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LEARNING TO BE A FAMILY CAREGIVER FOR SEVERELY DEBILITATED STROKE SURVIVORS DURING THE FIRST YEAR IN TAIWAN

by

Chiung-man Wu

An Abstract

Of a thesis submitted in partial fulfillment
of the requirements for the Doctor of
Philosophy degree in Nursing
in the Graduate College of
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ABSTRACT

Stroke is a major health problem in Taiwan often causing disability and dependence for elderly persons. Family caregivers shoulder major caregiving tasks while caring for their stroke survivors at home. Despite the availability of home healthcare service for family caregivers, the quality of care outcomes remain poor. According to role acquisition theory, sufficient preparation before discharge is positively related to quality of care. Caregiver education is proposed as the way to increase quality of care outcomes, yet current educational programs in Taiwan have not incorporated three fundamental learning determinants: readiness to learn, learning needs, and learning styles. The purpose of this descriptive qualitative study was to describe the experiences of Taiwanese family caregivers learning to caregiver for a stroke survivor during the first year after discharge. Participants included 16 stroke survivors cared for by 17 family caregivers and 11foreign care attendants during at-home and in-hospital phases. Data collection included three formal interviews and one care activity observation. While still in the hospital, family caregivers took on the caregiver role. They sought out resources to learn caregiving. They learned some care skills and stated that they felt ready to go home prior to discharge. Yet, once at-home, they immediately described a sense of uncertainty –not knowing what to do in new care situations. Fifteen challenges were identified. The most common ones were diet preparation, elimination problems, transportation, breathing and sputum problems, and rehabilitation resources. Three time periods were identified as the time for readiness to learn: before discharge, the first month after discharge, and when facing new care situations. All of the family caregivers were unprepared for the new care situations before discharge because of problematic preparation and fragmented health care services. Recommendations include further studies on the three learning determinants, development of an organized and systemic discharge planning protocol, and increased in-home nursing and rehabilitation services.

Abstract Approved: ____

Thesis Supervisor

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CERTIFICATE OF APPROVAL

PH. D. THESIS

This is to certify that the Ph. D. thesis of

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has been approved by the Examining Committee for
the thesis requirement for the Doctor of Philosophy degree
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CHAPTER I

INTRODUCTION

In Taiwan, stroke is the second leading cause of death (Department of Health, Executive Yuan, 2005) and disability among those age 65 and over (Chuang, Wu, Yeh, Chen & Wu, 2005). A stroke is a sudden interruption in the blood supply of the brain. The World Health Organization (WHO) (1978) defines stroke as "a clinical syndrome consisting of rapidly developed signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours." There are several types of stroke, and each type has different causes. The two main types of stroke are ischemic and hemorrhagic. Ischemic stroke, caused by a clot or other blockage within an artery leading to the brain, is the most common type of stroke and accounts for almost 80% of all strokes (Hsu, Chen, Chang, Hsieh & Wu, 1995). Hemorrhagic stroke is caused by bleeding into brain tissue when a blood vessel bursts. Because stroke occurs rapidly and requires immediate treatment, stroke is also called a brain attack (Centers for Disease Control and Prevention, 2008).

After a stroke, 35-45% of stroke survivors become partially or totally dependent on others to meet their abilities in activities of daily living (ADLs) (Chiu, Shyu & Chen, 1997; Chuang, Wu, Yeh, et al., 2005; Lee, 1991). Upon discharge from the hospital, 42-57% of stroke survivors are cognitively impaired (Chao & Wu, 1997; Lin, Liu, Lin & Huang, 1999) and 20-30% are confused (Chuang, Wu, Ma, Chen & Wu, 2005). Due to high rates of functional and cognitive limitations, 20 to 25% of stroke survivors are discharged with an average of 2.38 tubes; including nasal-gastric (NG) feeding tubes, urinary Foley catheters, and tracheal tubes (Chen, Shyu & Wu, 2001; Chuang, Wu, Ma, et al., 2005). Additionally, 9-15 % of stroke survivors are discharged to the home environment with impaired skin integrity and wound ulcers necessitating wound care (Chuang, Wu, Ma, et al., 2005; Hung, et al., 1999). Taking on the new role of caregiver and managing complex care needs in the home care situation requires specialized nursing knowledge and skills.

This new set of nursing care skills is often relegated to family caregivers with 85-90% of stroke survivors returning to their home in the care of family caregivers (Lin, Chai, Liao, Huang, Chen & Liao, 2003; Wu, Chuang & Chen, 2004). Clearly, family caregivers are not substitute nurses, nor would it be the intent that they act as nurses; rather they need ongoing education, consultation and decision-making support from nurses as they take on and learn a new caregiving role for a severely disabled elder. Family caregivers report that they are not ready to face and manage the complexity of the care skills and associated demands after discharge (Shyu, 2000). As a result, not only do family caregivers become physically and psychosocially overwhelmed (Chou, 2000; Elmstahl, Malmberg & Annerstedt, 1996), but care outcomes for stoke survivors such as high death and unplanned hospital re-admission rates are unacceptable.

To address the care needs of family caregivers learning to care for elder stroke survivors, the Bureau of National Health Insurance funds in-home health care services through home care agencies. These services are available for family caregivers caring for severely dependent survivors who have tube placements and/or wound care needs. Home care nurses are responsible for providing skilled nursing care, such as tube replacement and wound care, as well as teaching family caregivers how to provide ongoing care for their elder stroke survivors in the care situation. While in-home nursing service is expected to improve stroke survivor outcomes, mortality and morbidity rates are problematic. The death rates for stroke survivors at the first six months are 46.5% and 62.0% for one year (Huang, et al., 2006; Yeh, Wen & Shu, 1998). For elders receiving home care services during the first six months post discharge, only 4-13% have an improvement in self-care ability (Hung, et al., 1999; Liao, Shao, Lee & Shyu, 2000; Tu & Wang, 1998; Yeh & Wen, 2001). The reported hospital re-admission rates are 44-77% (Chou et al., 2006; Chung, Chou, Chuang & Chen, 2003; Lo, Chen & Hu, 1999; Yeh &

Wen, 2001). The major reasons for re-hospitalization include pneumonia, pain, sepsis, urinary tract infection (UTI), and gastrointestinal bleeding (Chen, Yeh & Shyu, 2003; Chou, et al., 2006; Dai, Wu & Weng, 2002). In total, infections account for over 60% of deaths and unplanned re-hospitalization for home health care stroke survivors.

Tube placements and wound care problems are the primary reasons for the high mortality rate, unplanned hospital re-admission, and multiple complications for stroke survivors. While stroke rehabilitation evidence encourages weaning from invasive devices (Huang, et al. 2006), the reported rates of weaning from NG, Foley and trachea devices remain low, from 2.7% to 4.0 % (Yeh & Wen, 2001). On the other hand, many of the infections and other health conditions that develop in the home care environment are preventable with skilled nursing care by family member caregivers. The reported rates of correctly performed care skills for preventing infections and nutrition problems are low: nutritional management (36%), position change (43%), posture support (31%), wound care (12%), urinary catheter care (11%), and chest care (10%) (Hung, Liu & Kuo, 2002). Purportedly this is because 85-95% of family caregivers are untrained (Sun, et al., 2005; Tseng, Shyu, See & Chen, 2001) and often lack sufficient caregiving knowledge and skills (Chuang, Wu, Ma, et al., 2005; Hung, et al., 2002). This has led to a lack of family caregiver knowledge - identified as one of the major reasons and preventable causes for unplanned hospital re-admission (Shyu, 2000; Williams & Fitton, 1988).

Problem Statement

Although increasing family member caregivers’ knowledge about stroke has been positively related to home care quality (Acton & Winter, 2002), only three educational intervention studies have been conducted in Taiwan. These studies demonstrate an increase in caregiver knowledge and quality of life; however, the researchers typically do not take into account the various learning needs at different phases of the caregiver career. Family caregivers who are learning to become caregivers have a developing set of learning needs as the stroke caregiving situation changes at different time periods (Eames, McKenna, Worral & Read, 2003; Grant, Glandon, Elliott, Giger & Weaver, 2004; Shyu, 2000). In the United States (US) family caregiving situation, researchers have found some positive outcomes, including increased caregiver esteem, increased satisfaction with the caregiving role and caregivers' finding meaning in the care situation (Hunt, 2003; Tralow et al., 2004); however, only challenges are identified in Taiwanese stroke care situation. Thus a more complete description of the care situation (challenges and benefits) and associated learning needs is warranted.

Schumacher (1995) conceptualizes a role acquisition model to explain the family caregiver role-taking process. Family caregivers' readiness for taking on the caregiving role is based on an individual's previous experience, knowledge and relationships with the care receiver, and the appraisal of the anticipated situations and evaluation of the likely effect on one's life. From the situational appraisal, family caregivers recognize their needs and seek various resources to deal with their needs (Nolan, Grant & Keady, 1996). A family member's commitment to the caregiving role is based on the appraisal and satisfactions of personal needs. Education is the primary modality for creating optimal conditions for role mastery and transition (Schumacher & Meleis, 1994). While this role acquisition model has been developed in the US, it has not been employed in Taiwanese stroke caregiving research.

Bandura's self-efficacy theory (Bandura, 1995) is commonly applied in studies on learning to become a caregiver (Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002). Self-efficacy theory states that one's expectation of successfully performing a behavior affects individual behavior, motivational level, thought patterns, and emotional reactions in response to a situation (Bandura, 1995). According to adult learning principles' and characteristics of adult learners, three determinants of learning include: learners readiness to learn (when the learner is motivated and ready to learn), learning needs (what the learner needs to learn), and learning style (how the learner best learns) (Kitchie, 2003).

Readiness to learn occurs when the adult learner is receptive to learning and is willing and able to participate in the learning process (Knowles, 1980; Knowles, Holton & Swanson, 2005). Time and learner motivation are two major concerns for the learners readiness to learn. The first month has been reported as the critical time for a family caregiver to learn necessary information (Grant, et al., 2004; Shyu, 2000; Silva-Smith, 2007). Furthermore, they often face new care situations in the home settings (Huang, et al., 2006).Thus it is expected that family caregivers have different needs of learning new information along with care situation change. However, the critical learning time for Taiwanese stroke family caregivers is still unknown and needs further study.

In Chinese culture, obligation, reciprocation and Karma are major reasons for family members to take on caregiver roles. For spouses and children, care obligation is often accompanied with affection; in contrast, for daughters-in-law, obligation is based on cultural and social expectations. Additionally, spouses and daughters provide more personal care than sons and daughters-in-law. Children or daughters-in-law have more competing needs with caregiving tasks (Wu & Lin, 1999). Therefore, with differing family relationships, family members might express different reasons for taking on the caregiving role and describe different challenges, benefits and learning needs. However, there is no study that provides this critical information on the readiness of family members as they take on the caregiving role for an elder stroke survivor.

In addition to readiness to learn, nurses also need to assess care situation learning needs (what) and adult learning styles (how) before providing education (Bastable & Rinswalske, 2003). Learning needs are defined as gaps in knowledge that exist between a desired level of performance and the actual level of performance. Such gaps exist because of a lack of knowledge, attitude, or skills (Kitchie, 2003). While it is necessary to understand family caregivers’ needs before providing education, educational programs are often based on health care providers' views of what family members need to learn without an understanding of the family caregivers' experience in learning how to become a caregiver for a stroke survivor. The discrepancies between the provided information and caregivers' real needs have been reported in many studies (Cook, Pierce, Hicks & Steiner, 2006; Pierce, Rupp, Hicks & Steiner, 2003; Rodgers, Bond & Curless, 2001). Forster, Smith, Young, House and Wright (2001) highly recommend that future work address the expressed needs of caregivers and identify appropriate teaching strategies which can be successfully implemented within clinical practice. On the other hand, previous studies show family caregivers indicate different learning needs from hospitalization to early discharge (Eames, et al., 2003; Grant, et al., 2004; Hanger, Walker, Paterson, McBride & Sainsbury, 1998; Rodgers, et al., 2001; Shyu, 2000). While there are four studies focusing on the learning needs of Taiwanese family caregivers of stroke survivors (Chen, et al., 2001; Chiou, Lu, Hsu, Ju Chen & Liu, 1988; Chung & Hung, 1999; Liu, Hwu & Lee, 1998), these studies all employed a cross-sectional descriptive design and lack the capability to depict family caregiver learning needs at different time periods. The needs for Taiwanese family caregivers who are learning to care for a stroke survivor at the different care situations are under explored. There is a critical need to understand the situational experience of Taiwanese family caregivers who are learning to care for their family members and better understand the timing of learning needs.

Learning style refers to the ways individual's process information (Kolb, 1984). Each learner is unique and complex, with a distinct learning style preference that distinguishes one learner from another. No learning style is better or worse than another. Kolb (1984) indicates given the same content, most learners can assimilate information with equal success, but how they go about mastering the content is determined by their individual style. A variety of preferred styles of learning exist, and assessing how someone learns best will help the educator to select teaching approaches accordingly.

Assessment of learning style assists educators in determining how health care consumers prefer to learn and enables the development of individually tailored teaching programs. Caregivers primarily learn information by talking, reading, observing, listening and doing. In addition, 59% of them use a trial-and-error approach and previous caregiving experience as their ways of learning (Stewart, Archbold, Harvath & Nkongho, 1993). However, one standard learning style may not be suitable for all family caregivers. For example female and male caregivers demonstrated different learning styles (Garity, 1997). Female caregivers preferred learning by doing and watching. Male caregivers tended to learn by watching and thinking. Likewise, there is no study focused on understanding Taiwanese family caregivers' preferred learning styles.

Taken together, three gaps were identified from the overview of family care studies in Taiwan: (1) Different family caregivers' readiness to learn and take on the caregiving role; (2) An understanding of the care situations (challenges and benefits) and associated learning needs for different family caregivers from in hospital to after discharge; and (3) the preferred learning styles of different family caregivers. As a result, family caregivers often are unprepared for their caregiving career resulting in poor outcomes for the stroke survivor, caregiver stress and burden, and unnecessary social and economic costs in health utilization.

Purpose

The purpose of this study was to explore and describe the situational experience of Taiwanese family members who were learning how to become a caregiver for a stroke survivor during the first year after discharge. The research study aimed to (1) describe family caregiver readiness for learning and taking on the caregiver role for a stroke survivor; (2) explore and describe the care situation and associated learning needs of family caregiver of stroke survivor at home during the first years post discharge; and (3) describe family caregivers preferred learning styles.

Research Questions

With the intention of addressing the purpose of the study, three research questions were formed as follows: (1) What does the primary family caregiver describe as their readiness to learn and take on the caregiver role for a stroke survivor? (2) What are the care situations and learning needs of the primary family caregiver at home during the first year post discharge? (3) What does the primary family caregiver describe as their preferences for learning new care skills and knowledge?

Significance

This information is essential to addressing the gaps in knowledge concerning the learning needs of Taiwanese family members who are taking on a new role as a caregiver. This knowledge is crucial for the design of nursing interventions and educational programming for hospital and home care nurses as they assist family members to become caregivers and to perform their new caregiver career. Thus this work was to begin to develop a program of research and basic descriptive knowledge on which to design future interventions that will facilitate Taiwanese family caregiver role acquisition with improved stroke survivor, caregiver and system outcomes. Finally, the outcomes are expected to inform National Health Insurance Bureau policy and programming.

