preparing couples for community life after a stroke. Therefore, preliminary studies are warranted to understand specific contextual factors that facilitate the delivery of a culturally sensitive intervention in Asia, prior to the design and implementation of any support intervention (Medical Research Council, 2008). For instance, in Ghana, stroke is often perceived as a 'ghost' illness and people have no idea as to why a stroke would occur (Sanuade, 2018). It is therefore important to understand the cultural meanings of stroke, and beliefs about stroke recovery in couples of different ethnic communities.

2.2 Study aims, objectives, and hypotheses

The ultimate aims of this study were to develop, evaluate the feasibility, and test the preliminary effects of an intervention to support post-stroke living and recovery in persons with stroke and their spousal caregivers. The study was systematically underpinned by the first two stages of the Medical Research Council (2008) framework in terms of a literature review and qualitative study.

The study objectives are as follows:

Objective 1: To systematically develop an intervention to support couples in their living and recovery after a stroke through conducting a literature review and qualitative study in Singapore.

Objective 2: To evaluate the acceptability, feasibility and preliminary effects of an intervention supporting couples in living and post-stroke recovery, using an embedded mixed-methodology.

Hypothesis: There are no statistically significant differences in dyadic coping, dyadic adjustment, and anxiety and depression variables in persons with stroke and their spousal caregivers who took part in the proposed intervention (T_1- three weeks after the intervention) compared to pre-intervention (T_0-baseline).

2.3 Study significance

Several studies in the literature noted that couples living with other chronic medical conditions coped better after participating in hospital-based interventions developed by healthcare practitioners. For instance, Stewart and colleagues (2001) designed a 12-week support group for couples whose spouse had been diagnosed with a first-time myocardial infarction. The group-based intervention yielded positive effects on couples' coping and confidence, and on the strengthening of the marital relationship (Stewart et al., 2001). In another study, the Caring for Couples Coping with Cancer (4Cs) intervention was developed to support Chinese couples coping with a cancer diagnosis (Li et al., 2015). The intervention improved couples' communication, coping, stress appraisal, and quality of life in hospital before the person with cancer was discharged to go home (Li et al., 2015). The development and implementation of a post-stroke intervention, which would form part of a routine nursing care plan, could help couples feel more confident in their ability to cope with the after-effects of stroke, even after the person who had the stroke is discharged from the hospital (Quinn et al., 2014). This is the first attempt for an intervention to be established and tested in a Singaporean context to support couples in post-stroke living and recovery. In terms of study significance, it is anticipated that from Objective 1 of the study, the findings from the review (Ramazanu et al., 2020a) and interpretive descriptive qualitative study (Ramazanu et al., 2020b) will provide direction and justification for the development of an intervention. Feasibility testing and preliminary results evaluation (Objective 2) is a vital step in methodological research, and it is the preparatory work that is usually skimped on (Campbell et al., 2000). The results of this scientific exercise will inform strategies to progressively refine the intervention, before embarking on a full-scale true experimental design study (Eldridge et al., 2004).

2.4 Operational definitions

This section highlights the operational definitions of common terms used in this thesis.

Couple

In traditional terms, ‘couple’ denotes a husband or wife after a legal marriage. In this thesis, the terms ‘couple’, ‘spouse’, and ‘spousal caregiver’ are utilised interchangeably.

Stroke recovery

‘Stroke recovery’ refers to the gradual improvement of cognitive and physical function of persons with stroke (Palmer & Palmer, 2011, p. 15). The extent of stroke recovery differs from one individual to another. The Centers for Disease Control and Prevention (2018) have reported that although some persons make a full recovery from a stroke, others may suffer disabilities, such as paralysis, over the long term.

Transition of care

‘Transition of care’ refers to a set of actions implemented to facilitate a coordinated patient’ movement between healthcare locations and levels of care, promoting patients’ continuity of health and well-being (Olson et al., 2011). A patient’s journey in the healthcare system may involve care transitions from acute care to rehabilitation care and eventually home care (National Transitions of Care Coalition, 2016). It has also been highlighted that an effective care transition through healthcare services coordination is of paramount importance to prevent unnecessary emotional suffering, for patients as well as for their caregivers (World Health Organisation, 2016).

CHAPTER THREE

METHODOLOGY

3.1 Methodology based on MRC framework in developing the 3H intervention

The first two stages of the Medical Research Council (MRC, 2008) framework (**Figure 1**) were adopted to systematically guide the development (Section 4.2 of Chapter 4), feasibility testing, and preliminary results evaluation (Section 4.3 of Chapter 4) of the proposed intervention.

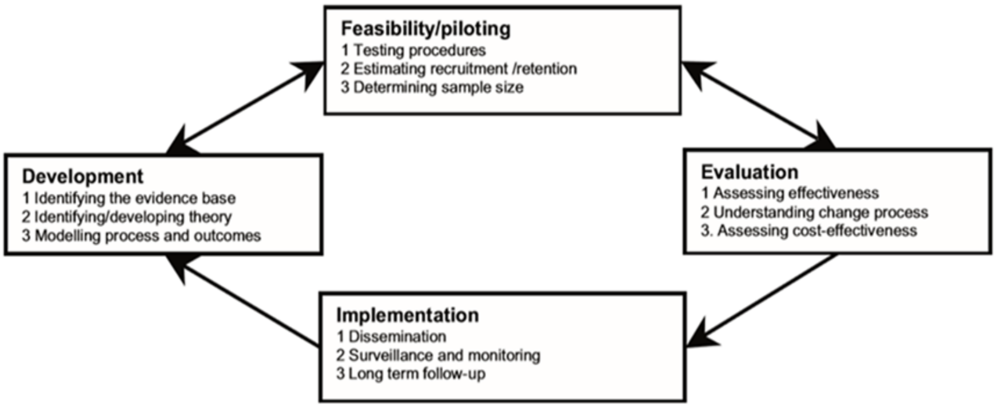
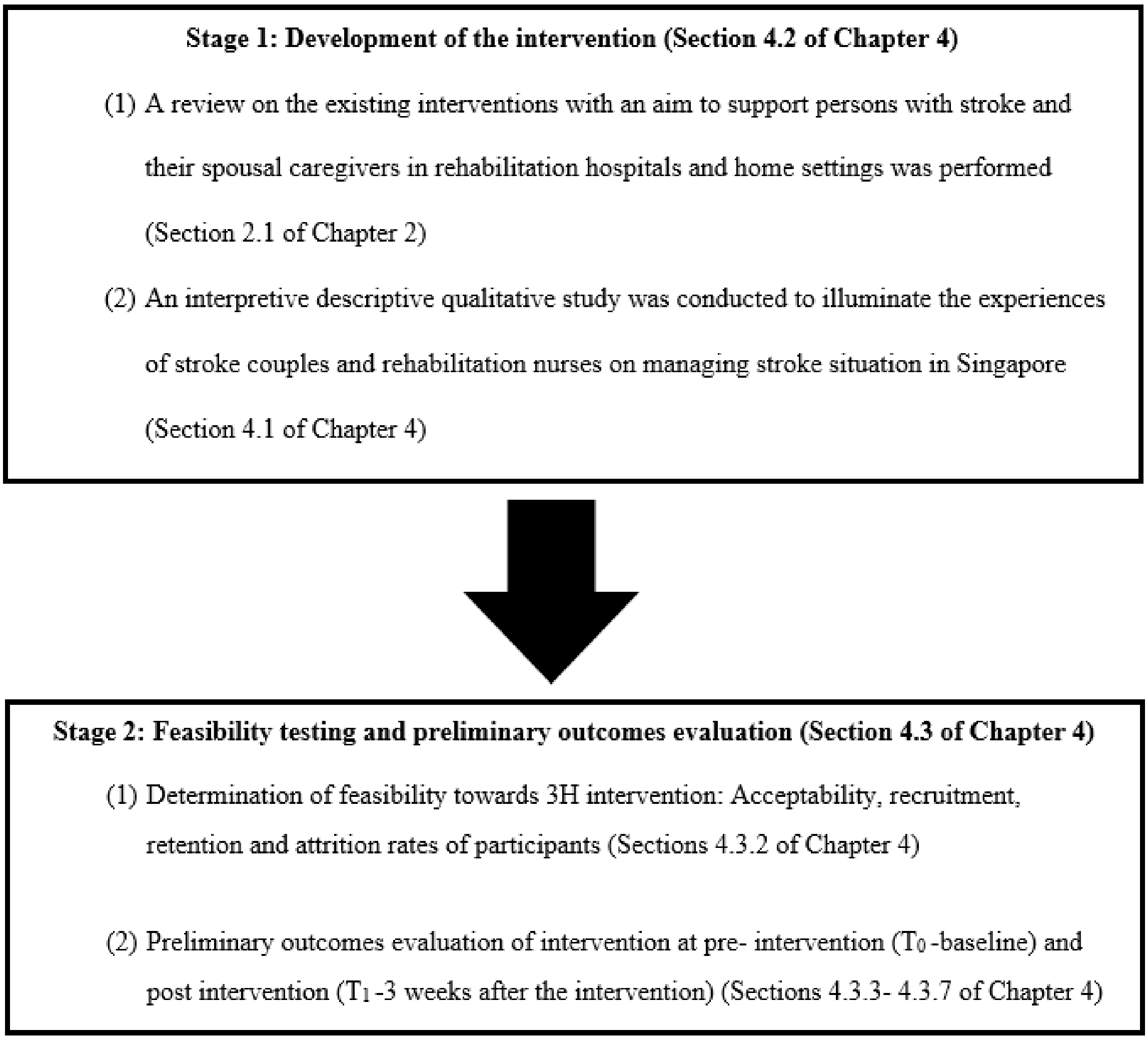


Figure 1: Stages of MRC framework

Source: Campbell et al. (2000)

The MRC framework was selected to underpin the overall study, which aimed to develop the intervention programme for stroke couples, as the best research practice is to first develop healthcare interventions systematically, with the available existing evidence, selection of a suitable theory, and testing of interventional feasibility (Craig et al., 2008). A feasibility study evaluation of an adolescent-based sexual health intervention in rural Zimbabwe found that a classroom-based programme was infeasible due to the differences in cultural norms, teaching styles, and teacher-student relationships within this context (Power et al., 2004). This study demonstrated the need for carefully planned feasibility studies comprised of process evaluations, prior to conducting large scale randomised controlled trials in the community (for example, this would also be the case in Singapore, which is multi-cultural). **Figure 2** illustrates a summary diagram on the flow of study stages for the development and implementation of the 3H intervention in this study.



Stage 1: Development of the intervention (Section 4.2 of Chapter 4)

1. A review on the existing interventions with an aim to support persons with stroke and their spousal caregivers in rehabilitation hospitals and home settings was performed (Section 2.1 of Chapter 2)
2. An interpretive descriptive qualitative study was conducted to illuminate the experiences of stroke couples and rehabilitation nurses on managing stroke situation in Singapore (Section 4.1 of Chapter 4)

Stage 2: Feasibility testing and preliminary outcomes evaluation (Section 4.3 of Chapter 4)

1. Determination of feasibility towards 3H intervention: Acceptability, recruitment, retention and attrition rates of participants (Sections 4.3.2 of Chapter 4)
2. Preliminary outcomes evaluation of intervention at pre- intervention (T_0 -baseline) and post intervention (T_1 -3 weeks after the intervention) (Sections 4.3.3- 4.3.7 of Chapter 4)

Figure 2: Summary diagram on the flow of study stages

3.2 Stage 1: Methods of an interpretive descriptive study in Singapore on facilitating recovery for couples after a stroke

3.2.1 Study design

To facilitate the understanding of clinical practices in terms of health, illness, and experiences in a healthcare context, an interpretive description was chosen (Hunt, 2009; Sandelowski, 1986; Thorne et al., 1997). In previous studies (Forbes et al. 2012; Stevenson et al., 2015), this study design has been used to uncover knowledge of factors that drive successful nursing practices. It is anticipated that the findings of this interpretive descriptive study can guide the development of a support intervention for persons with stroke and their spousal caregivers in Singapore. The objectives of this study were to, (a) understand how persons with stroke and their spousal caregivers cope with stroke recovery; (b) explore the social and cultural factors hindering couples' recovery post-stroke; (c) identify how nurses distinguish what supports and prevents couples' recovery from stroke in the community; and (d) explore the meaning of stroke recovery from the perspective of couples and rehabilitation nurses.

3.2.2 Sampling strategies and setting

Study participants were recruited through purposive sampling to gather their rich, first-hand knowledge of the subject matter (Polit & Beck, 2010). An interpretive description can be performed with any sample size (Thorne et al., 1997). In most studies, the sample sizes vary from five to 30 participants (Thorne, 2008, p.94). Registered nurses, persons with stroke, and their spousal caregivers were recruited from a stroke rehabilitation hospital in Singapore for this study.

3.2.3 Inclusion and exclusion criteria

Participants who fulfilled the following inclusion criteria were invited to take part in the study: (a) able to provide written consent and at least 21 years of age, (b) person with stroke had experienced either an ischaemic or haemorrhagic stroke episode, (c) spousal caregivers who self-identify as both a spouse and the primary family caregiver to the person with stroke, (d) registered nurses with experience working in the stroke rehabilitation ward, (e) able to communicate comfortably in English, and (f) persons with minor stroke (scores 1-4) using The National Institutes of Health Stroke Scale (NIHSS).

Exclusion criteria included persons who had suffered a stroke who had cognitive impairment, scoring less than seven out of 10 using the Abbreviated Mental Test (AMT). In addition, persons with stroke with severe dysarthria, as assessed by a speech therapist assessment report, were excluded. This measure prevents the risk of persons with stroke becoming emotionally distressed during the interviews (Savage, 2006).

3.2.4 Data collection

Data collection commenced 1 June 2018 and ended 30 June 2018. Each interview ranged in duration from approximately 20 to 60 minutes. A semi-structured interview topic guide was utilised to facilitate how the interviews were conducted. Couples were asked the following open-ended questions during the interviews: (a) Would you like to share your story of how you experienced stroke, (b) What experiences stood out as challenging for you, (c) What experience was important in stroke recovery when you were going to be discharged home, (d) What advice might you share with someone who is trying to cope after a stroke?

Registered nurses who took part in the interview were asked the following questions: (a) What are your experiences of providing care for persons with stroke and their spousal caregivers in a ward setting, (b) What is a typical day for you like when caring for persons with stroke and their spousal caregivers, (c) What makes your work with stroke couples particularly challenging, (d) What facilitates your work with stroke couples, (e) What would be your advice to a newly registered community nurse who is caring for persons with stroke and their spouses?

3.2.5 Data analysis

Data analysis began with the independent coding of transcripts by the researcher (PhD candidate) and two supervisors in the study team. NVivo 11 software (QSR International, 2014) was used to manage the codes and coding structure. The transcribed data was first grouped into codes based on Thorne’s (2008) interpretive description. Similar code patterns were categorised by relationships and associations. Theorisation occurred using an iterative reasoning process by focusing on how patterns of codes operated that shaped the structure of themes. As the themes provided a coherent structure of constructs, reconceptualisation occurred, hence, indicating the patterns and meanings of stroke recovery among couples living with stroke and registered nurses in the rehabilitation hospital (Thorne, 2008).

Utilising the criteria as proposed by Tobin and Begley (2004), research rigour was determined in terms of credibility, dependability, reflexivity, and transferability. As study findings were scrutinised by the researcher and supervisors to address participants' experiences, credibility was established. Credibility was also achieved using peer debriefing with the study supervisors, who had more than 18 years of combined experience and expertise in qualitative research methodology. To enhance dependability, during data analysis, the researcher and a supervisor were involved in the coding and recoding process. Consensus in the coding process was achieved with the verification of any discrepancies by seeking the expertise of the third research team member. The researcher who had collected data through qualitative interviews kept a reflexive diary. Reflections allowed the researcher to remain conscious of the dynamics of the interviewer-interviewee relationship, and the ways in which her role (as a nurse and researcher) shaped the conception of different knowledge. Finally, by considering the applicability of findings with the audit trail, as established from the above in a rehabilitation hospital context in Singapore, the transferability of the findings was ensured.

3.2.6 Ethical approval

Ethical approval was sought from two institutions. First, it was obtained from the Human Subjects Ethics Applications Review System of the Hong Kong Polytechnic University (reference number HSEARS20180205008). Next, it was obtained from the National Healthcare Group Domain Specific Review Board in Singapore (reference number 2018/00117).

3.3 Stage 2: 3H intervention methods of feasibility testing and preliminary outcomes evaluation

3.3.1 Study design

An embedded mixed-methods approach was subsequently adopted to test the feasibility and preliminary outcomes of the 3H intervention. An embedded design is a mixed-methods design, “in which one data set provides a supportive, secondary role in a study based primarily on the other data type” (Creswell et al., 2003, p. 67). Such an approach mixes a quantitative design with a qualitative design, with the latter being embedded within the former (Caracelli & Greene, 1993; Creswell et al., 2003). A single set of either quantitative or qualitative data may not be sufficient to answer all of the research questions raised in a study. The key strength of an embedded mixed-methods design is that it allows different research questions to be answered. One challenge in using a mixed-methods approach is that it can be difficult to integrate the quantitative and qualitative datasets to answer different research questions (Creswell et al., 2003). However, unlike the mixed-methods approach for data triangulation, in an embedded design there is no need to achieve a convergence of quantitative and qualitative data. Creswell and colleagues (2003) emphasised that researchers can report the results of quantitative and qualitative analyses separately in their reports.

The 3H (Head, Heart, and Hands) intervention, so developed, was first tested for acceptability and recruitment feasibility by the quantitative assessment of study participant recruitment, retention, and attrition rates. The preliminary outcomes of this intervention were evaluated through a pre- and post-test quasi-experimental design with no control group. Like the RCT, a quasi-experimental study tested the casual hypotheses (United Nations Children's Fund / UNICEF, 2014). A limitation of the single-group pre- and post-test quasi-experimental design is the possible threat to the study's internal validity, where the pre-test may increase participant sensitivity to the intervention and later influence their post-test performance (Harris et al., 2006). Despite the limitation, Harris et al. (2006) asserted that a pre- and post-test quasi-experimental design with no control group is a commonly applied study design in healthcare research. In this study, a single pre-test measurement was taken (T_0), followed by an intervention (X), and then a post-test measurement (T_1).

Following the quasi-experimental study, interpretive descriptive qualitative interviews were conducted to evaluate the feasibility of the 3H intervention. The eight domains for feasibility testing include acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy (Bowen et al., 2009, p. 453). It is an inductive qualitative methodological design that moves beyond description to uncover possible "associations, relationships and patterns within the phenomenon" (Thorne, 2008, p. 50). In this study, we focused on recognising potential associations and relationships between the experiences of couples living with stroke after taking part in a 3H intervention, and the subsequent perceived effects on their ability to cope after a stroke. Through this method, we discovered how different contextual factors could affect the ways in which couples living with stroke respond and cope with stroke. Semi-structured interviews were conducted with persons with stroke and their spousal caregivers in order to collect data on their experience of participating in the 3H intervention (Hsieh & Shannon, 2005).

3.3.2 Study setting

A rehabilitation hospital in Singapore comprised of inpatient stroke rehabilitation wards was selected as the study setting for participant recruitment. Ethical approval from the hospital, and permission was sought from the Nursing Director and Nursing Manager of the related ward prior to implementing the 3H intervention.

3.3.3 Inclusion and exclusion criteria

The criteria for participant inclusion were, (a) adult couples (aged >21 years old); (b) person with stroke who had a medical diagnosis of either ischaemic or haemorrhagic stroke; (c) both the person with stroke and their spousal caregiver agreed to take part in the study, (d) spoke fluent English, and (e) persons with minor stroke (scores 1-4) using NIHSS scale. Persons with stroke with severe cognitive impairment, and / or severe dysarthria were excluded from the study. An Abbreviated Mental Test (AMT) score of less than seven out of 10 (Hodkinson, 2012), and a speech therapist's assessment report of dysarthria were used to screen out ineligible participants.

3.3.4 Sample size

Study participants were recruited by convenience sampling (Polit & Beck, 2010). They were selected based on their availability to participate in the study. As a rule of thumb, 12 participants per group is sufficient for a feasibility or pilot study (Julious, 2005). Taking into consideration a participation refusal rate of approximately 20%, a total of 32 couples was approached and recruited for study participation. Of these 32 couples, seven persons with stroke and seven spousal caregivers were purposively chosen to share their experiences of participating in the 3H intervention. Creswell (1998) recommended that five to 25 participants be interviewed to achieve data saturation.

3.3.5 Data collection

The 3H intervention programme, so developed, was tailored to the duration of a rehabilitation hospital stay by a typical person who had had a stroke. A mixed-methods pilot study found that the total dosage of six sessions was appropriate (Robinson-Smith et al., 2015). For this study, a total of six sessions was carried out over a period of three weeks in the ward. The intervention was conducted face-to-face in groups (sessions 1, 2, 4, and 6), and in individual dyadic sessions (sessions 3 and 5) (Appendix I). The duration of each intervention session was approximately one hour, as informed by the results of previous intervention studies for couples living with stroke, which have ranged from 60 to 70 minutes (Clark et al., 2003; Ostwald et al., 2014). The 3H intervention was conducted by the researcher, who has worked as a registered nurse in stroke settings for six years.

For participants who met the study eligibility, the researcher explained the 3H intervention using an information sheet (Appendix II) and invited them to participate. Written consent was then sought from both persons with stroke and their spousal caregivers (Appendix III). Prior to the implementation of the 3H intervention, participants were required to complete a set of baseline questionnaires

(T_0). Thereafter, persons with stroke and their spousal caregivers took part in the 3H intervention for three weeks. The researcher had prepared slides to guide the delivery of each intervention sessions that comprise of ‘heart’, ‘heart’ and ‘hands’ components. In addition, as for skills training ‘hands component’, participants were gathered in circles to observe mobility transfers of person with stroke. At the end of the sessions, participants redemonstrated the skills they had learnt. In sessions 3 and 5 that involve shared-decision making ‘heart component’, couples spoke about their social support after a stroke diagnosis and ways they could strengthen their marital relationship, utilizing the guidelines of shared-decision making (as shown in Appendix XII). During the intervention sessions, the researcher encouraged participants to share their stroke coping experiences, their challenges and ways they had overcome their challenges as a couple with other participants.

Three weeks after participating in the 3H intervention, participants completed the post-intervention questionnaire (T_1). Each couple was given 3H intervention bags comprised of (a) stroke management brochures, and (b) a stress ball (Appendix IV). Participants were strongly encouraged to attend other groups’ sessions if their scheduled session had clashed with other scheduled activities. The researcher made telephone calls to remind the participants about attending the 3H intervention sessions. A flowchart of the data collection process is illustrated in **Figure 3**.

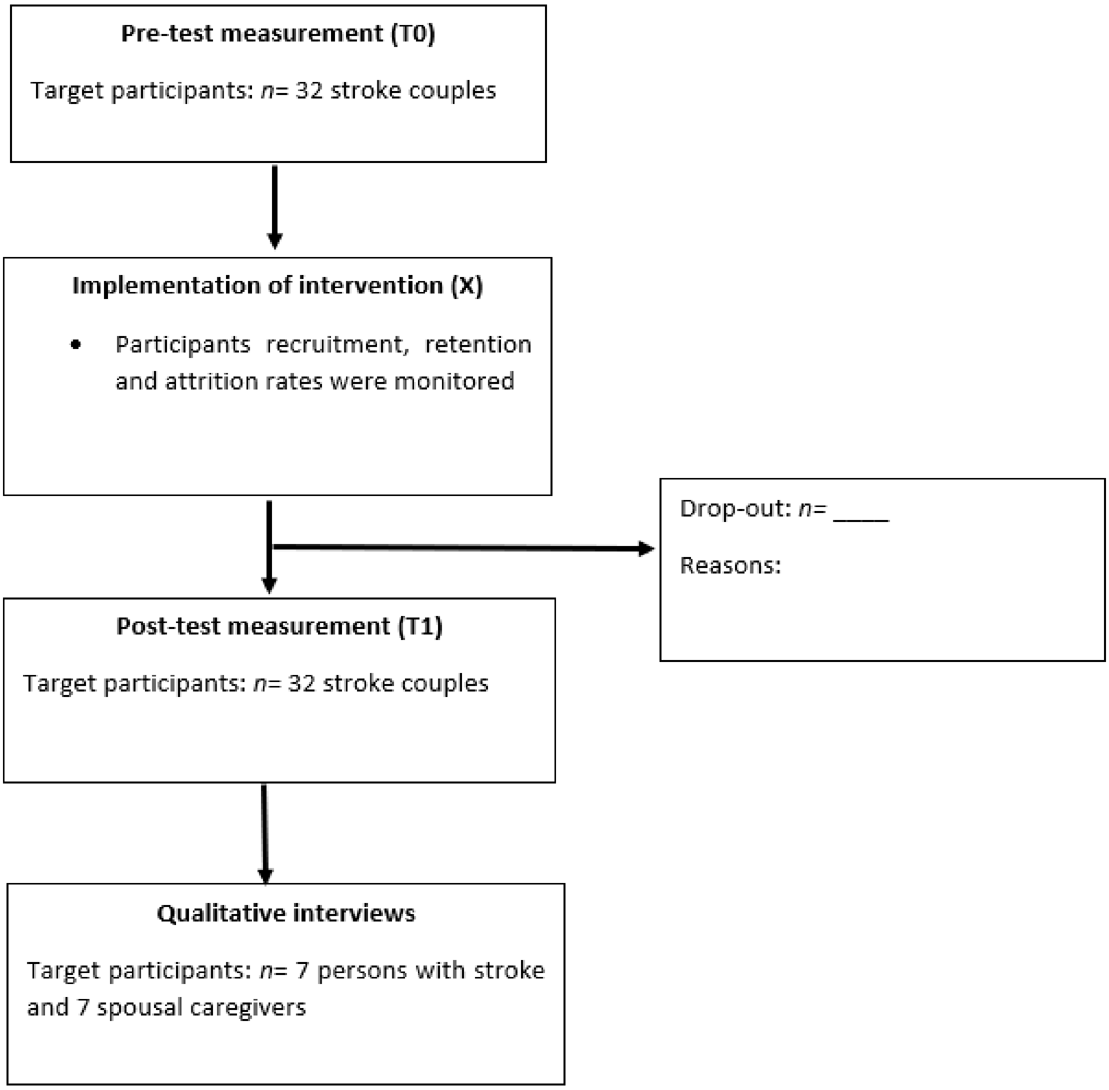


Figure 3: A flowchart of the data collection process

As a component of the embedded mixed-methods design, qualitative interviews were conducted to explore the experiences of couples after their participation in the 3H intervention and to evaluate intervention feasibility. A semi-structured interview guide was developed to facilitate individual interviews with participants (Appendix V). The guide was developed based on the Kallio et al. (2016) framework, which includes: (a) identifying the prerequisites for using semi-structured interviews; (b) formulating a preliminary semi-structured interview guide; (c) pilot testing the guide; and (d) presenting the complete set of guidelines to use. The interview guide was initially pilot tested with the first three interviews. Since no revisions of the interview guide were required and the interviews were of high quality, providing significant information about the research topic, the pilot interviews were included in the data analysis. Each face-to-face semi-structured interview was conducted for an estimated duration of 20-50 minutes. All of the interviews were audio-recorded and transcribed verbatim for data analysis.

3.3.6 Treatment fidelity

Treatment fidelity refers to putting procedures in place to ensure that the researcher delivers the intervention as intended (Prowse & Nagel, 2015). Several methods were adopted to scrutinise the fidelity of the 3H intervention. To facilitate the intervention's standardised training, a 3H intervention manual was developed to deliver the intervention according to a detailed protocol (Karas & Planki, 2016). The researcher enrolled in, studied, and was certified as a Mental Health Ambassador by The Hong Kong Polytechnic University, Office of Counselling and Wellness during the 3H intervention implementation. With training as a Mental Health Ambassador, the researcher was able to better guide participants on how to handle negative emotions and deal with post-stroke stress effectively (The Hong Kong Polytechnic University, 2013). Nurse manager of the rehabilitation hospital monitored if the 3H intervention was delivered in a similar fashion for every session according to the intervention protocol. The researcher followed the manual in conducting the intervention, and there was consistency in the delivery of 3H as there was not another person who conducted the 3H in this study.

3.3.7 Measurements

The primary outcome measure determined the intervention's acceptability and recruitment feasibility based on participant recruitment, as well as study retention and attrition rates. The secondary outcome measure evaluated the preliminary effects of the 3H intervention based on (a) anxiety and depression levels, (b) dyadic coping, and (c) dyadic adjustment pre-intervention (T_0) and post-intervention (T_1), in the third week after persons with stroke and their spousal caregivers had participated in the 3H intervention.

Recruitment acceptability and feasibility

The primary outcome measure focused on assessing the acceptability and feasibility of the 3H intervention recruitment of persons with stroke and their spousal caregivers. Acceptability is defined as, "the multi-faceted construct that reflects the extent to which people delivering or receiving the healthcare intervention consider it to be appropriate" (Sekhon et al., 2017, p.8). Sekhon and colleagues (2017) emphasized that acceptability is the key consideration in the design, implementation, and evaluation of complex interventions in healthcare.