Summary

Stroke is a major health problem in Taiwan and it often causes disability and dependence for elder persons. Family caregivers shoulder the major caregiving tasks and responsibilities at home. Home care service is the only resource for family caregivers after discharge. However the home care outcomes are unsatisfactory. Education has been suggested as the best way of increasing both the satisfaction of caregiver role-taking and quality of care at home. Yet currently the education programs for family caregivers are lacking in an understanding of three learning determinants for learners - readiness to learn, learning needs and learning styles. The learning determinants have been under explored in Taiwan. Three gaps are identified from current care situations and research. Thus the purpose of the current study was intended to fill these gaps. With the findings, an educational program will be designed for hospital and home care nurse to facilitate Taiwanese family caregiver role acquisition, subsequently improving stroke survivor, caregiver, and system outcomes.

CHAPTER II

REVIEW OF LITERATURE

In this chapter, the general stroke care from hospital to home care settings in Taiwan is overviewed. The caregiving situations and outcomes are discussed. Then role acquisition and learning theories are described. Three learning determinants for designing an appropriate education program are identified and compared with current Taiwanese studies.

Overview of Stroke Care in Taiwan

Stroke is the second leading cause of death in Taiwan (Department of Health, Executive Yuan, R. O. C., 2005) and a major reason of disability among elders (Chuang, Wu, Yeh, et al., 2005). After a stroke, elder stroke survivors frequently acquire long-term cognitive, motor and/or somato-sensory disabilities caused by conscious and cognitive impairment, the deficits of motor and somato-sensory and impaired balance and coordination (Grant, 1996). In Taiwan, upon discharge, 20-30% of stroke survivors are confused including 5.3% of unconscious survivors (Chuang, Wu, Ma, et al., 2005). Around 42-57% of stroke survivors have cognitive impairment (Chao & Wu, 1997; Lin, Liu, et al., 1999). Cognitive impairment and motor deficit affect the stroke survivors' independent function. Individual physical function is often assessed by activities of daily life (ADL). The Barthel Index is a scale of ADL which consists of ten fundamental items, including feeding, grooming, bathing, dressing, bowel and bladder care, toilet use, ambulation, transfers, and stair climbing. The total scores range from 0–100, with higher scores signifying better degrees of function (Mahoney & Barthel, 1965). It is one standardized scale widely used by clinicians and researchers to assess disability caused by a stroke (Hsueh, Lee & Hsieh, 2001). As a result, 25-30% stroke survivors become partially dependent, and 10-15 % are severely or totally dependent (Chiu, Shyu, et al., 1997; Chuang, Wu, Yeh, et al., 2005; Hsu et al., 1995; Lee, 1991). On the other hand, because of high rates of cognitive impairment and functional limitations, stroke survivors often need a tube placement, including NG tubes, urinary Foley catheters and trachea tubes, to compensate for their self-care deficiencies. Around 25% of stroke survivors are discharged with tubes (Chen, et al., 2001; Chuang, Wu, Ma, et al., 2005), 18 % with NG tubes, 4% with Foley catheter, and 6% with tracheal tubes (Chen, et al., 2001). In addition, 9-15 % of stroke survivors are discharged with wounds (Chuang, Wu, Ma, et al., 2005; Hung, et al., 1999).

Caregiving at Home

After discharge 85-90% of stroke survivors are cared for by family members at home, including around 10-15% cared for by employed caregivers at home (Chiu, Tang, et al., 1998; Lin, et al., 2003; Lin, Hsiao, et al., 2000; Lin, Lee, Huang, Liu & Lin, 2000; Lin, Liaw, Lin, Liu & Lin, 1999; Wu, et al., 2004). Even though the pattern of long-term care is changing due to social and family structure changes, the family is still the main source of long-term care (Wu & Lin, 1999). Family members continue to take the major responsibilities of caregiving for stroke survivors.

After discharge, the home care agency is the only health professionals’ in-home service for family or patients in Taiwan. Eligible persons can receive physician home visits every other month and nursing service twice a month. However, not all stroke survivors can receive home care services. The National Health Insurance Bureau delineates three criteria for receiving home care services: (a) the recipient’s ADL score is lower than 60 assessed by Chinese version of Barthel index; (b) the recipient has certain medical and nursing care needs, such as replacing NG tubes or nutritional consultation; (c) the recipient’s general health condition is stable (Bureau of National Health Insurance, 2009 c). Thus, the major users of home care services are persons with severe functional disabilities.

Accordingly, 70 % of the stroke survivors receiving home health care services are older than 65 years old, and 60-70% of them have multi-diseases and over five to six medications daily. Over 60% of them are cognitive impaired and 20-35% are unconscious (Chiou, Hsu & Wu, 2003; Lin, Liu, et al. 1999; Lin & Shyu 1998; Wu & Chiou 1997). With respect to the self-care limitations, 90 to 100% of them are severely or totally dependent. Around 90% of them have tube placements, including NG tubes, Foley catheters, trachea tubes, and 16-40% have wounds (Chiu, Pai, Tang & Wang, 1996; Chiu, Tang, et al., 1997; Chou, Chen & Lu, 2000; Hsu & Chiou, 2004 a; Huang, et al., 2006; Wu & Chiou 1997). Reported mean numbers of tubes are 2.38 (Chuang, Wu, Ma, et al., 2005). It is expected that a caregiver requires specialized nursing knowledge and skills for managing the complex care needs in the home care situation.

The reported mean ages of family caregivers is 45 to 55 years old, with about one third of the family caregivers age 65 and older. The educational levels of family caregivers tend to be low. Around 40 to 70 % of them have less than six years of education or are illiterate (Shyu & Chang, 1992). Females account for 60-85% of family caregivers. Thirty to fifty percent of them are care receivers' spouses, followed by daughters-in-law (20-30%) and daughters (15-20%). In some studies the rates of sons as caregivers are up to 20-35% (Chin, You & Huang, 1999; Pan, Tang & Chang, 1998; Shyu, Chen & Lee, 2004; Tseng et al., 2001). Sons, however, often play a role as a decision maker instead of a hands-on family caregiver (Shyu, 2000).

Concerning the family caregiving manpower, around 40-60% of family caregivers identify that they have to provide care alone. Due to this shortage of family manpower, there has been an increase in the trend of hiring a helper as alternative care for disabled family members (Hu, Kuo & Wang, 1996). The rate of hiring a helper at home has increased from 8.1 % in 1995 (Hu, et al., 1996) to 43% in 2004 (Hsu & Chou, 2004 a). Since 1992, the government has granted the introduction of foreign care attendants to temporarily assist the labor shortage issue of households (Council of Labor Affairs, R. O.

C., 2009). Since then, the percentage of hiring of a foreign care attendant as a major physical care provider has increased (Chuang, Wu, Dai & Ma, 2007). In Chiou et al. (2003), the percentage of foreign care attendants was up to 90%. Typically, those hired foreign care attendants come from countries in South East Asia, such as Thailand, The Philippines, and Indonesia. The cost for non-Taiwanese care attendants is lower than for Taiwanese nurse aides. Communication problems and elder abuse have been identified as a concern of those who hire foreign caregivers (Li & Tang, 2001). Although identified, those issues are still under explored in current research.

Caregiving Nursing Problems

According to the stroke survivors' characteristics, it is expected that the family caregivers face complex and highly technical nursing needs and problems. In Lo, et al. (1991), at the first home visit, the mean nursing problems was 7.2. During the first month after discharge, family caregivers have to manage the limitations from self-care deficiency, difficulties in tube and/or wound care, and difficulties in monitoring the disease (Lo, et al., 1991; Wu & Chiou, 1997). An estimated 80-90 % of family caregivers have caregiving knowledge deficits (82-90%) and technical caregiving problems (72%) managing complex care problems at home (Chen, Lin & Dai, 1999; Lo, et al., 1991; Wu & Chiou, 1997).

Providing self-care activities (98%) is the major caregiving activity at home. Self-care activities have been reported as the most difficulty and frustrated caregiving task (Shyu & Chang, 1992). However, approximately 60-75% of family caregivers can correctly perform the ADL skills at home (Hung, et al., 2002). Because of the high rate of tube placements and wound care, infections and malnutrition are vital care giving outcomes. Unfortunately, the rates of correctly performing the preventive tasks are very low: nutritional management (36%), position change (43%), posture and support (31%), chest care (10%), wound care (12%), perineal care (10%) and urinary catheter care (11%)

(Hung, et al., 2002). Incongruously, family caregivers have low rates of need for learning diet information (36%), rehabilitation (28%), NG feeding (25%), and chest care (expel sputum) (Chen, et al., 2001; Chiu, et al., 1996). Notably, only 3 to 7 % of family caregivers indicate they need to learn the knowledge and skills of tube care, wound care, and suction six months after discharge (Chen, et al., 2001). The reasons are unclear.

In addition to skilled nursing, family caregivers also face the difficulties of managing disease complications, medication related issues and emergency condition (Chen, et al., 1999). For home care survivors, the most common complains of health problems are constipation, cough, fever, skin problems, cognitive impairment, and gastro-intestinal (GI) bleeding (Huang, et al., 2006). Family caregivers often express difficulty in dealing with these complications. Administering medication is particularly problematic for caregivers. The reported average medications per day for home care survivors are 5.3 to 6.6 and 42% of them have four to nine medications per day (Chou, et al., 2006; Ni, Dai, Yip & Liang, 1998). Family caregivers have difficulty administering multiple medications and lack the ability to understand the instructional leaflet (Chiu, 1998). Caregivers also have difficulties in judging and dealing with emergency conditions immediately (Chin, 1995; Chiou et al., 2003; Shyu, 2000). In clinical settings, emergency conditions often cause family caregivers to feel high stress about providing caregiving at home.

*Caregiving Outcome*s

At home caregiving outcomes contain the outcomes for both the care receiver and the caregiver. From the studies in Taiwan, the outcomes for care receivers include the rates of death, re-admission, improvements of health problems and institutionalization. The outcomes for family caregivers include caregiver burden, depression, quality of life, and quality of care.

Outcomes for Care Receivers

Instead of a recovery rate, an improvement rate is used to evaluate the outcome of home health care. Whereas, the improvement of health conditions does not mean complete recovery or independence; instead, it means the tubes have been removed, the number of tubes has been reduced, or family caregivers are able to appropriately take care of disabled persons. Importantly, care receivers are still in a totally dependent situation. Unfortunately, the reported rates of overall improvement of health conditions tend to be low, from 13% to 30% (Huang, et al., 2006; Yeh, et al., 1998). In addition, 77% of the improvements occur in the first six months and 88% within the first year (Huang, et al., 2006). After two years there is no improvement of health conditions for home care survivors (Huang, et al., 2006).

After receiving home health care services, only 4-13 % of the home care survivors have an improvement in self-care ability, and 2.7 to 5.8% become worse during the first six months (Hung, et al., 1999; Liao, et al., 2000; Tu & Wang, 1998; Yeh & Wen, 2001). Notably, around 82 to 94 % of them remain at the same level of self-care condition, and 73% have no improvement in consciousness (Yeh & Wen, 2001). Receiving early and intensive rehabilitation can significantly improve stroke survivors’ self-care capabilities (Wang, Hsiung, Chen & Hsu, 2003). Moreover, the reported weaning rates of NG, Foley and trachea are seriously low, 4.0%, 2.7% and 2.7%, respectively. No studies investigate the reasons for the low weaning rates of tubes.

The overall reported death rates for disabled persons receiving home health care are from 38% in Lo, et al. (1991), 59% in Yeh et al. (1998) to 70% in Huang, et al. (2006). The death rates for stroke survivors at the first six months are 46.5% and 62.0% for one year (Hung, et al., 2006; Yeh, et al., 1998). The risk factors are placement of Foley catheter, pneumonia, pressure sores, and NG feeding. Reported odds ratios are 4.97, 4.48, 3.97, and 3.97, respectively (Huang, et al., 2006). Infection is the major cause of death for stroke patients. The overall unplanned re-hospitalizations are 44-77% (Chou, et al., 2006; Chung, et al., 2003; Lo, et al., 1991; Yeh & Wen, 2001). Like the reasons for death, the major reasons for re-hospitalizations are pneumonia, pain, sepsis, UTI, and gastrointestinal bleeding (Chen, et al., 2003; Chou, et al., 2006; Dai, et al., 2002). In total, infections account for over 60% of unplanned re-hospitalizations. In addition, the reported most common complications are pressure sores, UTI, and pneumonia. The most common complaints of health problems are constipation, cough, fever, skin problems, impaired cognition, and GI bleeding (Huang, et al., 2006). As a result, persons using home health care services have high utilization rates of emergency and outpatient services. Around 80% of them have utilized emergency services (Yeh & Wen, 2001) and each person has an average of 27 occurrences of outpatient visits per year (Chung, et al., 2003). A stroke survivor with moderate or severe self-care deficiencies, first stroke, presence of a wound, invasive nursing care, care from or by untrained family members and a full-time helper (Chuang, Wu, Ma, et al., 2005), and caregivers experiencing high caregiving strain (Shyu, et al., 2004) are the major reasons for unplanned re-admissions. In other words, the more complex caregiving tasks, coupled with care by either a novice or an untrained family caregiver, are important factors for unplanned re-hospitalization.

Accordingly, the first one to two months is the critical time period for a stroke survivor to improve his health condition and reduce the death and re-admission rates. However, because of the lack of nursing skills or adequate knowledge to provide care, the family caregivers, especially the novice or untrained ones, are unable to manage the complexity of the care demands and appropriately perform those highly technical caregiving tasks during the time period (Shyu, 2000). As a result, their care receivers have high rates of death, unplanned re-hospitalization and emergency utilizations during the first six months. Family caregivers lacking caregiving abilities also put their care receivers in jeopardy of institutionalization. Thoroughly preparing a novice family caregiver is therefore a critical issue for preventing the care receivers’ negative impact and improving care receiver’ quality of life and care at home.

Outcomes for Family Caregivers

For Taiwanese family caregiver studies, reported caregiver outcomes include depression, burden, quality of life, quality of care, finding a balance point, and family function (Chen, Chiou & Kao, 2006; Chiou et al., 1988; Dai, Chao & Lein, 1990; Lee & Wu, 1999; Wu & Chou, 1977; Shyu, 2002). Caregiver burden, stress or strain is the most common indicator for caregiver outcomes (Chiou, Hsu & Wu, 2002). However, no study explores the positive outcomes of caregiving, such as spiritual uplift and sense of mastery. Caregiver burden generally describes the perceived negative consequences that result from providing caregiving. Typically, it is the psychological status resulting from the combination of physical work, emotional pressure, social constraints, and the financial demands of caregiving (Dillehay & Sandys, 1990; Hunt, 2003). Insufficient caregiving knowledge and skills, and lack of social support are two strong predictors. Four studies indicated that caregiving knowledge and skills can reduce caregiver burden; however, Lee and Wu (1998) found family caregivers receiving health providers' instruction had higher caregiver burden. This is consistent with my own previous study (Wu, 1995). Lee and Wu (1998) explained health care providers lack of understanding about caregivers' perceived caregiving needs and failure to assess caregiver needs before providing teaching. Rather, health care providers focused the teaching from a professional perspective relative to the care receiver's illness conditions, resulting in a discrepancy between provided content and caregivers' needs. The learning outcome was discounted.

In contrast to caregiver burden, caregivers receiving more caregiving knowledge and skills, and having more social support positively predict the quality of care (Chen et al., 2006; Kao, Lu, Yeh & Liu, 1999; Lin, & Chiou, 1995; Wu & Chiou, 1997). That is, caregivers who are non-spouse, have better health conditions, longer duration of caregiving, a better relationship with the care receiver, higher education, less caregiver burden, a positive willingness to take on the caregiver role, and receive caregiving education, have been found to have a better quality of life. Receiving social support is an important buffer for preventing negative impact on family function (Kao, et al., 1999; Pan, et al., 1998).

In general, when caregivers are female and experienced, have better health conditions and better relationships with care receivers, and receive caregiving education and family manpower support, the caregiving outcomes move in a positive direction. In contrast, when caregivers are old and feel a high degree of difficulty associated with caregiving tasks and care receivers are highly dependent, the caregiving outcomes tend to be negative.

Interventions for Family Caregivers

Education, social support, counseling and multi-component programs are four major strategies of interventions for family caregivers (Acton & Winter, 2002; Forster, et al., 2001; Visser-Meily, van Heugten, Post, Schepers & Lindeman, 2005). Providing education is the most common intervention and nurses are often assumed as the most appropriate persons for providing caregiver education (Wiles, Pain, Buckland & McLellan, 1998). The reported outcome indicators for the interventions vary in different studies, including increasing caregiving knowledge and skills, coping strategies, caregiver strain or burden, quality of life, quality of care and family function.

Currently, there are five intervention studies for family caregivers with stroke or disabled persons conducted in Taiwan; three for stroke family caregivers and two for disabled or elder family caregivers. Three of them provide education programs (Chen, et al., 2002; Hung, et al., 1999; Kuo, Chiang, Wu & Kuo, 2006), and two interventions are mixed with education and social support (Chia & Li, 1999; Kuo, Shyu, Chiang & Chen, 2005). Only one study is a random control trial. Outcomes included family caregivers' caregiving knowledge and skills, burden and quality of life. All of these studies reported positive effects on the measured outcomes.

Serious methodological flaws negatively affect the acceptability and generalizability of these findings. First, the studies lacked a control group and accounting for potential confounders, such as caregivers' educational level, duration of providing care, care receivers' degree of dependence, and the numbers of tubes. Those factors have been reported as important factors for family caregivers' seeking and learning information. Second, four studies employed convenience sampling which might cause selection bias. As a result, it is difficult to conclude that the effect is due to the intervention. On the other hand, the quality of the data is based on the reliability and validity of the measurement. Nevertheless, all of the instruments for testing outcomes lacked appropriate psychometric measure. The unacceptable measurement reliability and validity also limited the internal and external validities of these studies.

One important phenomenon is noticed from these studies. Among these five studies, with the exception of Chia and Li (1999), all the education program content were based on the health providers' view instead of the family caregivers' perspective and used a unit format of education content for all participants. However, many scholars have highlighted that family caregivers' needs are changing at different time periods (Eames, et al., 2003; Grant, et al., 2004; Hanger, et al., 1998; Rodgers, et al., 2001; Shyu, 2000). Those studies did not identify the stage that caregivers were in nor tailor the provided information for each participant. As a result, the provided information might not meet caregivers' needs in their current situations. This could explain why only 30% of family caregivers increased caregiving knowledge and skills after receiving nurses' instruction in Hung et al. (1999). Obviously, researchers lacked an essential assessment before designing their education programs. It is therefore predictable that the effects should be limited.

After discharge, the home care agency is the only resource that family or patients can use to get services from health professionals in Taiwan. The in-home services can be viewed as one type of intervention for family caregivers. Unfortunately, the home health outcome is controversial. In Lo, et al. (1991), the first home visit, the mean nursing problems was 7.2. After three months of receiving home health care, the number of nursing problems was reduced to 3.9. The most improved nursing problems were knowledge deficit, interrupted family process, impaired skin integrity, and altered patterns of urinary elimination and nutrition. It seems the nursing problems had much improvement after receiving home health care services. However, with the exception of knowledge deficit and interrupted family process, the changes were very small (less 5%). In other words, over 90% of care receivers still had skin, urinary and nutrition problems. It is not meaningful enough for the clinical situation. Regarding the improvement of knowledge deficit, researchers only measured caregivers' medication knowledge to represent caregivers' overall knowledge deficit problem. We don't know if the overall knowledge deficit problem has been improved or not. Furthermore, Dai et al. (1990) found that after a stroke it took three months for the family function to stabilize. Thus the improvement of family function could be the natural recovery process of a family under a crisis situation. It is hard to conclude the improvement is due to the intervention. Taken together, it seems to over-conclude the home health care effects from this study. In addition, the outcomes of home care services were high rates of death, re-hospitalization and emergency utilization (Chou, Yeh & Yu, 1999; Chung, et al., 2003; Yeh & Wen, 2001). Consequently, the quality of home care service must be taken into account. In particular, infections account for over 60% of care receivers' death and re-hospitalization. Theoretically, most infections are preventable if family caregivers have the knowledge, skills and resources to provide appropriate care. However, I argue that due to limited service time, the home health care nurse is thwarted in providing adequate needs-based skilled nursing. The average time for each home visit is estimated only 40 to 60 minutes (Kuo & Hwu, 1998; Lin, Pan et al., 2000). During one hour, home care nurses spend around 25 minutes on performing skilled nursing, such as replacing NG or Foley tubes and wound care, and only spend eleven minutes for teaching (Lin, Pan et al., 2000). It is unknown if the family caregiver has enough time to learn components of the caregiving role.

Moreover, Yeh, Shu and Wen (1996), found that 75% of home care survivors were transferred at the same day of patients' discharge, 30% of patients were referred after discharge. Over 37% of them had the first home visit ten days or longer after discharge. It is questionable if home health care nurses have sufficient time to discuss family care plans with hospital staff members and time to access family caregivers' and patients' needs before providing care. Home care services might become fragmented or discontinuous. As a result, due to the insufficient time for learning, and delay or discontinuous home health care, the family caregivers often become unable to overcome their caregiving problems. Due to family caregivers' lack of caregiving knowledge and skills and insufficient health care service, care receivers have often already developed contraction of joints, pressure sores and urinary tract infections by the time they receive the first home visit (Hung, et al., 1999).

Role Transition Process

Role transition occurs when a role is added to or deleted from the role set of an individual or when the behavioral expectations for an established role change significantly (Schumacher, 1995). Family caregiver role is one new role due to her/his care receiver's health problems. The new role causes the dyad multidimensional changes, roles, relationships, abilities, and patterns of behaviors. The dyad need a time period for adjusting themselves to the new situation. The process has been reported to be filled with challenges, stress and burden (Hunt, 2003).

According to Lazarus and Folkman (1984), stress is defined as "a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (p 21)". When a person encounters a stress issue, he/she appraises the situation. The appraisal process includes primary, secondary and reappraisal. Primary appraisal judges the stress in three forms: harm/loss, threat and challenge. Harm/loss refers to damage the person has already sustained, threat refers to anticipated harms or losses, and challenge refers to events that hold the possibility for mastery or gain. Threat appraisals center on the potential harms and is characterized by negative emotions such as fear, anxiety, and anger. In contrast, challenge appraisals focus on the potential for gain or growth and they are characterized by pleasurable emotions such as eagerness or excitement. A stress issue can be appraised as threat and challenge simultaneously. But the threat can shift to challenge by effective coping strategies. Secondary appraisal is a judgment and expectation concerning what might and can be done (i. e., possible coping options) and the likelihood of particular outcomes (i. e., consequences of using a particular strategy). Bandura (1995) differentiates expectations into outcome expectancy and efficacy expectation. Outcome expectation refers to the person’s evaluation that a given behavior will lead to certain outcomes. Efficacy expectation refers to the person’s conviction that he or she can successfully execute the behavior required to produce the outcomes. Lazarus and Folkman (1984) delineate individuals who have a higher level of commitment, a belief of personal control, and more relative experience and knowledge; and the situation with high predictability and less uncertainty and ambiguity as able to intensify challenges and reduce perceived threats in the stress situation. Reappraisal refers to a changed appraisal based on new information from the environment and/or the person. Reappraisal follows an earlier appraisal and is the result of cognitive coping efforts.

Schumacher (1995) conceptualizes role acquisition theory to explain the family caregiver role-taking process. The cognitive stress appraisal process plays the core determinant for the role acquisition. Six transition conditions have been proposed as important factors influencing transition outcomes: meanings, expectations, level of knowledge and skill, level of planning, emotional and physical well-being, and the environment. Accordingly, before taking on the caregiving role, a new family caregiver begins with subjectively appraising the anticipated situations and evaluates the likely effect on one’s life. The anticipation is based on personal perspective and cultural context of the transition. An individual’s previous experience, level of knowledge and skills, level of planning, emotional and physical well-being, the relationship with the care receiver and the support resources affect the appraisals and evaluations. Incongruence of previous experience and the real transition situations, insufficient knowledge and skills preparation, under planning for the problems, issues, and needs arising during the transition, emotional unreadiness and physical discomfort, bad relationship and lacking in social support negatively influence the transition process. Those negative situations caused family caregivers to feel uncertainty and high stress during the process. In other words, if their expectation and preparation are inconsistent with the real situations, uncertainty occurs (Schumacher, 1995). The level of knowledge and skills relevant to a transition influences the level of uncertainty during the transition process and both caregiver and care receiver’s health outcomes (Schumacher, 1995; Schumacher & Meleis, 1994). In contrast, when one knows what to expect, has better preparation, higher mutuality with the care receivers and other family members, and social support, the stress associated with transition may be somewhat alleviated (Schumacher & Meleis, 1994).

Nolan, et al. (1996) emphasize that before taking a caregiving role the family member needs to be fully informed about the caregiving situation and empowering caregiving ability. Brereton (1997) also indicates that knowledge about the impact of the disability can improve family caregivers’ adaptation and coping ability. From the situational appraisal, family caregivers will recognize their needs due to the changing relations and situations, and seek various resources to find out appropriate ways to deal with their needs. Thus during the transition process, learning new skills and knowledge are needed.

Anticipatory preparation facilitates the transition experience, whereas lack of preparation is an inhibitor. Preparation is learning knowledge about what to expect during a transition and what strategies may be helpful. Sufficient preparation is a key factor for a healthy transition process (Schumacher, 1995). Importantly, a family member's commitment increases with the satisfactions of needs (Schumacher, 1995). Education has been indicated as the primary modality for creating optimal conditions in preparation for transition (Schumacher & Meleis, 1994). It is clear that providing knowledge and skills can better prepare family caregiving capability and empower family caregivers' perceptions of role mastery. In Schumacher' model, role mastery, subjective well-being, and family adaptation are indicators for a successful transition. Role mastery means individuals have competence, decision-making, and psychomotor skills, and self-confidence. Family caregivers also create meaning and pleasure through caregiving process. Subjective well-being indicates effective coping, management of one's emotions as well as sense of dignity and quality of life. Mutuality represents the positive quality of the relationship between the caregiver and care receiver and it is an indicator of positive caregiving outcomes (Archbold, Stewart, Greenlick & Harvath, 1990). On the other hand, during the transition process, disagreements or family disruption may occur, but when the process moves toward a successful conclusion, the well-being of family relationships is restored or promoted to adaptation (Schumacher & Meleis, 1994). In contrast, conflict between family members increases the transition stress. Unfortunately, a new caregiver often lacks any formal training and lacks sufficient resources for learning essential skills and knowledge. Research findings have consistently shown that family caregivers are not well-prepared before providing care (Forsberg-Warleby, Moller & Blomstrand, 2004; Grant et al., 2004). In Taiwan, 65% of family caregivers have no previous caregiving experience (Tseng, 2003), and 85-95% lack caregiver training (Chin, et al. 1999; Hung, et al., 1999; Sun, et al., 2005; Tseng, et al., 2001). Before discharge, only 11-13% of family caregivers have received any education from health care providers (Tsai, et al., 2004). Obviously, the preparation is seriously insufficient for Taiwanese family caregivers.

Lack of sufficient time for learning is one factor for family caregivers being unprepared for caregiving at discharge. Other reasons include being suddenly drawn into the caregiver role, short length of hospital stays and unapproachable busy healthcare providers (Bakas, Autstin, Jessup, Williams & Oberst, 2004; Kerr & Smith, 2001; O'Connell, Baker & Prosser, 2003; Rosenthal, Pituch, Greninger & Meteress, 1993; Wellwood, Dennis & Warlow, 1994). Unlike family caregivers for other chronic conditions such as dementia, caregivers of stroke survivors are often thrust suddenly into the caregiving role after a stroke event (Bakas, et al., 2004; Kerr & Smith, 2001; Lin, Hsiao, et al., 2000). Furthermore, the elder stroke survivors often have short hospital stays and are discharged early (Bakas, Austin, Okonkwo, Lewis & Chadwick, 2002). Thus caregivers have a sudden, more urgent need for skill attainment (Bakas, et al., 2004; Kerr & Smith, 2001; Lin, Lee, Huang, Liu & Lin, 2000). Caregivers have expressed that they do not have lengthy enough periods during which they can adapt to their new situation, or learn the skills required (Kerr & Smith, 2001). On the other hand, the health professionals, particularly nurses, are too busy to be approached (Chiu, Pai, Shyu, Chen & Chung, 1998; Rosenthal, et al., 1993; Smith, Lawrence, Kerr, Langhome & Lee, 2004; Wellwood, et al., 1994) and lacke adequate educational programs. As a result, family caregivers are consistently waiting for new information from health care providers during the hospitalization and early discharge stage (Silva-Smith, 2007).

Educational Interventions

Educational interventions are positively associated with reducing family caregiver burden and improving other family caregiving outcomes (Acton & Winter, 2002; Steffen, et al., 2002; Wellwood, et al., 1994). Moreover, providing education programs to increase caregiver knowledge is consistently and highly recommended from Taiwanese caregiver studies (Chien & Shyu, 2000; Chiu et al, 1996; Hsu & Chiou, 2004 b; Liu, et al., 1998). An ideal educational intervention should provide the information at the right time, with right content and with the right learning strategy. Learning theories provide frameworks to explain and predict the learning process and outcomes. Health care providers, in particular nursing staff, are the facilitators for helping family caregivers taking on the new role smoothly and successfully. A good facilitator needs to provide well-organized learning programs for family members. Unfortunately, a review of Taiwanese elder caregiving literature shows that learning theories are essentially overlooked by researchers and clinical staff. The literature includes untested assumptions for the nursing teaching and family caregiver learning process. These assumptions include: (1) that nurses' are the experts and teach the health content using traditional pedagogical principles; (2) formal written and verbal instruction (without demonstration or feedback) are appropriate and effective; (3) nurses know what learners' needs are; (4) nurses are able to teach effectively; regardless if they ever received any education about teaching principles and learning theories; and (5) all family caregivers have similar learning needs and are able to learn effectively. In the literature, only Lo, et al. (1991) and Lee and Wu (1998) questioned the nurses' teaching ability and family caregivers' learning process.

On the other hand, previous studies indicated family caregivers present with different learning needs from hospitalization to the early discharge (Eames, et al., 2003; Grant, et al., 2004; Hanger, et al., 1998; Rodgers, et al., 2001; Shyu, 2000). Nevertheless, this is not addressed in the Taiwanese family caregiver studies. Consequently, the information may not provide the right content and may account for the ineffective outcomes for the five intervention studies in Taiwan. It is important to better understand the caregiver learning situation from the perspective of role transition and learning theories to better identify the right time for family caregivers to learn the new role and better understand family caregivers' attitude and necessary educational information that will facilitate learning the new knowledge and skills for taking on a caregiving role.