If an intervention is deemed acceptable, persons with a chronic health condition and their caregivers are more likely to participate and derive benefits from improved clinical outcomes (Fisher et al., 2006; Hommel et al., 2013). However, if research participants do not consider the intervention to be acceptable, it may not be delivered as intended by the researcher, thereby impacting the intervention's overall effectiveness (Borrelli et al., 2005; Proctor et al., 2009). The 3H intervention's acceptability and recruitment feasibility was determined by calculating recruitment, and study participant retention and attrition rates (Lavoie et al., 2018). The reasons for 3H intervention participant attrition were identified and documented.

Study instruments

The following instruments were used in the study: (1) sociodemographic sheet, which is used to collect information on participants' gender, age, employment status, educational qualifications, and ethnicity; (2) dyadic coping inventory; (3) revised dyadic adjustment scale; and (4) the Hospital Anxiety and Depression Scale (Appendix VI).

The same set of study instruments was utilised to collect data at two time points, T_0 (baseline) and T_1 (three weeks post-intervention).

Dyadic coping inventory (DCI) is a 37-item questionnaire that measures couples' stress communication and coping (Meier et al., 2011). The DCI Cronbach's alpha (reliability) is .92 (Bodemann et al., 2006). The DCI internal consistency for persons with stroke is .883 and for spouses is .883 (Robinson-Smith et al., 2015), which is consistent for both parties.

The revised dyadic adjustment scale (RDAS) includes 14 items and is a self-reported questionnaire (Busby et al., 1995). It measures couples' relationships within three main categories of consensus: decision making, satisfaction in the relationship related to stability and conflict regulation, and cohesion as seen through activities and discussion. The RDAS has a Cronbach's alpha score of .90 (Crane et al., 2000).

The Hospital Anxiety and Depression Scale (HADS) is a validated and widely used self-reported tool that measures self-perceived levels of depression and anxiety (Meier et al., 2011). Cronbach’s alpha scores are .93 for the anxiety subscale, and .90 for the depression subscale (Herrmann, 1997).

3.3.8 Data analysis

Participant demographic data, as well as recruitment acceptability and feasibility, based on recruitment, retention, and attrition rates, were analysed with descriptive statistics. The data analysis for evaluating the 3H intervention preliminary outcomes and effects was conducted using inferential statistics by generalised estimating equations (GEE). As for the qualitative component, interview transcripts were analysed using conventional content analysis (Hsieh & Shannon, 2005).

Descriptive statistics

Descriptive statistics were generated to summarise the demographic characteristics of study participants based on age, class, gender, ethnicity, employment, and education. Similarly, descriptive statistics were utilised to tabulate participant recruitment, retention, and attrition rates in the 3H intervention.

Participant responses before and after the 3H intervention, assessing how they had adapted after a stroke in the family, were based on the Hospital Anxiety and Depression Scale (HADS), Revised Dyadic Adjustment Scale (DAS), and Dyadic Coping Inventory (DCI). Descriptively, all responses from the scales were scored and expressed as percentages, based on the total possible score for each item on the HADS, DAS, and DCI assessment tools. The quantified data were then tested for normality using the Shapiro-Wilk test (found to be non-normally distributed and null hypothesis is rejected). Therefore, subgroup analyses with Mann-Whitney test for independent samples were conducted to determine any statistically significant differences between the responses of persons with stroke and their spousal caregivers, whereas the Wilcoxon Test was used to compare couples’ responses before and after the intervention.

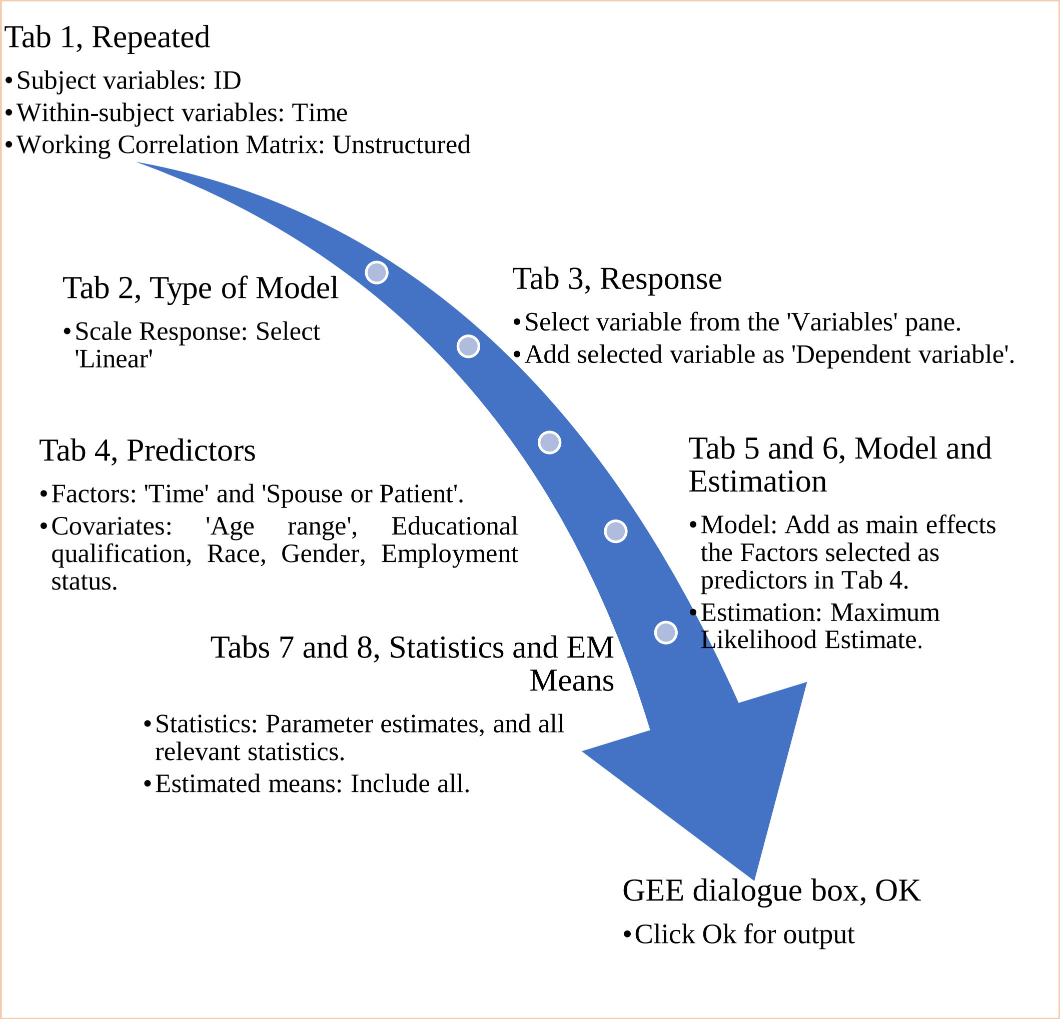
Generalised Estimating Equations (GEE)

The GEE approach was employed to model the 3H intervention’s effects on the adaptation of persons with stroke and their spousal caregivers using the Statistical Package for Social Scientists (SPSS v.20) (IBM Support, 2020). Aggregate scores for the adaptation mechanisms based on the assessment tools were created as dependent variables (Table 1).

Table 1 Summarised scores from the adaptation assessment tools

SCALE	Description
DAS-1	Dyadic Adjustment Scale (Consensus)
DAS-2	Dyadic Adjustment Scale (Satisfaction)
DAS-3	Dyadic Adjustment Scale (Cohesion)
HADS-1	Hospital Anxiety and Depression Scale (Anxiety)
HADS-2	Hospital Anxiety and Depression Scale (Depression)
DCI-1	Questions 1 to 4 (Outgoing stress communication)
DCI-2	Questions 5 to 15 (Incoming stress-coping behaviour)
DCI-3	Questions 16 to 19 (Incoming stress communication)
DCI-4	Questions 20 to 30 (Outgoing stress-coping behaviour)
DCI-5	Questions 31 to 35 (Couples’ stress-coping mechanism)
DCI-6	Questions 36 to 37 (Satisfaction with coping mechanism)

Scores from the scales had different variances pre- and post-test, therefore the unstructured covariance/correlation matrix was selected for the model. Age range, educational qualifications, ethnicity, gender, and employment status were treated as covariates in the model and not factors, because they did not exert a significant influence on the scores at either T_0 or T_1 (this was verified after running several iterations of the model). Time (as a function of the intervention) and participant identity, as either persons with stroke or spousal caregivers, were the only significant variables treated as factors in the model. Missing data were treated as ‘no response’ and included for analysis in the model. The analysis was therefore founded on the intention-to-treat principle (ITT). Selection of the best model after the iterations were run was based on the Quasi-Likelihood under the Independence Model Criterion (QIC) and its counterpart, the Corrected Quasi-Likelihood under the Independence Model Criterion (QICC), wherein the model with the smallest QIC was selected. Figure 3 presents the steps followed in SPSS for building the model using the GEE approach.



Tab 1, Repeated

- Subject variables: ID
- Within-subject variables: Time
- Working Correlation Matrix: Unstructured

Tab 2, Type of Model

- Scale Response: Select 'Linear'

Tab 3, Response

- Select variable from the 'Variables' pane.
- Add selected variable as 'Dependent variable'.

Tab 4, Predictors

- Factors: 'Time' and 'Spouse or Patient'.
- Covariates: 'Age range', Educational qualification, Race, Gender, Employment status.

Tab 5 and 6, Model and Estimation

- Model: Add as main effects the Factors selected as predictors in Tab 4.
- Estimation: Maximum Likelihood Estimate.

Tabs 7 and 8, Statistics and EM Means

- Statistics: Parameter estimates, and all relevant statistics.
- Estimated means: Include all.

GEE dialogue box, OK

- Click Ok for output

Figure 4: Steps followed in SPSS for building the model using the GEE approach

After calibrating the ideal model for the GEE approach, the intervention’s effects on couples’ adaptation were analysed. The following questions were addressed by results from the model:

a. How much of an improvement in different aspects of the couple’s adaptation was a direct result of the 3H intervention?

b. Is there a significant difference in the response of couples to the intervention based on whether they are persons with stroke or spousal caregivers?

Further subgroup analyses to evaluate the 3H intervention’s effects on couples’ adaptation were guided by the overall hypothesis that “couples who took part in the 3H intervention will adapt better with stroke situation in the family at three weeks after the intervention (T_1)”. The non-parametric Wilcoxon test was carried out to test this hypothesis, wherein a significance value (p) of less than 0.05 indicates “there are statistically significant differences in adaptation responses of participants before and after the intervention”.

Conventional content analysis

A total of 14 interviews was conducted and included in the analysis. No new data were generated in the final three interviews, thereby reflecting data saturation on the participants’ experiences of participating in the 3H intervention. In this study, a conventional content analysis was conducted (Hsieh & Shannon, 2005), in which the use of preconceived categories was avoided, and the categories were instead allowed to emerge from the data (Kondracki & Wellman, 2002). A conventional content analysis is also described as inductive category development (Mayring, 2000), where researchers immerse themselves in the data to synthesise new insights on the topic (Kondracki & Wellman, 2002).

Audio recordings were transcribed verbatim by the interviewer (the researcher) using NVivo 10 software (QSR International, 2014), while a supervisor double-checked the data transcripts. To familiarise themselves with the transcripts and gain an in-depth understanding of the content, both the researcher and study supervisors read all 14 transcripts several times. They independently coded extracts from all of the interviews, and then conducted several meetings to discuss and reach a consensus on the codes. Based on the codes, they developed an initial concept map. The themes that emerged were further reviewed and discussed until an agreement was reached.

Establishing methodological rigour

The qualitative study's rigour and trustworthiness was assured by adhering to the following four criteria: credibility, dependability, confirmability, and transferability (Polit, & Beck, 2014). The researcher and study supervisors have expertise in conducting qualitative studies. They also have clinical experience in caring for persons with long-term chronic diseases, thereby giving them credibility in managing and analysing qualitative data. The researcher is a registered nurse with six years of clinical experience in managing care for persons with stroke and their family caregivers. The same interviewer carried out all 14 interviews to ensure the study's confirmability and dependability. Meetings that were held with all supervisors during the data collection and analysis phases improved the study's dependability, as the results were verified in the process of reaching a consensus. The researcher constantly reflected on her dual roles as a registered nurse and interviewer, and recorded her thoughts in a reflexive diary. To allow the results to be transferable, detailed information on the context, participants, and data collection procedures were included in terms of an audit trail through the use of NVivo, which aided the data analysis (Marshall & Rossman, 1999).

3.3.9 Ethical considerations and budget

Ethical approval for the study was obtained through the Human Subjects Ethics Application Review System of the Hong Kong Polytechnic

University (HSEARS20190104005) (Appendix VII), and NHG Domain Specific Review Board (2018/00117) of Singapore (Appendix VIII). This study conforms to the World Medical Association Declaration of Helsinki ethical principles for conducting medical research (World Health Organization, 2001).

In line with the principles of autonomy and non-maleficence, the participants were given assurances that they had the right to voluntarily participate in the study without coercion (Polit & Beck, 2010). They were informed ahead of time that there would be no impact on their receipt of services if they declined to participate in the study or withdrew from participation. To ensure confidentiality, participant identities were only known to the interviewer. In all of the questionnaires and transcripts, the participants' names were replaced with serial numbers. They were identified with serial numbers ranging from "P1 to P32". None experienced distress during the course of the 3H intervention. For security purposes, all data were stored in a password-protected computer. Apart from the researcher and supervisors, no one had access to the research data. After study completion, all hard and electronic copies of the study materials and data were to be stored for at least six years, in accordance with NHG Domain Specific Review Board (DSRB) regulations (National Healthcare Group, 2018).

The 3H intervention costs HKD 4,572 (Appendix IX). This covers the cost of producing the 3H intervention bags. Educational materials, such as brochures related to stroke management, and stress balls were provided by the rehabilitation hospital.

CHAPTER FOUR

RESULTS

4.1 Interpretive descriptive study in Singapore on facilitating couples' recovery after a stroke that aided development of the 3H intervention

4.1.1 Participant characteristics

In total, 17 participants (five persons with stroke, four spousal caregivers, and eight registered nurses) were interviewed. The mean age of persons with stroke was 51.4 years, and 50.8 years for spousal caregivers, while the mean of their marriages was 19.5 years. As for the rehabilitation nurses, the mean of their clinical working experience was 4.9 years.

4.1.2 Theme 1: Diverse meanings of stroke recovery

The primary theme identified was the diverse meanings of stroke recovery for couples and nurses. The diverse meanings of stroke recovery were due to the differences in values that heightened values misalignments between persons with stroke, spousal caregivers, and rehabilitation nurses. The study found that a lack of conversation on care decisions between nurses, persons with stroke, and their spousal caregivers affected nurses' care coordination for persons with stroke and their spousal caregivers. Consequently, recovery from a stroke was not optimised for persons with stroke:

> *There are some family caregivers who refuse to take part in caregiver training. They feel that while the patient is in hospital, the nurses have to care for the patient's every need, and that they are paying for us, so they refuse to learn…* (Nurse 3)

In particular, spousal caregivers felt uncertain about the extent to which persons with stroke would recover. Therefore, most spousal caregivers resumed work to support their family financially, which in turn conflicted with their interest in caring for the person with stroke at home:

> *I think it is very difficult… It is so hard for me to manage alone. I need to pay all the bills*. (Spousal caregiver 3)

As spouses resumed working, most persons with stroke relied on their peers for emotional support in the hospital setting and at home upon discharge:

> *… During my hospitalisation, I made friends with a group of patients there. Even after discharge, we get together and talk… My wife is working and doesn't help me much*. (Person with stroke 3)

On the other hand, Muslim persons with stroke believed that they had had a stroke as a consequence of God's will and plans. They turned to spiritual coping and accepted their stroke diagnosis as being chosen by God:

> *… When God chooses you, you are the only selected one. God tests you for no formal reason. Whatever a stroke patient has to go through, the hassles of life after a stroke, just take it as a gift from God*. (Person with stroke 4)

Muslim spousal caregivers also believed that their spouse's stroke was a way of "cleansing past sins":

> *... Sometimes in Islam the way is that, you know why you get a sickness? It is because God loves you. It is God's way of cleaning up all of your sins*. (Spousal caregiver 2)

4.1.3 Theme 2: Challenges in nursing responsibilities that hindered persons with stroke recovery

There were three subthemes identified in the clinical setting that further hindered the recovery of persons with stroke. First, language barriers were observed. Nurses and couples could not always understand or communicate in each other's languages. Nurses faced difficulties in providing adequate education for couples before their discharge home:

> *I think we have problems with language barriers, since most older stroke patients and caregivers speak their native languages ... we are not used to speaking their languages, such as Hokkien and Mandarin. If they cannot understand, we need an interpreter, and we use another staff member to interpret for us*. (Nurse 2)

Second, nurses felt that a heavy clinical workload and staffing shortages may have hindered the optimal recovery of persons with stroke. Nurses found it challenging to juggle between daily routine nursing tasks, and providing sufficient support to couples dealing with stroke in the hospital:

> *One staff nurse is in charge of 17 patients, making the workload even heavier*. (Nurse 8)

Third, nurses were uncertain on how to strategically develop a care plan to meet the educational needs of working spouses. Nurses had discussed plans to involve both persons with stroke and their spousal caregivers in rehabilitation activities. However, initiatives on encouraging couples to cope together after a stroke were generally scarce:

> *... some spousal caregivers are available in the morning, while others are available in the evening. So, when we conduct bedside education in the morning, we will miss those who can only come at night*. (Nurse 2)

4.1.4 Essential implications out of the above qualitative study to refine the idea of 3H intervention

The study findings identified that the influence of cultural and religious beliefs associated with stroke may affect stroke recovery expectations. Similarly, another study reported that 59% of Indian Muslim stroke caregivers in Africa believed that a stroke occurred due to God's will, and no one is in a position to question God's plans (Bham & Ross, 2005). Hence, further education on stroke diagnosis and management is required for persons with stroke and their spousal caregivers.

Study findings also highlighted that the meanings of stroke are diverse, as seen by persons with stroke, spousal caregivers, and nurses. Furthermore, the responsibilities of nurses in facilitating the recovery of persons with stroke are challenging. Nurses found that care coordination for persons with stroke and their spousal caregivers was hindered due to a lack of conversation on care decisions. Shared decision making after a stroke is an evolving approach to facilitate care decision making amongst healthcare providers, patients, and their family caregivers (Visvanathan et al., 2017). While a systematic review has observed marital chaos in couples as a result of stroke, (Anderson & Keating, 2017), there remains a dearth of research involving coordinated, shared decision making on care to facilitate the recovery of persons with stroke. Instead, the literature has mainly focused on the treatment decisions of oral anticoagulant use to prevent stroke (Eckman et al., 2015; Ferguson & Hendriks, 2017; Kaiser et al., 2015; Visvanathan et al., 2017).

According to Armstrong, Shulman, Vandigo, & Mullins (2016), shared decision-making refers to a collaboration between healthcare providers, patients, and family caregivers that takes their preferences and values in recovering from a health condition into account. A systematic review on shared decision-making indicated that it led to better health outcomes, as patients had improved knowledge about their clinical condition, and enhanced trust in healthcare professionals (Shay & Lafata, 2015). Armstrong (2017) emphasised that shared decision-making enables patients and their caregivers to select the best care options available, based on their values and individual care preferences.

As shared decision-making promotes overall health awareness in patients and their caregivers (Deber, 1996; Saint-Germaine & Longman, 1993), the researcher asserts its need to be extended in Asia. In Singapore, training of rehabilitation nurses on how to conduct shared decision-making sessions and education may facilitate better support for persons with stroke and their spousal caregivers. A literature review by Olson & Juengst (2019) indicated that after a stroke, mechanisms to enhance transition of care from hospital to home include, (a) hospital-initiated support, (b) education for patient and family, (c) community-based support, and (d) management of chronic diseases. Palmer & Palmer (2011) also suggested key educational training components for couples living with stroke. These include, (a) setting the stage for life post-stroke, (b) ways in which stroke affects marriage and persons with stroke, shared decision-making about social support, (d) balancing the roles of the person living with stroke and their spousal caregiver, and (e) strategies for rebuilding a marriage after a stroke. It is of utmost priority for rehabilitation nurses in Singapore to facilitate care decision-making for couples, to ensure the smooth operation of these mechanisms in the transition of care from hospital to home for stroke recovery.

The 3H intervention empowers shared-decision making through Armstrong (2017) guidelines that emphasise the engagement of persons with stroke and their family caregivers coping after a stroke, as illustrated in Appendix XII. Insights into beginning the theorisation of a suitable intervention for couples living with stroke in a Singaporean context were introduced for further study, incorporating shared decision-making as an interventional component.

4.2 Development of the 3H (Head, Heart, Hands) intervention

Based on the findings of a literature review (Ramazanu & Chiang, 2019) and qualitative study (Ramazanu et al., 2020b), a novel intervention to support persons with stroke and their spousal caregivers was systematically developed in Singapore. The researcher coined the intervention 3H (Head, Heart, and Hands). As underpinned by previous literature (Clark et al., 2003; Ostwald et al., 2014; Ramazanu et al., 2020b; Robinson-Smith et al., 2015), the 3H intervention comprised multicomponent strategies of stroke, including informational support (“head”), shared decision-making (“heart”), and skills training (“hands”). A logo of the intervention has been designed. It depicts the holistic concept of Head, Heart, and Hands (3H) in support of couples living with stroke (**Figure 5**). The design was carefully conceptualised after discussions with members of the study team.

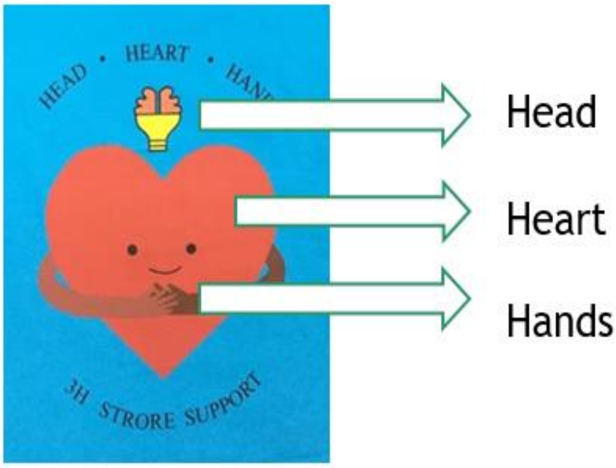


Figure 5: Design of Head, Heart, and Hands (3H) intervention logo

The informational support (Head) component of the 3H intervention was developed based in part on a book entitled, “When your spouse has a stroke: caring for your partner, yourself and your relationship” (Palmer & Palmer, 2011). Permission was granted from the authors to utilise the contents of the book. The concept and component of shared decision-making (Heart) was included to allow couples to discuss their decisions on social support (Armstrong, 2017). The steps in shared decision-making are comprised of: (a) the engagement of couples living with stroke, (b) a discussion of care decisions, (c) an assessment of the values of the persons with stroke and their spousal caregivers, and (d) the making of care decisions together (Armstrong, 2017). The component on skills training (Hands) focused on blood pressure monitoring, fall prevention, safe lifting, safe feeding, and the administration of medications (Singapore National Stroke Association, 2018;

Stroke Association, 2015, Tsur & Segal, 2010). An outline of the 3H intervention protocol is provided in Appendix I.

4.2.1 Identifying theory

In addition to the evidence discovered from the literature review and qualitative study that informs the development of 3H intervention, the intervention is theoretically and systematically underpinned by the double ABCX model of family stress and adaptation (Lavee et al., 1985). The model explained how families recover and adapt from a crisis (McCubbin, & Patterson, 1982), which was verified using structural equation modeling (Lavee et al., 1985). A metasynthesis of qualitative studies was also performed to investigate the application of the double ABCX model to determine how family members of persons with stroke adapted to a life after a stroke (Hesamzadeh et al., 2015). The elements of this model have been found relevant and applicable to evaluating the post-stroke life adaptation of family caregivers.

The key constructs of the double ABCX model consists of event (aA), adaptive resources (bB), perception (cC), and adaptation of stroke couples (xX). **Figure 6** depicts the modelling process and outcomes of the double ABCX model to systematically underpin the 3H intervention.

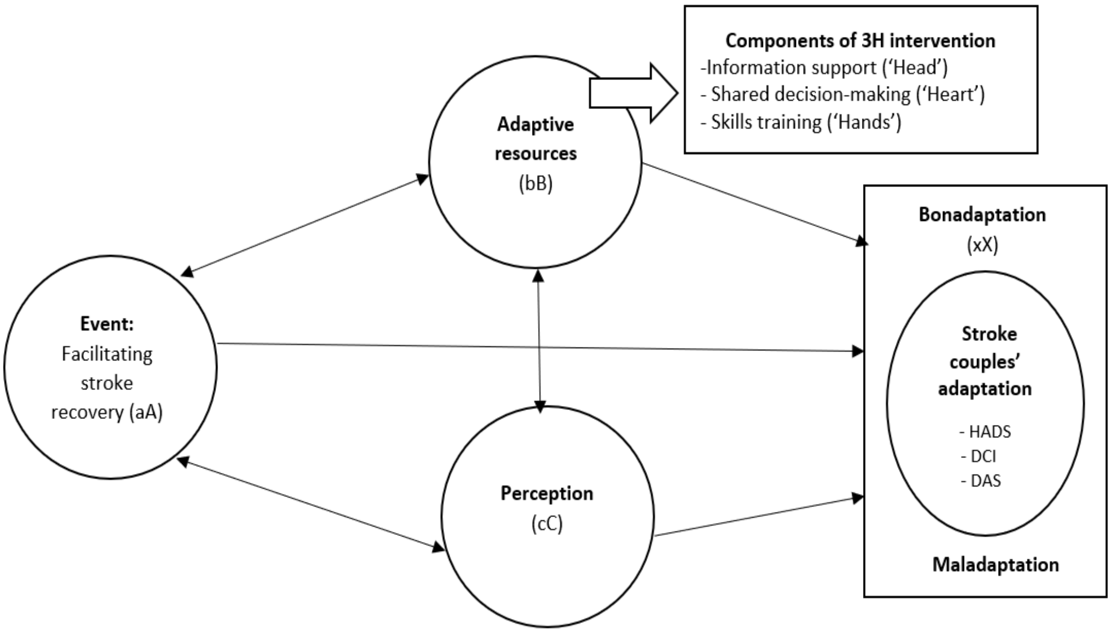


Figure 6: Modelling process and outcomes of the double ABCX model

Event (aA)

The double ABCX model (Lavee et al., 1985) predicts that after a stroke crisis, there would be a cumulative effect of stressors and strains on couples. Therefore, there is a need to facilitate stroke recovery through the proposed 3H intervention, which seeks to increase couples' adaptive resources, improve their perceptions of the stroke situation, and improve their adaptation to the stroke crisis in the family.

Adaptive resources (bB)

Adaptive resources refer to "the resources that are developed to strengthen the response of families to demands by a health crisis" (Lavee et al., 1985, p. 812). In this study, adaptive resources include the components of information support, skills training, and shared decision-making. These resources mediate between the growing demands that follow stroke event, thereby improving the ability of couples living with stroke to adapt.

Perception (cC)

Perception refers to a “family’s general orientation to the overall circumstances of a crisis” (Lavee et al., 1985, p. 813). From the perspective of the 3H intervention, it indicates the couple’s sense of acceptance of the crisis and their understanding after a stroke in the family. In addition to informational support, and shared decision-making and skills training, the 3H intervention group sessions (sessions 1, 2, 4, and 6) and individual dyadic sessions (sessions 5 and 6) facilitate participant interactions and discussions. Through their interactions and discussions on issues pertaining to stroke, participants will have a better sense of understanding and acceptance towards stroke in the family.

Adaptation of couples living with stroke (xX)

Through participation in the 3H intervention, it is predicted that couples’ ability to cope would improve, therefore enhancing their adaptation to the post-stroke situation. There are two types of adaptation: maladaptation and bonadaptation.

Maladaptation is defined as “the negative end of the continuum, where there is a continuous imbalance between the piling up of demands and the stroke couples’ capabilities of meeting those demands” (Lavee et al., 1985, p. 813). Consequently, maladaptation affects the physical and psychological health of couples living with stroke. In contrast, bonadaptation is the positive end of the continuum, where a balance is achieved in the functioning of couples living with stroke, with minimal discrepancies between the piled-up demands and the couple’s adaptation capabilities. The 3H intervention study outcome measures include, (a) hospital anxiety and depression (Herrmann, 1997), (b) revised dyadic adjustment (Busby, Christensen, Crane & Larson, 1995; Crane et al., 2000), and (c) dyadic coping (Meier et al., 2011).

4.3 3H intervention feasibility and preliminary outcomes evaluation

4.3.1 Study participant characteristics

A total of five rounds of the 3H intervention was conducted by the researcher. Overall, 70 participants (35 couples) were approached. Out of this total, 64 participants (32 couples) were successfully recruited in the intervention, for a recruitment rate of 91.4%. Six participants declined to participate. The reasons were, (a) spousal caregivers were busy working (*n*=3), and (b) persons with stroke were unwilling to participate in the 3H intervention (*n*=3). Table 2 depicts the sociodemographic data of persons with stroke and their spousal caregivers who were included in the intervention.