Learning Theories

Learning encompasses a multitude of competencies, from knowledge of simple facts to great skill in complex and difficult procedures (Driscoll, 2005). Kolb (1984) defines learning as “the process whereby knowledge is created through the transformation of experience” (p. 38). A family caregiver often faces tremendous compound difficulties and challenges when taking the new role. In order to successfully perform the new role, family caregivers not only need to learn new knowledge and skills, but also need to learn how to manage their own emotional stress and adjust their life styles. Thus the family caregiving experience can be viewed as a process of continuous learning. The learning outcome is expected as a relatively permanent change in mental processing, emotional functioning, and behavior as a result of experience (Braugart & Braugart, 2003).Transfer is another indicator of a learning outcome. Transfer refers to knowledge and skills that can be applied in new ways, with new content, or in situations different from where they were acquired (Schunk, 2004). Similarly, after learning new skills or knowledge, we expect that family caregivers can transfer what they learn into their real-life situation and overcome their problems.

The most common theories used to explain learning are: behavioral, cognitive, and social learning theories. Behavioral theory views learning as the product of the stimulus conditions (S) and the response (R). Learning is demonstrated following the presentation of a specific environmental stimulus. The primary concern is how the association between the stimulus and response is made, strengthened or maintained. Thus behaviorists closely observe responses and then manipulate the environment to bring about the intended change. According to behavioral theories, reinforcement can motivate learning (Braugart & Braugart, 2003). Behavioral theory views the mind as a “black box” and ignores what goes on inside the individual. In contrast to behavioral theories, cognitive learning theorists stress the importance of what goes on “inside” the learner. The key to learning and changing is the individual’s cognition (Schunk, 2004).

According to this perspective, individuals must change their cognitions to learn. Information process is one major branch of cognitive learning theories. Information process emphasizes a cognitive process of learning. The process includes individual’s thinking processes; thought, reasoning, the way information is encountered and stored, and memory functioning (Driscoll, 2005; Schunk, 2004). Gagne (1985) identifies four phases of learning process: receiving the stimulus situation, phase of acquisition on input, storage or retention phase, and retrieval or recall. Teaching strategies with well-organized material, clearly structured instruction and more time for retaining and rehearsing information can enhance the learning outcomes (Alutu, 2006).

Social cognitive theory, self-efficacy theory, as developed by Albert Bandura is largely a cognitive theory but incorporates principles of behaviorism. Social learning theory is the study of how people, behaviors, and the environment are inner-related. From the perspective of social learning theory indicates that learning occurs by observation. Learning is often a social process, and other individuals, especially “significant others,” provide compelling examples or role models for how to think, feel, and act (Braugart & Braugart, 2003). Bandura’s social learning theory, self-efficacy theory, is the most common applied theory in enhancing family caregiver learning (Steffen et al., 2002). The self-efficacy theory states that specific efficacy beliefs affect individual behavior, motivational level, thought patterns, and emotional reactions in response to any situation (Bandura, 1995). Bandura (1977) defines self-efficacy as the expectation that one can successfully perform a specific task or behavior. In applying this theory to caregiver issues, psycho-educational strategies and personal mastery of relevant skills with instructive feedback can enhance caregiver perceiving capability to cope with the demands of one’s specific caregiving situation (Steffen et al., 2002; Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999). DiBartolo (2002) explained that self-efficacy could empower caregivers by increasing their confidence and competence, which consequently improves both their physical and emotional health.

Considering the characteristics of the learners, adult Taiwanese family caregivers, it is important to review adult learning theory (andragogy). Andragogy means “the science or art of teaching adults.” The term is coined by Knowles in order to contrast their beliefs about learning to the pedagogical model. Knowles devises a set of six assumptions that differentiated adults from children learners (pedagogy). From the andragogy view, the characteristics of adult learners are viewed as being self-directed, autonomous and independent; deciding for themselves what is important and meaningful to be learned; having prior experiences as a rich learning resource and validating the information based on their beliefs and experience; readiness to learn for what they experience as a need to learn, expecting what they are learning to be immediately useful; and being problem-centered in their orientation to learning and being motivated to learn by both internal and external motivators (Kerka, 2002; Knowles, et al., 2005).

Knowles believes that an andragogical approach to teaching adults is vitally important in order to take the adult’s learning needs into account and to “teach adults how to learn”(Knowles, 1980). Before providing an education program, an educator needs to: assess adult learner’s learning needs for their current interest or problems; determine learners’ background knowledge and skills; relate current learning to appropriate past experiences and to make it meaningful learning; and logically organize teaching materials. Importantly, adult learners are motivated to learn if they perceive that learning will help them perform tasks or deal with problems that they confront in their life. The teaching process should be in a collaborative and supportive, i.e. safe, trusting and respectful environment. Recently, though andragogy has been debated regarding the flaws of assumptions and insufficient research support (DeYoung, 2003; Kerka, 2002; Milligan, 1997), the three determinants are useful teaching-learning principles for health care providers when providing education to adult learners. Unfortunately, those learning theories were not applied in the Taiwanese education studies.

Three Determinants for Learning

For a formal teaching-learning process, educators need to assess the determinants of learning. According to learning theories, adult learning principles and characteristics of aged learners, three determinants of learning indicated by Kitchie (2003) are essential for designing an appropriate education program: learners' readiness to learn (when the learner is motivated and ready to learn), learning needs (what the learner needs to learn), and learning style (how the learner best learns). Good assessment is the cornerstone of providing quality of education (Bastable & Rinswalske, 2003). Mismatch between learner needs, teaching strategies and learning styles increases the learning time and decreases retention of knowledge (C. R. Chase, 2001).

Readiness to Learn

It is important for an educator to evaluate and incorporate learner's attitude and belief toward caregiving before providing an educational program. Rosenal (1992) indicates readiness to learn is a self-evidence attitude and belief toward learning. Kitchie (2003) defined readiness to learn as the time when the learner demonstrates an interest in learning the type or degree of information necessary to maintain optimal performance or to become more skillful in a job. Vanetzian (1997) also defines readiness to learn as evidence of motivation and ability to learn at a particular time; it is a dynamic state that influences the outcomes of teaching. In turn, readiness to learn occurs when the learner is receptive to learning and is willing and able to participate in the learning process. In addition, at the beginning of caregiving and facing new situations are opportunities to develop new caregiving patterns (Nkongho, & Archbold, 1996). Health care providers should provide the necessary information, help the caregiver perform correct caregiving skills and establish appropriate caregiving routine. Thus it is important to identify the vital time period for learning the caregiver role. Research indicated the first month is the critical time for a family caregiver to learn necessary information (Grant, et al., 2004;

Shyu, 2000; Silva-Smith, 2007). However, caregiving is a dynamic process and family caregivers face new care situations during the process. Only one study (Shyu, 2000) was conducted on Taiwanese family caregivers. Altogether, it is hard to conclude the stroke family caregiver's critical learning time is the same as other populations.

Kitchie (2003) indicates four types of readiness to learn: physical, experiential, knowledge, and emotional readiness. Common factors related to physical readiness are learner's age, gender, health status, and the complexity of tasks. Older adults or those with low literacy skills will feel it particularly difficult and time-consuming, and they may even refuse to learn (Kitchie, 2003). Higher-educated caregivers generally desire to learn more information than lower-educated caregivers (van Veenendaal, Grinspun & Adriaanse, 1996). Ill or unhealthy learners have lower energy available for learning than healthy learners (Kitchie, 2003; Tiivel, 1997; Vanetzian, 1997). The more complex tasks will require more cognitive, affective and psychomotor skills to perform. Experiential readiness refers to the learner's past experiences with learning. Learners with positive experiences are more likely to be motivated or willing to learn. Past coping mechanisms and cultural background affect learner's past learning experience (Kitchie, 2003; Tiivel, 1997). Knowledge readiness refers to the learner's present knowledge base, the level of learning capability, and the preferred style of learning (Kitchie, 2003). For Taiwanese family caregivers, around 60-85% of are female and around 30% of Taiwanese family caregivers are older, illiterate and have health problems. Likewise, there is no study focused on understanding learning readiness for Taiwanese family caregivers.

Emotional status can influence the individual's ability to learn, including anxiety level and motivation. Anxiety is a factor that influences the ability to perform at a cognitive, affective, and psychomotor level. A moderate degree of anxiety is a motivator to learn, but low or high anxiety will interfere with readiness to learn (Kitchie, 2003; Vanetzian, 1997). Female, spouse, older caregivers tend to be more anxious and report more stress and depression symptoms than male, non-spouse and younger caregivers (Forsberg-Warleby et al., 2004; Parks & Pilisuk, 1991).

Before taking on the caregiving role, family caregivers' motivation, preparedness and caregiving ability are the key determinates for the quality of care. Willingness to take on a caregiving role has been reported as an important factor with caregiver burden (Lu, 2005). Under Chinese culture, obligation, filial piety, reciprocation and the concept of Karma are major reasons for family caregivers taking on their caregiver roles. Karma (Yin-Guo) means that a person inevitably reaps what he or she sows. Simply speaking, if A owes B or B owes A something in a previous life, then A and B are related in this life in order to return the debt between them (Kao, & Stuifbergen, 1999). Thus Yin-Guo may resolve in one life or may be carried over into other lives. The concept came from Buddhism, the most popular form of religion and is mixed with Taoism and Confucianism in Taiwan folk religion (Hsu & Shyu, 2003; Kao & Stufbergen, 1999). People believe if they have to pay a large service to someone but do not receive back equivalent rewards; the reason must be that they owed the person from their previous life.

For spouses and children, obligation is accompanied with affection. Spouse family caregivers are much more willing to care for their spouse because of strong affection. Older couples strongly believe that marriage involves reciprocity and mutual support throughout their entire life, so caring for each other when aged and sick is important. Children often say that caring for parents is “a matter of course,” “a universal truth,” and an “obligation” (Chien & Wu, 1999; Hsu & Shyu, 2003; Kao & Stuifbergen, 1999). Filial piety is a socially approved virtue and contains attributes of respecting, caring for, and loving the parents (Dai & Dimon, 1998). Adult children with higher filial piety demonstrate a higher willingness to care of their parents (Chien & Wu, 1999). Therefore, spouses and children tend to have higher willingness to take on the caregiver role. In contrast, for daughters-in-law, obligation is based on cultural and social expectations. Under cultural expectations, a daughter-in-law is expected to fulfill her role and should not complain too much. Therefore, for a daughter-in-law caregiver, caring for the parents-in-law come from a feeling of “should-be,” “being-called,” and “equity of responsibility sharing” (Chao & Roth, 2000; Hsu & Chiou, 2004 a). Thus they easily become emotionally distressed, *Wu-Nine* (frustrated, unpleasant, depressed, and conflicted) (Chao & Roth, 2000). Therefore, daughters-in-law are often passive to take on their caregiving roles.

The various types of relationships not only affect the motivation for taking on caregiving roles, but also affect the context of providing care and caregiving outcomes. In Wu and Lin (1999), spouses and daughters provided more personal care than sons and daughters-in-law. Daughters-in-law rarely managed family financial issues. Simultaneously, children or daughters-in-law had more competing needs with other family caregiving tasks. Moreover, sons are delegated with more power and authority (Shyu, 2000). They often play the role of decision maker for their dependents (including their elderly parents). Therefore, with different relationships, family caregivers might identify and commit to their caregiving roles with different perceptions and expectations of caregiving contexts. They might demonstrate different motivation and define different needs for learning caregiving knowledge and skills as well. However, there is no study focusing on understanding the perceptions of caregiving roles, context and needs among different caregiving roles for Taiwanese family caregivers.

Learning Needs

In addition to assessing readiness to learn, nurses also need to assess learning needs (what) before providing education (Bastable & Rinswalske, 2003). Mismatch between learner needs, teaching strategies and learning styles increases the learning time and decreases retention of knowledge. Learning needs are defined as gaps in knowledge that exist between a desired level of performance and the actual level of performance. Such gaps exist because of a lack of knowledge, attitude, or skills (Kitchie, 2003).

Caregivers heavily rely on health professionals (77-88%) to get necessary information (Rosenthal, et al., 1993; van Veenendaal, et al., 1996; Wiles, et al., 1998). In particular nurses are viewed as the appropriate health professional to provide information to patients and caregivers because they are accessible and have adequate knowledge to provide information (Wiles, et al., 1998). Yet, around 40% to 70% of caregivers who have been given information still indicate that the educational information is unsatisfactory or unneeded (Eames, et al., 2003; Rodgers, et al., 1999; van Veenendaal et al, 1996). Healthcare providers are lacking in skills for appropriate evaluation of caregiver needs before providing information (Rosenthal, et al., 1993; van Veenendaal, et al., 1996). This includes recognizing the importance of reassessing caregiver needs as they change over the course of the caregiver career. Nevertheless, there is a common error made by healthcare educators: Nurses are often assumed to be able to recognize the information that patients and caregivers need (Johnson, Pearson & McDivitt, 1997). The education programs are often predominantly derived from the professional viewpoints rather than from family caregivers' views. Consequently, there are discrepancies between the provided information and caregivers' real needs (Cook, et al., 2006; Pierce, et al., 2003; Rodgers, et al., 2001).

On the other hand, caregivers' learning needs are changing during different time periods (Eames, et al., 2003; Grant, et al., 2004; Hanger, et al., 1998; Rodgers, et al., 2001; Shyu, 2000). Shyu (2000) employes a role tuning model to explain the development and patterns of caregiving roles in the transition from hospital to home for Taiwanese family caregivers with disabled elders. During the role transition process, family caregivers demonstrate various needs in different stages. Before discharge, caregivers need the information of disease symptom monitoring and management. Right after discharge, caregivers need to master personal care skills, and handle the care receiver's emotions. Then caregivers need emotional support for themselves at the later stage. Unfortunately, only four studies have been conducted on understanding the needs of Taiwanese family caregivers with stroke survivors (Chen, et al., 2001; Chiou, et al., 1988; Chung & Hung, 1999; Liu, et al., 1998). These studies all employed cross-sectional descriptive design with serious methodological concerns, such as using convenient sampling and lacking acceptable psychometric values of assessment tools. Moreover, the outcomes lack the capability to depict family caregiver needs in different time periods. Thus the real picture of the needs for Taiwanese family caregivers across the different time periods remains unclear. Forster, et al. (2001) systemically reviewed 36 studies of information provision for stroke patients and their caregivers. They concluded that future work should emphasize addressing the expressed needs of patients and caregivers and seek to identify appropriate teaching strategies which can be successfully implemented within clinical practice.

Learning Styles

Caregivers learn information by talking, reading, observing, listening and doing. Around 70% of the information is provided by “talking with the doctors or nurses in the hospital”, and 40-50% is received by “reading pamphlets” and “reading books about stroke” (Stewart, et al., 1993; van Veenendaal et al.,1996). Some caregivers learn nursing skills and physiotherapy exercise by observing and listening to the professionals at work on the wards (Smith et al., 2004). In addition, 59% of them use a trial-and-error approach and previous caregiving experience as their ways of learning (Stewart, et al., 1993). However, those learning ways are not suitable and effective for each family caregiver. Learning style refers to the preferred ways of an individual’s processing of information (Kitchie, 2003). Kolb (1984) defines learning styles as acquired, consistent patterns of learner-environment interaction. According to Kolb (1984) experiential learning, which is developed based on Piaget’s model of learning and cognitive development, learning is a four-stage cycle involving four adaptive learning modes -concrete experience (feeling), reflective observation (watching, listening), abstract conceptualization (thinking), and active experimentation (doing). Learning evolves from a concrete experience mode that concerns involvement in experiences leading to the reflective observation mode in which experiences are reflected on, thus forming the basis for the abstract conceptualization mode. In the abstract conceptualization mode, concepts are created that integrate those reflections into theoretical explanations. The cycle then evolves to the active experimentation. Four types of learning styles are formed by the combinations of two of four learning modes: diverger, assimilator, converger and accommodator. The diverger emphasizes on concrete experience and reflective observation, and learns by feeling and watching. The assimilator emphasizes on reflective observation and abstract conceptualization, and learns by watching and thinking. The converger emphasizes on abstract conceptualization and active experimentation, and learns by doing and thinking. The accommodator emphasizes on concrete experience and active experimentation, and learns by feeling and doing. Each learner demonstrates one of four style types predominantly and an individual's learning style has been identified as a significant factor affecting how that person learns. Learning styles measure a person's strengths and areas of weakness specific to learning. There is no right or wrong for individual learning preference (Kolb, 1984).