Table 2 Sociodemographic data of persons with stroke and their spouses

	Spouses (n = 32)		**Patients** (n = 32)	
	Count (n)	**Proportion (%)**	**Count (n)**	**Proportion (%)**
Age range				
40 – 49	1	3	1	3
50 – 59	4	13	8	25
60 – 69	18	56	14	44
70 – 79	6	19	5	16
80+	3	9	4	13
Gender				
Male	22	69	10	31
Female	10	31	22	69
Ethnicity				
Chinese	15	47	14	44
Indian	11	34	12	38
Malay	6	19	6	19
Employment				
Full-time	7	22	8	25
Part-time	2	6	5	16

Retired	21	66	16	50
Unemployed	2	6	3	9
Education				
Primary	17	53	17	53
Secondary	7	22	11	34
Tertiary	6	19	3	9
No education	2	6	1	3

4.3.2 Participant acceptability, recruitment, retention, and attrition rates

The 3H intervention participants found the programme to be acceptable. A key lesson learnt is that all of the recruited persons with stroke and their spousal caregivers were interested in participating in the 3H intervention, to learn about how they could cope with the aftermath of a stroke. At post-test (T_1), 54 participants (84.4%) remained and completed the intervention. There was an attrition rate of 10 participants (15.6%) throughout the study. Nine were spousal caregivers. The researcher tried various ways to retain all 64 participants until the end of the 3H intervention. The retention efforts included, (a) creating a welcoming atmosphere throughout the study, (b) informing persons with stroke and their spousal caregivers about their role as research participants, (c) establishment of an intervention routine whilst maintaining flexibility, and (d) staff training. First, a welcoming atmosphere was ensured throughout the study to allow couples to enjoy participating in the 3H intervention. The researcher and registered nurses were welcoming and respectful towards all participants. Most importantly, the researcher was non-judgemental when participants shared their difficult post-stroke experiences with one another. Also, the study interviews were conducted in an enclosed and comfortable room where privacy was ensured. Second, in an effort to improve study participant retention, the significance of taking part in the 3H intervention was reinforced when a participant decided to withdraw from the study.

Evaluating their experiences of participating in the 3H intervention, whether positive or negative, was crucial in allowing the researcher to understand ways to improve intervention delivery in the future. Participants' anticipated challenges and barriers to attending the intervention were documented. Third, a routine was established, at the same time each week, for the 3H intervention delivery. Reminder phone calls were made to all spousal caregivers two days before the intervention. For participants who missed an intervention session, flexibility in rescheduling the intervention session was ensured, and a missed session was arranged in the following weeks. Fourth, registered nurses were educated about the 3H intervention by the researcher, who also addressed participant non-adherence concerns in clinical research. Registered nurses explored and documented the possible reasons for research participants dropping out, before the completion of all six intervention sessions over a three-week period.

Despite the attempts employed to retain the participants, some withdrew from the 3H intervention due to unavoidable reasons such as: (a) resumed working at a job (*n*=4), (b) feeling unwell (*n*=3), (c) resided overseas in Malaysia and could not frequently travel to Singapore (*n*=1), and (d) preferred the intervention to be conducted in the Malay language instead of English (*n*=1). A person living with stroke withdrew due to their deteriorating health and cognitive decline (n=1).

4.3.3 Preliminary outcomes evaluation using GEE modelling

GEE modelling responses on HADS

With attrition, there were 23 spousal caregivers and 31 persons with stroke remaining at $T_{1.}$ The analysis of missing data due to attrition was therefore founded on the intention-to-treat principle (ITT). Results from modelling responses on the

Hospital Anxiety and Depression Scales (HADS) revealed that overall, there was no significant group by time effect for either the HADS-Anxiety scale ($\beta=1.35, p= .726$) or HADS-Depression scale ($\beta=-1.07, p= .646$), as outlined in Table 3. Nevertheless, there were statistically significant outcomes in group effects of anxiety ($\beta=5.8, p < .001$) and depression ($\beta=14.89, p < .001$) amongst couples after the intervention.

Table 3 Parameter estimates for the GEE model for the Hospital Anxiety and Depression Scale (HADS) scale

Outcomes	**Group Effect**				**Time Effect**				**Group by Time Effect**			
	B (95% CI)	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***
Anxiety	5.8 (2.28- 9.32)	1.8	10.42	.001	17.69 (12.41-22.98)	2.7	43.03	.001	1.35 (-6.18-8.88)	3.84	0.123	.726
Depression	14.89 (2.28- 9.32)	2.93	25.77	.001	6.85 (3.09-10.61)	3.09	12.77	.001	-1.07 (-5.62-3.48)	2.32	0.211	.646

Subgroup analysis with Wilcoxon Test was then performed to compare the responses of stroke patients and their spouses respectively, at T_0 (before) and T_1 (after) of 3H intervention participation (Tables 4-5). **Table 4** indicated that stroke patients' overall mean anxiety scores decreased from 21.6% (at T_0) to 3.9% (at T_1) ($p < .001$). Similarly, the overall mean anxiety scores for spouses decreased from 28.7% (at T_0) to 9.7% (at T_1) (p < .001). **Table 5** indicates that stroke patients' overall mean depression scores decreased from 17.7% (at T_0) to 10.9% (at T_1) ($p= .005$). Similarly, the overall mean depression scores of spouses decreased from 31.5% (at T_0) to 25.8% (at T_1) ($p < .001$).

Table 4 Participant average scores for HADS (Anxiety) before and after the intervention

SCALE	PATIENTS					SPOUSES				
	Time 0	**Time 1**	**Mean difference**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**Z**	**P**
I feel tense or wound up	21.9	8.7	13.2	-2.842	.004	34.4	8.6	25.8	-3.898	.001
I get a frightened feeling 'butterflies in the stomach'	31.2	24.6	6.6	-2.271	.023	40.6	37.6	3	-0.828	.408
I am frightened something awful is about to happen	17.7	1.4	16.3	-2.739	.006	26	5.4	20.7	-3.502	.001
I feel restless, as if I am on the move	18.7	21.7	-3	-0.816	.414	32.3	30	2.3	-1	.317
Worrying thoughts go through my mind	50	20.3	29.7	-3.412	.001	44.8	18.3	26.5	-3.796	.001
I get sudden panic feelings	15.6	15.9	-0.3	-0.272	.785	38.5	32.3	6.3	-1.638	.101
I can sit at ease and feel relaxed	14.6	2.9	11.7	-2.97	.003	30.1	11.1	19	-2.701	.007
Overall score (mean)	**21.6**	**3.9**	17.7	-4.767	**.001**	**28.7**	**9.7**	19	-4.629	**.001**

Table 5 Participant average scores for HADS (Depression) before and after the intervention

SCALE	PATIENTS					SPOUSES				
	Time 0	**Time 1**	**Mean difference**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**Z**	**P**
I feel as if I am slowed down	14.6	10.1	4.4	-1.342	.18	53.1	39.8	13.3	-3.217	.001
I still enjoy things I used to enjoy	20.8	1.4	19.4	-3.557	.001	16.7	5.4	11.3	-2.877	.004
I have lost interest in my appearance	2.1	1.4	0.6	-1	.317	10.4	6.5	4	-2	.046
I can laugh and see the funny side of things	13.5	2.9	10.6	-1.725	.084	31.2	12.2	19	-2.923	.003
I look forward with enjoyment to things	18.7	10.1	8.6	-1.633	.102	16.7	14	2.7	-1.414	.157
I feel cheerful	12.5	0	12.5	-2.428	.015	18.7	9.7	9.1	-2.04	.041
I can enjoy a good book, radio, or TV programme	22.9	21.7	1.2	-0.272	.785	31.1	26.9	4.2	-1.633	.102
Overall score (mean)	**17.7**	**10.9**	6.8	-2.781	**005**	**31.5**	**25.8**	5.7	-3.726	**.001**

GEE modelling responses on RDAS

Unlike the HADS, the results from modelling responses on the revised dyadic adjustment subscales showed variable responses in persons with stroke. **Table 6** reveals a statistically significant group by time effect for *consensus* (*β= -14.17, p= .002*), *satisfaction* (*β= -20.47, p= .02*), and *cohesion* (*β= -12.34, p= .027*).

Table 6 Parameter estimates for the GEE model for the **RDAS** (Revised Dyadic Adjustment Scale)

Outcomes	**Group Effect**				**Time Effect**				**Group by Time Effect**			
	B (95% CI)	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***
Consensus	10.11 (4.43-21.21)	6.56	8.968	.003	12.82 (-2.74-22.95)	4.28	2.377	.123	-14.17 (-23.23 - 5.11)	4.62	9.398	.002
Satisfaction	20.78 (5.09-36.48)	8.01	6.735	.009	17.5 (1.59-33.41)	8.12	4.469	.031	-20.47 (-37.78 - 3.16)	8.83	5.373	.02
Cohesion	14.84 (2.81-26.88)	6.14	5.841	.014	6.25 (-3.82-16.32)	5.14	1.479	.224	-12.34 (-23.3 - 1.42)	5.58	4.901	.027

As shown in both **Figure 7** and **Table 7**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of consensus for persons with stroke declined from 59% (at T_0) to 46.1% (at T_1) (*p*= .16). However, as with spouses, the overall mean score of consensus statistically improved from 54.9% (at T_0) to 56.3% (at T_1) (*p*= .044).

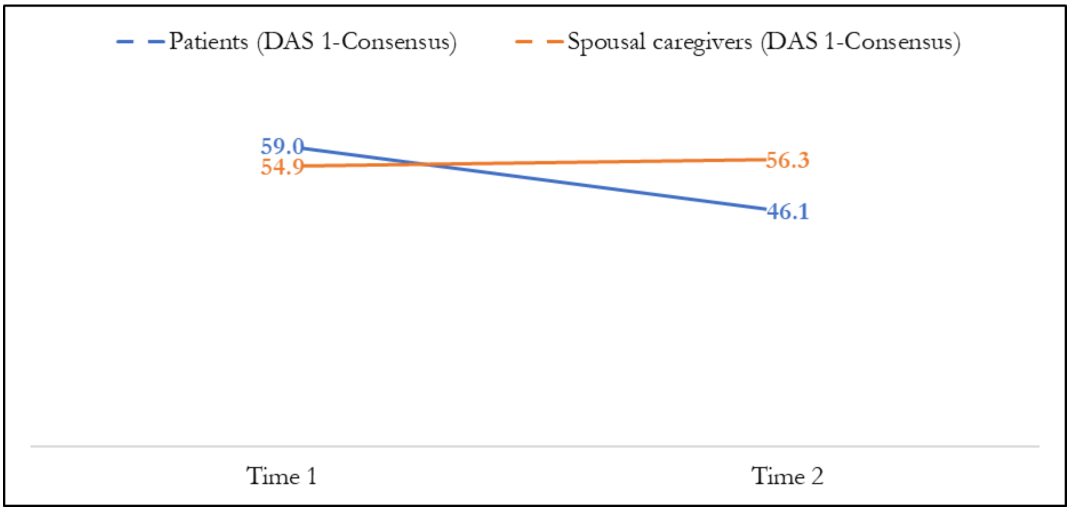


Figure 7 Change in dyadic consensus for persons with stroke and their spousal caregivers after the intervention

Table 7 Average participant scores for DAS-1 (Consensus) before and after the intervention

SCALE	PATIENTS						SPOUSES					
	Time 0	**Time 1**	**Mean difference**	**Z**	**df**	**P**	**Time 0**	**Time 1**	**Mean difference**	**Z**	**df**	**P**
Religious matters	81.3	86.1	-4.8	-2.236	53	.025	81.9	81.3	0.6	0	60	1
Demonstrations of affection	71.9	78.3	-6.4	-2.121	53	.034	67.3	73.3	-6	-2.887	58	.004
Making major decisions	65	75.7	-10.7	-2.653	53	.008	59.4	68.4	-9	-3.26	61	.001
Conjugal (sexual) relations	61.1	63.1	-2	0	29	1	62.4	62.5	-0.1	0	31	1
Conventionality	73.3	81.1	-7.8	-1.318	43	.187	74.1	75.8	-1.8	-1.732	49	.083
Career decisions	66.3	66.3	0.1	-0.707	33	.48	56.7	63.3	-6.7	-2.449	34	.014
Overall score (mean)	**59**	**46.1**	12.9	-1.404	-	**.16**	**54.9**	**56.3**	-1.4	-2.013	-	**.044**

As shown in both **Figure 8** and **Table 8**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of satisfaction for persons with stroke decreased from 81.9% (at T_0) to 64.4% (at T_1) (*p*= .607). However, as with spouses, the overall mean score of satisfaction improved statistically from 82.2 % (at T$_0$) to 85.2% (at T$_1$) (*p*= .005).

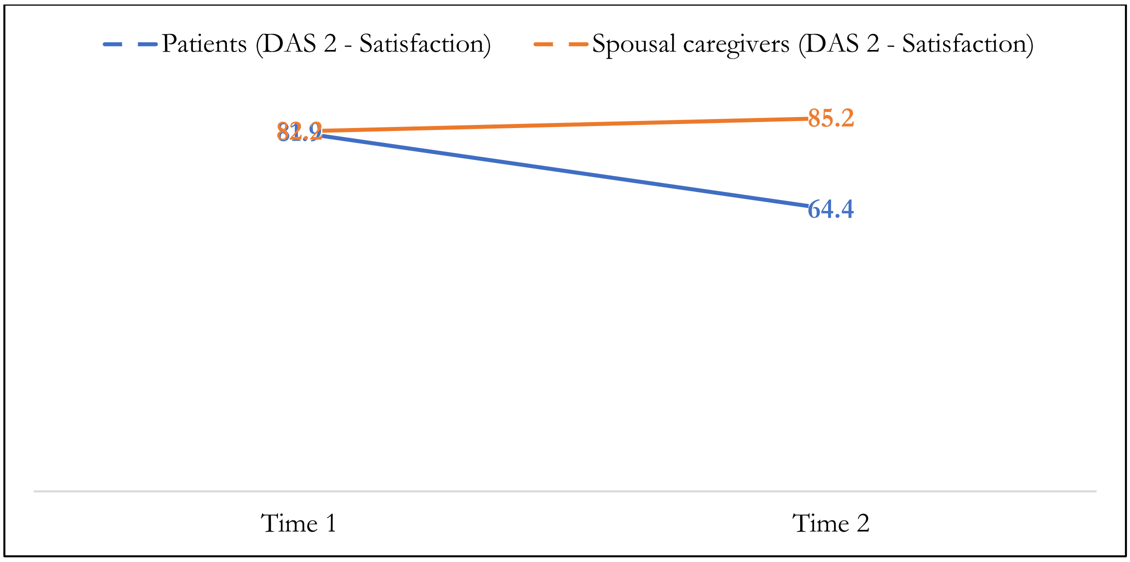


Figure 8 Change in dyadic satisfaction for persons with stroke and their spousal caregivers after the intervention

Table 8 Participant average scores for DAS-2 (Satisfaction) before and after the intervention

	PATIENTS						**SPOUSES**					
SCALE	**Time 0**	**Time 1**	**Mean difference**	**Z**	**df**	**P**	**Time 0**	**Time 1**	**Mean difference**	**Z**	**df**	**P**
How often have you considered divorce?	85.6	92.2	-6.5	-2.714	53	.007	89.4	91.6	-2.2	-1.508	61	.132
How often do you and your partner quarrel?	78.1	87	-8.8	-2.967	53	.003	73.1	83.2	-10.1	-3.771	61	.001
Do you ever regret that you got married?	89.4	93	-3.7	-1.613	53	.107	89.4	92.3	-2.9	-1.311	61	.19
How often do you get on each other's nerves?	74.4	86.1	-11.7	-3.08	53	.002	76.9	84.5	-7.6	-2.804	61	.005
Overall score (mean)	**81.9**	**64.4**	17.5	-0.514	-	**.607**	**82.2**	**85.2**	-3.0	-2.783	-	**.005**

As shown in both **Figure 9** and **Table 9**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of cohesion for persons with stroke decreased from 52.2% (at T$_0$) to 45.9% (at T$_1$) (*p*= .9). However, as with spouses, the overall mean score of satisfaction improved statistically from 54.6% (at T_0) to 60.8% (at T_1) (*p*= .001).

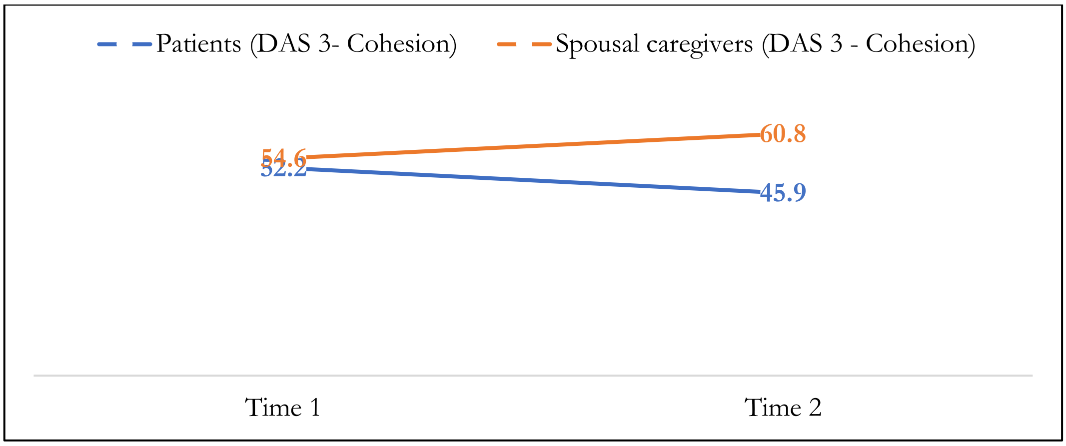


Figure 9 Change in dyadic cohesion for persons with stroke and their spousal caregivers after the intervention

Table 9 Participant average scores for DAS-3 (Cohesion) before and after the intervention

SCALE	PATIENTS						SPOUSES					
	Time 0	**Time 1**	**Mean difference**	**Z**	**df**	**P**	**Time 0**	**Time 1**	**Mean difference**	**Z**	**df**	**P**
Do you engage in outside interests together?	41.9	46.1	-4.2	-1.414	53	.157	44.4	45.8	-1.4	-0.816	61	.414
Have a stimulating exchange of ideas	60	80.9	-20.9	-3.531	53	.001	61.3	75.5	-14.2	-3.402	61	.001
Work together on a project	33.1	33.9	-0.8	-0.447	53	.655	31.3	38.7	-7.5	-2.887	61	.004
Calmly discuss something	73.8	94.8	-21	-3.114	53	.002	81.9	91	-9.1	-3.3	61	.001
Overall score (mean)	**52.2**	**45.9**	6.3	-0.126	-	**.9**	**54.6**	**60.8**	-6.2	-3.878	-	**.001**

GEE modelling responses on DCI

Table 10 indicates statistically significant results of group by time effect on the dyadic coping of couples living with stroke (DCI 1-5). The model revealed that outgoing stress communication (DCI-1) *(β= -16.88, p= .009*), incoming stress-coping behaviour (DCI-2) *(β= -16.96, p= .008*), incoming stress communication (DCI-3) (*β= -17.03, p= .01),* outgoing stress-coping behaviour (DCI-4) (*β= -21.81,* *p= .002),* and couple's stress-coping mechanism (DCI-5) (*β= -19.5, p= .004)* improved significantly after couples' participation in the 3H intervention. However, insignificant statistical results are reported for couples' satisfaction with coping mechanism (DCI-6) (*β= -14.38, p= .055),* in group by time effect interaction.

Table 10 Parameter estimates for the GEE model for the Dyadic Coping Inventory (DCI) scale

Outcomes	**Group Effect**				**Time Effect**				**Group by Time Effect**			
	B (95% CI)	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***	**B (95% CI)**	**SE**	**Wald χ^2**	***p***
Outgoing stress communication (DCI-1)	18.13 (5.49-30.77)	6.45	7.899	.005	5 (-6.46-16.46)	5.85	0.731	0.392	-16.88 (-29.62-4.13)	6.5	6.736	.009
Incoming stress-coping behaviour (DCI-2)	19.94 (7.64-32.23)	6.27	10.1	.001	10.16 (-1.34-21.65)	5.86	2.999	0.083	-16.96 (-29.52-4.42)	6.4	7.021	.008
Incoming Stress Communication (DCI-3)	18.28 (5.82-30.74)	6.36	8.271	.004	6.41 (-5.71-18.52)	6.18	1.074	0.3	-17.03 (-29.97-4.1)	6.6	6.66	.01
Outgoing stress-coping behaviour (DCI-4)	20.31 (5.95-34.68)	7.33	7.683	.006	15.06 (2.47-27.65)	6.42	5.499	0.019	-21.81 (-35.48-8.15)	6.97	9.79	.002
Couples' Stress-coping Mechanism (DCI-5)	15.13 (2.83-27.42)	6.27	5.811	.016	11.5 (0.04-22.96)	5.85	3.866	0.049	-19.5 (-32.61-6.36)	6.69	8.499	.004
Satisfaction with coping mechanism (DCI-6)	15.31 (1.06-29.56)	7.27	4.436	.035	10.63 (-2.88, 24.13)	6.89	2.379	0.123	-14.38 (-29.04-0.29)	7.48	3.69	.055

As shown in both **Figure 10** and **Table 11**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of outgoing stress communication (DCI-1) for persons with stroke decreased from 56.3% (at T_0) to 51.3% (at T_1) (*p*= .851).

However, as with spouses, the overall mean score of outgoing stress communication (DCI-1) improved statistically from 57.5% (at T_0) to 69.4% (at T_1) ($p< .001$).

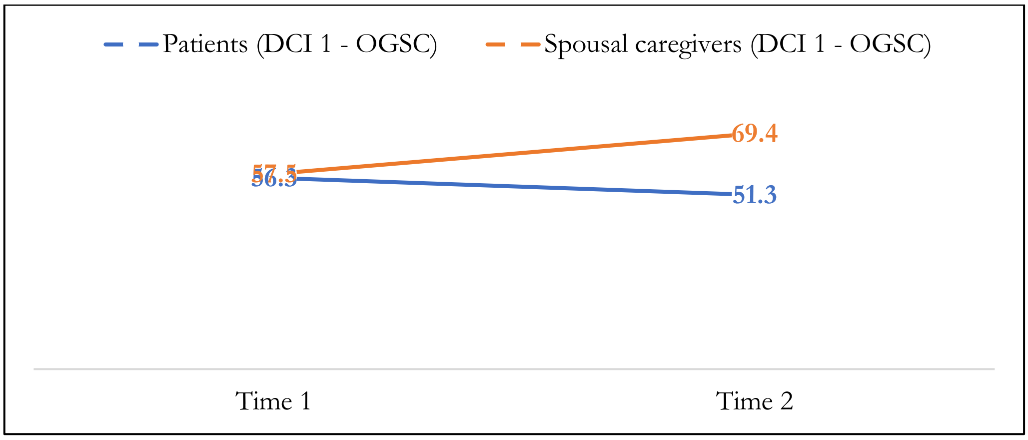


Figure 10 Change in stress levels between persons with stroke and their spousal caregivers after the intervention based on DCI 1- Outgoing stress communication

Table 11 Participant average scores for DCI 1 - Outgoing stress communication (questions 1-4) before and after the intervention

SCALE	PATIENT						SPOUSE					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
I let my partner know I appreciate their support	59.4	78.3	-18.9	53	-4.185	.001	56.3	74.2	-17.9	61	-4.644	.001
I ask my partner to help me when I have too much to do	49.4	63.5	-14.1	53	-3.819	.001	52.5	65.8	-13.3	61	-3.944	.001
I show my partner I have problems through my behaviour	60	68.7	-8.7	53	-2.31	.021	65	72.9	-7.9	61	-3	.003
I tell my partner openly how I feel and that I would appreciate their support.	56.3	74.8	-18.5	53	-3.535	.001	56.3	73.6	-17.3	61	-4.242	.001
Overall score (mean)	**56.3**	**51.3**	5.0	-	-0.187	**.851**	**57.5**	**69.4**	-11.9	-	-4.29	**.001**

Similarly, as shown in **Figure 11** and **Table 12**, a subgroup analysis with Wilcoxon Test indicated that the overall mean score of incoming stress communication (DCI-3) for persons with stroke decreased from 57.3% (at T_0) to 50.9 % (at T_1) ($p= .836$). However, as with spouses, the overall mean score of incoming stress communication (DCI-3) improved statistically from 58.6% (at T_0) to 69.2% (at T_1) ($p < .001$).

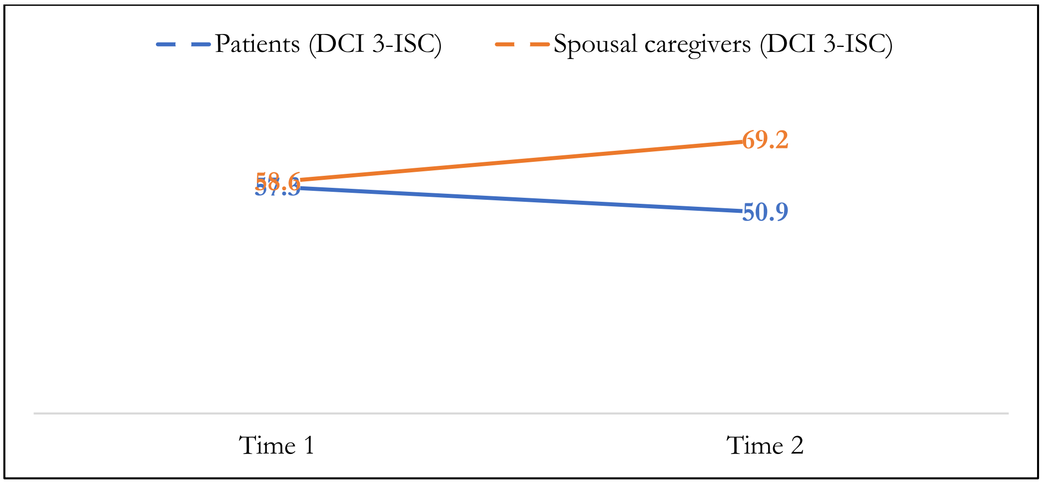


Figure 11 Change in stress levels between persons with stroke and their spousal caregivers after the intervention based on DCI 3 - Incoming stress communication

Table 12 Participant average scores for DCI 3 - Incoming stress communication (questions 16-19) before and after the intervention

SCALE	PATIENT						SPOUSE					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
My partner lets me know they appreciate my support.	55.6	70.4	-14.8	53	-3.877	<0.001	55	72.3	-17.3	61	-4.563	<0.001
My partner asks me to do things for them when they are too busy.	56.3	66.1	-9.8	53	-2.84	.005	56.9	67.1	-10.2	61	-3.441	.001
My partner shows they are not doing well through their behaviour	62.5	73	-10.5	53	-2.636	.008	66.9	73.5	-6.7	61	-2.887	.004
My partner tells me openly how they feel and that they would appreciate my support	55	73.9	-18.9	53	-3.852	<0.001	55.6	72.9	-17.3	61	-4.455	<0.001
Overall score (mean)	**57.3**	**50.9**	6.4	-	-0.206	**.836**	**58.6**	**69.2**	-10.6	-	-4.288	**<.001**

As shown in both **Figure 12** and **Table 13**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of incoming stress coping behaviour (DCI-2) for persons with stroke decreased from 61.4% (at T_0) to 51.2% (at T_1) (*p*= .822). However, as with spouses, the overall mean score of incoming stress coping behaviour (DCI-2) improved statistically from 64.3% (at T_0) to 71.2% (at T_1) (*p*< .001).

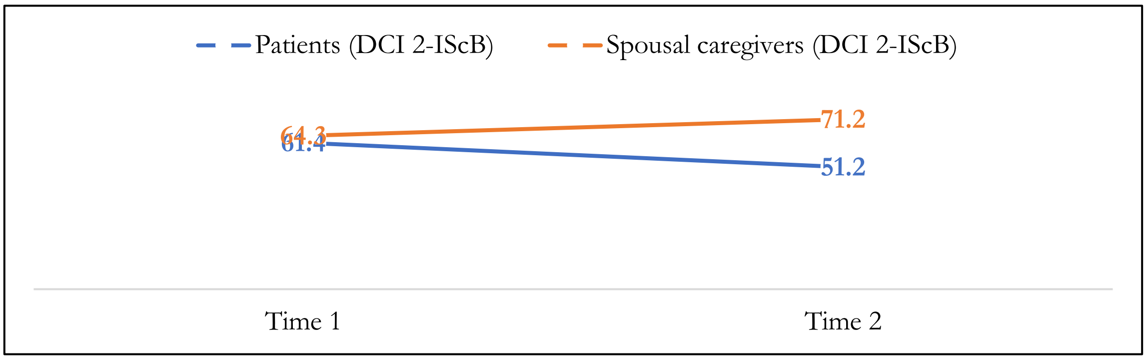


Figure 12 Change in stress levels between persons with stroke and their spousal caregivers after the intervention based on DCI 2- Incoming stress coping behaviour

Table 13 Participant average scores for DCI 2 - Incoming stress coping behaviour (questions 5-15) before and after the intervention

SCALE	PATIENT						SPOUSE					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
My partner shows me empathy and understanding	68.1	81.7	-13.6	53	-3.213	.001	70.6	80.7	-10	61	-3.771	<.001
My partner expresses the fact that they are on my side.	59.4	78.3	-18.9	53	-3.947	<.001	61.3	71	-9.7	61	-3.411	.001
My partner blames me for not coping well with stress.	50.6	51.3	-0.7	53	-1	.317	48.1	47.1	1	61	-0.277	.782
My partner helps me see stressful situations in a different light.	58.8	69.6	-10.8	53	-3.125	.002	61.3	70.3	-9.1	61	-3.742	<.001
My partner listens and gives me an opportunity to communicate my stress.	59.4	74.8	-15.4	53	-2.887	.004	69	75.5	-6.5	60	-2.066	.039

SCALE	PATIENT						SPOUSE					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
My partner does not take my stress seriously.	56.9	52.7	4.1	52	-1.386	.166	44.7	45.2	-0.5	59	0	1
My partner provides support in an unwilling manner.	46.9	43.5	3.4	53	-0.775	.439	49	45.8	3.2	60	-1.231	.218
My partner takes on my tasks in order to help me out.	61.9	67.8	-6	53	-2.828	.005	66.3	73.6	-7.3	61	-2.81	.005
My partner helps me analyse situations so that I can better face my problems.	63.8	73.1	-9.3	53	-2.887	.004	66.9	74.2	-7.3	61	-2.517	.012
My partner helps me out when I am too busy.	58.8	67	-8.2	53	-2.653	.008	63.8	74.2	-10.4	61	-3.418	.001
My partner tends to withdraw when I am stressed.	60	56.5	3.5	53	-1.265	.206	48.4	45.8	2.6	60	-1.069	.285
Overall score (mean)	**61.4**	**51.2**	10.2	-	-0.225	**.822**	**64.3**	**71.2**	-6.9	-	-4.164	**<.001**

Similarly, as shown in **Figure 13** and **Table 14**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of outgoing stress coping behaviour (DCI-4) for persons with stroke decreased from 75.6% (at T_0) to 60.5 % (at T_1) (*p*= .791). However, as with spouses, the overall mean score of outgoing stress coping behaviour (DCI-4) improved statistically from 74.1% (at T_0) to 80.8% (at T_1) (*p*< .001).