An assessment of learning style can assist educators in determining how health care consumers prefer to learn and enable the development of individually tailored teaching programs. Assessing the learning style and then focusing teaching strategies to meet those individual styles can increase motivation, improve retention and make the teaching-learning session more effective (T. M., Chase, 2001). Garity (1997) also indicates that analyzing learners' (caregivers') learning styles before providing information could strengthen caregivers' learning and their problem solving abilities.

An overview of the preceding discussion identifies three gaps in family care studies in Taiwan: (1) Different family members' readiness to learn and take on the caregiving role; (2) An understanding of the care situation (challenges and benefits); and associated learning needs for different family members from in the hospital to after discharge; and (3) the preferred learning styles of different family members. Thus, based on learning theories and an overview of family caregiver studies, an effective education-learning process is founded on a learner’s attitude, knowledge, and skill needs. In other words, it is proposed that at different points in time from hospital to home care, family caregivers need different information toward performing caregiving responsibilities and contexts. It is important to better understand if caregiver's readiness to learn is influenced by different caregiver characteristics, caregiver experiences, learning needs, and learning styles from the perspectives of and actions of family caregivers in-home care situations.

Summary

In this chapter, the general stroke care, caregiving at home and the caregiving outcomes were reviewed. After a stroke, 20-30% of the stroke survivors become confused and are discharged with tube placements. Around 90% of stroke persons are discharged to home and cared for by their family members. Obligation, affection and Karma are the major reasons for family caregivers taking on the caregiving role. Unfortunately, 85-90% of the family caregivers are unprepared for the caregiving tasks. They often face multiple care difficulties and challenges at home. Home care nurses provide the only in-home service after discharge. Nevertheless, the care receivers’ mortality rate, unplanned re-hospitalization and emergency room admission are considerable. Infections are the major reason for admission. The caregiving situations also cause family caregivers to experience personal stress. According to the role acquisition model, sufficient preparedness before discharge is positively related to the quality of care. The research then leads to the question of how caregivers learn their caregiving skills and knowledge, what they need to learn, and when is the best time for learning. With the learning determinant framework, ideally a well-designed education program is based on the learner’s readiness to learn, learning needs, and preferred learning styles; however, the three learning determinants remain under-explored in Taiwan.

CHAPTER III

METHODOLOGY

Chapter one and two presented the background on the experience of a family member learning to be a family caregiver for an elder person who had survived a stroke. A comprehensive literature review, gaps from previous studies, significance of the research, and research questions for this study were identified and delineated. This chapter outlines the research methodology.

Research Design

A qualitative approach holds that reality is socially constructed through individual or collective definitions of the situation (Taylor & Bogdan, 1984) and attempts to make sense of or interpret phenomena in terms of the meanings people bring to them in their natural settings (Creswell, 1998). Qualitative research is concerned with understanding the social phenomenon from the participants' perspectives through involvement in the life of those participants (Taylor & Bogdan, 1984). Through immersion in the phenomenon of interest, qualitative researchers build a complex, holistic picture, analyze words, report detailed views of the participants, and conduct the research in a natural setting (Creswell, 1998).

Patton (2002) indicates four major reasons for doing a qualitative approach: (1) questions about people's experiences, (2) inquiry into the meanings people make of their experiences, (3) researching a person in the context of her or his social/interpersonal environment, and (4) research where not enough is known about a phenomenon for standardized instruments to have been developed or even to be ready to be developed. Currently, only four studies focus on family caregivers with stroke survivors and no research investigates caregiving issues for caregivers with stroke survivors receiving home health care. There is a lack of sufficient research on the Taiwanese family caregivers’ experience of learning how to become a caregiver for an elder who has survived a severely debilitating stroke during the first year after discharge.

Sandelowski (2000) and Sullivan-Bolyai, Bova and Harper (2005) state the purpose of a qualitative description study is to seek a precise account of the experiences, events, and process that most people would agree is accurate. Unlike traditional qualitative methods (e.g., grounded theory, phenomenology, and ethnography) that tend to high level interpretation and theory development from data, the final product of a qualitative descriptive research is a lucid description of the participants’ experiences. Qualitative descriptive research offers a comprehensive summary of an event from the participants’ point of views using everyday language. Thus a qualitative description is easily understood by the lay population and clinicians. The goal of qualitative description is not trying to build a thick description of a culture (ethnography), develop a theory (grounded theory) or interpret the meaning of an experience (phenomenology); instead the goal is to communicate with clinicians and health care policy makers. Furthermore, Sullivan-Bolyai, et al., (2005) indicate that qualitative descriptive research is useful for conducting needs assessments and development of interventions.

The purpose of this research is to provide a comprehensive description of the care situation and associated learning needs and learning styles of family members who are providing care for their family stroke members at home during the first year post discharge. The research is expected to provide a descriptive picture of the family stroke caregiver experience during the critical period. The results are expected to inform National Health Insurance Bureau policy and programming, and future development and testing of educational interventions to improve family stroke caregiving outcomes. Taken together, a qualitative descriptive design is an appropriate methodology for this research (Sandelowski, 2000; Sullivan-Bolyai, et al., 2005).

Setting

Seventeen family caregivers were recruited from three collaborative hospitals: Chung Ho Memorial Hospital, Kaohsiung Municipal Min Sheng Hospital, and Ping Tong Christian Hospital. All the participants were living in Kaohsiung or Ping Tong areas, Taiwan (Appendix A). The former two hospitals are located in Kaohsiung City, which is the second largest city in Taiwan; the latter one is located in Ping Tong County. Those hospitals were chosen because they provide the major stroke care in these areas. The primary place for conducting interviews and observation was the family caregiver's home. This allowed family caregivers to feel more secure and free to tell their stories in a familiar environment. This also allowed a clear assessment of the environment and caregiving activity observations.

Sample

Purposeful sampling was used to recruit family members who were learning to provide home care for an elder who had suffered a severe stroke. Theoretical sampling with maximum variation (as data collection and analysis progress) was used to identify potential participants in this qualitative descriptive research (Sullivan-Bolyai, et al., 2005). The population was family caregivers of stroke survivors who were eligible for home health care services (described above). The inclusion criteria for stroke survivors were : (1) Stroke survivor was dependent after the current stroke; (2) Stroke survivor's current Barthel Index score was less than 60; (3) Stroke survivor was staying at home; (4) Stroke survivor was cared for either by one or more family members or/and a hired person. The inclusion criteria for family caregivers were : (1) Family caregiver identified as the family member who was primarily responsible for the stroke survivor's care at home; (2) The family caregiver was 18 years of age or older; (3) Family caregiver was able to communicate fluently in Chinese or Taiwanese languages. The participants were purposely sampled to include family caregivers who were a female or male spouse, daughter-in-law, daughter, or son.

Eight of the 16 stroke survivors were cared for by foreign care attendants. Therefore, the foreign care attendant was considered as a participant in this research. The inclusion criteria for foreign care attendants were: (1) The foreign care attendant was able to communicate fluently in Chinese or Taiwanese languages; (2) The foreign care attendant was able to give consent with the Chinese version of the consent form. In contrast, if the foreign care attendant was incompetent in Chinese or Taiwanese and unable to give consent, she was excluded from this research.

Recruitment of Participants

After the research had been approved by the three collaborating hospitals, the University of Iowa (IRB ID #: 200805766) (Appendix B) and by the hospital administration, the researcher clearly explained the research purpose and eligibility for family members' participation to the discharge planners and the home health care nurses. An IRB approved brochure (Appendix D) with the research purpose, criteria, researcher contact information, and a prepaid envelope was given to the discharge planners and home health care nurses for distribution to eligible participants. Twenty one family caregivers who expressed an interest in learning more about the research were contacted by the researcher by phone. After providing detailed descriptions of this research and screening for eligibility, 17 of the 21 potential participants were eligible. Data collection was conducted from July 7th to November, 15th, 2008.

Informed Consent

The stroke survivors were cared for by (1) family members only, (2) family members and hired foreign care attendants, (3) hired foreign care attendants but under family caregiver supervision. Therefore, if the stroke survivor was cared for by family members only, the researcher consented both family caregiver and stroke survivor. If the stroke survivor was cared for under the (2) and (3) conditions, the researcher consented family caregiver, stroke survivors and the foreign care attendant. The foreign care attendant was only consented for the observation of caregiving activities.

Two tools, Chinese versions of “Evaluation to Sign an Informed Consent Document for Research” and the “Mini Mental State Examination” (MMSE), were used to assess participants’ abilities of giving consent to participate in the research (Appendix C). The principle investigator evaluated family caregivers’ and stroke survivors’ abilities of giving consent to participate in the research study with "Evaluation to Sign an Informed Consent Document for Research." If they were unable to give a legally effective informed consent, verbal assent was obtained and verbal consent was obtained from their legally authorized representative. Foreign care attendants were assessed for their language competence by asking family caregiver and talking with the foreign care attendant. Those foreign care attendants, who were not able to read, speak or understand Chinese or Taiwanese language, were not consented or observed in the home care setting. If a participant was able to give consent, the researcher provided a detailed explanation of the research purpose, design, the advantages and risks of participation, and answered questions before he/she provide verbal consent (Appendix D). Upon consent, the time for data collection was scheduled for a mutually convenient time.

Data Collection and Measure

To be assured of receiving emic stroke care situational data, multiple strategies were used to systemically explore and describe the holistic picture of the caregiving situation as viewed by family caregivers (Sullivan-Bolyai, et al., 2005). An in-depth description of stroke care was conducted through interviewing the family, reviewing public documents and observation. These strategies included: (1) A description of the social and cultural context; and (2) one caregiving activity observation. Observation was conducted before or after each interview to include a description of the home physical environment, persons who were living in the home, stroke family member location in the home, and performed care activities. (3) Three formal interviews: the first interview was at the family caregiver's convenient time. The second interview was scheduled two to four weeks after the first interview. The third interview was conducted with four participants for validation of the findings by phone.

In qualitative research, the researcher is the tool of measurement. It is important to disclose the researcher's experience with the phenomenon under study and perspective that is brought to the research. The researcher provided care for her disabled grandmother for five years after her grandmother had fallen and suffered a stroke. Additionally, the researcher saw a need to do this research after establishing and running a home care agency for two years. These experiences provided the researcher with a desire to better understand stroke family caregivers' situations.

In order to assure the rigor of the collected data, two interview protocols and an observational protocol were developed (Appendix E). The protocols were refined following pilot testing with three caregivers. To foster credibility of data collection, brief field notes were taken by the researcher during observation and expanded upon immediately after the interviews. The researcher also wrote a personal journal right after each interview to capture immediate impressions, perceptions, and personal reactions experienced concerning the research process.

Confidentiality was assured to all participants before each face-to-face interview. The first interview focused on exploring their experience of providing care for their stroke survivors and describing family caregivers' readiness to learn, learning needs and learning style. The first interviews ranged from one to two hours. All interviews were audio-taped with the participant's consent. Questions were asked related to the caregiver's experience of dealing with and caring for their stroke survivors from onset of the stroke to the time of the interview, perceptions toward the experiences, what they needed to learn and how they learned caregiving knowledge and skills. The interviews were loosely structured so participants could freely and comfortably share their experiences. Following participant's answers, follow-up questions were raised and asked in order to describe a rich understanding of family caregivers' experiences. For example, participants were often reluctant to give recommendations when asked, "What would you say is your advice to others who are just beginning to take on this care role?" The same question, rephrased as a role-playing question, "Now if I am a family member and facing the exact same situation as you, what would you suggest to me?" tended to be more effective in eliciting feedback.

After the first interview, the audio-tapes were transcribed verbatim. Field notes and personal journal entries were transcribed. Personal journal entries were reviewed and areas of concern discussed with the committee chair to facilitate credibility of researcher during data collection and analysis. The researcher read the transcription thoroughly to obtain a sense of the overall data. The data was then clustered to depict a descriptive picture for each family caregiver's experiences. Areas of uncertainty or points without sufficient information from the first interview were marked and follow-up questions were created. For example, most family caregivers indicated a critical need for rehabilitation knowledge and resources; however, they consistently described range of motion as the only rehabilitation activities at home. Two new questions were phrased, "According to your family member's condition, what rehabilitation activities would you say are necessary for your stroke survivor?" and "According to your understanding, what are rehabilitation procedures?"

The second interview was scheduled two to four weeks later and lasted one to one and one-half hours. The preliminary analysis was taken back to participants to expand on, validate and/or refute the description and analysis. Areas of uncertainty and follow-up questions were asked to get richer information. In addition, any family caregivers' description of changes in the care situation and their learning needs/styles were identified. Observations were conducted before or after the interview. The inside and outside living environment was drawn on the observation protocol. Memo and field notes were taken during the observation. Each observation was transcribed immediately after each visit.

Data Management

Several steps were used to manage the collected data: (1) Creating one demographic file to keep the data intact and retrievable; (2) Coding each family caregiver as “F-1”, “F-2”… on each participant’s interview protocol, recorded-tapes, and observation field notes, and keeping the participant’s name and codes locked in a separate file from their data; (3) Transcribing tape recordings and field notes and entering transcribed qualitative data into NVivo 8.0 software for data management and analysis; (4) Entering both quantitative and qualitative data into both software programs as soon as possible; (5) Saving all of the coded electronic files on one computer and two portable hard drives with three different passwords; (6) Backing up all files and printing hard copies after each new data entry; (7) Keeping all documents in a secure fire and water resistant box.

Analytic Plan

Data collection and analysis were performed concurrently. Qualitative content analysis is an effort to understand the manifest and the latent content of data (Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Recommended steps for analyzing-synthesizing qualitative descriptive data include: Breaking down transcribed data into smaller units; recording insights and reflections on the data; sorting through the data to identify similar phrases, patterns, themes, sequences and important features; identifying major themes in the language of the participants; identifying and separating major common and major divergent ideas among all participants; naming representative themes of the major ideas to all participants; stating major ideas in the language of the researcher; constructing a description of the phenomenon from a synthesis of the themes in the language of the researcher (Miles, & Huberman, 1994; Sullivan-Bolyai et al., 2005).

In this research, comparisons of different sources of data were used to describe the family caregiving situation of an elder stroke survivor. Several steps were used to analyze the collected data: (1) For each interview of each participant, the researcher read through all collected information to obtain a sense of the overall data and highlighted and coded information with participants' language in the description; (2) The investigator wrote preliminary findings in the form of memos and reflective notes; (3) The preliminary analysis was taken back to participants to validate the information at the second interview; (4) The themes were developed based on the memos and codes. The themes contained detailed descriptions and interpretations based on participants' language and what the researcher observed; (5) The themes were compared among participants and were classified into several dimensions; (6) The themes and the dimensions were estimated with respect to the magnitude and compared with family caregivers' and care receivers' demographic data; (7) Since the interview information was in Chinese, the researcher translated the first two participants' interviews into English and analyzed the interviews in Chinese. Then the major findings and terms were translated into English. The researcher met weekly and discussed the analysis process, findings and terms with Dr. Lisa Skemp to facilitate the appropriateness of the analysis process. After the appropriateness of the analysis process was satisfied, the researcher analyzed the rest of the interviews in Chinese. Then the findings and themes were translated into English. In order to confirm that the whole analysis process was appropriate, three analyses of interviews were randomly sampled. The analyses content were translated back to Chinese to confirm the language and meaning equivalence; (8) The descriptions of the themes and dimensions were translated into English by the researcher. One bilingual Chinese health care researcher provided the evaluation of translated materials based on the documents from which the translations originated; (9) Those themes and dimensions were discussed with Dr. Lisa Skemp; (10) The final report was based on the nine steps of analysis.