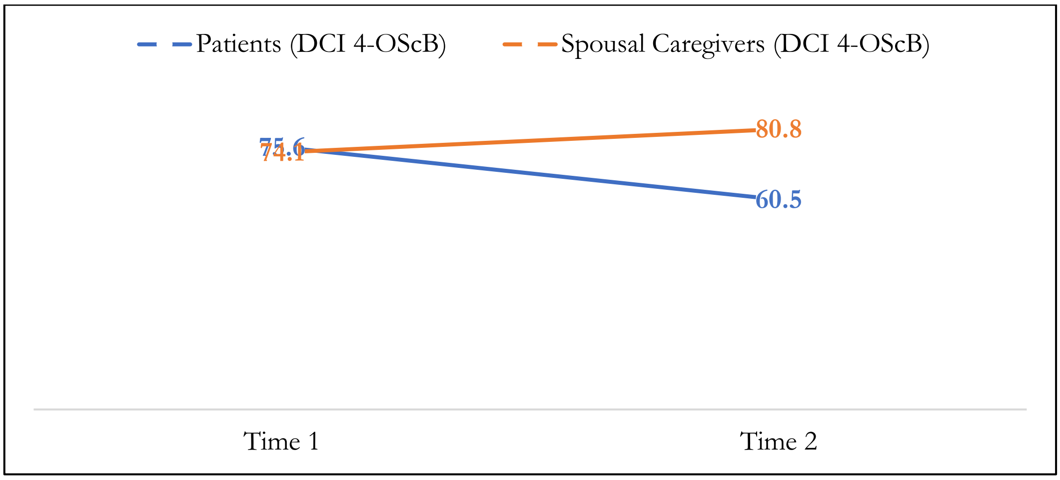


Figure 13 Change in stress levels between persons with stroke and their spousal caregivers after the intervention based on DCI 4- Outgoing stress coping behaviour

Table 14 Participant average scores for DCI 4 - Outgoing stress-coping behaviour (questions 20-30) before and after the intervention

SCALE	**PATIENT**						**SPOUSE**					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
I show empathy and understanding to my partner.	45.6	33	12.6	53	-2.919	.004	45	40.6	4.4	61	-2.646	.008
I tell my partner that I am on their side.	56.3	43.5	12.8	53	-3.119	.002	56.8	44.5	12.3	60	-4.146	<.001
I blame my partner for not coping well enough with stress.	73.8	73	0.7	53	-0.707	.48	71	80	-9	60	-3.116	.002
I tell my partner their stress is not so bad and help them see their situation differently.	60.6	52.2	8.5	53	-2.653	.008	58.1	52.3	5.9	61	-2.324	.02
I listen to my partner and give them space to communicate their stress.	56.9	47.8	9	53	-2.337	.019	56.1	43.9	12.3	60	-3.578	<.001
I do not take my partner's stress seriously.	80	83.5	-3.5	53	-0.577	.564	74.4	79.4	-5	61	-1.941	.052
I tend to withdraw when my partner is stressed.	69.4	71.3	-1.9	53	-0.707	.48	68.1	73.5	-5.4	61	-1.89	.059
I provide support in an unwilling manner, because I think they should cope with their stress on their own.	76.1	78.3	-2.1	52	-0.264	.792	72.9	78.7	-5.8	60	-1.994	.046
I take on things that my partner would normally do in order to help them out.	54.2	47.8	6.4	52	-2.121	.034	53.1	47.7	5.4	61	-2.324	.02
I try to analyse the situation together with my partner in an objective manner and help them understand the problem.	53.5	42.6	10.9	52	-2.887	.004	51.6	44.5	7.1	60	-2.64	.008
When my partner feels they have too much to do, I help them out.	47.7	37.4	10.4	52	-2.64	.008	54.4	43.9	10.5	61	-3.087	.002
Overall score (mean)	**75.6**	**60.5**	15.1	-	-0.265	**.791**	**74.1**	**80.8**	-6.7	-	-4.351	**<.001**

As shown in both **Figure 14** and **Table 15**, subgroup analysis with Wilcoxon Test indicated that the overall mean score of couples' stress coping mechanism (DCI-5) for persons with stroke decreased from 61.0% (at T_0) to 49.5% (at T_1) (p= .804). However, as with spouses, the overall mean score of couple's stress coping mechanism (DCI-5) improved statistically from 56.6% (at T_0) to 64.6% (at T_1) (p< .001).

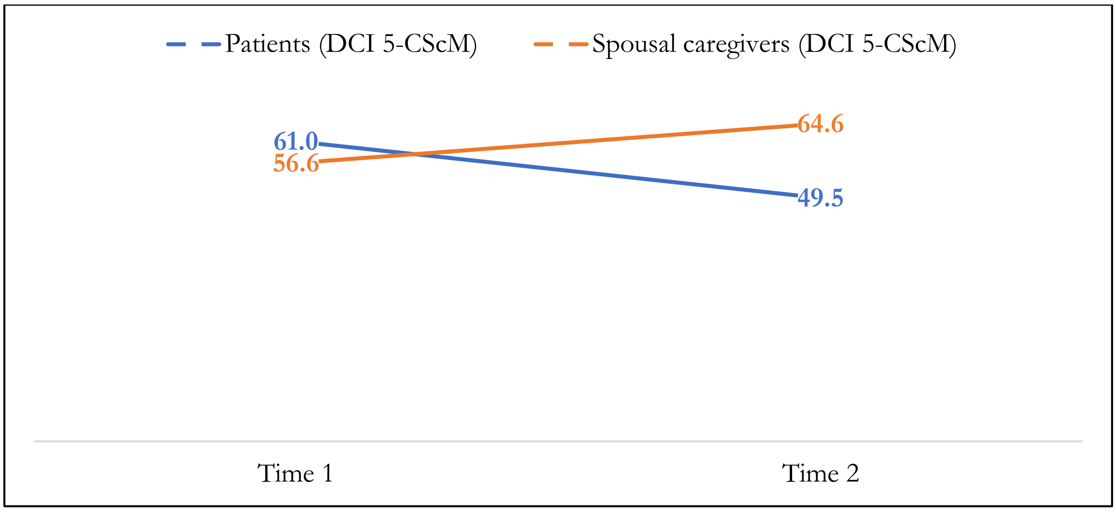


Figure 14 Change in stress levels between persons with stroke and their spousal caregivers after the intervention based on DCI 5- Couple's stress coping mechanism

Table 15 Average participant scores for DCI 5 – Couple's stress-coping mechanism (questions 31-35) before and after the intervention

SCALE	PATIENT						SPOUSE					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
We try to cope with the problem and search for solutions.	50	41.7	8.3	53	-3.162	.002	53.5	45.2	8.4	60	-3.5	0
We engage in a serious discussion about the problem and think through what has to be done.	56.3	42.6	13.6	53	-3.217	.001	54.2	43.9	10.3	60	-3.398	.001
We help one another view the problem in a new light.	53.1	41.7	11.4	53	-3.207	.001	56.1	46.5	9.7	60	-3.358	.001
We help each other relax with things like massage, taking a bath together, or listening to music together.	63.8	59	4.7	51	-1.134	.257	71.7	63.3	8.4	57	-3.357	.001

SCALE	**PATIENT**						**SPOUSE**					
	Time 0	**Time 1**	**Mean difference**	**df**	**Z**	**P**	**Time 0**	**Time 1**	**Mean difference**	**df**	**Z**	**P**
We are affectionate with each other, make love to cope with stress.	68.1	60	8.1	51	-2.496	.013	63.6	64	-0.4	56	-0.632	.527
Overall score (mean)	**61.0**	**49.5**	11.5	-	-0.248	**.804**	**56.6**	**64.6**	-8.0	-	-3.557	**<.001**

Although GEE model reported insignificant statistical results for couples' satisfaction with coping mechanism (DCI-6) (*β= -14.38, p= .055)* using group by time effect interaction, a further subgroup analysis with Wilcoxon Test reported otherwise. Subgroup analysis indicated that the overall mean score of couples' satisfaction with coping mechanism (DCI-6) for persons with stroke decreased from 69.4% (at T0) to 58.8% (at T1) (p= .765). However, as with spouses, the overall mean score of couples' satisfaction with coping mechanism (DCI-6) statistically improved from 70.3% (at T0) to 74.1% (at T1) (p= .002).

Comparing the GEE modelled results (**Tables 3, 6, 9**) with those from the Wilcoxon paired analyses presented in **Tables 4-5, 7-9, 11-15**, it was revealed that spousal caregivers responded much better in their adaptation than their partners who were affected by stroke. This is based on the fact that spousal caregivers scored significantly better on more items from the Hospital Anxiety and Depression Scales (HADS), the Revised Dyadic Adjustment Scales (RDAS), and the Dyadic Coping Inventory (DCI) assessment tools than their stroke-affected partners. As further illustrated in **Table 16**, using Mann-Whitney U test, a comparison of average adaptation scores between spousal caregivers and persons with stroke before (at T_0) and after (at T_1) the intervention revealed that spousal caregivers adapted more significantly after the intervention based on anxiety (HADS-1) (p= .007), depression (HADS-2) (p <.001), outgoing stress communication (DCI 1) (*p*= .043), and incoming stress coping behaviour (DCI 2) (*p*= .008).

Table 16 Comparison of average adaptation scores between spousal caregivers and persons with stroke before and after the intervention

Subscales	Time 0			Time 1		
	Spousal caregiver	**Stroke patient**	**Z (p-value)**	**Spousal caregiver**	**Stroke patient**	**Z (p-value)**
HADS-1 (Anxiety)	28.7	21.6	-1.628 (.104)	9.7	3.9	-2.674 (.007)
HADS-2 (Depression)	31.5	17.7	-3.746 (<.001)	25.8	10.9	-4.298 (<.001)
DAS-1 (Consensus)	54.9	59.0	-0.863 (.388)	56.3	46.1	-0.606 (.544)
DAS-2 (Satisfaction)	82.2	81.9	-0.162 (.871)	85.2	64.4	-1.136 (.256)
DAS-3 (Cohesion)	54.6	52.2	-0.628 (.530)	60.8	45.9	-1.713 (.087)
DCI-1 (Outgoing stress communication)	57.5	56.3	-0.694 (.488)	69.4	51.3	-2.026 (.043)
DCI-2 (Incoming stress coping behaviour)	64.3	61.4	-1.584 (.113)	71.2	51.2	-2.636 (.008)
DCI-3 (Incoming stress communication)	58.6	57.3	-0.272 (.786)	69.2	50.9	-1.835 (.067)
DCI-4 (Outgoing stress coping behaviour)	74.1	75.6	-0.29 (.772)	80.8	60.5	-1.492 (.136)
DCI-5 (Couple's stress-coping mechanism)	56.6	61.0	-1.176 (.240)	64.6	49.5	-0.744 (.457)
DCI-6 (Satisfaction with coping mechanism)	70.3	69.4	-0.312 (.755)	74.1	58.8	-0.316 (.752)

NB: Significant differences in the average adaptation scores between persons with stroke and their spousal caregivers are based on the Mann-Whitney test (U)

4.3.4 Qualitative findings

This section of Chapter 4 reports the qualitative findings from the experiences of persons with stroke and their spousal caregivers who undertook the 3H intervention programme. The following content describes the characteristics of the participants who engaged in the interview discussions.

4.3.5 Characteristics of participants enrolled in qualitative interviews

In total, seven persons with stroke and seven spousal caregivers were individually approached to participate in the interviews. The characteristics of the participants in the qualitative interviews are summarised in Table 17.

Table 17 Characteristics of participants in qualitative interviews

No.*	Gender	Age range	Ethnicity	Educational level	Occupation
P1	M	60-69	Indian	Secondary	Retiree
S1	F	60-69	Indian	Primary	Working part-time
P2	F	50-59	Chinese	Tertiary	Unemployed
S2	F	60-69	Indian	Primary	Unemployed
P3	M	60-69	Indian	No education	Unemployed
S3	F	50-59	Chinese	Secondary	Unemployed
P4	M	70-79	Malay	Primary	Retiree
S4	F	60-69	Malay	Primary	Working part-time
P5	M	70-79	Chinese	Tertiary	Retiree
S5	F	60-69	Chinese	Primary	Working part-time
P6	M	60-69	Indian	Tertiary	Working full-time
S6	F	60-69	Chinese	Primary	Retiree
P7	M	60-69	Chinese	Primary	Retiree
S7	M	40-49	Malay	Secondary	Working part-time

* Participant type (P = person with stroke; S = spousal caregiver)

4.3.6 Themes

The qualitative component of the embedded mixed-methods study explored the experiences of persons with stroke and their spousal caregivers after participating in the 3H intervention during hospitalisation for rehabilitation. *Becoming more prepared to face the storm* was recognised as the main theme, which illustrated a gradual improvement in couples' ability to cope, despite *struggling with the stroke situation* at the initial stage, after the sudden onset of stroke. Concurrently, *breaking the silence and engaging in conversations*, *cultivating a sense of support*, *conveniently fulfilling their educational needs,* and *extending the 3H intervention for community nursing* emerged as subthemes.

Becoming more prepared to face the storm

After participating in the 3H intervention, the persons with stroke and their spousal caregivers mostly described a process in which they were *becoming more prepared to face the storm*.

> *I previously didn't have good knowledge about stroke. I tried to search on the Internet about stroke, but I didn't understand much. This is the first time both my husband and I are taking part in a 3H intervention together. Both of us liked it. It was a scary experience for me when my husband had a stroke. I was in shock. Now, after attending the 3H intervention, I have begun to realise more about the stroke condition and how to care for my husband. I feel that more patients and spouses should benefit from the 3H intervention.* (Stroke caregiver 2)

The term "storm" denotes the feelings of worry and uncertainty as a result of the stroke situation in the family. At the "pre-intervention phase" (i.e., prior to the 3H intervention), the participants were *struggling with the stroke situation as a couple*. The "intra-participation phase" is the time when the participants took part in the 3H intervention. During this phase, the intervention facilitated the couples in going through the *process of coping* after a stroke. Persons with stroke and their spousal caregivers coped by *breaking the silence and engaging in conversations*, *cultivating a sense of support* with other stroke couples in the ward, and *conveniently fulfilling their educational needs*. The "post-intervention" phase refers to the time after the 3H intervention was conducted. During this phase, *extending the 3H intervention for community nursing* was suggested as an approach to facilitate the transition of care from hospital to home. The state of becoming more prepared to face the storm was reported as follows:

Struggling with the stroke situation as a couple

A stroke situation in the family affects both the person with stroke and their spousal caregiver – it affects them as a couple. Before participating in the 3H intervention, couples struggled to adapt and cope with the aftermath of the stroke. Persons with stroke were particularly concerned and worried about their uncertain future, with possible or actual disabilities. Similarly, the spousal caregivers' lives were in turmoil, as they did not understand the behavioural changes and mood fluctuations of their spouse, who was living with stroke, contributing to stressful caregiving situations:

> *I feel uncertain and worried about my own future after I am discharged from this hospital. I also feel fearful about my life after a stroke. Caregiving can be very stressful after a stroke. My spouse has lost four to five kilograms of weight since I had a stroke. It is not easy* (patient cries). (Person with stroke 2)

> *I feel very sad about why my husband who got a stroke. He keeps crying and that is affecting me. We didn't expect that he would get a stroke. Until today, his stroke seems very bad. He cannot move well; he needs someone to assist him to get up from the bed at all times. Each day I feel down when I visit my husband in the hospital.* (Spousal caregiver 3)

Couples' coping processes

At the intra-participation phase of the 3H intervention, the couples coped better with the stroke situation through *breaking the silence*: *engaging with each other in conversation*; *cultivating a sense of support*; and *conveniently fulfilling their educational needs*.

(a) Breaking the silence: Engaging with each other in conversation

Couples felt that it was easier to engage in conversation with their spouse during their participation in the 3H intervention, hence strengthening their post-stroke marriage relationship:

> *I am very fortunate that there is someone here in the ward to tell us more about stroke and how to better relate to our spouse through communication. Otherwise, I wouldn't have understood all of the hidden issues that my*

> *husband is facing, and more misunderstandings between us might have occurred.* (Spousal caregiver 1)

> *I liked it when we had a discussion -myself and my wife. She told me that she loves me very much. She visits me every day and after knowing that we can dance here in the garden, we actually danced. I think that is the best part!* (Person with stroke 7)

> *After my husband had a stroke, I learned that communication is important. Actually, my husband doesn't like me to go to work. He wants me to just stay at home and take care of our daughter. You see, if I don't work, how would we get the money for our household? My husband is grumpy that I am now working. After what we saw and heard from the 3H course, I think it is important that I talk to my husband about why I started to work in the first place. Or else, he may be angry with me.* (Spousal caregiver 4)

(b) Cultivating a sense of support

The 3H intervention group sessions allowed participants to cultivate new friendships and bonds between. Besides emotional support, affirmative support was also evident, where participants freely shared and validated their stroke experiences with the other participants who were recovering from a stroke:

> *I personally feel that this intervention is where many patients and their spouses can come together and participate. We can share our problems and feelings openly, and learn from one another. There was one patient who*

> *comforted me during the 3H intervention. She had a stroke three times. She told me to just have faith and I will recover. I also felt encouraged when other patients came and spoke with me after the 3H intervention.* (Person with stroke 1)

> *I spoke to the wife of one of the stroke patients. She was sharing her experiences of caring for her husband with stroke with me. It was nice to share with each other. We can learn about stroke together and help each other. I can get to know about her problems in caring for her husband. It also improves my insight into how I can prevent problems, like falling at home and caring for my husband better.* (Spousal caregiver 2)

On the other hand, a few stroke patients lacked interest in developing new friendships with other intervention participants. It is therefore necessary to motivate persons with stroke to interact with other participants during the 3H intervention, thereby preventing social isolation:

> *Not all patients here can be my friends. I have my own behaviours and likes... Our character will not match with other people all the time. At times, after my stroke, I don't even like to talk with others. It is better when I am alone and I can avoid problems with other patients in the ward. Not everyone can be friends, you see.* (Person with stroke 4)

> *No, I didn't make any friends during the programme... I just like being by myself.* (Person with stroke 5)

Spousal caregivers were the “forgotten” care recipients who tended to neglect their own health and well-being while providing care to their spouse with stroke. Through the 3H intervention discussions with other spousal caregivers, spouses learned the importance of cultivating self-care, so they could better provide care and support to their spouse with stroke:

> *I learned that it is important to take care of myself after taking part in the 3H programme. Many a time I forgot about myself. My life used to be for my husband. Now, I think that when I am good and healthy, I can care for my husband better. When I become sick, it will be hard for both of us. Usually, I don’t go out and relax. Maybe next week, I will watch a movie or go shopping to feel relaxed.* (Spousal caregiver 3)

The participants suggested the continuation and extension of “cultivating a sense of support” from the “intra” to the “post-intervention” phase. They felt there are many other couples suffering from stroke in the community, who have little support. Involving these couples in stroke interventions would allow them to be more informed about stroke and its management:

> *When we attend such programmes, we can learn more and it keeps us updated on stroke. Stroke is getting so common nowadays in Singapore. I know many people who are having strokes and they are suffering by themselves. They don’t share their pain with anyone. If we don’t attend such programmes, we will not be informed about stroke at all. We will be lost on how to move on with life after a stroke.* (Spousal caregiver 2)

(c) Conveniently fulfilling educational needs

Persons with stroke and their spousal caregivers fulfilled their educational needs on coping after a stroke through their convenient participation in the 3H intervention. An accessible venue and the intervention's appropriate timing made it convenient for the couples to participate:

> *The timing of the education is good, as it matches the visiting hours of our family members. Therefore, both the patient and spouse can attend.* (Person with stroke 1)

> *I like that the 3H programme is conducted in the hospital's dining room, after dinner. I don't need to hurry to other places – if the programme is conducted in different places* (Spousal caregiver 5)

In order to provide financial support for their family, most spousal caregivers resumed working after their spouse was diagnosed with a stroke. In such a situation, spousal caregivers found the timing of the 3H intervention to be feasible, as they were able to participate in it after their daily work:

> *I started working as a cleaner, so that I can earn some income to support my husband, who had a stroke. I have a daughter with Down syndrome. My husband was working previously. Now that he has had a stroke, it is very difficult for our family. Every day, I take care of my daughter, who has Down syndrome. Then I go to work.* (Spousal caregiver 4)

Persons with stroke and their spousal caregivers appreciated being given the 3H intervention bags containing stroke prevention pamphlets and a stress ball. The potential tensions of patients and their spouses, stemming from a lack of information on stroke, eased as the participants were able to access all necessary information on stroke diagnosis and management, in the 3H intervention bags:

> *My wife and I feel happy to have received the 3H intervention goodie bag. It is free, and we can use it again when I am discharged home. When I see the bag, it reminds me of what I have learned here.* (Person with stroke 4)

Extending the 3H intervention for community nursing

Stroke couples also shared their insights on ways of extending the 3H intervention in the community, instead of ending it early during rehabilitation hospitalization stay. Several participants stated they would have preferred a tailored intervention for participants whose native language was Chinese, Malay, or Tamil:

> *I would prefer it if the education could be conducted in the Tamil language in future. If there are Malay nurses, they too can deliver the education in Malay. There is a personal touch to the education if it is conducted in our own native language. I feel that in such a way, the education will be more personalised.* (Person with stroke 1)

Some spousal caregivers recommended an online 3H intervention. They felt that having the intervention accessible online would make it easier to access information related to coping and recovery after a stroke:

> *Some days it is difficult for me to come down to the ward. I feel sick and I need to rest. I suggest that online teaching would be good.* (Spousal caregiver 7)

4.3.7 Embedding of quantitative and qualitative results

Both the quantitative and qualitative results informed us that the 3H intervention was acceptable amongst persons with stroke and their spousal caregivers. Quantitative results indicated that a vast majority of all recruited participants (84.4%) participated throughout the intervention. Spousal caregivers who had dropped out of the 3H intervention programme (*n*=9) had reasonable justifications, such as resuming work or feeling unwell. In comparison with the quantitative findings of participant recruitment and attrition rates, the qualitative findings also implied that the 3H intervention was generally accepted and feasible among persons with stroke and their spousal caregivers. Given the convenient venue and timing of the 3H intervention at the rehabilitation hospital, participants told us in the qualitative interviews that they were able to fulfil their educational needs on stroke with ease. Since the intervention was conducted in the evening, from 6 p.m. to 7 p.m., spousal caregivers who were working revealed they were easily able to participate after their daily work.

Although the 3H intervention generally improved participant adaptation, GEE modelling effects indicated that spousal caregivers responded better than persons with stroke. Results of group by time effect reported that the scores on the items of the Revised Dyadic Adjustment Scale (RDAS) and Dyadic Coping Inventory (DCI) were significantly better in spousal caregivers than in persons with stroke. When compared with the qualitative findings, it was evident that spousal caregivers also had better coping and adjustment after attending the 3H intervention. Spousal caregivers informed us in the qualitative interviews that they had learnt essential skills on self-care to take charge of their personal health and well-being, whilst caring for their spouse affected by stroke. This most likely correlates with the improved adjustments and coping they learned by attending the 3H intervention. In contrast, subgroup analysis with Wilcoxon Test indicated that RDAS and DCI scores for persons with stroke declined three weeks after their participation in the intervention. Some persons with stroke reported that they would have preferred the 3H intervention to be conducted in languages other than English, to facilitate easy understanding and comprehension. Lack of local language skills in multi-ethnic Singapore could have potentially hindered their ability to fully comprehend and learn from the 3H intervention. Scheppers et al. (2006) highlighted the fact that people from an ethnic minority may feel especially inept at expressing their feelings related to the subject matter that was discussed, due to language and reading difficulties. Furthermore, a few persons with stroke lacked interest in developing friendships with other programme participants. This prevented persons from ethnic minorities living with stroke from gaining new insights into ways to cope and adjust after a stroke, compared to the others. It is therefore necessary to motivate persons with stroke to interact with other participants during the 3H intervention, thereby preventing social isolation.

The GEE modelling using group by time effect showed non-significant findings for couples' anxiety and depression scores (HADS scale), and couples' satisfaction with coping mechanism (DCI-6) ($\beta = -14.38, p = .055$). Nevertheless, subgroup analysis with Wilcoxon paired analyses and Mann-Whitney U test indicated that the anxiety and depression scores decreased, while mean scores for couples' satisfaction with coping mechanism had improved. Although non-significant results were found in group by time effect, qualitative findings indicated that participants felt emotionally supported after taking part in the 3H intervention. Qualitative findings reported that before attending the 3H intervention, persons with stroke and their spousal caregivers felt worried about their uncertain future, leading to emotional problems such as anxiety and depression. In particular, spousal caregivers had experienced stress, as they could not comprehend the mood fluctuations and changes in their spouse’s behaviour after a stroke. However, after attending the 3H intervention, couples felt they were better able to engage in conversations with one another, and they had cultivated a sense of support with other participants, hence facilitating post-stroke adaptation. Wan-Fei et al. (2017) asserted that post-stroke depression and anxiety are common in persons with stroke and their family caregivers. Post-stroke depression and anxiety in persons with stroke may compromise rehabilitation outcomes and coping mechanisms promoting recovery (Fang et al., 2017). Barker-Collo (2007) identified that at three months post-stroke, depression and anxiety was still evident in 73 individuals with stroke in a rehabilitation hospital. Wan-Fei et al. (2017) observed that the depression and anxiety levels of persons with stroke and their caregivers affect one another through the process of emotional contagion. ‘Emotional contagion’ is where people unconsciously attach their emotions to one another during their interaction processes (Hatfield et al.,1993). Although subgroup analysis with Wilcoxon test and qualitative study findings indicate that the 3H intervention appears to be of incremental value in alleviating depression and anxiety in rehabilitation care, further follow-up on the 3H intervention is necessary over a longer time period.

CHAPTER FIVE

DISCUSSION

5.1 Intervention development

The development of 3H intervention was based on the first two stages of the MRC framework (Campbell et al., 2000). A series of literature reviews and a qualitative study were conducted in the Singaporean community, which underpinned the systematic development of the novel intervention. Another study (Shields et al., 2012), which developed family-oriented interventions focusing on stroke education and support, found mixed evidence that these interventions led to enhancements in the functioning of persons with stroke or their caregivers. For example, a home-based intervention for cognitively intact persons with stroke and their caregiver (Glass et al., 2012) found no significant differences in participant depression scores when compared to usual care. Another study by Smith and colleagues (2004), an education intervention for persons with stroke and their caregivers, found a reduction in anxiety levels in persons with stroke post-intervention. Inconsistent findings in depression and anxiety scores were reported in persons with stroke and their caregivers who took part in these family-oriented interventions. Shields and colleagues (2012) revealed that a lack of theory and specific target mechanisms underpinning these interventions may have produced the inconsistent results in the outcome variables.

Theories can provide systematic guidance for the development and refinement of an intervention. Theories predict that the mechanisms, if targeted in the intervention, may elicit change (Shields et al., 2012). Uchino (2004, p.177) recommended that future studies integrate a theoretical foundation to address the question of "Who provides what to whom with what effect?" The choice of theoretical underpinning is driven by the research question. In programme or intervention-oriented research, researchers have some flexibility in choosing the best fit theory in accordance with the context and research outcomes sought (Gibbs et al., 2011). Careful consideration and theory selection strengthens the opportunities for reflective analysis of the measured success and failure of an intervention (Baranowski et al., 2003). A lack or an inappropriate underpinning of a theoretical framework is likely to result in inconsistent or negative outcomes (Gibbs et al., 2011).