Rigor

Lincoln and Guba (1985) establish “trustworthiness” as the term for the quality of qualitative research. They use the terms “credibility,” “transferability,” “dependability,” and “confirmability” as the equivalents for the respective quantitative terms “internal validity,” “generalizability”, “reliability,” and “objectivity.” Specifically for qualitative descriptive research rigor, Milne and Oberle (2005) recommend ensuring participants’ freedom to speak, ensuring participants’ voices are heard, and ensuring participants’ perceptions are accurately represented. To ensure freedom to speak, a purposeful sampling plan and participant-driven data collection are two major strategies. A purposeful sampling plan indicates choosing participants who can provide in-depth information of relevance to the research question/purpose and the sampling of participants based on the evolving analysis process until the data reach saturation. Participant-driven data means employing a flexible topic guide and allowing participants to tell their own stories in their own ways, which can ensure an emic perspective and build the trust relationship between researcher and participants. In order to ensure participants’ voices are heard, attention is paid to cues that suggest a participant might have more to tell with probes used to clarify and increase descriptive detail about the elder stroke care situation. Timely transcription, re-reading and comparing the transcribed data and tapes are ways to ensure the participants’ perceptions are accurately represented. On the other hand, using participant-driven codes, critical reviewing coding during the on-going data collection and analysis, and using participants’ language and meaning are ways to ensure credibility. Furthermore, triangulating among different data sources, writing with detailed description in participants’ language, and taking the narrative back to participants in member checking are procedures to assure credibility and transferability (Creswell, 1998; Milne & Oberle, 2005).

In this research, the ways for promoting the credibility (internal validity) and dependability (reliability) include: (1) choosing participants based on a theoretical sampling strategy and including diverse family caregivers who had a willingness to share experiences; (2) establishing a trusting relationship by being introduced by a home health nurse if possible; (3) using participant-driven data collection and probing questions for clarification and depth by the flexible interview questions for participants to tell their own stories and probes to focus on a description of care situations; (4) accurately representing participants' perceptions by timely transcription of the interview. The data were coded with participant-driven codes and using participants' language and meaning. (5) Triangulating the collected data from interviews, observation field notes and discussing preliminary group level analysis with other researchers and home health care nurses; (6) Respondent validation was fostered by taking the analyses, interpretations and themes from the data back to the participants. (7) Researcher credibility was fostered by the use of a personal journal for reflection on how the researcher was influencing and being influenced by the interview and observation experiences. (8) The researcher had regular communication with her committee chair both by e-mail and virtual conferencing via Elluminate®. These regularly scheduled meetings were used to discuss research experiences, any areas of difficulties, and strategies for conducting the research.

The transferability (external validity) of the research was addressed through ongoing descriptions of the caregiver experiences so that readers may judge appropriateness to other caregiver populations. Lincoln and Guba (1985) suggest that confirmability is achieved when audibility (dependability), truth value (credibility), and applicability (transferability) are established. Thus the confirmability (objectivity) of findings was fostered by the use of multiple strategies of data collection and analysis.

Ethical Issues

Researchers have an ethical responsibility to recognize and protect the rights of human research participants. Human rights that require protection in research are the (1) right to self-determination, (2) right to privacy, (3) right to anonymity and confidentiality,

(4) right to fair treatment, and (5) protection from discomfort and harm (American Nurses Association, 1985). These five principles of human rights also guided ethical consideration for this research. The ways of protecting the five human rights were divided into three parts: before, during, and after data collection.

Before data collection, the research was approved by Human Subject Review Committees of the collaborative hospitals and the University of Iowa. All of the persons who could possibly review any of the collected data completed the required training on the use of human subjects (either the University of Iowa workshop or the online training offered by the National Cancer Institute). After obtaining approval, the research process was begun. For the participants, the researcher provided detailed information to protect the five human rights as described in the consent form. The information included: (1) A detailed description of the purpose and procedure of the research; (2) The benefits and risks of joining this research. There were no expected risks for participants during the research period. The only inconvenience for participants was they might feel uncomfortable and inconvenienced while answering questions during interviews and the researcher’s presence in their living places; (3) They had the right to decide to participate in this research, and they could withdraw from this research at any time; (4) If they decided not to participate, their decisions would not impact on the quantity and quality of care for their family member from home health care nurses; (5) The collected information was kept confidentially and only the researcher could access those data; (6) The collected data would not be disclosed or identified with an individual’s name. After the participant verbalized an understanding of the explained information and signed the consent forms, the researcher started to collect data.

Instead of using the participant’s name, each participant’s code (described above) was used to label any collected documents, observational and interview protocols, and recorded tapes. Those collected documents or recorded tapes were locked in a file box. After data collection, all collected data was transcribed and entered into one computer and two back-up copies in two portable hard drives. Three different passwords were set up to access the computer and two hard drives. Only the researcher knew the three passwords. All of the printed documents or raw data were locked in a file box and only the researcher could access those data. Those data were deleted or shredded and discarded after the research was finished.

Summary

With the intention of describing a picture of the stroke family caregiver experience at home, the research was conducted with a qualitative descriptive methodology. The research had been approved by three collaborative hospitals, located in Kaohsiung City and Ping Tong areas, Taiwan, and the University of Iowa. Data were collected by three formal interviews and one caregiving activity observation. Participants were recruited from the three hospitals. Purposeful sampling and theoretical sampling were used to identify participants. The participants included stroke survivors who were eligible for receiving home care services; family caregivers who identified as the family members who were primary responsible for their stroke survivors' care at home setting; and foreign care attendants who were able to communicate fluently in Chinese or Taiwanese languages. The participants were consented before conducting interviews or care activity observations. Two interview protocols and observational protocol were developed to ensure the rigor of the collected data. Each participant was assigned a code number to protect participants' confidentiality. The interviews ranged from one to two hours. All interviews were audio-taped with the participants' consents. Collected data were transcribed verbatim and entered into NVivo 8.0 software for management and analysis. All electronic files were protected with passwords and documents were kept in a secure box. Ten analysis steps were developed based on the recommendations for analyzing-synthesizing qualitative descriptive data. Eight strategies were used to enhance the rigors of this research (Milnes & Oberle, 2005).

CHAPTER IV

TAIWAN CONTEXTUAL OVERVIEW AND PARTICIPANT DESCRIPTIONS

The research design, data collection procedures, and data analysis were addressed in the previous chapter. This chapter provides an overview of the care environments in Taiwan for elders who have suffered a stroke. These include an overview of the health care system and a description of the participants' home care situational profiles. In-depth descriptions of the participants are provided in Appendix F.

Taiwan Health and Home Care Systems

In Taiwan, the health care system comprises hospital care and community care systems. The hospitals are categorized into five levels based on the services, quality and equipment of hospital, medical center, district hospital, regional hospital and clinics (Department of Health, Executive Yuan, R. O. C., 2008 a). The medical centers and district hospitals usually aggregate in urban areas. For example, there are three medical centers and eight district hospitals in Kaohsiung City, which is the second biggest city located in Southern Taiwan. In contrast, the remote areas often lack sufficient medical services. As such there are only three district hospitals located in Ping Tong County, which is an agricultural and remote county (Department of Health, Executive Yuan, R. O. C., 2008 a). Therefore, when a person has a critical or severe disease, she/he is often transferred to a medical center. The traffic times from Ping Tong to Kaohsiung City are from 30 minutes to three hours.

Currently, almost 99% of Taiwanese are covered by National Health Insurance (Department of Health, Executive Yuan, R. O. C., 2008 a). Hospitals or clinics can reimburse payment from the Bureau of National Health Insurance. The reimbursements are based on the patient's diagnosis related group. Patients have a 10% co-payment. If they run out of reimbursement monies, patients or their family have to pay the full amount. For a person diagnosed with a stroke, the hospital can reimburse the payment for one month of hospital treatment. If a person who has a stroke needs further treatment, the physician must file for an extension (Bureau of National Health Insurance, 2009 a). Otherwise, the family members have to pay out of pocket for care. The rehabilitation service beds are extremely limited at 4.1 beds per ten thousand people (Department of Health, Executive Yuan, R. O. C, 2008 b). As a result, persons who have survived a stroke often need to be discharged from the hospital and wait for rehabilitation therapy at home. The average length of time from stroke onset to the beginning of rehabilitation therapy is 24.8 + 17.3 days (Lin, Wei, Liu, Huang & Lin, 1999). Before discharge, a discharge planner coordinates the discharge preparation, including preparing family caregivers' for home care knowledge and skills, referring to welfare resources and home care services, and recommending equipment for care. A long-term care management center has been set up in 25 counties and cities. The center integrates the long term care services and social welfare resources for persons who are in need of long term care in the community, such as for elder and disabled persons (Department of Health, Executive Yuan, R. O. C., 2008 a). Before discharge, the hospital discharge planner refers the eligible patients to the center. After the referral, the center will contact and provide necessary information to the referred families. Currently there are limited social welfare monies to reduce family's economic burden. First, the government subsidizes the expenditures for disabled persons to purchase supplies such as a hospital bed, wheelchair, electronic air mattress, and for hiring a home care nurse assistant (Department of Social Affairs Ministry of The Interior, 2009). Second, the co-payments can be exempted for a person who is disabled or has a catastrophic illness, such as relying on ventilator treatment over three months (Bureau of National Health Insurance, 2009b).

For the three collaborative hospitals, one hospital has one discharge planner in the neurological and neurosurgical wards, respectively. The other two hospitals have one discharge planner who coordinates the discharge preparation for all patients from the hospital. Only certain patients qualify for discharge planning services. Persons who have suffered a stroke and require tube placements are eligible for home care service (Bureau of National Health Insurance, 2009 c). Each hospital has one home care unit for post discharge service. If the elder stroke survivor's living place is out of the home care unit service area, she/he will be referred to another home care agent near her/his house.

After discharge, only home care agents provide in-home skilled nursing services for a person with severe disease, such as those who have suffered a severe stroke. These agencies are categorized into three types of home care agencies: hospital-based, health station based (for remote areas) and free standing. Registered nurses provide the health services. While physician home visiting is a requirement for home care service; physicians are not members of the home care agencies. There is no physical therapy, occupational therapy, diet consultation, housekeeping, or self-care services provided. The home care services include two nursing services per month and one physician home visit every two months (Bureau of National Health Insurance, 2009 c). The costs of home care services have been reimbursed since the establishment of the National Health Insurance (NHI) in March 1995. If frequency of visits is more than twice a month, the family has to pay out of pocket.

Home care services focus on skilled nursing. These services are three categories. The first one is skilled nursing activities, such as replacing nasal-gastric (NG) tubes, urinary catheters and tracheal tubes, wound care and bowel enemas. Replacing NG tubes and urine catheters accounts for 50- 90% of home care services (Huang, Lo, Hurng & Hung, 2001; Liou & Wu, 1999; Wu & Chiou, 1997). The second part is prevention and patient or caregiver education. The activities include general health assessment, providing education about nutrition and diet preparation, simple rehabilitation activity, medication and hands on care provision. The third service category is referral, such as seeking social welfare and services for their clients. Except for a few free standing home care agencies, all of the home care services hours are limited to weekdays, from 8 am to 5 pm. If families encounter any emergency situations, they have to send their family members to an emergency room.

Due to a rapid change in the family structure, the availability of family members is decreasing in Taiwan. To address this, since 1992, the government has granted the introduction of foreign care attendants to temporarily assist the labor shortage issue of households (Council of Labor Affairs, 2009). The cost of hiring a Taiwanese nurse aid is around 60,000 dollars (around 2,000 US dollars) per month, compared to hiring a foreign care attendant for around 20,000 dollars (667 US dollars) per month. As such, the number of foreign care attendants as a major care provider at home has increased sharply over the last ten years (Chuang, Wu, Dai & Ma, 2007). For government approval to hire a foreign care attendant, a disabled person must need 24 hours of care and approval by two health care providers (Council of Labor Affairs, 2009). After receiving the approval, family caregivers can contact a manpower agency. The manpower agency is responsible for managing the hiring process and supervising the foreign care attendants in Taiwan. They usually visit the foreign care attendants once a month and provide necessary translation for their employers.

The typical house construction models in Taiwan are san-ho-yuan (Chinese traditional rectangular courtyard with houses on three sides), townhouse, apartment, and multi-story building (Appendix H). For a traditional house building, one must walk over a front step and a doorsill from the courtyard into the house. The front step is under the eaves and around 30 cm higher than the courtyard. These two barriers are often difficult for a disabled person to traverse. Inside of the building, there is often a doorsill between rooms. This step also causes an uneven surface and difficulty for a disabled person to move or walk from one room to another room. For townhouses and apartments with less than five levels, usually there is no elevator. Thus it is hard for a disabled person to get in and out of the home using the stairs. The indoor floor surface is smooth, providing for free movement, but usually there is a door sill in front of the bathroom. The floor of the bathroom is usually covered with tiles that become slippery when wet. Furthermore, environmental modifications, such as ramps, grab bars and resistant mats, are rarely recommended by health care providers, nor are family members aware of them. Family caregivers usually call for help to overcome the barriers. If able, the disabled person usually chooses to live on the first floor of the building.

Profile of the Participants

Participants included 16 stroke survivors who were cared for by 17 family caregivers (the Fong family, Siang and De were a couple who cared for Mi). Sixteen family members completed two in-depth interviews. One family caregiver did not complete the second interview because he was out of the country. Nine of them completed care activity observations. The reasons for declining observations included; two primary family caregivers refused, one stroke survivor was hospitalized, and four foreign care attendants were unable to consent because of language barriers. Among the nine observations, six of the observations were performed by family caregivers, two by foreign care attendants and one by both family members and care attendants. The observations included bathing, shampooing, diet preparing, NG tube feeding, changing position and clothes, transferring from bed to wheelchair or other places, and providing Foley care and wound care. To protect the participants' anonymity, the researcher assigned an alphabetical surname for each family and foreign care attendants; and randomly assigned pseudonyms for family caregivers and care receivers. Each participant was described in a family unit, including the persons (the stroke survivor, the primary family caregiver, foreign care attendant, and other family members), the stroke, home settings, and care situations at home. Detailed information about each family is provided in table 1 and Appendices F and G.

The 16 stroke survivors received home care services from six home care agents, three of whom were associated with the three hospitals and three were free standing home care agents. The time periods from the discharge date of the current stroke to the first interviews were from 20 days to 11 months. Four of them were less than three months, seven participants were in four to six months, and six were in seven to eleven months. Six families lived in Kaohsiung City or County and ten in Ping Tong County.

Ten elder stroke survivors were females who ages ranged from 47 to 91. This was the first stroke for eight elders. Infarction was the cause of the stroke for ten elders. Hypertension (n=9) and diabetes (n=7) were the most common health problems for the elder stroke survivors and only six of them had regular control. Length of stay in the hospital for the current stroke was from six days to five months. At discharge, nine stroke survivors were unclear or in a coma. Thirteen stroke survivors' score of Barthel Index were zero. All of them were discharge with tube placements, including NG tubes, Foley catheters, and tracheostomies. Five had wounds (one operation wound and four pressure sores). After discharge, two elder stroke survivors' were weaned from their NG tubes and one from their Foley catheter. Family members indicated that the wounds were improved, while three were completely healed.