5.2 Feasibility and process evaluation of the 3H intervention

The purpose of a clinical research study is to evaluate whether an intervention is widely feasible among research participants, and to render the best evidence of treatment effects (Cooley et al. 2003). An inability to successfully recruit the targeted number of participants within the stipulated timeframe is deemed a constant threat to the triumph of a research study in a clinical setting (Gross & Fogg 2001, Rubin et al. 2002). The following section provides a rich discussion of the feasibility of the 3H intervention as underpinned by the eight feasibility domains: acceptability, demand, implementation, practicality, adaptation, integration, expansion, and limited efficacy (Bowen et al., 2009).

5.2.1 *Acceptability*

Acceptability of healthcare interventions is of paramount importance, so that patients and their caregivers are more likely to adhere to the treatment recommendations and benefit from better clinical outcomes (Hommel et al., 2013). In the present study, 84.4% of all participants were retained in the programme and study, while 15.6% of participants were lost to attrition. Although Kneipp & McIntosh (2001) pointed out that some participant attrition is expected in research studies, bias is expected in findings when the attrition rate is above 20% (Polit & Beck, 2014). In particular, nine out of 10 participants who dropped out of the current study were spousal caregivers. Similar to Gul & Ali (2010), participant-related factors, such as lack of time and physical limitations due to sickness, were common reasons for caregiver withdrawal from the 3H intervention. In order to improve participant recruitment and retention rates, researchers need to identify and implement strategies that eliminate barriers hindering research participation (Gul & Ali, 2010). Factors such as collecting data at opportune times, for instance on the weekend, at places convenient to participants' homes, and after work hours were suggested to facilitate the process of participant recruitment and retention (Gross & Fogg, 2001; Corrigan & Salzer 2003; Preston et al., 2016). On reflection, several effective efforts were implemented to improve participant retention in the 3H intervention since the commencement of intervention. They include, (a) the creation of a welcoming atmosphere throughout the intervention, (b) informing participants about their role in the study, (c) development of a routine to conduct the intervention while at the same time ensuring flexibility, and (d) intervention training for registered nurses in the hospital. The 3H intervention was conducted routinely, at the same time of the day every week.

5.2.2 *Demand*

Findings from the qualitative results indicate a demand for participation in the 3H intervention. Most intervention participants were keen to cultivate new friendships with other couples living with stroke. Lavrakas (2008) reported that self-selection results in biased data, as motivated participants who choose to participate in the intervention may not represent the entire targeted population. This might potentially be apparent, as the participants were motivated to share and learn from each other’s stroke related experiences. Spousal caregivers in particular understood the need for taking charge of their own health through engagement in self-care. However, in this study, the risk of self-selection bias in persons with stroke was minimal, as some appeared to lack interest and motivation to interact with other 3H intervention programme participants. Overall, the study results may not be biased, in terms of favouring participants who were motivated to attend the 3H intervention. In future, participant preferences for participating in a group versus at an individual level should be taken into consideration, prior to 3H intervention delivery. Greaves & Campbell

(2007) argued that a one-size fits all group interventional approach seldom meets the needs of all participants. Despite the limitations of a group-based interventional approach, Ven (2003) highlighted several advantages of psychosocial group interventions in diabetes care. Prior to the implementation of the 3H intervention, the researcher could explain the benefits of participating in a group level intervention, in addition to the individual level sessions. Some advantages of group and couples-based dyadic interventions include, (a) gaining emotional support from other persons with similar health conditions, and (b) improvement in the sense of belonging in a group by giving and receiving help from other participants. As suggested by Ven (2003), the researcher should identify participants with inadequate interpersonal patterns and skills before intervention commencement, and explore how these longstanding intrapersonal problems could be better addressed individually.

5.2.3 *Implementation*

During the 3H intervention implementation, the researcher had prepared the essential requisites needed to conduct the intervention (Appendix X). From anecdotal experiences, communication issues surfaced with clinical staff when the 3H intervention was first implemented in the ward setting. The researcher had only informed about the overall nurse in-charge of the shift about the selected study participants. However, this communication was not effectively disseminated to other registered nurses and healthcare assistants who provide care for persons with stroke. Consequently, some participants were left waiting at their respective bedsides for the 3H intervention to commence, instead of being present in the dining area. This led to some participants feeling frustrated due to the lack of information on the study location. To ensure effective communication between the researcher and stroke healthcare professionals, the purpose of the intervention, and the intervention dates and time were later documented in the ward communication book. Effective communication in healthcare practice is of utmost importance. If either a healthcare provider or patient lacks a clear understanding of the information being conveyed, the delivery of care could be compromised. Consequently, ineffective healthcare delivery increases the probability of negative patient outcomes (Ratna, 2019).

5.2.4 *Practicality*

Because the 3H intervention was conducted in a rehabilitation ward setting where stroke patients were hospitalised, it was a convenient location for the couples to participate in the intervention. In addition, the intervention was conducted during visiting hours, from 6 p.m.-7 p.m. A convenient venue and timing for the 3H intervention encouraged most couples to attend the intervention sessions. Stroke patients and their spousal caregivers attended the intervention together. Therefore, there was no time loss in terms of couples' personal interactions during visiting hours. Moreover, the 3H intervention was free of charge for all participants who met the study criteria.

5.2.5 *Adaptation*

Participants in the 3H intervention recommended some modifications to the intervention. Some stroke patients requested the following information to be included in 3H intervention: (a) What are the possibilities of returning to work after a stroke, (b) What to do if we are unable to return to our current job, and (c) What is some alternatively available support when one is unable to resume one's usual job after a stroke? Gallo, Bradley, Teng, and Kasl (2006) found that negative health implications, such as increased cardiac disease, depression, social isolation, and poor coping ability were apparent as a result of a failure to return to work after stroke recovery. Returning to work is an attainable goal for most persons with mild to moderate stroke after an optimal recovery through rehabilitation. Evidence suggests that the return to work rate after a stroke differs between countries (Westerlind, Persson, & Sunnerhagen, 2017). An Australian study reported that 75% of persons with stroke return to work within the first year of stroke diagnosis (Hackett, Glozier Jan, & Lindley, 2012). A six-year follow-up study in Sweden revealed that 48% of persons had returned to work after a stroke (Singam, Ytterberg, Tham, & von Koch, 2015). In Singapore, an average of 45.9% of stroke patients were employed within the first year after a stroke diagnosis (Chan, 2008). Therefore, nurses should initiate a discussion, identifying a person's short-term and long-term goals regarding work resumption, and advocate accordingly to achieve those goals (Harris, 2014).

5.2.6 *Integration*

The 3H intervention is recognised for its potential for integration into usual clinical practice by rehabilitation hospital nursing administrators. Before the 3H intervention's integration into usual clinical practice, a full clinical trial is warranted for the process of evidence-based practice development. The researcher identified a number of potential barriers that might impede the successful implementation of the intervention in clinical settings in future. These may include healthcare professionals feeling overwhelmed, and a lack of on-site champions to facilitate the intervention. To overcome these barriers, education and training must first be organised for healthcare professionals to be equipped with the essential skills required for engaging couples living with stroke in a clinical practice setting (Forchuk et al., 2013).

In future, Cullen & Adams' (2012) application-oriented four-phase approach can be used to successfully implement evidence-based practice initiatives in a clinical setting. The steps include, (1) creating awareness and interest in the intervention in healthcare professionals and stakeholders, (2) building knowledge of and commitment to the intervention, (3) promoting action and adoption, and finally (4) pursuing intervention integration and sustainability (Cullen & Adams, 2012) (Appendix XI). In the current feasibility study, the researcher has created awareness and built knowledge about the 3H intervention among healthcare professionals. After a trial study, once the 3H intervention is considered to be integrated into clinical practice, the researcher needs to focus on initiatives to promote the adoption and sustainability of the intervention over a period of time. Some suggested strategies include, the development of a workflow on when and how to conduct the 3H intervention, checking the skills competence of healthcare professionals who could potentially deliver the intervention, and recognising the efforts of healthcare professionals who champion the 3H intervention, e.g., through certificate presentations (Cullen & Adams, 2012).

5.2.7 *Expansion*

Study participants suggested ways of extending the 3H intervention for community nursing in future. In a study by Tsai and Lee (2016), it was reported that southeast Asian immigrants in Taiwan were at higher risk of poor health outcomes due to language and communication barriers that affected their access to healthcare. Although English is the official language in Singapore, the participants' preference was to have the 3H intervention delivered in their native languages of Chinese, Malay, and Tamil. This must be taken into full consideration in the future development of the intervention. It will be necessary to translate the 3H intervention and associated health education materials into participants' preferred languages, to minimise language and communication barriers.

Some spousal caregivers proposed the development of an online version of the 3H intervention. Results from a recent systematic review of 17 studies concluded that online interventions were able to reduce depressive symptoms, anxiety, and distress among informal caregivers of persons living with chronic disease in the community (Ploeg et al., 2017). Since positive health outcomes are evident in informal caregivers who have taken part in online interventions, the researcher should consider implementing the 3H intervention through an online approach in the future. This would facilitate easier access to post-stroke information pertaining to coping and recovery amongst persons with stroke and their spousal caregivers. As persons with stroke and the facilitating nurse are in the rehabilitation ward, spousal caregivers may join them online for the 3H intervention free-of-charge. The advantages of such an approach are that it would make the intervention widely available, easily accessible, and more cost-effective (Kang et al., 2018). Despite the advantages of online interventions, the drawbacks include non-adherence to the intervention and high dropout rates, which could range from 22% to 41% (Aalbers et al., 2011). To reduce the possibility of a high dropout rate, interactive methods, such as online discussions, could be incorporated (Kang et al., 2018).

5.2.8 *Limited efficacy*

The current study makes novel contributions to couples-based interventions for persons with stroke and their spousal caregivers in the Singaporean community. Despite its strengths, it is of paramount importance to identify the limited efficacy of this research study. The first limitation is the weakness of a single group pre-and post-intervention study design, which may carry possible bias and threats to its internal validity (Knapp, 2016). To address and tackle the challenges of a single pre- and post-test group, the only recommended solution is to use a more rigorous design in future, incorporating randomisation and control groups to complete the process for better evidence-based practice development (Spurlock, 2018). Hence, it is highly recommended to rigorously test the 3H intervention on a larger scale with better power, by utilising a multisite RCT design. In addition to that, multisite RCTs with a good feasibility of recruitment can produce large sample sizes, thus contributing to greater power whilst testing the research hypothesis (Sedgwick, 2015).

5.3 Preliminary results: Striving towards bonadaptation in coping with stroke

Compared to persons with stroke, statistically significant differences in the preliminary results of the 3H intervention were more apparent in spousal caregivers at T_1 (three weeks after the intervention) compared toT_0 (pre-intervention). Beyond expectations, persons with stroke appeared to have adapted less effectively to the stroke situation than did their spousal caregivers after participating in the 3H intervention. Horton and colleagues (2015) identified the fact that a stroke could impair communication ability, causing significant deficits in expressive and receptive language in persons with stroke. Therefore, prior to conducting any healthcare interventions, Wray & Clarke

(2017) recommended that healthcare professionals be mindful of a stroke patient’s significant loss and emotional upheaval related to communication challenges, as they may be at a different stage incoming to terms with changes post-stroke.

Most spousal caregivers in this present study juggled their return to work to support their families, while taking various degrees of responsibility for caring of their spouse with stroke. With nine million people diagnosed with their first stroke episode each year, a large number of people worldwide are suffering from moderate to severe disabilities (The Global Burden of Disease, 2008). Persons with stroke suffer from fatigue (Andersen et al., 2012), physical disability (Wang et al., 2014), and depression (Wozniak & Kittner, 2002), disrupting both their physical and mental functioning, contributing substantially to the economic burden of stroke in the community. Furthermore, Arwert et al. (2017) indicated that a patient’s inability to work is a major consequence of stroke. To maintain a flow of income, most spousal caregivers of persons with stroke took up part-time jobs. A few studies found that people were found living longer with chronic debilitating conditions (Åberg et al., 2004; Adamson & Donovan, 2005). Spousal caregivers continuously strove to achieve continuity and normality, by resuming part-time work, for example, to minimise the disruptions to their marriage and life.

Spouses from various cultural and religious backgrounds were expected by society to be responsible for caring for a spouse who had been diagnosed with stroke (Bäckström et al., 2010; Kitzmüller et al., 2012). Studies in the Asian context indicated that marital obligations and the ethical responsibility to provide care prevented caregivers from leaving an ill spouse (Qiu et al., 2018; Xiao et al., 2014). Similarly in Korea, four in 10 older adults found themselves in the position of being the primary caregiver for their chronically ill spouse (Choi, 2018). Supporting spousal caregivers in their efforts to balance work and caregiving tasks is of paramount importance to prevent them from feeling overwhelmed with responsibilities after their spouse has had a stroke.

Prior to taking part in the 3H intervention, the participants in this study were struggling with stroke. The persons with stroke worried about their future, dealing with stroke-related disabilities. On the other hand, the spousal caregivers were also stressed, as they could not comprehend their spouse's mood fluctuations and behavioural changes, contributing to caregiver strain. The diagnosis of chronic disease can serve as a significant stressor for persons suffering from such disease and their family caregivers, most notably spouses. Persons with chronic disease and their spouses must therefore learn ways to gradually adapt to the challenges of living and coping with a chronic medical condition (Zajdel et al., 2018). Couples coping with a chronic disease tend to feel close as they empathise and converge emotionally with one another (Bucki et al., 2019). Nevertheless, previous studies (Hatfield & Cacioppo, 1994; Monin & Schulz, 2009) have shown that when couples coping with chronic disease were unable to detach themselves from their spouse's suffering, it would lead to personal distress, with detrimental effects on their physical and psychological health over time.

It was evident in several studies (Bäckström et al., 2010; Brann et al., 2010; Quinn et al., 2014) that persons with stroke and their spousal caregivers were "suffering in silence." Consistent with the findings of the current study, previous studies (Brereton & Nolan, 2000; Coombs, 2007) reported that some spousal caregivers concealed their frustrations from the person with stroke, to establish a sense that life was going on as usual in the family. Consequently, spousal caregivers felt supressed and overwhelmed, as they were unable to openly express their emotions (Coombs, 2007). Promisingly, participants in this study adapted to the stroke situation better after participating in the 3H intervention. Signs of bonadaptation were evident throughout the 3H intervention. Participants who participated in the interviews verbalised that they were able to break their silence and engage in conversations with one another. Similarly, participants learned how to tactfully communicate and openly express their feelings.

5.4 The added value of multicomponent strategic interventions research

Multicomponent family-oriented interventions are increasingly being utilised to deal with the concerns of families and persons who have been diagnosed with chronic health conditions (Gonzalez et al., 2002; Steinglass et al., 2011). The interventions were usually delivered on a one-day, weekly, or biweekly basis over three to six sessions (Rolland, 2019). These interventions enable persons suffering from chronic disease and their families to confront the demands related to the disease. Similar to the preliminary findings of the 3H intervention, a review and meta-analysis of multicomponent couples-oriented interventions for chronic illness identified that these interventions are proven to be more efficacious than care as usual or individual patient-centric psychosocial interventions (Martire et al., 2010). The review focused on couples coping with chronic illnesses such as cancer, diabetes, arthritis, chronic pain, HIV, and cardiovascular disease. It was found that couples-based interventions had significant effects on the depressive symptoms of patients, marital functioning, and pain (Martire et al., 2010).

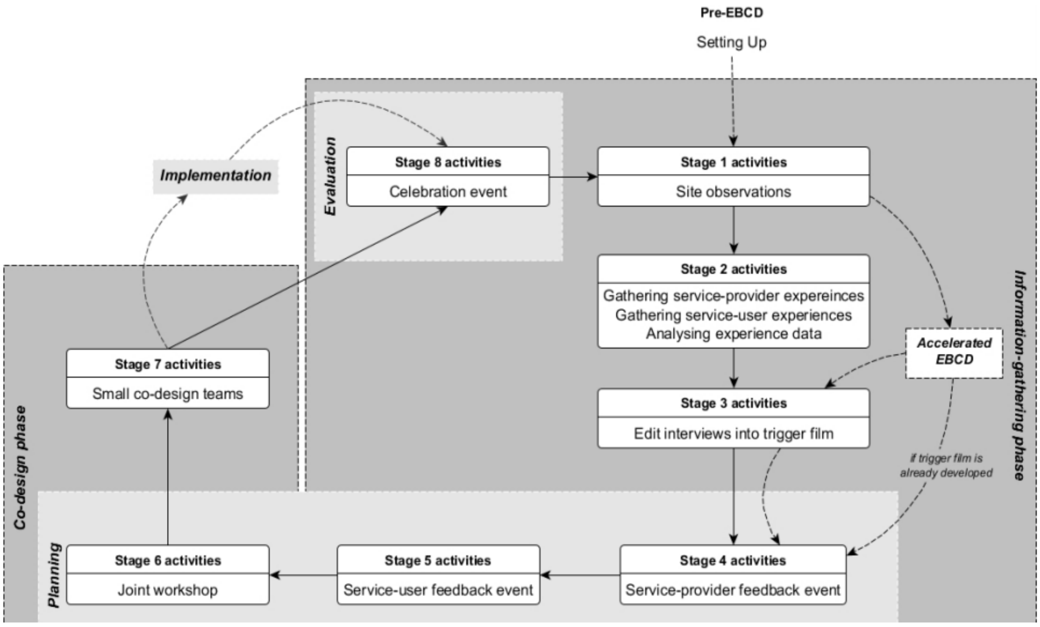
Likewise, the 3H intervention added value for study participants by giving them an opportunity to voice their personal concerns in relation to adaptation and coping with the stroke disease process. Through the intervention’s group sessions, it was evident in the qualitative findings that cross-family alliances with other spouses in similar caregiving roles were formed. Cultivating a sense of support through the structured multicomponent intervention services indeed improved family networks and minimised their feelings of isolation (Rolland, 2019).

5.5 Strengthening the 3H intervention implementation using an experience-based codesign (EBCD) approach in the Singaporean community

Prior to the implementation of a RCT, it is necessary to enhance the delivery of the 3H intervention using an experience-based codesign (EBCD) approach. One of the common strategies adopted to improve patient experience in the clinical setting is engagement of patient and family caregivers through patient-family caregiver health education (Carman et al., 2013). Although engagement with patients and their family caregivers enhances quality of health, the discussion is focused on a micro-level approach with individual meetings of health education among patients, family caregivers, and healthcare professionals (Coulter, 2012). More recently, experience-based codesign (EBCD) approach was introduced to collectively engage patients, family caregivers and healthcare professionals in the re-design processes of healthcare delivery that focus on system-level approach (Fucile et al., 2017). The active engagement of healthcare professionals, patients, and their caregivers in the planning and development of healthcare services is the fundamental key to clinical effectiveness (Crawford et al., 2002). A limitation of the 3H intervention is that it did not gather sufficient evidence on healthcare professionals' views and suggestions for further improving the service delivery. To fill this gap, experience-based codesign (EBCD) is a holistic approach that engages patients, caregivers, and healthcare staff in a partnership to develop and strengthen healthcare services (Green et al., 2019). It is necessary to enhance the delivery of the 3H intervention using the EBCD approach.

In particular, EBCD focuses on patient, caregiver, as well as healthcare professional emotions and experiences related to service delivery. By empowering healthcare staff, patients, and their caregivers to make changes, the EBCD approach identifies opportunities for service usability and sustainability (The Point of Care Foundation, 2020). Service users and healthcare professionals will either be filmed, interviewed, or observed to understand their positive and negative experiences of participating in an intervention. These shared experiences serve as a change catalyst where service users, such as patients and their caregivers, sit side-by-side with healthcare professionals to better design, implement, and test improvements to healthcare service interventions (Institute for Healthcare Improvement, 2020). For instance, the EBCD approach was used in the emergency department of a large teaching hospital in London. The study explored the feasibility of an intervention to improve palliative care services for older persons, their families, and healthcare professionals (Blackwell et al., 2017). It has been identified that EBCD can encourage collaborative working between vulnerable persons, caregivers, and healthcare professionals in healthcare settings. Therefore, participants' specific needs are accounted for, further strengthening the implementation of the complex intervention. Similarly, Brady and colleagues (2020) used the EBCD approach to enhance a pre-treatment care pathway for persons diagnosed with head and neck cancer. A total of 14 members, comprised of patients, radiation oncologist, clinical nurse specialists, dietitians, and speech-language therapists took part in the study. Seven key areas for practice improvements were jointly identified by the patients and staff members. They include, (a) revision of patient and caregiver information materials, (b) establishment of a patient experience video, (c) timeline information on cancer recovery, (d) a buddy system for patients during their cancer trajectory, (e) appointment scheduling flexibility, (f) seamless care transitions between settings, and (g) rebranding of departmental building (Brady et al., 2020). These key areas for practice improvements, involving patients in new roles as codesigners, embraces new perspectives for healthcare professionals to view patients as equal partners in developing and implementing healthcare interventions. The EBCD encourages healthcare professionals to leave their comfort zone, and examine new ways to interact and share experiences with patients in order to realise eye-opening solutions and new visions for care (Gustavsson & Andersson, 2019). Raynor and colleagues (2020) reported that EBCD is a pragmatic approach that identifies and reflects healthcare provider, patient, and family caregiver priorities as part of the research process to strengthen the implementation of an intervention for subsequent testing through a randomised controlled trial. To further strengthen the implementation of the 3H intervention prior to conducting a RCT, eight stages of EBCD, as informed by the Point of Care Foundation, will be adhered to in future studies (**Figure 16**) (Green et al., 2019; Palumbo, 2016). The eight stages include, (1) site observations, (2) gathering the experiences of service providers and recipients, (3) interviewing and filming participants' perspectives to initiate discussions (4) gathering feedback from service providers, (5) collecting feedback from service users, (6) joint workshop, (7) implementation of small codesign teams, and (8) conducting celebration events.

Figure 15: The eight stages of EBCD approach (Green et al., 2019; Palumbo, 2016)



CHAPTER SIX

LIMITATIONS, RESEARCH SIGNIFICANCE, IMPLICATIONS, AND CONCLUSION

6.1 Limitations

While this study was implemented and reported using rigorous scientific methods, there were some limitations that were beyond the researcher’s control. The first is that this study was conducted in the English language among people of diverse ethnic and cultural backgrounds, such as Chinese, Malay, and Indian. Based on the qualitative interview findings, six persons with stroke and two spousal caregivers reported that they were more comfortable conversing and comprehending in their own native language of Chinese, Malay, or Tamil rather than English. Qualitative findings also suggested that some participants would prefer if the associated 3H intervention educational materials were translated into the Chinese, Malay, and Tamil languages respectively. Further studies should have the programme translated into participants’ native languages to improve the generalisability of the 3H intervention in different cultural contexts.

Secondly, social desirability bias was possibly present in three persons with stroke who took part in the 3H intervention. Social desirability bias refers to a tendency for research participants to provide socially desirable answers in a questionnaire, instead of selecting answers that truly reflect their feelings (Grimm, 2010). These participants were pleased with the 3H intervention. Before filling in the questionnaire, they responded verbally that they would select better questionnaire responses. To address this challenge, these participants were immediately advised to select responses that were indicative of their true feelings. They were further reassured that research participant confidentiality and anonymity will be always maintained in the study, thereby increasing their confidence in responding truthfully to the questionnaires and interview questions.

Third, potential participant attrition bias from the 3H intervention was evident in this study. To further encourage couples' participation, an online mode of the 3H intervention could be developed and tested in future. There is evidence suggesting that online healthcare interventions are cost-effective, can minimise resources duplication, and facilitate prompt updating of new information, even in different languages, in a timely manner (Andersson & Titov, 2014).

The fourth limitation is that two couples stated that the baseline questionnaires were too lengthy to be completed, contributing to potential response bias. Nevertheless, all participants took approximately 15-20 minutes to complete the questionnaires. To avoid tiring out persons with stroke and their spousal caregivers, efforts should be made to shorten the questionnaires when the 3H intervention is conducted in the future.

6.2 Implications

6.2.1 Implications for research

Our innovative intervention is the first study to incorporate shared decision-making amongst stroke couples, which is an evolving approach in stroke research (Armstrong, 2017). Stroke happens unexpectedly, and persons with stroke are usually cared for by an informal caregiver, such as a spouse. With rapidly aging populations worldwide, the burden of stroke is expected to increase in many countries. Besides the persons with stroke, spousal caregivers face challenges in providing care to a spouse with stroke. Therefore, holistic support through the implementation of the 3H intervention is pivotal for both persons with stroke and their spousal caregivers. All of these study findings add new knowledge, by showing that the 3H intervention supports persons with stroke and their spousal caregivers in their adaptation post-stroke. Living with stroke can be a challenge for couples, significantly affecting their physical and emotional health, as well as their marital relationship.

Future research will evaluate the impact of the 3H intervention using the experience-based codesign (EBCD) approach. In addition, future research will follow up with participants after their discharge home into the community. This will add to new findings, if the 3H intervention allows for a seamless transition from hospital to home for couples coping after a stroke. Thereafter, a full randomised controlled trial of the 3H intervention will be conducted to determine the effectiveness of the 3H intervention programme in a clinical setting.

6.2.2 Implications for practice

The 3H intervention provides evidence on how to support persons with stroke and their spousal caregivers in a clinical setting. To strengthen the delivery of the 3H intervention in the future, nurses should collaborate with couples and, while the patient is still in the hospital, synthesise their knowledge and evidence on their expectations of life and recovery after a stroke, before the patient is discharged to return home. Based on the findings, nurses could at that time work together further with stroke couples to establish a realistic plan to advance their support, in terms of providing knowledge about stroke, and educating couples on the skills required to deal with stroke, and on the resources that are available to them in the hospital (Creasy et al., 2016). For nurses to support stroke couples effectively, they must be provided with training on how to implement evidence-based interventions. This will equip nurses with the skills they need to effectively engage couples in a dyadic stroke care approach. In addition, nursing administrators verbalized that they had recognised the importance of developing, on an ongoing basis, an intervention to provide support for stroke patients and their spousal caregivers as couples.

Nursing administrators were encouraged to recognise the importance of evidence-based development and of providing support interventions for persons with stroke and their spousal caregivers as couples, instead of the current care focus, which predominantly seeks to support individual stroke patients. The current support of the 3H intervention would be considered and integrated into nursing clinical practice after it is further strengthened with the EBCD approach and evaluated in a trial study.

6.2.3 Implications for policy development

To inform health policy and intervention investment decisions, future studies would include the economic evaluation of the 3H intervention. An economic evaluation of an intervention would bring a greater understanding of the cost-effectiveness of alternative implementation efforts (Reeves et al., 2019). In succeeding studies, economic evaluation of the 3H intervention will be assessed using the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) checklist (Husereau at al., 2013). This checklist was developed to improve reporting transparency and to enhance the clarity of published economic evaluations.

6.3 Conclusion

This study serves as an important contribution to new research evidence on the development, feasibility testing, and preliminary outcomes evaluation of the 3H intervention in Singapore to support couples in post-stroke living and recovery. Based on the findings of a literature review and qualitative study, the development of the 3H (Head, Heart, Hands) intervention was systematically presented. The theoretical framework, ABCX model of family stress and adaptation, was recognised and justified to underpin the 3H intervention.

After conducting a feasibility study and evaluating its preliminary effects, study results showed that the 3H intervention was feasible and acceptable in improving the post-stroke adaptation of couples in Singapore. In addition, this 3H intervention was well received (accepted) by persons with stroke and their spousal caregivers. Even though, when compared to persons with stroke, spousal caregivers reported better outcomes in their post-stroke adjustment, coping, anxiety and depression scores after participating in the 3H intervention, it is important for hospitals and the community to implement support initiatives such as the 3H intervention. This helps healthcare professionals to better understand the needs and ease the difficult life situation of both persons with stroke and their spousal caregivers as a unit of care.

Qualitative findings demonstrated that persons with stroke and their spousal caregivers initially struggle with the stroke situation. After participating in the 3H intervention, they were found to have improved their coping processes together to deal with stroke in the family. Intervention participants became more prepared to face the storm signifying the stroke, as they coped effectively by breaking their silence, engaged in conversations and shared decision-making, cultivated a sense of support, and conveniently fulfilled their educational needs. To ensure a seamless healthcare transition for couples living with stroke from hospital to home, extending the 3H intervention for community nursing should be prioritised. Appropriate support programmes, such as the 3H intervention, allow healthcare professionals to understand and alleviate the difficult life situation and needs of persons with stroke and their spousal caregivers in their journey to recovery.

It is evident that further development and the implementation of a series of 3H intervention programmes in future, utilising the EBCD approach and rigorous evaluation of the programme through larger and multisite RCTs, is warranted. A key strength of the EBCD is that healthcare professionals, persons with stroke, and their spousal caregivers can jointly contribute to knowledge of ways to support couples in coping after a stroke. Patients and spousal caregivers who are experts in their own experiences should be given an opportunity to be involved and further improve the 3H intervention service. Having said that, the experiences of healthcare professionals might differ from the experiences of persons with stroke and their spousal caregivers. Therefore, collaboration is required to capture areas for improvement in the 3H intervention developmental efforts to enhance support.

Appendices

Appendix I 3H intervention protocol

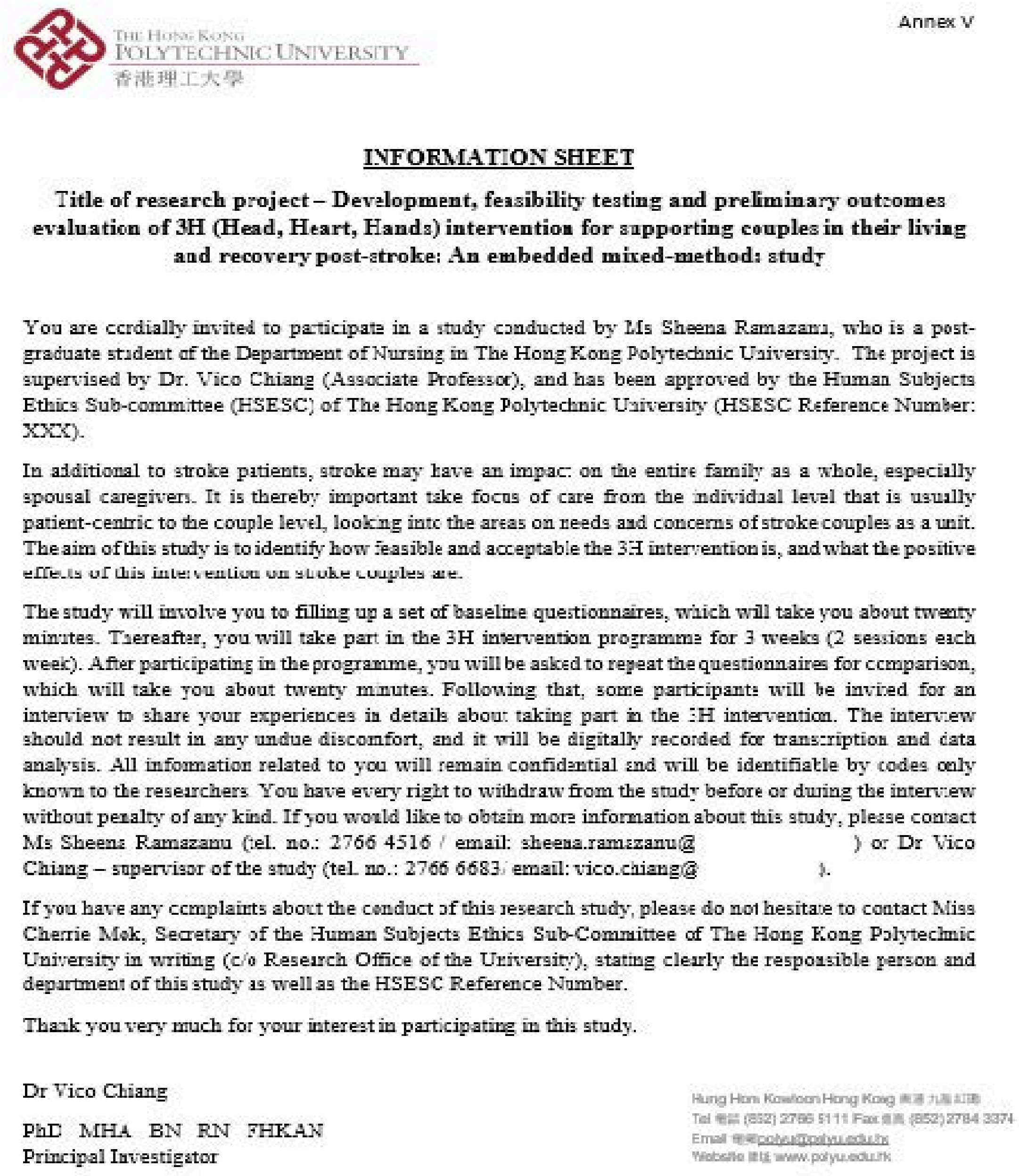
Sources: Palmer & Palmer (2011), Singapore National Stroke Association (2018)

Week	**Session**	**Domain of focus based on identified model**	**Content outline**	**Type of session**	**Duration**
1	1	Adaptive resources (bB) and Perception (cC)	**Topic: Setting the stage for life after a stroke** Content • Stroke happens to both of you • What exactly is stroke? • Different types of stroke • Consequences of stroke • The course of illness and the prognosis of recovery • Rehabilitation of persons living with stroke • Spouses: Partners in stroke recovery • Caregivers in society • Skills training: Blood pressure monitoring	Group	1 hour
	2		**Topic: When stroke moves in - How stroke affects you and your marriage** Content • The caregiver experiences • Stresses and strains of caregiving • Health consequences of caregiving • Stroke, caregiving, and marriage	Group	1 hour

Week	Session	Domain of focus based on identified model	Content outline	Type of session	Duration
			• Skills training: Falls prevention and safe lifting		
2	3		**Topic: Shared decision making on the secret ingredient - Stroke and social support** Content • Decisions on family social support after stroke • Decisions on marital support and stroke outcomes • Practical tips for supporting your spouse	Individual couples	1 hour
	4		**Topic: You are the one - Balancing the roles of caregiver and marriage partner** Content • Getting stuck in the caregiver role • Getting unstuck together • Practical tips for balancing the roles of caregiver and marriage partner • Skills training: Safe medication administration	Group	1 hour
3	5		**Topic: Shared decision making on rebuilding your marriage after stroke - In sickness and in health** Content • Build on the strengths of your relationship	Individual couples	1 hour

Week	Session	Domain of focus based on identified model	Content outline	Type of session	Duration
			• Change relationship patterns that don't work • Recovery ups and downs • Find the "silver lining" • Practical tips for rebuilding your marriage after stroke		
	6		**Topic: Give me a break-support for the caregiving spouse and partner** <u>Content</u> • Social support for caregivers and partners • Taking care of yourself • Advocacy - Importance of shared decision making • Tapping into caregiving resources • Practical tips for support of the caregiving spouse and partner • Skills training: Safe feeding	Group	1 hour

Appendix II Information sheet



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Annex V

INFORMATION SHEET

Title of research project – Development, feasibility testing and preliminary outcomes evaluation of 3H (Head, Heart, Hands) intervention for supporting couples in their living and recovery post-stroke: An embedded mixed-methods study

You are cordially invited to participate in a study conducted by Ms Sheena Ramazanu, who is a post-graduate student of the Department of Nursing in The Hong Kong Polytechnic University. The project is supervised by Dr. Vico Chiang (Associate Professor), and has been approved by the Human Subjects Ethics Sub-committee (HSESC) of The Hong Kong Polytechnic University (HSESC Reference Number: XXX).

In additional to stroke patients, stroke may have an impact on the entire family as a whole, especially spousal caregivers. It is thereby important take focus of care from the individual level that is usually patient-centric to the couple level, looking into the areas on needs and concerns of stroke couples as a unit. The aim of this study is to identify how feasible and acceptable the 3H intervention is, and what the positive effects of this intervention on stroke couples are.

The study will involve you to filling up a set of baseline questionnaires, which will take you about twenty minutes. Thereafter, you will take part in the 3H intervention programme for 3 weeks (2 sessions each week). After participating in the programme, you will be asked to repeat the questionnaires for comparison, which will take you about twenty minutes. Following that, some participants will be invited for an interview to share your experiences in details about taking part in the 3H intervention. The interview should not result in any undue discomfort, and it will be digitally recorded for transcription and data analysis. All information related to you will remain confidential and will be identifiable by codes only known to the researchers. You have every right to withdraw from the study before or during the interview without penalty of any kind. If you would like to obtain more information about this study, please contact Ms Sheena Ramazanu (tel. no.: 2766 4516 / email: sheena.ramazanu@) or Dr Vico Chiang – supervisor of the study (tel. no.: 2766 6683/ email: vico.chiang@).

If you have any complaints about the conduct of this research study, please do not hesitate to contact Miss Cherrie Mok, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing (c/o Research Office of the University), stating clearly the responsible person and department of this study as well as the HSESC Reference Number.

Thank you very much for your interest in participating in this study.

Dr Vico Chiang

PhD MHA BN RN FHKAN
Principal Investigator

Hung Hom Kowloon Hong Kong 香港 九龍 紅磡
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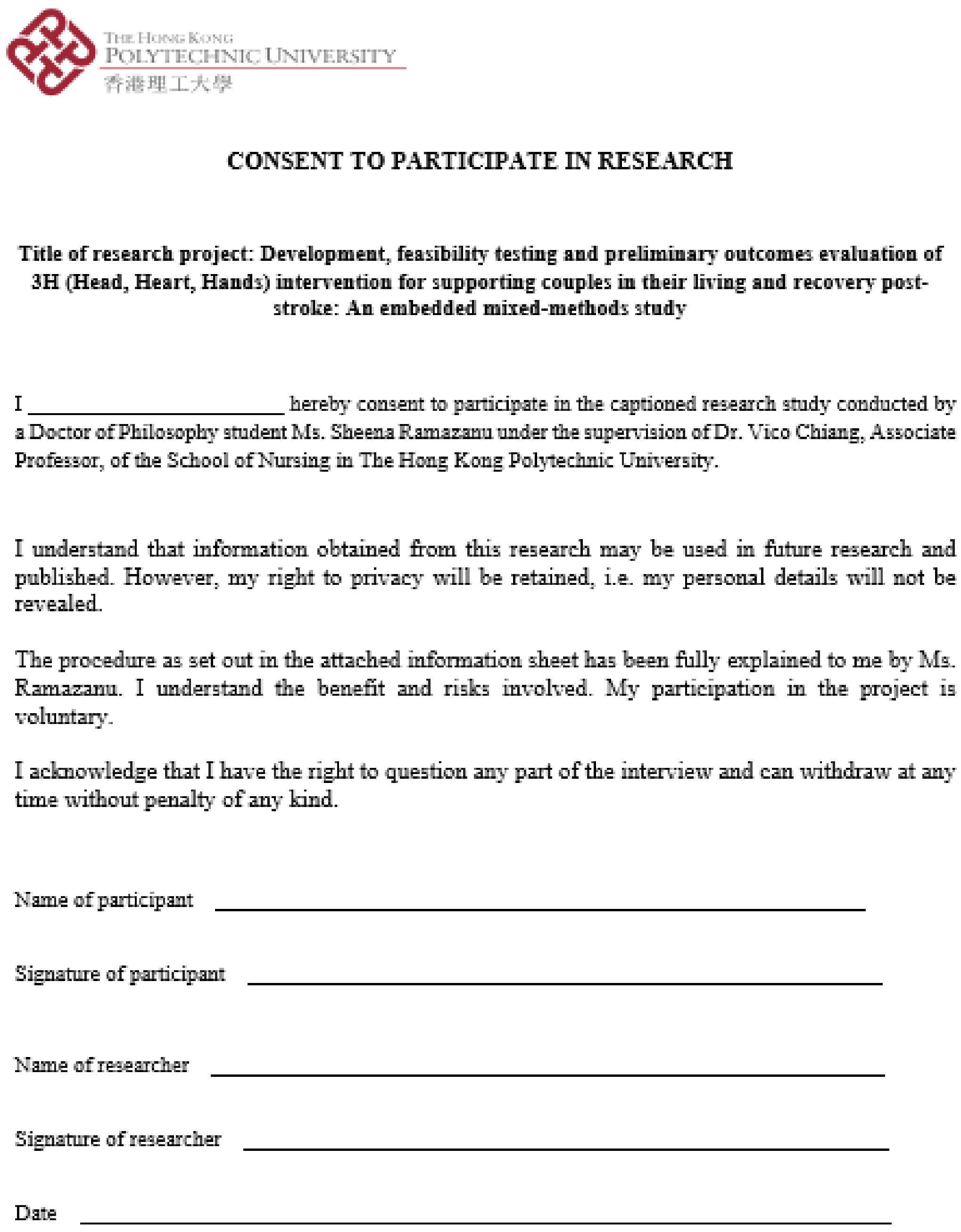
Appendix III Written consent



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CONSENT TO PARTICIPATE IN RESEARCH

Title of research project: Development, feasibility testing and preliminary outcomes evaluation of 3H (Head, Heart, Hands) intervention for supporting couples in their living and recovery post-stroke: An embedded mixed-methods study

I ________________________ hereby consent to participate in the captioned research study conducted by a Doctor of Philosophy student Ms. Sheena Ramazanu under the supervision of Dr. Vico Chiang, Associate Professor, of the School of Nursing in The Hong Kong Polytechnic University.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e. my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained to me by Ms. Ramazanu. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the interview and can withdraw at any time without penalty of any kind.

Name of participant ____

Signature of participant ____

Name of researcher ____

Signature of researcher ____

Date ____

Appendix IV 3H intervention bag

Appendix V Semi-structured interview guide

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Interviews began with the broad question:

1. How do you feel about participating in the 3H intervention?

The interview guide then included questions to deepen our knowledge about the participants’ experiences during and after taking part in the 3H intervention. Examples were:

2. How have the skills and knowledge gained from the 3H intervention benefitted you?
3. Overall, what are your thoughts and feelings about the 3H intervention?
4. How will your participation in the 3H intervention help you when you are discharged home?

Probing follow-up questions such as the following were included to encourage the participants to converse and to generate rich data about their experiences taking part in the 3H intervention:

5. What about the content of the intervention?
6. How satisfied (or not satisfied) were you when participating in the 3H intervention?

Appendix VI Study instruments

QUESTIONNAIRE FOR COUPLES **Date:** ____________________

To be filled in by researcher	
Code	
Time of intervention	T0/ T1 (to circle)
Type of participant	Spouse/ Person with stroke

Particulars

1. Sex

1 ☐ M
2 ☐ F

2. Age
1 ☐ 20- 29
2 ☐ 30- 39
3 ☐ 40- 49
4 ☐ 50- 59
5 ☐ 60- 69
6 ☐ 70- 70
7 ☐ 80+

3. Employment status:
1 ☐ Working full-time
2 ☐ Working part-time
3 ☐ Unemployed
4 ☐ Retiree

4. Educational qualification
1 ☐ No education
2 ☐ Primary
3 ☐ Secondary
4 ☐ Tertiary

5. Race
1 ☐ Chinese
2 ☐ Malay
3 ☐ Indian
4 ☐ Eurasian

1. HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Instructions: Read each item and **circle** the reply which comes closest to how you have been feeling in the past week.

I feel tense or 'wound up':	**A**
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I feel as if I am slowed down:	**D**
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I still enjoy the things I used to enjoy:	**D**
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like 'butterflies in the stomach':	**A**
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I get a sort of frightened feeling like something awful is about to happen:	**A**
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I have lost interest in my appearance:	**D**
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I can laugh and see the funny side of things:	**D**
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

I feel restless as if I have to be on the move:	**A**
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

Worrying thoughts go through my mind:	**A**
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I look forward with enjoyment to things:	**D**
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I feel cheerful:	**D**
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I get sudden feelings of panic:	**A**
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

2.

I can sit at ease and feel relaxed:	**A**	**I can enjoy a good book or radio or TV programme:**	**D**
Definitely	0	Often	0
Usually	1	Sometimes	1
Not often	2	Not often	2
Not at all	3	Very seldom	3

REVISED DYADIC ADJUSTMENT SCALE (DAS)

Please indicate below the approximate extent of agreement or disagreement between you and your spouse for each item on the following list. Kindly **circle**.

	Always Agree	**Almost Always Agree**	**Occasionally Agree**	**Frequently Disagree**	**Almost Always Disagree**	**Always Disagree**
1. Religious matters	5	4	3	2	1	0
2. Demonstrations of affection	5	4	3	2	1	0
3. Making major decisions	5	4	3	2	1	0
4. Sexual relations	5	4	3	2	1	0
5. Conventionality (Proper behaviour)	5	4	3	2	1	0
6. Career decisions	5	4	3	2	1	0

	All the Time	**Most of the time**	**More often than not**	**Occasionally**	**Rarely**	**Never**
7. How often do you discuss or have you considered divorce or separation?	0	1	2	3	4	5
8. How often do you and your partner quarrel?	0	1	2	3	4	5
9. Do you ever regret that you married?	0	1	2	3	4	5
10. How often do you and your mate “get on each other’s nerves’’?	0	1	2	3	4	5

	Everyday	**Almost Everyday**	**Occasionally**	**Rarely**	**Never**
11. Do you and your partner engage in outside interests together?	4	3	2	1	0

Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list. Kindly **circle**.

How often would you say the following events occur between you and your spouse?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas	0	1	2	3	4	5
13. Work together on a project	0	1	2	3	4	5
14. Calmly discuss something	0	1	2	3	4	5

3. DYADIC COPING INVENTORY (DCI)

The next questions are designed to measure how you and your spouse cope with stress. Please **circle** the first response that you feel is appropriate.

This section is about how you communicate your stress to your partner.

	Very rarely	Rarely	Sometimes	Often	Very often
1. I let my partner know that I appreciate his/her practical support, advice, or help.	1	2	3	4	5
2. I ask my partner to do things for me when I have too much to do.	1	2	3	4	5
3. I show my partner through my behaviour when I am not doing well or when I have problems.	1	2	3	4	5
4. I tell my partner openly how I feel and that I would appreciate his/her support.	1	2	3	4	5

This section is about what your partner does when you are feeling stressed.

	Very rarely	**Rarely**	**Sometimes**	**Often**	**Very often**
5. My partner shows empathy and understanding to me.	1	2	3	4	5
6. My partner expresses that he/she is on my side.	1	2	3	4	5
7. My partner blames me for not coping well enough with stress.	1	2	3	4	5
8. My partner helps me see stressful situations in a different light.	1	2	3	4	5
9. My partner listens to me and gives me the opportunity to communicate what really bothers me.	1	2	3	4	5
10. My partner does not take my stress seriously.	1	2	3	4	5
11. My partner provides support, but does so in an unwilling and unmotivated manner.	1	2	3	4	5
12. My partner takes on things that I normally do in order to help me out.	1	2	3	4	5
13. My partner helps me analyse the situation so that I can better face the problem.	1	2	3	4	5
14. When I am too busy, my partner helps me out.	1	2	3	4	5
15. When I am stressed, my partner tends to withdraw.	1	2	3	4	5

This section is about how your partner communicates when he/she is feeling stressed.

	Very rarely	**Rarely**	**Sometimes**	**Often**	**Very often**
16. My partner lets me know that he/she appreciates my practical support, advice, or help	1	2	3	4	5
17. My partner asks me to do things for him/her when he/she has too much to do.	1	2	3	4	5
18. My partner shows me through his/her behaviour that he/she is not doing well or when he/she has problems.	1	2	3	4	5
19. My partner tells me openly how he/she feels and that he/she would appreciate my support	1	2	3	4	5

This section is about what you do when your partner makes known his/her stress.

	Very rarely	**Rarely**	**Sometimes**	**Often**	**Very often**
20. I show empathy and understanding to my partner.	5	4	3	2	1
21. I express to my partner that I am on his/her side.	5	4	3	2	1
22. I blame my partner for not coping well enough with stress.	5	4	3	2	1
23. I tell my partner that his/her stress is not that bad and help him/her to see the situation in a different light.	5	4	3	2	1
24. I listen to my partner and give him/her space and time to communicate what really bothers him/her.	5	4	3	2	1
25. I do not take my partner’s stress seriously.	5	4	3	2	1
26. When my partner is stressed, I tend to withdraw.	5	4	3	2	1
27. I provide support, but do so in an unwilling and unmotivated manner because I think that he/she should cope with his/her problems on his/her own.	5	4	3	2	1
28. I take on things that my partner would normally do in order to help him/her out.	5	4	3	2	1
29. I try to analyse the situation together with my partner in an objective manner and help him/her to understand and change the problem.	5	4	3	2	1
30. When my partner feels he/she has too much to do, I help him/her out.	5	4	3	2	1

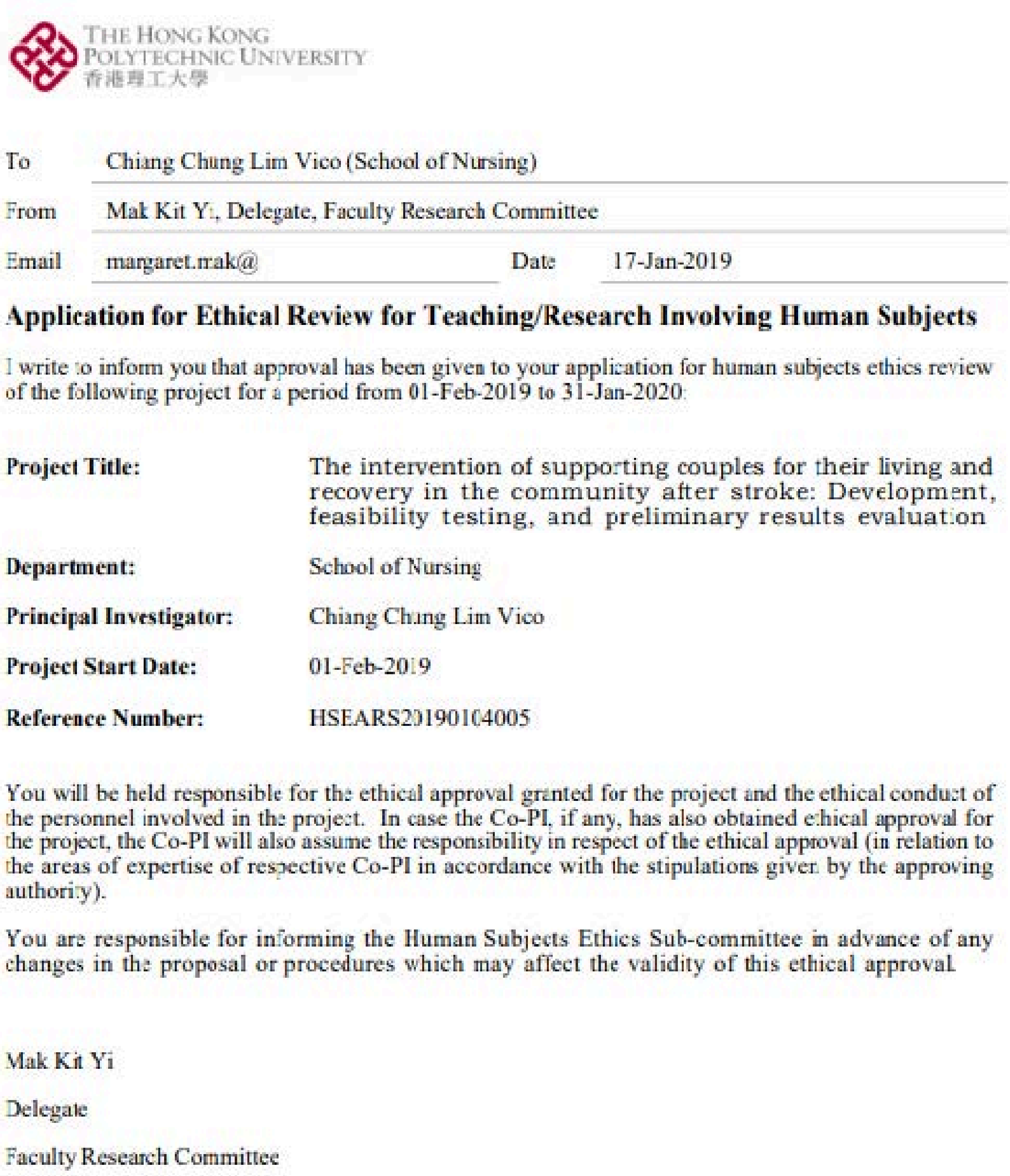
This section is about what you and your partner do when you are both feeling stressed

	Very rarely	**Rarely**	**Sometimes**	**Often**	**Very often**
31. We try to cope with the problem together and search for solutions	5	4	3	2	1
32. We engage in a serious discussion about the problem and think through what has to be done.	5	4	3	2	1
33. We help one another put the problem into perspective and see it in a new light.	5	4	3	2	1
34. We help each other relax with things like massage, taking a bath together, or listening to music together.	5	4	3	2	1
35. We are affectionate with each other, make love, and try that way to cope with stress	5	4	3	2	1

This section is about how you evaluate your coping as a couple.

	Very rarely	**Rarely**	**Sometimes**	**Often**	**Very often**
36. I am **satisfied** with the support I receive from my partner and the way we deal with stress together.	5	4	3	2	1
37. I am satisfied with the support I receive from my partner and I find as a couple, the way we deal with stress together is **effective.**	5	4	3	2	1

Appendix VII Ethical approval from Hong Kong Polytechnic University



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

To Chiang Chung Lim Vico (School of Nursing)
From Mak Kit Yi, Delegate, Faculty Research Committee
Email margaret.mak@ Date 17-Jan-2019

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 01-Feb-2019 to 31-Jan-2020:

Project Title:	The intervention of supporting couples for their living and recovery in the community after stroke: Development, feasibility testing, and preliminary results evaluation
Department:	School of Nursing
Principal Investigator:	Chiang Chung Lim Vico
Project Start Date:	01-Feb-2019
Reference Number:	HSEARS20190104005

You will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In case the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Human Subjects Ethics Sub-committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

Mak Kit Yi

Delegate

Faculty Research Committee

Appendix VIII Ethical approval from Singapore Review Board

National Healthcare Group
Adding years of healthy life

3 Fusionopolis Link
#03-08 Nexus@one-north
Singapore 138543
Tel: 6496 6600 Fax:6486 6870
www.nhg.com.sg
RCB No. 200002150H

NHG DSRB Ref: **2018/01025**

31 January 2019

Ms Sheena Ramazanu
Department of Nursing
Yishun Community Hospital

Dear Ms Sheena

NHG DOMAIN SPECIFIC REVIEW BOARD (DSRB) APPROVAL

STUDY TITLE: The intervention of supporting couples for their living and recovery in the community after stroke: Development, feasibility testing, and preliminary result evaluation

We are pleased to inform you that the NHG Domain Specific Review Board has approved the application as titled above to be conducted in **Yishun Community Hospital**.

The approval period is from **31 January 2019** to **30 January 2020**.The NHG DSRB reference number for this study is **2018/01025**. Please use this reference number for all future correspondence.

Please note that this is a human biomedical research that is regulated by the Human Biomedical Research Act (HBRA) and researchers are required by law to comply with all the relevant regulatory requirements of the HBRA.

The documents reviewed are:

a) NHG DSRB Application Form: **Version No. 1**
b) 3H intervention protocol: Palmer & Palmer, 2011; Singapore National Stroke Association, 2018
c) Questionnaire for stroke couples: Version 1 dated 21 January 2019
d) Interview questions for stroke patients and spouses: Version 1 dated 21 January 2018
e) Informed Consent Form: Version 1 dated 25 January 2019

Continued approval is conditional upon your compliance with the following requirements:
1. Only the approved Informed Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

2. No deviation from or changes to the study should be implemented without documented approval from the NHG DSRB, except where necessary to eliminate apparent immediate hazard(s) to the study subjects.

3. Any deviation from or changes to the study to eliminate an immediate hazard should be promptly reported to the NHG DSRB within seven calendar days.

4. Please note that for studies requiring CTA/CTN/CTC, apart from the approval from NHG DSRB, no deviation from, or changes of the Research Protocol and Informed Consent Form should be implemented without documented approval from the Health Sciences Authority unless otherwise advised by the Health Sciences Authority.

5. Please submit the following to the NHG DSRB:

a. All Unanticipated Problems Involving Risk To Subjects Or Others (UPIRTSOs) must be reported to the NHG DSRB. For more than minimal risk studies, all problems involving local deaths must be reported as soon as possible, but not later than **7 calendar days** after first knowledge by the Investigator, regardless of the causality and expectedness of the death event, and any additional relevant information about the death should be reported within **8 calendar days** of making the initial report. For no more than minimal risk studies, only problems involving local deaths that are related or possibly related to the study must be reported as soon as possible, but not later than **7 calendar days** after first knowledge by the Investigator, and any additional relevant information about the death should be reported within **8 calendar days** of making the initial report. For problems which are life threatening, it should be reported as soon as possible, but not later than **7 calendar days** after first knowledge by the investigator, and any additional relevant information about the problems should be reported within **8 calendar days** of making the initial report. All other problems that fulfil the UPIRTSOs reporting criteria must be reported as soon as possible but not later than **15 calendar days** after first knowledge by the Investigator.

b. Report(s) on any new information that may adversely affect the safety of the subject or the conduct of the study.

c. NHG DSRB Study Status Report Form – this is to be submitted 4 to 6 weeks prior to expiry of the approval period. The study cannot continue beyond **30 January 2020** until approval is renewed by the NHG DSRB.

d. Study completion – this is to be submitted using the NHG DSRB Study Status Report Form within 4 to 6 weeks of study completion.

With the enactment of the Human Biomedical Research Act, Health Products Act, Medicines Act and their subsidiary legislations, Principal Investigators are reminded to ensure that their research complies with the regulatory requirements stipulated in the applicable Acts. Contraventions under any of these Acts are criminal offences and would result in fines or imprisonment or both, subject to the nature of the offence.

Established since May 2006, the NHG Research Quality Management (RQM) Program seeks to promote the responsible conduct of research in a research culture with high ethical standards, identify potential systemic weaknesses and make recommendations for continual improvement. Hence, this research study may be randomly selected for a review by the Research Quality Management (RQM) team. For more information, please visit www.research.nhg.com.sg.

The NHG DSRB operates in accordance to the ICH GCP and all applicable laws and regulations.