Thirteen family caregivers were female and their ages ranged from 22 to 77 years old. Their relationships with the stroke survivors were: four spouses, five daughters, three sons, four daughters-in-law and one granddaughter. Their educational level tended to be high. Ten had twelve or more years of education. Of them, nine were housewives or retired and six had a full time job. Sixteen of them reported to be in good health condition and five had chronic diseases, including hypertension, diabetes and thyroid disease. Nine families hired eleven foreign care attendants (two families had two because of changing foreign care attendants). All foreign care attendants were from Indonesia; ten were married and had young children in their country. For half of the foreign attendants, this was their first time in Taiwan. Half of the foreign attendants did not speak Chinese and had difficulty with communication.

Table 1: The Characteristics for the 16 Families

Primary caregivers							**Care receivers**						**Foreign care attendant**
Assigned Family Name	Name	Age	Relationship	Role*	Education	Length of time at 1st interview (months)	Name	Age	Types of stroke	Conscious	Tubes and wounds at discharge	Bathing type	Name
Ai	Lee	58	Daughter	S+P*	Primary	3.0	Mei	90	I*	Alert	NG	Shower	Ann
Bi	Huo	77	Husband	S	Junior college	2.5	Ying	73	H*	Alert	NG	Sponge	Beth
Chow	Zu	55	Wife	P	Primary	4.0	Sing	60	I	Alert	NG	Both	
Duh	Jen	27	Daughter	P	University	6.0	Wen	47	H	Coma	NG, wound	Both	
Fong	Siang	38	Daughter-in-law	S+P	Junior high	20 days	Mi	67	H	Coma	NG, Foley, Trachea	Sponge	Faith
	De	38	Son	S+P	Junior high	20 days							
Gao	Ya	44	Daughter	S+P	Junior college	5.0	Ji	67	H	Unclear	NG, Foley	Sponge	Grace /Gwen

* Role indicates the family member's role in the caregiving situation. S: Supervising the hired foreign care attendant; P: Providing direct; S+P: Providing part of direct cares and supervising the hired foreign care attendant

Table 1 continued

Primary caregivers							**Care receivers**						**Foreign care attendant**
Assigned Family Name	Name	Age	Relationship	Role*	Education	Length of time at 1st interview (months)	Name	Age	Types of stroke	Conscious	Tubes and wounds at discharge	Bathing type	Name
Ho	Chin	37	Daughter	S	Senior high	4.0	Yue	62	I	Unclear	NG, Trachea, Wound	Sponge	Hannah /Helen
Inn	Hui	44	Daughter-in-law	S+P	Senior high	4.0	Rou	71	I	Alert	NG, Foley	Shower	Iris
Ju	Zong	36	Son	P	University	11.0	Siong	67	I	Alert	NG, wound	Sponge	
Kuo	Bao	60	Wife	P	Primary	9.0	Yi	61	H	Unclear	NG, Foley, Trachea, wound	Sponge	
Lu	Jin	50	Daughter	P	Junior high	11.0	Mian	91	I	Coma	NG	Sponge	

* Role indicates the family member’s role in the caregiving situation. S: Supervising the hired foreign care attendant; P: Providing direct; S+P: Providing part of direct cares and supervising the hired foreign care attendant

Table 1 continued

Primary caregivers							Care receivers						Foreign care attendant
Assigned Family Name	Name	Age	Relationship	Role*	Education	Length of time at 1st interview (months)	Name	Age	Types of stroke	Conscious	Tubes and wounds at discharge	Bathing type	Name
Ma	Pin	33	Grand-daughter	P	Senior high	11.0	Siu	79	I	Coma	NG, Foley	Both	
Niu	Tsai	51	Son	S	Junior college	5.0	Lian	80	I	Unclear	NG, Foley	Sponge	Nancy
Ou	Hua	47	Daughter-in-law	S	Senior high	2.0	Ming	71	I	Alert	NG, Foley	Sponge	Olive
Pan	Chiou	57	Wife	P	No formal education	7.0	Lin	74	H	Alert	NG, Wound	Both	
Ran	Quan	42	Daughter-in-law	S	Senior high	5.0	Chuan	76	I	Unclear	NG	Sponge	Rachel

* Role indicates the family member's role in the caregiving situation. S: Supervising the hired foreign care attendant; P: Providing direct; S+P: Providing part of direct cares and supervising the hired foreign care attendant

The daily care activities for the 16 elder stroke survivors were similar. Caregivers often did morning cleanliness routines for their elder around 6 AM, then fed them every three to four hours and changed their position every two hours. Two of them had a regular soft diet after their NG tubes were removed, one was on a regular diet, and the others had NG tubes. One caregiver provided a home-made NG feeding diet, six had home-made and commercial formulas alternatively, and six had commercial formulas only. Most family caregivers or foreign care attendants performed range of motion therapy twice a day, in the morning and afternoon.

Seven family caregivers assisted their elder out of the bed every day, of them five elders were cognitively intact. Three stroke survivors went outside to sunbathe once a day. All stroke survivors were given a sponge bath or shower every day, usually at noon or in the evening. The bathing types included sponge (n=10), shower (n=2) or both (n=4). Three families had a shower chair.

Ten of the 16 stroke survivors lived in a townhouse, three in a traditional house, two in an apartment and one in a multi-story building. Thirteen of them stayed on the first floor. Only two families installed a ramp for accessing the home from the outside and one family had a ramp for accessing the bathroom. One family installed a slip-resistant mat and a grab bar in the bathroom.

Summary

The care environments in Taiwan for elders who have experienced a stroke and participants' care situation profiles were described in this chapter. The health care environment includes hospital, community, and family care. Before discharge, stroke survivors have one month of acute therapy in the hospital. The discharge planner is responsible for preparing family caregivers, including providing necessary education, recommendations for assistive care devices, and referrals for home care service and to long term care management centers. The long term care management center contacts the family and provides further social welfare information. Home care service provides in-home health service after discharge. The home care services include nurse visits two times each month and one physician visit every two months.

The common house styles are traditional Chinese building, townhouse, apartment, and multi-floor building. There are many environment barriers that often limit a disabled person from freely moving indoors. Sixteen stroke survivors were cared for by 17 family caregivers. Of them, six lived in Kaohsiung City or County and ten in Ping Tong County. Ten lived in a townhouse, three in a traditional house, two in an apartment, and one in a multi-story building. Most families had environment barriers; however, three families did some environmental modifications. Thirteen of the elder stroke survivors’ rooms were on the first floor. Ten elder stroke survivors were female and their age ranged from 47 to 91. At discharge, nine of the elders were cognitively impaired or in a coma. All of them were discharge with tube placements and five had wounds. Thirteen family caregivers were female and their ages ranged from 22 to 77 years old. They were the elder stroke survivors’ spouses, daughters, sons, daughters-in-law and grand-daughter. Their educational level tended to be high. Of them, nine were housewives or retired and six had a full time job. Sixteen reported to be in good health. Nine families hired eleven foreign care attendants. All foreign care attendants were from Indonesia, ten of them were married and had young children in their country of origin. For half of the foreign care attendants it was their first time in Taiwan. Half of the foreign care attendants did not speak Chinese and had communication problems. The daily care activities were similar between the family participants. The next two chapters described the reasons for taking on the caregiver roles, the overviews of early preparing for certainty in the hospital, and managing uncertainty at home.

CHAPTER V

RESULTS: PREPARING FOR CERTAINTY

After the first interview, the researcher read the verbatim transcriptions and summarized informants' experiences. At the second interview, the summarizations were confirmed by the informants. The rough picture and preliminary themes were identified. Next, the interviews, caregiving activity observations and field notes were transcribed verbatim into word files and coded in NVivo 8. One hundred and eight free nodes were coded as preliminary codes. The codes were clustered and eleven themes identified in the language of the participants. The themes were then categorized into four dimensions. As recommended by Sandelowski (2000) and Milne & Oberle, (2005), the descriptive contextual findings are presented in chronological order based on family caregivers' trajectory beginning in the hospital and extending to the in-home care situation.

After the family encountered the stroke, family members faced a series of questions before discharge from the hospital. The first question was if the family member would go home or to a long term care institution and who would "shoulder the responsibility" for the caregiver role. Subsequently the caregiver describes how they prepare to care for the family member before they bring them home. There are two dimensions in this phase: taking on the role, and learning to care.

Taking on the Role

Within the dimension of taking on the role, these family members had to make the decision if the elder would go home or go to a long-term care institution. The reasons family caregivers decided to provide care for their family member at home are described in the themes: "No institutional care," and "She is my mother, I want to care for her."

No Institutional Care

The major reason family members decided to keep their stroke survivors at home was because they had a negative impression toward institutional long-term care. Additional reasons were: they had someone available who had the time to provide the care, it was financially best to care for the elder at home and the elder preferred to remain at home. For example, Hua explained. “We don’t dare to do that (institutional care), because we still have time to care for him and he prefers to stay home. We are still okay with manpower and finances. So we never think about institutional care for him.”

Fourteen family caregivers, (four spouses, one son, five daughters, the granddaughter, and three daughters-in-law), expressed ‘time available’ as a reason for considering taking on the role (Figure 1). Of them, nine were housewives, retired or did not have a job and six of them (four spouses and two daughters), indicated ‘no other caring competing needs’. On the other hand, of the other five family caregivers, two had part time and three had full time jobs that were flexible for providing care. For example, Hua (daughter-in-law) ran an art studio alone, so she said, “I could adjust my own work time schedule.” And De (son, a fisherman) had the resources to be able to temporarily stop his work for four months to care for his mother.

Thirteen family caregivers had initial negative impressions toward institutional care such as “institutional care means waiting for death,” and “worrying about the quality of care and elder abuse.” Five of these families considered institutional care; however, they all decided against it because of their own or other family members’ concerns about institutional care. For example, Chiou described her impression after visiting several nursing homes:

> So many persons rest over there and nobody takes a look at them! She (the nursing aide) has to take care for so many persons at one time. She doesn’t have time to look at each person! She doesn’t even know a fly or mosquito is there! I looked at several facilities. Even the higher price facilities-they are all the same! Coolly and quietly! Lying there alone! ... Then how about bathing! She said three times a week. So I watched how they bathed the persons. Like killing a hog! ...Then how about the food. They prepare a whole bucket of milk or rice

> gruel; then using a syringe push the food. It looks like feeding a cow! Then move to the next person. No, I don't like this! I want to care for him myself….

The other four family caregivers were receptive to using institutional care; however, they preferred to care for their stroke survivors at home. One family (Ma) initially Siu stayed in a nursing home after she had her first stroke and developed some dementia symptoms. Yet, two and half years later, her son decided to take her back home because "she cried every time when we visited her. She won't stay there anymore. (Pin)" All families chose to care for their stroke survivors at home, the next theme describes why they chose to take on this role.

She is My Mother; I Want to Care for Her

Seventeen family members provided the care for 16 stroke survivors. With the exception of Pin and Ya, 15 out of 17 family caregivers were responsible for their stroke survivors' health needs before this stroke. Typical explanations for their care situations before this stroke include: "I bring food for her every day and run errands for her. So she relies on me very much (Jin)" and "We lived together before and I am always responsible for the major family matters. So it is very natural to take on this role (Hua)."

With the new care situation post stroke, reasons for family members continued (n=15) or took on this new caregiving role (n=2) included (1) This is my responsibility, (2) We have a good relationship before, (3) My time is flexible, (3) I have to pay off this life, and (5) I am helping my children.

<u>This is My Responsibility</u>

Excepting only Zu, 16 family caregivers considered that caring for their care receiver was their role responsibility, they typically stated, "she is my (mother); this is my responsibility as a (daughter)." Especially for the eldest child or daughter-in-law, they expressed strongly the traditional and social expectations One son, two daughters and three daughters-in-law described how being the eldest was the key reason for taking on the role (figure 1). Lee (daughter) said, “I am the oldest one. I have to be a model for them (her siblings).” In addition, the meaning of “eldest one” extended to the surviving eldest one. Tsai was the fourth child, but he was the second son in his family. He described his perspective:

> As a child, this is what we should do. Because my elder brother has passed away and I am the second son, I have to shoulder the responsibility. That’s what I am supposed to do. That’s a natural thing; you should take care of your parents when they have problems. I have only one Mom. It is my responsibility!

Three of the four daughters-in-law were the eldest. Hui explained, “She is my husband’s mother and he is the eldest one” and Hua described how “I should say it is a responsibility for a daughter-in-law! And my husband is the eldest one. …A responsibility! So I don’t have any choice. I could not refuse to take care of him. I encountered it and I had to do it, unless I refused to manage it, right? We are Taiwanese daughters-in-law!” Quan described how “First of all, in general, the eldest daughter-in-law should have the understanding. I have to put in more effort and take more responsibility. It seems likes a reasonable and natural thing.”

Despite traditional responsibility one daughter and the three daughters-in-law described how they were forced to take on the role in spite of their unwillingness. Jen described how “My father is never responsible for any family matters. Because I am the oldest one, he assumes I have to take on the responsibility….Why do I have to do all of these? I am not the only child!” Quan described how:

> Because I am the eldest daughter-in-law, I have to and I am forced to do this….You might have the opportunity to refuse. You can say no and you might also think I don’t want to. But there is no chance for you to say no. We have to do this with somewhat reluctance. You should accept this work... But frankly speaking if you want me to quit my job to care for him, I really don’t want to do that.

We Have a Good Relationship Before

Except for Chin and Zu (wife) who indicated they had a history of a bad relationship with their stroke survivors, 15 family caregivers expressed a previous “good relationship and “good affection” as core reasons to take on the role, especially for spouses and daughters-in-law. Chiou’s description highlights how affection is a key reason for her to take on the role.

> We have very good affection! The key point is he treats me very nice! He is very thoughtful and gentle for me! Never argues with me and never limits what I am doing! ….After all he treats me very nice! He is a nice husband. I am very fully satisfied. No matter what happen I should care for him. If we don’t have a good relationship, it is impossible for me to care for him...He is very nice to me. So I think this is what I owe him and this is my mission and responsibility. I have to care for him.

Four daughters-in-law consistently indicated that they had a history of a “good relationship” with their parents-in-law before the stroke and this was an important consideration for taking on the role. Hua described how: “I never view my father-in-law as an outsider. I treat him like my own father and do my best to provide care for him.... We lived together before. We have affection. I could not stay away.” Quan explained how “I have a good affection with him. We lived together before so I don’t reject the responsibility.”

With the interweaving with role responsibility and affection, three sons and the granddaughter considered that caring for their parents or grandmother was a great chance of paying them back for being raised by them in this lifetime. Zong (son) described how “Parents give me the greatest grace.” He viewed “being able to caring for parents is a good fortune. Without the good fortune, a person has no chance to provide care for his parents.” Pin (granddaughter) provided her reasons of taking on the role because “She is my grandmother. She nurtured me when I was a child. Now I am grown up. It is my turn to care for her….When she was in the nursing home; she was so reluctant for me to leave every time I visited her. It broke my heart.” In addition to paying back for what was given in this life, family caregivers also described paying back the elder in this life for what had occurred in former lives, or Karma.

I Have to Pay Off This Life

Karma also played an important reason for eight family caregivers, three wives, two sons, two daughters, and one daughter-in-law, to take on their caregiver role (Figure 1). Hui (daughter-in-law) provided a typical description, "This is my Karma from my previous life, so I have to pay off this life. If I finish it, I won't do it anymore." Chiou also described, "This is what I owe him! I should repay to him! The main thing is we owe each other! I have to do....I have to take care of him until his time is out. Then I repay all I owe him." Especially for Zong and Chin (whose stroke survivors had both been abusive), Karma was the central reason for them to take on the role. Zong was a faithful Buddhist. He deeply believed in Karma:

> The major reason is I believe in Buddhism. From what I learn I have generated lots of reflexive and causal relationship! ….I believe my father and I have been rolled together in Karma in our previous three or five lives. I understand why I have to take on the role; the role has its causation, so I have to shoulder it on.