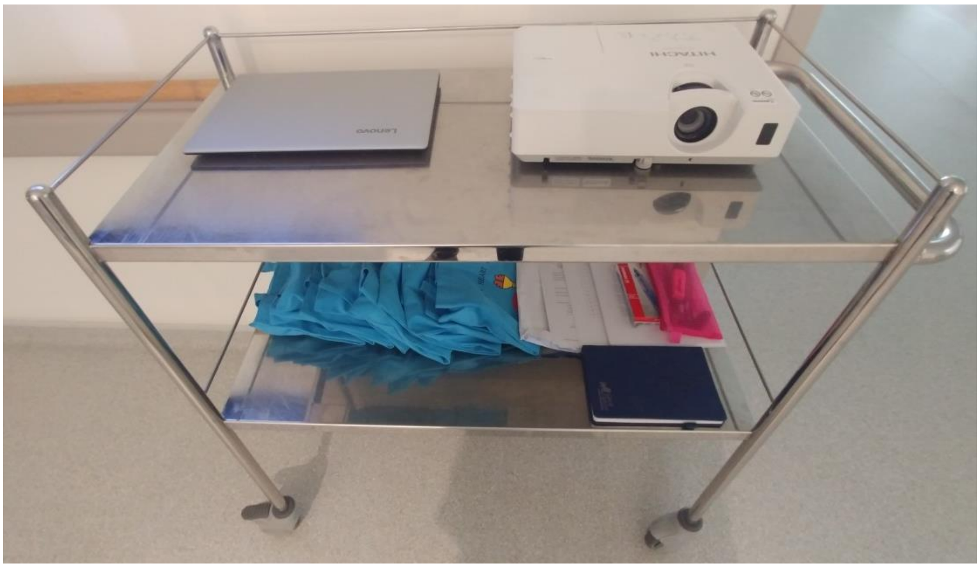
Yours Sincerely

A/Prof Adeline Seow
Chairperson
NHG Domain Specific Review Board F1

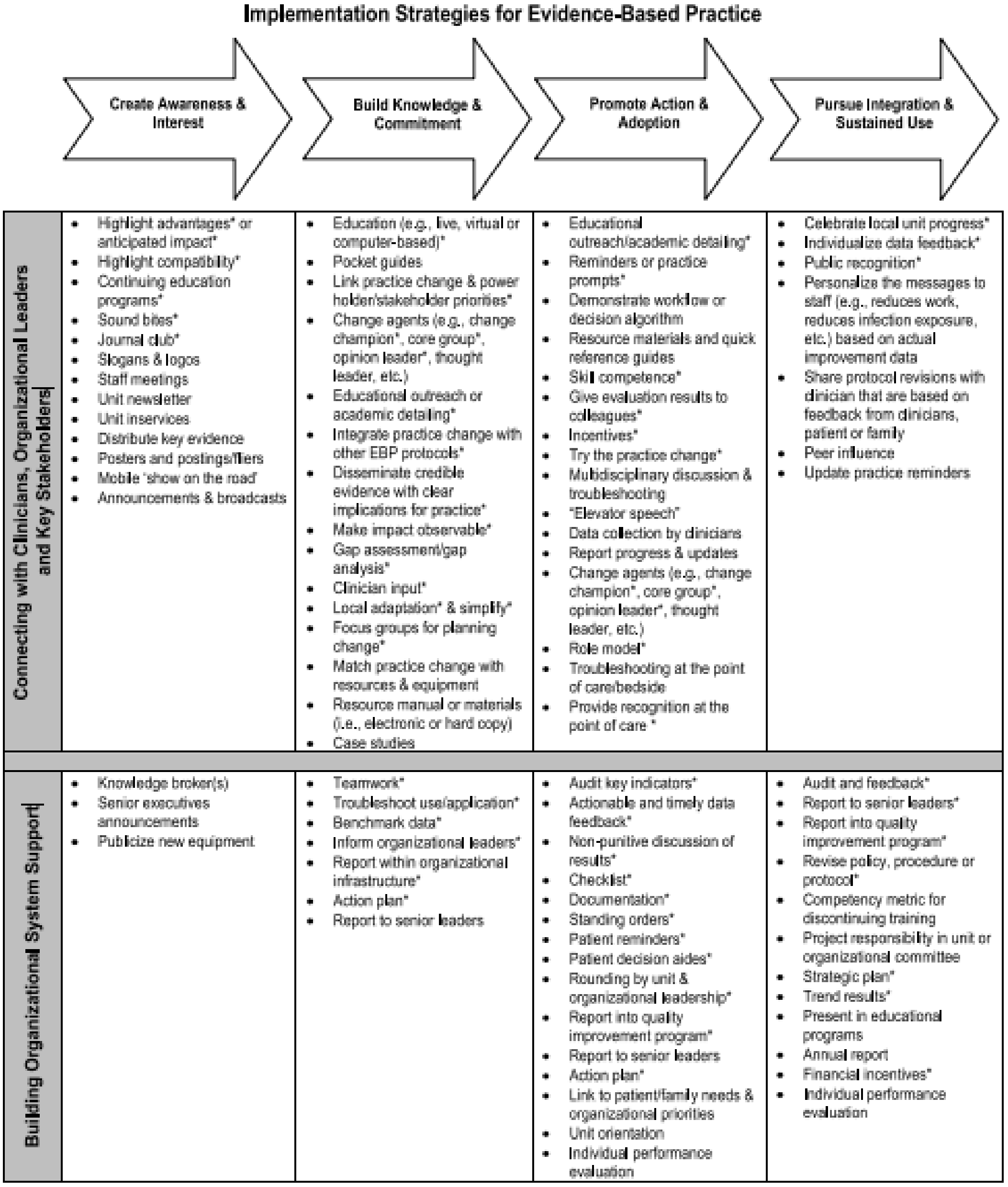
Appendix IX 3H intervention budget

No	Item type	Quantity	Unit price	Cost
1	3H intervention bag	150 pieces	30.48 HKD	4,572 HKD

Appendix X Essential items prepared to conduct 3H intervention



Appendix XI Evidence-based practice implementation guide (Cullen & Adams, 2012)



Implementation Strategies for Evidence-Based Practice

	Create Awareness & Interest	Build Knowledge & Commitment	Promote Action & Adoption	Pursue Integration & Sustained Use
Connecting with Clinicians, Organizational Leaders and Key Stakeholders	• Highlight advantages* or anticipated impact* • Highlight compatibility* • Continuing education programs* • Sound bites* • Journal club* • Slogans & logos • Staff meetings • Unit newsletter • Unit inservices • Distribute key evidence • Posters and postings/fliers • Mobile 'show on the road' • Announcements & broadcasts	• Education (e.g., live, virtual or computer-based)* • Pocket guides • Link practice change & power holder/stakeholder priorities* • Change agents (e.g., change champion*, core group*, opinion leader*, thought leader, etc.) • Educational outreach or academic detailing* • Integrate practice change with other EBP protocols* • Disseminate credible evidence with clear implications for practice* • Make impact observable* • Gap assessment/gap analysis* • Clinician input* • Local adaptation* & simplify* • Focus groups for planning change* • Match practice change with resources & equipment • Resource manual or materials (i.e., electronic or hard copy) • Case studies	• Educational outreach/academic detailing* • Reminders or practice prompts* • Demonstrate workflow or decision algorithm • Resource materials and quick reference guides • Skill competence* • Give evaluation results to colleagues* • Incentives* • Try the practice change* • Multidisciplinary discussion & troubleshooting • "Elevator speech" • Data collection by clinicians • Report progress & updates • Change agents (e.g., change champion*, core group*, opinion leader*, thought leader, etc.) • Role model* • Troubleshooting at the point of care/bedside • Provide recognition at the point of care *	• Celebrate local unit progress* • Individualize data feedback* • Public recognition* • Personalize the messages to staff (e.g., reduces work, reduces infection exposure, etc.) based on actual improvement data • Share protocol revisions with clinician that are based on feedback from clinicians, patient or family • Peer influence • Update practice reminders
Building Organizational System Support	• Knowledge broker(s) • Senior executives announcements • Publicize new equipment	• Teamwork* • Troubleshoot use/application* • Benchmark data* • Inform organizational leaders* • Report within organizational infrastructure* • Action plan* • Report to senior leaders	• Audit key indicators* • Actionable and timely data feedback* • Non-punitive discussion of results* • Checklist* • Documentation* • Standing orders* • Patient reminders* • Patient decision aides* • Rounding by unit & organizational leadership* • Report into quality improvement program* • Report to senior leaders • Action plan* • Link to patient/family needs & organizational priorities • Unit orientation • Individual performance evaluation	• Audit and feedback* • Report to senior leaders* • Report into quality improvement program* • Revise policy, procedure or protocol* • Competency metric for discontinuing training • Project responsibility in unit or organizational committee • Strategic plan* • Trend results* • Present in educational programs • Annual report • Financial incentives* • Individual performance evaluation

Appendix XII Guidelines on how to conduct shared decision making (Armstrong, 2017)

Shared decision making on the secret ingredient - Stroke and social support (session 3)		
Steps	**Guidelines**	**Documentation of matters discussed**
1	Engage patient and their spousal caregiver in the decision-making process	
2	Describe the decision and the options available for stroke and social support, including each option's potential benefits and risks (if any)	
3	Further assess the patient's and caregiver's values and goals, specifically as they relate to the available options	
4	Make the decision together	

Shared decision making on rebuilding your marriage after stroke - In sickness and in health (Session 5)		
Steps	**Guidelines**	**Documentation of matters discussed**
1	Engage patient and their spousal caregiver in the decision-making process	
2	Describe the decision and the options available for stroke and social support, including each option's potential benefits and risks (if any)	
3	Further assess the patient's and caregiver's values and goals, specifically as they relate to the available options	
4	Make the decision together	

References

Aalbers, T., Baars, M.A., & Rikkert, M.G. (2011). Characteristics of effective internet mediated interventions to change lifestyle in people aged 50 and older: a systematic review. *Ageing Research Reviews, 10*(4), 487–497. doi: 10.1016/j.arr.2011.05.001

Aberg, A.C., Sidenvall, B., Hepworth, M., O'Reilly, K., & Lithell H. (2004). Continuity of the self in later life: Perceptions of informal caregivers. *Qualitative Health Research, 14*(6), 792–815. doi: 10.1177/1049732304265854

Adamson, J. & Donovan, J. (2005). 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK. Social Science & Medicine, 60(1), 37–48. doi: 10.1016/j.socscimed.2004.05.002

Adriaansen, J.J.E., Leeuwen, C.M.C., Visser- Meily, J.M.A., Bos, G.A.M., & Post, M.W.M. (2011). Course of social support and relationships between social support and life satisfaction in spouses of patients with stroke in the chronic phase. *Patient Education and Counseling*, 85 (2), 48-52. doi: 10.1016/j.pec.2010.12.011

American Stroke Association (2019). *For family caregivers*. Available at: https://www.strokeassociation.org/en/help-and-support/for-family-caregivers (accessed 21 May 2019).

Andersen, G., Christensen, D., Kirkevold, M., & Johnsen, S.P. (2012). Post-stroke fatigue and return to work: a 2-year follow-up. *Acta Neurologica Scandinavica, 125*(4), 248– 253. doi: 10.1111/j.1600-0404.2011.01557.x

Anderson, S., & Keating, N. (2017). Marriage after the transition to stroke: a systematic review. *Ageing & Society,* 1-39. doi: 10.1017/S0144686X17000526

Anderson, S., Keating, N.C., & Wilson, D.M. (2017). Staying married after stroke: a constructivist grounded theory qualitative study. *Topics in Stroke Rehabilitation, 24*(7), 479-487. https://doi.org/10.1080/10749357.2017.1342335

Andersson, G., & Titov, N. (2014). Advantages and limitations of internet-based interventions for common mental disorders. *World Psychiatry, 13,* 4–11. doi: 10.1002/wps.20083

Armstrong, M. J. (2017). Shared decision-making in stroke: an evolving approach to improved patient care. *Stroke and Vascular Neurology,* 1-4. doi:10.1136/svn2017-000081

Armstrong, M.J., Shulman, L.M., Vandigo, J., & Mullins, D. (2016). Patient engagement and shared decision-making: what do they look like in neurology practice? *Neurology Clinical Practice,* 6 (2), 190-197. Doi: 10.1212/CPJ.0000000000000240

Arwert, H.J., Schults, M., Meesters, J.J.L., Wolterbeek, R., Boiten, J., & Vlieland, V.T. (2017). Return to work 2–5 years after stroke: A cross sectional study in a hospital- based population. *Journal of Occupational Rehabilitation, 27*(2), 239–246. doi: 10.1007/s10926-016-9651-4

Bäckström., K. Asplund., K., & Sundin, K. (2010). The meaning of middle-aged female spouses' lived experience of the relationship with a partner who has suffered a stroke, during the first-year post discharge. *Nursing Inquiry, 17*(3), 257–268. doi: 10.1111/j.1440-1800.2010.00490.x

Badr, H., Chhabria, K., Sandulache, V.C., Chiao, E., & Wagner, T. (2019). Results of a randomized pilot trial of SHARE: A self-management intervention for head and neck cancer patients undergoing radiotherapy and their spousal caregivers. *Cancer Epidemiology Biomarkers & Prevention, 28*(3), 620. doi: 10.1158/1055-9965.EPI-19-0088

Bakas, T., McCarthy, M., & Miller, E.T. (2017). Update on the state of the evidence for stroke family caregiver and dyad interventions. *Stroke, 48*(5), 122-125. doi: 10.1161/STROKEAHA.117.016052.

Baranowski, T., Cullen, K., Micklas, T., Thompson, D., & Baranowski, J. (2003). Are current health behavioral change models helpful in guiding prevention of weight gain efforts? *Obesity Research, 11* (10), 23-43. doi: https://doi.org/10.1038/oby.2003.222

Barker-Collo, S.L. (2007). Depression and anxiety 3 months post stroke: Prevalence and correlates. *Archives of Clinical Neuropsychology, 22* (4), 519-531. doi: 10.1016/j.acn.2007.03.002

Bham, Z, & Ross, E. (2005). Traditional and western medicine: cultural beliefs and practices of South African Indian Muslims with regard to stroke. *Ethnicity & Disease,* 15(4), 548-554.

Blackwell, R.W., Lowton, K., Robert, G., Grudzen, C., & Grocott, P. (2017). Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes. *International Journal of Nursing Studies, 68,* 83-94. doi: 10.1016/j.ijnurstu.2017.01.002

Bodemann, G., Pihet, S., Shantinath, S.D., Cina, A., & Widmer, K. (2006). Improved dyadic coping in coping with a stress-oriented approach. *Behavior Modification, 30* (5), 571-597 10.1177/0145445504269902

Borrelli, B., Sepinwall, D., Ernst, D., Bellg, A.J., Czajkowski, S., Breger, R., DeFrancesco, C., Levesque, C., Sharp, D.L., & Ogedegbe, G. (2005). A new tool to assess treatment fidelity and evaluation of treatment fidelity across 10 years of health behavior research. *Journal of Consulting and Clinical Psychology,* 73(5), 852–860. doi: 10.1037/0022-006X.73.5.852

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L., Fabrizio, C., & Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine,* *36*(5), 452-457. doi: 10.1016/j.amepre.2009.02.002

Brady, G.C., Goodrich, J., & Roe, J.W.G. (2020). Using experience-based co-design to improve the pre-treatment care pathway for people diagnosed with head and neck cancer. *Supportive Care in Cancer* **,** *28* (2), 739–745. doi: 10.1007/s00520-019-04877-z.

Brann, M., Himes, K.L., Dillow, M.R., & Weber, K. (2010). Dialectical tensions in stroke survivor relationships. *Health Communication, 25*(4), 323–332. doi: 10.1080/10410231003773342

Brereton, L., & Nolan, M. (2000). “You do know he’s had a stroke, don’t you?' Preparation for family care-giving – the neglected dimension. *Journal of Clinical Nursing, 9* (4), 498–506. doi: 10.1046/j.1365-2702.2000.00396.x

Bucki, B., Spitz, E., & Baumann, M. (2019). Emotional and social repercussions of stroke on patient-family caregiver dyads: Analysis of diverging attitudes and profiles of the differing dyads. *PLoS ONE 14*(4), 1-15. doi: 10.1371/journal.pone.0215425

Busby, D. M., Christensen, C., Crane, D. R., & Larson, J. H. (1995). A revision of the dyadic adjustment scale for use with distressed and non-distressed couples: Construct hierarchy and multidimensional scales. *Journal of*

Marital and Family Therapy, 21(3), 289-308. doi: 10.1111/j.1752-0606.1995.tb00163.x

Campbell, M., Fitzpatrick, R., & Haines, A. (2000). Framework for design and evaluation of complex interventions to improve health. *British Medical Journal, 321*(7262), 694–696.

Caracelli, V. J., & Greene, J. C. (1993). Data analysis strategies for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis, 15*(2), 195–207. doi: 10.3102/01623737015002195

Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. Health Affairs, 32 (2), 223-231. doi:10.1377/hlthaff.2012.1133

Carmo, J.F., Morelato, R.L., Pinto, H.P., & Oliveira, E.R.A. (2015). Disability after stroke: a systematic review. *Physical Therapy in Movement, 28* (2), 407-418. doi: 10.1590/0103-5150.028.002.AR02

Centres for Disease Control and Prevention. (2018). *Recovering from stroke.* Retrieved from https://www.cdc.gov/stroke/recovery.htm

Chan, M.L. (2008) Description of a return-to-work occupational therapy programme for stroke rehabilitation in Singapore. *Occupational Therapy International, 15*(2), 87-99. doi: https://doi.org/10.1002/oti.248

Choi, H. (2018). Giving or receiving spouse care and marital satisfaction among older Korean individuals. *Social Science & Medicine*. doi: 10.1016/j.socscimed.2018.12.012

Clark, M.S., Rubenach, S., & Winsor, A. (2003). A randomized controlled trial of an education and counselling intervention for families after stroke. *Clinical Rehabilitation, 17* (7), 703- 712. doi: 10.1191/0269215503cr681oa

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112* (1), 155-159.

Collins, K. M. T, Onwuegbuzie, A. J., & Sutton, I. L. (2006). A model incorporating the rationale and purpose for conducting mixed methods research in special education and beyond. Learning Disabilities. *A Contemporary Journal, 4*(1), 67–100.

Cooley, M.E., Sarna, L., Brown, J.K., Williams, R.D., Chernecky, C., Padilla,

G. & Danao, L.L. (2003). Challenges of recruitment and retention in multisite clinical research. *Cancer Nursing, 26* (5), 376–384. doi: 10.1097/00002820-200310000-00006

Coombs, E.U. (2007). Spousal caregiving for stroke survivors. *Journal of Neuroscience Nursing, 39* (2), 112 – 119. doi: 10.1097/01376517-200704000-00008 ✓

Corrigan, P.W., & Salzer, M.S. (2003). The conflict between random assignment and treatment preference: implications for internal validity. *Evaluation and Program Planning, 26* (2), 109–121. doi: 10.1016/S0149-7189(03)00014-4

Coulter, A. (2012). Patient engagement—What works? *Journal of Ambulatory Care Management, 35* (2), 80-89. doi: 10.1097/JAC.0b013e318249e0fd

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). *Developing and evaluating complex interventions: new guidance.* Retrieved from https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

Crane, D. R., Middleton, K. C., & Bean, R. A. (2000). Establishing criterion scores for the Kansas Marital Satisfaction Scale and the Revised Dyadic Adjustment Scale. *American Journal of Family Therapy, 28*(1), 53-60. doi:10.1080/019261800261815

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal, 325* (1263), 1-5. doi:10.1136/bmj.325.7375.1263

Creasy, K.R., Lutz, B.J., Young, M.E., & Stacciarini, J.R. (2016). Clinical implications of family-centered care in stroke rehabilitation. *Rehabilitation Nursing, 40*(6), 349–359. doi:10.1002/rnj.188.

Creswell, J. W. (1998). *Qualitative inquiry and research design: choosing among the five traditions.* Thousand Oaks, CA: Sage Publications.

Creswell, J. W., Plano Clark, V. L., Gutmann, M., & Hanson, W. (2003). *Advanced mixed methods research designs.* Thousand Oaks, CA: Sage.

Cullen, L., & Adams, S.L. (2012). Planning for implementation of evidence-based practice. *The Journal of Nursing Administration, 42* (4), 222-230. doi: 10.1097/NNA.0b013e31824ccd0a

Davis, L.L., Gilliss, C.L., Deshefy-Longhi, T., Chestnutt, D.H., & Molloy, M. (2011). The nature and scope of stressful spousal caregiving relationships. *Journal of Family Nursing, 17*(2), 224-440. doi: 10.1177/1074840711405666.

Deber, R.B. (1996). Shared decision-making in the real world. *Journal of General Internal Medicine, 11* (6), 377-378. doi: 10.1007/BF02600052

Donkor, E.S. (2018). Stroke in the 21st century: A snapshot of the burden, epidemiology, and quality of life. *Stroke research and treatment*, 1-10. doi: https://doi.org/10.1155/2018/3238165

Eckman, M.H., Wise, R.E., & Naylor, K. (2015). Developing an atrial fibrillation guideline support tool (AFGuST) for shared decision making. *Current Medical Research & Opinion, 31* (4), 603–614. doi:10.1185/03007995.2015.1019608

Eldridge, S., Ashby, D., Feder, G., Rudnicka, A.R., Ukoumunne, O.C. (2004). Lessons for cluster randomized trials in the twenty-first century: a systematic review of trials in primary care. *Clinical Trials,* 1(1), 80-90. doi: 10.1191/1740774504cn006rr

Eriksson, E., Wejåker, M., Danhard, A., Nilsson, A., & Kristofferzon, M. (2019). Living with a spouse with chronic illness – the challenge of balancing demands and resources. *BMC Public Health, 19* (422), 1-9. doi: 10.1186/s12889-019-6800-7

Fang, Y., Mpofu, E., & Athanasou, J. (2017). Reducing depressive or anxiety symptoms in post-stroke patients: Pilot trial of a constructive integrative psychosocial intervention. *International Journal of Health Sciences, 11*(4), 53-58.

Feigin, V.L., Norrving, B., Mensah, G.A. (2017). Global burden of stroke. *Circulation Research, 120* (3), 439–448. doi: https://doi.org/10.1161/CIRCRESAHA.116.308413

Ferguson, C., & Hendriks, J. (2017). Partnering with patients in shared decision-making for stroke prevention in atrial fibrillation. *European Journal of Cardiovascular Nursing, 16* (3), 178–80.doi:10.1177/1474515116685193

Fisher, P., McCarney, R., Hasford, C., & Vickers, A. (2006). Evaluation of specific and nonspecific effects in homeopathy: feasibility study for a randomised trial. *Homeopathy,* 95(4), 215–222. doi: 10.1016/j.homp.2006.07.006

Foley, N., Teasell, R., Bhogal, S., & Speechley, M. (2010). *The efficacy of stroke rehabilitation*. Retrieved from https://www.researchgate.net/profile/Sanjit_Bhogal/publication/228607631_5_The_Efficacy_of_Stroke_Rehabilitation/links/09e415148f3c6225dd000000.pdf

Forbes, D. A., Finkelstein, S., Blake, C. M., Gibson, M., Morgan, D. G., Markle-Reid, M., Culum, I., Thiessen, E. (2012). Knowledge exchange throughout the dementia care journey by Canadian rural community-based health care practitioners, persons with dementia, and their care partners: An interpretive descriptive study. *Rural and Remote Health, 12*(4), 1-15.

Forchuk, C., Martin, M.L., Jensen, E., Ouseley, S., Sealy, P., Bearl, G., Reynolds, W., Sharkey, S. (2013). Integrating an evidence-based intervention into clinical practice: ‘transitional relationship model’. *Journal of Psychiatric and Mental Health Nursing, 20* (7), 584-594. doi: 10.1111/j.1365-2850.2012.01956.x

Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J.J., & Young, J. (2012). Information provision for stroke patients and their caregivers. *Cochrane Database of Systematic Reviews, 11,* 1-106. doi: 10.1002/14651858.CD001919.pub3.

Fucile, B., Bridge, E., Duliban, C., & Law, M.P. (2017). Experience-based co-design: A method for patient and family engagement in system-level quality improvement. *Patient Experience Journal, 4*(2), 53-60. doi: 10.35680/2372-0247.1209.

Gallo, W.T., Bradley, E.H., Teng, H., & Kasl, S.V. (2006). The effect of recurrent involuntary job loss on the depressive symptoms of older US workers. *International Archives of Occupational and Environmental Health, 80,* 109–116. doi: 10.1007/s00420-006-0108-5

Gibbs, L., Waters, E., Leger, L.S., Green, J., Gold, L., & Swinburn, B. (2011). A settings-based theoretical framework for obesity prevention community interventions and research. *Australian and New Zealand Journal of Public Health, 35* (2), 104-106. doi: 10.1111/j.1753-6405.2010.00688.x

Glass, T.A., Berkman, L.F., Hiltunen, E.F., Furie, K., Glymour, M.M., Fay, M.E., & Ware J. (2012). The families in recovery from stroke trial (FIRST): primary study results. *Psychosomatic Medicine, 66*(6), 889-897. doi: 10.1097/01.psy.0000146326.01642.ca

Gonzalez, S., Steinglass, P., & Reiss, D. (2002). *Application of multifamily discussion groups in chronic medical disorders.* New York, NY: Guilford Press.

Gorelick, P.B. (2019). The global burden of stroke: persistent and disabling. *The Lancet, 18* (5), 417-418. doi: https://doi.org/10.1016/S1474-4422(19)30030-4

Greaves, C.J., & Campbell, J.L. (2007). Supporting self-care in general practice. *The British Journal of General Practice, 57*(543), 814-821.

Green, T., Bonner, A., Teleni, L., Bradford, N., Purtell, L., Douglas, C., Yates, P., MacAndrew, M., Dao, H.Y., & Chan, R.J. (2019). Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ Quality & Safety,* 0, 1-13. doi: 10.1136/bmjqs-2019-009570

Grimm, P. (2010). *Social desirability bias*. Retrieved from https://onlinelibrary.wiley.com/doi/full/10.1002/9781444316568.wiem02057

Gross, D., & Fogg, L. (2001). Clinical trials in the 21st century: the case for participant-centered research. *Research in Nursing and Health, 24* (6), 530–539. doi:10.1002/nur.10010

Gul, R.B., & Ali, P.A. (2010). Clinical trials: the challenge of recruitment and retention of participants. *Journal of Clinical Nursing, 19,* 227–233. doi: 10.1111/j.1365-2702.2009.03041.x

Gustavsson, S.M.K., & Andersson, T. (2019). Patient involvement 2.0: Experience-based co-design supported by action research. *Action Research, 17*(4), 469–491. doi: 10.1177/1476750317723965

Hackett, M.L., Glozier, N., Jan, S., & Lindley, R. (2012). Returning to paid employment after stroke: the Psychosocial Outcomes In StrokE (POISE) cohort study. *PloS one. 7*(7), 1-8. doi: 10.1371/journal.pone.0041795

Harris, C. (2014). Return to work after stroke: A nursing state of the science. *Stroke, 45* (9), 174-176. doi:10.1161/STROKEAHA.114.006205

Harris, A. D., McGregor, J. C., Perencevich, E. N., Furuno, J. P., Zhu, J., Dan E., Peterson, D. E., & Finkelstein, J. (2006). The use and interpretation of quasi-experimental studies in medical informatics. *Journal of the American Medical Informatics Association,* 13(1), 16-23. doi: 10.1197/jamia.M1749

Hatfield E., & Cacioppo J.T. (1994). *Emotional contagion*. New York, NY: Cambridge University Press.

Hatfield, E., Cacioppo, J.T., & Rapson, R.L. (1993). Emotional contagion. *Current directions in psychological science, 2* (3),96–100. doi: 10.1111/1467-8721.ep10770953

Health Promotion Board, Singapore (2018). *Tips to prevent and manage chronic diseases in the workplace.* Retrieved from https://www.hpb.gov.sg/article/tips-to-prevent-and-manage-chronic-diseases-in-the-workplace

Herrmann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale- A review of validation data and clinical results. *Journal of Psychosomatic Research, 42* (1), 17-41. doi: 10.1016/S0022-3999(96)00216-4

Hesamzadeh, A., Dalvandi, A., Maddah, S., Khoshknab, M. F., & Ahmadi, F. (2015). Family adaptation to stroke: A metasynthesis of qualitative research based on double ABCX Model. *Asian Nursing Research, 9*(3), 177-184. doi: 10.1016/j.anr.2015.03.005

Hodkinson, H. M. (2012). Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age and Ageing, 41*(3), 35-40. doi: 10.1093/ageing/afs148

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). “Just got to live life as it comes”: A case study of the spousal-dyad longitudinal mild stroke transitional experience. *Brain Injury, 33* (9), 1200-1207. doi: 10.1080/02699052.2019.1629625

Hommel, K.A., Hente, E., Herzer, M., Ingerski, L.M., & Denson, L.A. (2013). Telehealth behavioral treatment for medication nonadherence: a pilot and feasibility study. *European Journal of Gastroenterology & Hepatology,* 25(4), 469–473. doi:10.1097/MEG.0b013e32835c2a1b

Horton, S., Lane, K., Shiggins, C. (2015). Supporting communication for people with aphasia in stroke rehabilitation: transfer of training in a multidisciplinary stroke team. *Aphasiology 30*(5), 1-28. doi: 10.1080/02687038.2014.1000819

Hsieh, H.F., & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15* 9), 1277–1288. doi: 10.1177/1049732305276687

Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research, 19*(9), 1284-1292. https://doi.org/10.1177/1049732309344612

Husereau, D., Drummond, M., Petrou, S., Carswell, C., Moher, D., Greenberg, D., Augustovski, F., Briggs, A.H., Mauskopf, J., & Loder, E. (2013). Consolidated health economic evaluation reporting Standards (CHEERS) statement. *International Journal of Technology Assessment in Health Care, 11* (6), 2-6. doi:10.1186/1478-7547-11-6

Hu, S., Zhan, L., Liu, B., Gao, Y., Li, Y., Tong, R., Wu, L., Yu, B., & Gao, Shen. (2013). Economic burden of individual suffering from atrial fibrillation – related stroke in China. *Value Health in Regional Issues,* 2 (1), 135–140. doi: https://doi.org/10.1016/j.vhri.2013.02.008

IBM Support (2020). *Downloading IBM SPSS statistics 20.* Retrieved from https://www.ibm.com/support/pages/downloading-ibm-spss-statistics-20

Institute for Healthcare Improvement (2020). *Experience-based co-design of health care services.* Retrieved from http://www.ihi.org/resources/Pages/Publications/Experience-Based-Co-Design-Health-Care-Services-Innovation-Case-Study.aspx

Julious, S.A. (2005). Sample size of 12 per group rule of thumb for a pilot study. *Pharmaceutical Statistics,* 4 (4), 287–291. doi: 10.1002/pst.185

Kaiser, K., Cheng, W.Y., & Jensen, S. (2015). Development of a shared decision-making tool to assist patients and clinicians with decisions on oral anticoagulant treatment for atrial fibrillation. *Current Medical Research & Opinion, 31* (12), 2261–2272.doi:10.1185/03007995.2015.1096767

Kallio, H., Pietila, A., Johnson, M., & Kangasniemi, K. (2016). Systematic methodological *Advanced Nursing, 72*(12), 2954–2965. doi: 10.1111/jan.13031

Kang, H.S., Kim, H., Park, S.M., & Kim, J. (2018). Online-based interventions for sexual health among individuals with cancer: a systematic review. *BMC Health Services Research, 18*(167), 2–10. doi: 10.1186/s12913-018-2972-6

Karas, S., & Plankis, L. (2016). Consideration of treatment fidelity to improve manual therapy research. *The Journal of manual & manipulative therapy*, *24*(4),233–237. doi:10.1080/10669817.2015.1135555

Katzan, I.L. (2017). Acute ischemic stroke. *Neuro-Geriatrics,* 49-66. doi: https://doi.org/10.1007/978-3-319-56484-5_6

Kim, J.S. (2014). Stroke in Asia: a global disaster. *International Journal of Stroke, 9* (7), 856-857. doi: 10.1111/ijs.12317.

Kim, Y.D., Jung, Y.H., & Saposnik, G. (2016). Traditional risk factors for stroke in East Asia. *Journal of Stroke, 18*(3): 273–285. doi: 10.5853/jos.2016.00885

Kitzmüller, G., Häggström, T., Asplund, K., & Gilje, F.L. (2012). The existential meaning of couples' long-term experience of living with stroke. *Illness Crisis & Loss, 20*(4), 339-362. doi: 10.2190/IL.20.4.c

Knapp, T.R. (2016). Why is the one-group pretest–posttest design still used? *Clinical Nursing Research, 25* (5), 467-472. doi:10.1177/1054773816666280

Kneipp, S.M., & McIntosh, M. (2001). Handling missing data in nursing research with multiple imputation. *Nursing Research, 50* (6), 384–389. doi: 10.1097/00006199-200111000-00010

Kondracki, N.L., & Wellman, N.S. (2002). Content analysis: Review of methods and theirapplications in nutrition education. *Journal of Nutrition Education and Behavior, 34* (4), 224–230. doi:10.1016/S1499-4046(06)60097-3

Lavee, Y., McCubbin, H. I., & Patterson, J. M. (1985). The double ABCX model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and Family, 47*(4), 811-825. doi: 10.2307/352326

Lavoie, P., Clarke, S.P., Clausen, C., Purden, M., Emed, J., Mailhot, T., & Frunchak, V. (2018). Acceptability and feasibility of recruitment and data collection in a field study of hospital nurses' handoffs using mobile devices. *Pilot & Feasibility Studies, 4* (163), 1-11. doi: 10.1186/s40814-018-0353-x

Lavrakas, P.J. (2008). *Self-selection bias*. Retrieved from https://methods.sagepub.com/reference/encyclopedia-of-survey-research-methods/n526.xml

Lee, J., Soeken, K., & Picot, S.J. (2007). A meta-analysis of interventions for informal stroke caregivers. *Western Journal of Nursing Research, 29*(3), 344-356. doi: 10.1177/0193945906296564

Leech, N., & Onwuegbuzie, A.J. (2010). Guidelines for conducting and reporting mixed research in the field of counseling and beyond. *Journal of Counseling and Development, 88* (1), 61-69. doi: 10.1002/j.1556-6678.2010.tb00151.x

Legg, L.A., Quinn, T.J., Mahmood, F., Weir, C.J., Tierney, J., Stott, D.J., Smith, L.N., & Langhorne, P. (2011). Non-pharmacological interventions for caregivers of stroke survivors. Cochrane *Database of Systematic Review, 10*, 1-53. doi: https://doi.org/10.1002/14651858.CD008179.pub2

Li., Q., Xu, Y., Zhou, H., & Loke, A.Y. (2015). Testing a Preliminary Live with Love Conceptual Framework for cancer couple dyads: A mixed-methods study. *European Journal of Oncology Nursing*, *19*(6), 619-628. doi: 10.1016/j.ejon.2015.03.010

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-Based Healthcare, 13(*3), 179–187. doi: 10.1097/XEB.0000000000000062

McCarthy, M.J., & Bauer, E. (2015). In sickness and in health: couples coping with stroke across the life span. *Health & Social Work, 40*(3), 92-100. https://doi.org/10.1093/hsw/hlv043

Magdon-Ismail, Z., Benesch, C., Cushman, J.T., Brissette, I., Southerland, A.M., Brandler, E.S., Sozener, C.B., Flor, S., Hemmitt, R., Wales, K., Parrigan, K., & Levine, S.R. (2017). Establishing recommendations for stroke systems in the thrombectomy era: The upstate New York stakeholder proceedings. *Stroke, 48* (7), 2003–2006. doi: 10.1161/STROKEAHA. 117.017412

Marshall, C., & Rossman, G.B. (1999). *Designing qualitative research* (3rd ed.). Thousand Oaks: Sage.

Martire, L.M., Schulz, R., Helgeson, V.S., Small, B.J., & Saghafi, E.M. (2010). Review and meta-analysis of couple-oriented interventions for chronic illness. *Annals of Behavioral Medicine, 40*(3), 325–342.doi: 10.1007/s12160-010-9216-2

Mayring, P. (2000). *Qualitative content analysis. Forum: Qualitative social research.* Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1089/2385

McCubbin, H. I., & Patterson, J. M. (1982). *Family stress, coping and social support.* Springfield, Illinois: Charles C Thomas Publisher.

Medical Research Council (2008). *Developing and evaluating complex interventions: new guidance.* Retrieved from http://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/

Mehndiratta, M.M., Khan, M., Mehndiratta, P., & Wasay, M. (2014). Stroke in Asia: geographical variations and temporal trends. *Journal of Neurology, Neurosurgery, and Psychiatry, 85*(12), 1308–1312. doi: 10.1136/jnnp-2013-306992

Meier, C., Bodenmann, G., Mörgeli, H., & Jenewein, J. (2011). Dyadic coping, quality of life, and psychological distress among chronic obstructive pulmonary disease patients and their partner. *International Journal of COPD, 6,* 583–596. doi: 10.2147/COPD.S24508

Milbury, K., Engle, R., Tsao, A.,Liao, Z., Owens, A., Chaoul, A., Bruera, E., & Cohen, L. (2018). Pilot testing of a brief couple-based mind-body intervention for patients with metastatic non-small cell lung cancer and their partners. *Journal of Pain and Symptom Management, 55* (3), 953-961. doi: 10.1016/j.jpainsymman.2017.11.027

Ministry of Health, Singapore. (2018). *Stroke: Rehabilitation and discharge care plans.* Retrieved from https://www.healthhub.sg/a-z/medical-and-care-facilities/71/stroke-rehabilitation-and-discharge-care-plans#1

Ministry of Health, Singapore. (2017). *Community hospital care*. Retrieved from https://www.moh.gov.sg/content/dam/moh_web/Publications/Educational%20Resources/2017/Handbook%20on%20CH%20care%20for%20patients%20(final_291117).pdf

Minshall, C., Pascoe, M.C., Thompson, D.R., Castle, D.J., McCabe, M., Chau, J.P.C., Jenkins, Z., Cameron, J., & Ski, C.F. (2019). Psychosocial interventions for stroke survivors, carers and survivor-carer dyads: a systematic review and meta-analysis. *Topics in Stroke Rehabilitation,* doi: 10.1080/10749357.2019.1625173

Monin J. K., & Schulz R. (2009). Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and Aging, 24*(3), 681–695. doi:10.1037/a0016355

National Healthcare Group (2018). *NHG Research Online Administration & Management: Online DSRB Application Form Guidebook for Population Health Study Version 4.0.* Available https://www.research.nhg.com.sg/wps/wcm/connect/fa9b84004c97773da7f5f780b322e4c9/DSRB+App+Form+Guidebook+Population+Health+v3.pdf?MOD=AJPERES

National Healthcare Group Polyclinics, Singapore (2017). *About us.* Retrieved from https://www.nhgp.com.sg/About_Us/

National Institute of Neurological Disorders & Stroke. (2018). *Stroke Statistics*. Retrieved from http://www.strokecenter.org/patients/about-stroke/stroke-statistics/

National Registry of Diseases Office (2018). *Singapore Stroke Registry Annual Report 2016.* Retrieved from https://www.nrdo.gov.sg/docs/librariesprovider3/Publications---Stroke/singapore-stroke-registry-annual-reprot-2016_upload_nrdo_website.pdf?sfvrsn=0

National Stroke Association (2018). What is stroke? Retrieved from http://www.stroke.org/understand-stroke/what-stroke

National Transitions of Care Coalition. (2016). *The national transitions of care coalition*. Retrieved from www.ntocc.org/aboutus.aspx

Ng, C.S., Toh, M.P.H.S., Ng, J., & Ko, Y. (2015). Direct medical cost of stroke in Singapore. *World Stroke Organization*, 10, 75-82. doi: 10.1111/ijs.12576

Olson, D. M., Bettger, J. P., Alexander, K. P., Kendrick, A. S., Irvine, J. R., Wing, L., Coeytaux, R. R., Dolor, R. J., Duncan, P. W., & Graffagnino, C. (2011). Transition of care for acute stroke and myocardial infarction patients: from hospitalization to rehabilitation, recovery, and secondary prevention. *Evidence report/technology assessment*, (202), 1–197.

Olson, D.M., & Juengst, S.B. (2019). The hospital to home transition following acute stroke. *Nursing Clinics of North America, 54* (3), 385-397. doi: https://doi.org/10.1016/j.cnur.2019.04.007

Ostwald, S.K., Godwin, K.M., Cron, S.G., Kelley, C.P., Hersch, G., & Davis, S. (2014). Home-based psychoeducational and mailed information programs for stroke-caregiving dyads post-discharge: a randomized trial. *Disability & Rehabilitation, 36*(1), 55-62. doi: 10.3109/09638288.2013.777806.

Palmer, S. & Palmer, J.B. (2011). *When your spouse has a stroke: Caring for your partner, yourself, and your relationship.* Baltimore, Maryland: The John Hopkins University Press.

Palmer, A.J., Valentine, W.J., Roze, S., Lammert, M., Spiesser, J., & Gabriel, S. (2005). Overview of costs of stroke from published, incidence-based studies spanning 16 industrialized countries. *Current Medical Research and Opinion*, 21 (1), 19– 26. doi: 10.1185/030079904X17992

Palumbo, R. (2016). Contextualizing co-production of health care: a systematic literature review. *International Journal of Public Sector Management, 29* (1), 72-90. doi: 10.1108/IJPSM-07-2015-0125

Persson, J., Ferraz-Nunes, J., & Karlberg, I. (2012). Economic burden of stroke in a large county in Sweden. *BMC Health Services Research, 12*, 341. https://doi.org/10.1186/1472-6963-12-341

Ploeg, J., Markle-Reid, M., Valaitis, R., McAiney, C., Duggleby, W., Bartholomew, A., & Sherifali, D. (2017). Web-based interventions to improve mental health, general caregiving outcomes, and general health for informal caregivers of adults with chronic conditions living in the community: Rapid evidence review. *Journal of Medical Internet Research, 19*(7), 263. doi:10.2196/jmir.7564

Poghosyan, L., Norful, A.A., Liu, J., & Friedberg, M.W. (2018). Nurse practitioner practice environments in primary care and quality of care for chronic diseases. *Medical care, 56*(9), 791–797. https://doi.org/10.1097/MLR.0000000000000961

Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: Appraising evidence for nursing practice (7th edition).* Philadelphia: Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2014). *In Essentials of nursing research: Appraising evidence for nursing practice (8th ed.).* Philadelphia, PA: Wolters Kluwer Health; Lippincott Willians & Wilkins.

Power, R., Langhaug, L.F., Nyamurera, T., Wilson, D., Bassett, M.T., & Cowan, F.M. (2004). Developing complex interventions for rigorous evaluation--a case study from rural Zimbabwe. *Health Education Research*, 19(5), 570-575. doi: 10.1093/her/cyg073

Prasad, K., Kaul, S., Padma, M. V., Gorthi, S. P., Khurana, D., & Bakshi, A. (2011). Stroke management. *Annals of Indian Academy of Neurology, 14*(1), 82–96. doi: https://doi.org/10.4103/0972-2327.83084

Preston, N.J., Farquhar, M.C., Walshe, C.E., Stevinson, C., Ewing, G., Calman, L.A., Burden, S., Wilson, C.B., Hopkinson, J.B., & Todd, C. (2016). Strategies designed to help healthcare professionals to recruit participants to research studies. *Cochrane Database of Systematic Reviews, 2*, 1-31. doi: 10.1002/14651858.MR000036.pub2.

PRISMA (2015). *Transparent reporting of systematic reviews and meta-analyses*. Retrieved from http://www.prisma-statement.org/

Proctor, E.K., Landsverk, J., Aarons, G., Chambers, D., Glisson, C., & Mittman, B. (2009). Implementation research in mental health services: an emerging science with conceptual, methodological, and training challenges. *Administration and Policy in Mental Health and Mental Health Services Research,* 36(1), 24–34. doi:10.1007/s10488-008-0197-4.

Prowse, P., & Nagel, T. (2015). A meta-evaluation: The role of treatment fidelity within psychosocial interventions during the last decade. *Journal of Psychiatry, 18* (2), 2-7. doi: 10.4172/2378-5756.1000251

Qiu, X., Sit, J.W.H., & Koo, F.K. (2018). The influence of Chinese culture on family caregivers of stroke survivors: a qualitative study. *Journal of Clinical Nursing, 27*(2), 309–319. doi: 10.1111/jocn.13947

QSR International (2014). *NVivo qualitative data analysis software.* Retrieved from https://www.qsrinternational.com/nvivo/support-overview/faqs/how-do-i-cite-qsr-software-in-my-work

Quinn, K., Murray, C., & Malone, C. (2014). Spousal experiences of coping with and adapting to caregiving for a partner who has a stroke: a meta-synthesis of qualitative research. *Disability and Rehabilitation, 36*(3), 185-198. doi: 10.3109/09638288.2013.783630

Ramazanu, S., & Chiang, V.C.L. (2019*). Interventions facilitating care transition of stroke couples from hospitals to home: A mixed-methods systematic review*. Unpublished manuscript.

Ramazanu, S., Loke, A. Y., & Chiang, V. C. L. (2020a). Couples coping in the community after the stroke of a spouse: A scoping review. *Nursing Open, 7*(2), 472-482. doi: https://doi.org/10.1002/nop2.413

Ramazanu, S., Leung, D., & Chiang, V.C.L. (2020b). What is it about the recovery for couples after stroke in Singapore: An interpretive descriptive study. *The Journal of Nursing Research*. Manuscript Accepted for publication.

Ratna, H. (2019). *The importance of effective communication in healthcare practice.* Retrieved from http://harvardpublichealthreview.org/healthcommunication/

Raynor, D.K., Ismail, H., Blenkinsopp, A., Fylan, B., Armitage, G., & Simcock, J. (2020). Experience-based co-design—Adapting the method for a researcher-initiated study in a multi-site setting. *Health Expectations, 23* (3), 562-570. doi: 10.1111/hex.13028

Reeves, P., Edmunds, K., Searles, A., & Wiggers, J. (2019). Economic evaluations of public health implementation-interventions: a systematic review and guideline for practice. *Public Health, 169,*101-113. doi: 10.1016/j.puhe.2019.01.012.

Rigby, H., Gubitz, G., & Phillips, S. (2009). A systematic review of caregiver burden following stroke. *International Journal of Stroke,* **4** (4), 285–292. doi: 10.1111/j.1747-4949.2009.00289.x.

Roberts, E., & Struckmeyer, K.M. (2018). The impact of respite programming on caregiver resilience in dementia care: A qualitative examination of family caregiver perspectives, *Inquiry, 55,* 1-11. doi: 10.1177/0046958017751507

Robinson-Smith, G., Harmer, C., Sheeran, R., & Vallo, E. B. (2015). Couples' coping after Stroke - A pilot intervention study. *Rehabilitation Nursing, 41*(4), 218–229. doi: 10.1002/rnj.213

Rolland, J.S. (2019). *Families, health, and illness.* Retrieved from https://onlinelibrary.wiley.com/doi/abs/10.1002/9781119420743.ch15#

Ross, L., Holliman, D., & Dixon, D.R. (2003). Resiliency in family caregivers: implications for social work practice. *Journal of Gerontological Social Work, 40* (3), 81-96. doi: 10.1300/J083v40n03_07

Rubin, R.R., Fujimoto, W.Y., Marrero, D.G., Brenneman, T., Charleston, J.B., Edelstein, S.L., Fisher, E.B., Jordan, R., Knowler, W.C., Lichterman, L.C., Prince, M., & Rowe, P.M. (2002). The diabetes prevention program: recruitment methods and results. *Controlled Clinical Trials, 23* (2), 157–171. doi: 10.1016/S0197-2456(01)00184-2

Saint-Germaine, M.A., & Longman, A.J. (1993). Breast cancer screening among older Hispanic women: knowledge, attitudes, and practices. *Health Education and Behaviour, 20* (4), 539-553. doi: 10.1177/109019819302000412

Saka, O., McGuire, A., & Wolfe, C. (2009). Cost of stroke in the United Kingdom. Age Ageing, 38 (1), 27–32. doi: 10.1093/ageing/afn281

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, *8*(3), 27-37. https://doi.org/10.1097/00012272-198604000-00005

Sanuade, O. (2018). Understanding the cultural meanings of stroke in the Ghanaian setting: A qualitative study exploring the perspectives of local community residents. *Welcome Open Research, 3 (87*), 1-23. doi: 10.12688/wellcomeopenres.14674.2

Savage, T. A. (2006). Ethical issues in research with patients who have experienced stroke. *Topics in Stroke Rehabilitation, 13*(4), 1-10. https://doi.org/10.1310/tsr1304-1

Scheppers, E., Dongen, E, Dekker, J., Geertzen, J., & Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: a review. *Family Practice, 23* (13), 325–348. doi: 10.1093/fampra/cmi113

Sedgwick, P. (2015). Randomised controlled trials: the importance of sample size. *BMJ*, 350, 1-12. doi: 10.1136/bmj.h1586

Sekhon, M., Cartwright, M., & Francis, J.J. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research,* 17 (88), 1- 13. doi: 10.1186/s12913-017-2031-8

Shay, L.A., & Lafata, J.E. (2015). Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making, 35*(1), 114- 131. doi: 10.1177/0272989X14551638

Shields, C.G., Finley, M.A., Chawla, N., & Meadors, P. (2012). Couple and family interventions in health problems. *Journal of Marital & Family Therapy, 38* (1), 265-280. doi: 10.1111/j.1752-0606.2011.00269.x

Singapore National Stroke Association (2018). *Who are we?* Retrieved from http://www.snsa.org.sg/about-snsa/who-we-are/

Singapore Silver Pages (2018). *Community rehabilitation centre*. Retrieved from https://www.silverpages.sg/care-services/day-care/Day%20Rehabilitation%20Centre

SingHealth Group (2014). *Stroke in Singapore*. Retrieved from https://www.singhealth.com.sg/DoctorsAndHealthcareProfessionals/Medical-News/2012/Pages/Stroke-in-Singapore.aspx

Smith, J., Forster, A., & Young, J. (2004). A randomized trial to evaluate an education programme for patients and carers after stroke. *Clinical Rehabilitation, 18* (7), 726–736. doi: 10.1191/0269215504cr790oa

Spurlock, D.R. (2018). The single-group, pre- and posttest design in nursing education research: It's time to move on. *Journal of Nursing Education, 57* (2), 69-71. doi: 10.3928/01484834-20180123-02

Steinglass, P., Ostroff, J. S., & Steinglass, A. S. (2011). Multiple family groups for adult cancer survivors and their families: A 1-day workshop model. *Family Process*, *50*(3), 393–409. doi:10.1111/j.1545- 5300.2011.01359.x

Stevenson, K.N., Jack, S.M., O'Mara, L., & LeGris, J. (2015). Registered nurses' experiences of patient violence on acute care psychiatric inpatient units: An interpretive descriptive study. *BMC Nursing,* 14, Article 35. https://doi.org/10.1186/s12912-015-0079-5

Stewart, M., Davidson, K., Meade, D., Hirth, A., & Weld-Viscount, P. (2001). Group support for couples coping with a cardiac condition. *Journal of Advanced Nursing, 33*(2), 190-199. doi: 10.1111/j.1365-2648.2001.01652.x

Stroke Association (2015). *Swallowing problems after a stroke*. Retrieved from https://www.stroke.org.uk/sites/default/files/complete_guide_to_swallowing_problems_after_stroke.pdf

Stroke Association, UK (2018). *State of the nation: Stroke statistics*. Retrieved from https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2018.pdf

Suddick, K.M., Cross, V., Vuoskoski, P., Stew, G., & Galvin, K.T. (2019). The acute stroke unit as a meaningful space: The lived experience of healthcare practitioners. *Health & Place, 57*, 12-21. doi: https://doi.org/10.1016/j.healthplace.2019.02.004

The Global Burden of Disease. 2008. *Global health estimates*. Retrieved from http:// www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf.

The Hong Kong Polytechnic University (2013). *Mental health caring project-About us.* Retrieved from http://www.polyu.edu.hk/sao/mhcp/about-us.html

The Joanna Briggs Institute (2014). *JBI reviewer's manual: The JBI approach to mixed method Systematic reviews.* Retrieved from https://wiki.joannabriggs.org/display/MANUAL/8.3+The+JBI+approach+to+mixed+method+systematic+reviews

The Point of Care Foundation (2020). *What is Experience-based co-design?* Retrieved from https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design/

The Stroke Foundation Australia. (2019). *Grief after a stroke.* Retrieved from https://strokefoundation.org.au/Blog/2015/05/19/Grief-after-stroke

Thorne, S. (2008). *Interpretive description.* Walnut Creek, California: Left Coast Press, Inc.

Thorne, S., Reimer, K. S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing* and *Health*, *20*(2), 169-177. https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I.

Thrift, A.G., Thayabaranathan, T., Howard, G., Howard, V.J., Rothwell, P.M., Feigin, V.L., Norrving, B., Donnan, G.A., & Cadilhac, D.A. (2017). Global stroke statistics. *International Journal of Stroke, 12* (1), 13-32. doi: https://doi.org/10.1177/1747493016676285

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing, 48*(4), 388-396. https://doi.org/10.1111/j.1365-2648.2004.03207.x

Tooth, L., McKenna, K., Barnett, A., Prescott, C., & Murphy, S. (2005). Caregiver burden, time spent caring and health status in the first 12 months following stroke. *Brain Injury*, *19*, 963-974. https://doi.org/10.1080/02699050500110785

Tsai, T., & Lee, S.D. (2016). Health literacy as the missing link in the provision of immigrant health care: A qualitative study of Southeast Asian immigrant women in Taiwan. *International Journal of Nursing Studies, 54,* 65-74. doi: 10.1016/j.ijnurstu.2015.03.021

Tsur, A., & Segal, Z. (2010). Falls in stroke patients, risk factors and risk management. *The Israel Medical Association Journal, 12*(4), 216-219.

Tufanaru, C., Munn, Z., Aromataris, E., Campbell, J., & Hopp, L. (2017). Chapter 3: Systematic reviews of effectiveness. *In Joanna Briggs Institute Reviewer's Manual.* (eds Aromataris, E., Munn, Z.) The Joanna Briggs Institute, Adelaide. Retrieved from https://reviewersmanual.joannabriggs.org/

Uchino, B. N. (2004). *Social support and physical health: Understanding the health consequences of relationships.* New Haven, Connecticut: Yale University Press.

United Nations Children's Fund (UNICEF) (2014). Quasi-experimental design and methods. Retrieved from https://www.unicef-irc.org/publications/pdf/brief_8_quasi-experimental%20design_eng.pdf

UT Southwestern Medical Center (2020). *Stroke statistics*. Retrieved from http://www.strokecenter.org/patients/about-stroke/stroke-statistics/

van Exel, N.J., Koopmanschap, M.A., van den Berg, B., Brouwer, W.B., & van den Bos, G.A. (2005). Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. *Cerebrovascular Diseases, 19,* 11-17. https://doi.org/ 10.1159/000081906

Ven, N. (2003). Psychosocial group interventions in diabetes care. *Diabetes Spectrum, 16* (2), 88-95. doi: https://doi.org/10.2337/diaspect.16.2.88

Venketasubramanian, N., & Chen, C.L. (2008). Burden of stroke in Singapore. *International Journal of Stroke, 3,* 51-54. doi:10.1111/j.1747-4949.2008.00181.x

Venketasubramanian, N., Yoon, B.W., Pandian, J., & Navarro, J.C. (2017). Stroke epidemiology in South, East, and South-East Asia: A review. *Journal of Stroke, 19*(3), 286–294. doi: 10.5853/jos.2017.00234

Visser-Meily, A., Post, M., Port, V. I, Maas, C., Forstberg-Wärleby, G., & Lindeman, E.(2009). Psychosocial functioning of spouses of patients with stroke from initial inpatient rehabilitation to 3 years poststroke: course and relations with coping strategies. *Stroke, 40*(4),1399-1404. doi: 10.1161/STROKEAHA.108.516682

Visvanathan, A., Dennis, M., Mead, G., Whiteley, W.N., Lawton, J., & Doubal, F.N. (2017). Shared decision making after severe stroke—How can we improve patient and family involvement in treatment decisions? *International Journal of Stroke, 12*(9) 920–922. doi: 10.1177/1747493017730746

Wan-Fei, K., Hassan, S., Sann, L. M., Ismail, S., Raman, R. A., & Ibrahim, F. (2017). Depression, anxiety and quality of life in stroke survivors and their family caregivers: A pilot study using an actor/partner interdependence model. *Electronic physician*, *9*(8), 4924–4933. doi: 10.19082/4924

Wang, Y.C., Kapellusch, J., & Garg, A. (2014). Important factors influencing the return to work after stroke. *Work, 47*(4), 553–559. doi: 10.3233/WOR-131627.

Westerlind, E., Persson, H.C., & Sunnerhagen, K.S. (2017). Return to work after a stroke in working age persons; A six-year follow up. *PLoS One*, *12*(1), 1-14. doi: 10.1371/journal.pone.0169759

World Health Organisation (2016). *Transitions of care.* Retrieved from http://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-eng.pdf;jsessionid=8ED42E124DCEE609DA7CE3E3666CDE46?sequence=1

World Health Organisation. (2018). *Disability and rehabilitation.* Retrieved from http://www.who.int/disabilities/cbr/en/

World Health Organization. (2019). *Stroke, Cerebrovascular accident.* Retrieved from https://www.who.int/topics/cerebrovascular_accident/en/

World Health Organization (2001). Declaration of Helsinki. *Bulletin of the World Health Organization,* 79 (4), 373-374.

Wozniak, M.A., & Kittner, S.J. (2002). Return to work after ischemic stroke: a methodological review. *Neuroepidemiology*, *21*(4), 159–166. doi: 10.1159/000059516

Wray, F., & Clarke, D. (2017). Longer-term needs of stroke survivors with communication difficulties living in the community: a systematic review and thematic synthesis of qualitative studies. *BMJ Open, 7*(10), 1-18. doi: 10.1136/bmjopen-2017-017944

Xiao, L.D., Wang, J., He, G., Bellis, A.D., Verbeeck, J., & Kyriazopoulos, H. (2014). Family caregiver challenges in dementia care in Australia and China: a critical perspective. *BMC Geriatrics, 14*(6), 1-13. doi: 10.1186/1471-2318-14-6

Zachrison, K.S., Dhand, A., Schwamm, L.H., & Onnela, J. (2019). A network approach to stroke systems of care. *Circulation: Cardiovascular Quality and Outcomes, 12,* 1-11. doi: 10.1161/CIRCOUTCOMES.119.005526

Zajdel, M., Helgeson, V.S., Seltman, H.J., Korytkowski, M.T., & Hausmann, L.R.M. (2018). Daily communal coping in couples with Type 2 diabetes: Links to mood and self-care. *of Behavioral Medicine, 52*(3), 228–238. doi: 10.1093/abm/kax047