Chin was a daughter and had a bad relationship with her mother (Yue). She described:

> My dad said: 'Maybe I stabbed her 36 times with a knife in previous life.' Then I said: 'Maybe I also stabbed her once.' That's why we have to take care of her to pay off this life. By thinking this way, I feel much better. This is a cause-and-effect. I won't feel so much suffering if I think so. We did not do a great job for her in previous life, so this life we have to pay back…

Lastly, five female family members described the importance of providing care for the elder to help out the other family members.

I Am Helping My Family

Five family caregivers, three wives, one daughter, and one daughter-in-law, said that their providing care was helping other family members (Figure 1). They considered that if they hadn't taken on the role, their other family members would be unable to concentrate on their work. This was particularly important for the three wives. Although Zu had a bad relationship with her husband, Sing, explained that "If I won't take care of him, my daughter and son should be very pitiful! They might not be able to work. I am helping my kids…" Chiou (wife) was concerned about their children's financial burden:

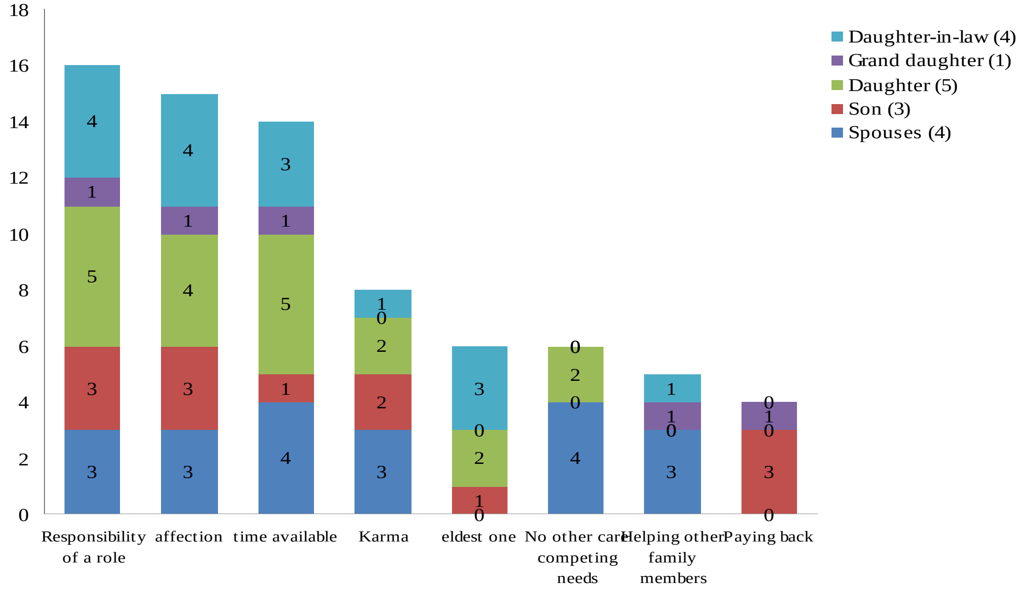
> Another concern is the financial problem. I told my children that my considerations are all for you. I can do my best to care for your dad. I can go through the hardships! If we borrow money from someone, who would have to pay the debt? Of course you have to! I don't want it to be so hard for you! Just let me bear that suffering instead!

For Chin, in addition to Karma, helping her father was another key reason. She said, "My brother won't take on this…..That's my responsibility as a daughter! My dad won't give up, I couldn't either….If I don't take care of my mom, how could my dad do it?!" On the other hand, Pin (granddaughter) believed her care was helping her father and "She is my grandma! At least everyone has to leave the world…so my father won't have any regret. At least my grandma will die under his care instead of under the institutional care ….At least my father can see her every day."

As can be seen in figures 1 and 2, for spouses, responsibility, affection, time available, no other caregiving competing needs, Karma, and helping their children weighed in almost evenly for them to take on the role. For sons, responsibility, affection, and paying back were the three major reasons, followed by Karma, eldest one and time available. For daughters and the granddaughter, responsibility, affection and time available were three major concerns for them to take on the role. The granddaughter also considered that taking on the role was a chance for paying back and helping her father. On the other hand, role responsibility, affection and time available were the three key reasons to take on their caregiver role for daughters-in-law. Especially when they were the eldest one, they had no chance of escaping from this role. Affection enhanced and encouraged them to continue their caregiver role.

Both female and male family caregivers explained that role obligation and affection were major reasons for them to take on the role. Females also had higher rates

Figure 1: Reasons for Taking on the Caregiver Role and Relationship



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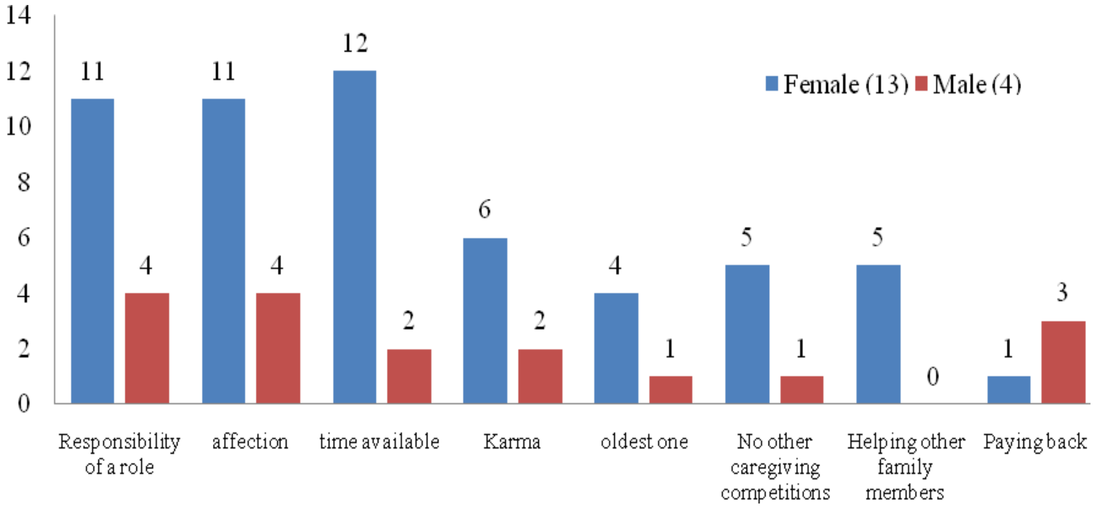
* Spouse (4) means four participants were spouses

Figure 2: Reasons for Taking on the Caregiver Role and Gender



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* Female (13) means 13 participants were female

of ‘time available’, ‘no other competing caregiving needs’ and ‘helping other family members’ than males. No males considered that their caregiver role was’ helping other family members’.

After taking on the role, not all family members provided direct care to their stroke survivors. All family caregivers were responsible for managing their stroke survivors’ care issues, such as decision making, and communicating with health care providers; but nine of the 16 families hired a private nurse aide or foreign care attendant to provide physical care for their stroke survivors. Therefore, according to their role activities, their caregiver roles were divided into three types: seven providing direct care, five supervising their hired foreign care attendant or nurse aide only, and five providing some of the care as well as supervising a hired foreign care attendant or nurse aide (Table 1). Six out of 13 female caregivers, including three wives, two daughters, and the granddaughter, were responsible for all direct care. In contrast, of the four daughters-in-law, only two of them provided part of care for their parents-in-law. They mainly played as a supervising role. Men provided less direct care for their stroke survivors. Similarly, daughters-in-law tended to hold primarily a supervising role.

In summary, the major reason family members decided to keep their stroke survivors at home was because they had a negative impression toward institutional long term care. Additionally, they had someone available who had the time to provide the care, it was financially best to care for the elder at home and the elder preferred to remain at home. Role responsibility and affection were core reasons for taking on the caregiving role. When the family caregivers were the eldest child or daughter-in-law, they identified a traditional elder care role. Females, especially wives, identified the importance of available time, Karma, no other care competing needs and helping other family members. All sons described that their care was paying back and two cited provided more hands-on care, while daughters-in-law and male caregivers tended to play a supervisory role. Overall, the family caregivers identified that they were “ready” to take on the role, although four of them were somewhat unwilling. The next dimension describes how the family caregiver prepared to care for the elder stroke survivor before they go home.

Learning to Care

Among the 17 family caregivers, five family caregivers hired a nurse aide or foreign care attendant to take care for their family members during hospitalization. Except for Quan, four of them indicated they learned some disease information and treatments, but did not learn any direct care skills before discharge. The remaining 13 family caregivers learned direct care skills before discharge. Four themes emerged in the dimension of learning to care: (1) Needing to perform the care at home; (2) Starting from zero; (3) Further observation and not enough time; (4) I feel ready to go home.

Needing to Perform the Care at Home

All of the family members preferred to have their family member at home. They found that “travel to the hospital was exhausting” (Quan), there are “lots of bugs in hospital. So if she is OK, I preferred she could come home earlier though I have to take care for her alone! (Ya)” and it was believed that it would be “easier for managing her matters. It was so inconvenient for me when she was in hospital. I had to sign documents before giving her Chinese medication and others. It was bothersome. (Chin)” However, all of the family caregivers also described that they did not know how to provide the care skills needed at home after discharge. Jin explained “I felt so hard because I never bumped into this before. I never faced a seriously sick person. This is my first time. I had no idea what I have to do for her….but if I want to take care of her, I must learn.” They believed that during hospitalization was the best time for learning “because they are all experts “(Pin). Zu explained:

> Because we have to do all of those (care skills) after discharge, we used the chance to learn. We were in learning process so we had to hands-on it. If we learned it, we might feel less pressure. We could not start to learn it after going home. So in the hospital, if we are unable to do it, we can ask for help from them (health providers).

While they described a strong desire, need and belief that the hospital was the best place to learn the skills, they also found that the experts often did not provide the information that they desired. For Chiou, the health care providers' poor care skills and attitude was a key motivation for her to learn those skills. She described:

> Asking them to teach me? No! That's not necessary! Some of them were nice and they told you how to do it! Some of them were cold and indifferent when I asked them questions. You only felt they were very busy and they wouldn't respond for a long time when you called them! As a family, I never felt comfortable at all at that time!
>
> I knew a little bit about suction, but I didn't have the confidence to do it. I didn't learn it until he was in the xx hospital. Because I called the nurse many times and I was almost bursting! Calling for a loooong time! Then when she was there, her suction was so terrible. His mouth filled with blood! I was so mad! Fine! That's not your body! ...Then I started to learn how to do suction.

Starting From Zero

All 13 family members expressed initial difficulty in learning to care for their family members. Ya described the learning process as "starting from zero and from can't to can." What family caregivers learned before discharge were: self-care skills, advanced nursing skills, range of motion (ROM), swallowing training information, nutrition and diet preparation, and disease and treatment information. Reported learned self-care skills were bathing (n=7), changing diaper (n=6), changing clothes (n=5), and shampooing (n=1). Five of the 13 family caregivers hired a private nurse aide to teach them how to perform those skills. Family caregivers articulated their reasons for hiring a nurse aide: (1) reducing their pressure from being unable to care; (2) nurses were too busy to teach those self-care skills, (3) a nurse aide had more experience than a nurse on performing self-care activities, such as bathing or changing diapers. Ya and Zu said,

> Because we have no ideas of how to care for a patient! A nurse aide can decrease my difficulty of providing care….... I believe a nurse aide had more understanding of how to give a bath to my mother! ... A nurse?! That's impossible for nurses to teach us those (skills)! They are always busy! (Ya)
>
> We have a nurse aide, so they won't teach you those things (skills)! (Zu)

In contrast, the family caregivers without a private nurse aide had to find their own ways and they spent more time learning those skills. Family caregivers indicated, “Nurses are too busy (Jen, Quan, Chiu, and Chiou)!” Jen described how “I never helped anyone to change clothes before. So I need to spend more time to complete this. In a big hospital, the nurses won’t teach you those things, such as bathing and other cleanliness. So I tried it on my own.” Chiou explained an early situation:

> At the beginning I didn’t know how to help him because his body became like this (rigid) due to the stroke! I was in a great hustle and bustle. It was not easy to give him a bath or clean his body, and change his clothes. I had no ideas how to start….So I did it slowly and spent more time on it. At that time I put on his clothes in the opposite way, so his back was not covered.

On the other hand, nurses tended to focused on tubing care and suction skills and expected families to know how to provide basic care for a bedridden person. Quan explained:

> At the beginning, we became familiar with NG feeding because we must learn that. …In hospital, the first time…we did not learn how to change a diaper for him. First time when he pooped, we lifted his legs up like a child. And we used three diapers, and ran out of one box of moist wipes and one box of tissues before it was done. We (Quan, her husband, and Chuan) were covered with sweat. He was tired and we were also exhausted.... Later the nurse came in. She said: “what are you doing?” “We are changing his diaper. He pooped.” Then she said: “Oh! You don’t know how to change the diaper?” I said “yes”. So she taught us how to do it.

Reported advanced nursing skills were NG feeding and care (n=12), sputum suction (n=8), position change (n=6), chest percussion (n=6), Foley catheter care (n=6), tracheostomy care (n=3), manual feces removing (n=3), wound care (n=3), pillow application (n=2), insulin injection (n=2), NG replacement (n=1), and applying a urinary bag (n=1). Again for the five families having a private nurse aide, they learned those skill cares primarily from their nurse aides except sputum suction and insulin injection. In contrast, for the eight families without a nurse aide, the nurses taught them all of those skills with the exception of Chiou. She expressed, “No, nurses won’t teach you!”

Family members explained that nurse aides and nurses all employed oral instructions and demonstrations. Though three of them experienced difficulty performing personal care at the beginning, family members felt learning was satisfactory with these care skills, except NG feeding, sputum suction and insulin injection. Many families indicated things like "these are not difficult. They just teach me one time then I can do it (Jin)" "No difficulty at all! (Bao)" All of those family caregivers indicated their ways of learning were by watching and doing. Chiou used a slang expression to describe how she learned those skills, "I never eat pork, but I know how a hog walks." That means if a person never learned something before, she/he can learn it after watching other persons' performances many times. Furthermore, they performed and practiced those skills everyday. They felt comfortable with those skills.

Jen, Huo, and Pin received video and leaflets from nurses in additional to oral instruction and demonstration. But they were not satisfied with the learning method.

> They played a video tape for us and some papers…such as how to prevent a fall, how to care for a stroke person…but I still don't understand after reading those papers and watching the video tape. I needed a real situation to increase my understanding (Jen, undergraduate, daughter).

> Honestly, a lay person might not be able to understand those leaflets and they won't read them! So I think the leaflets are not worthwhile. (Huo was a junior high school teacher before he retired)

> I read it every time. But later I won't keep them anymore because they provide the same leaflets to me every time….The content indicates what we have to notice bar…bar….But practically, it does not meet with our real situations. For example, they gave me the leaflet of NG feeding, but in a real situation my grandmother needs chest percussion. On the other hand, my perception is: It is easy to write, but in the real situation, it is not like this way. First, what's the patient's feeling when she has the percussion? For example, I tap her back (her daughter) when she has a cold. She cries because she feels uncomfortable. How about my grandma's feeling? She could not say anything! Second, it is very easy to say, giving the percussion for15 minutes. But sometimes we don't have so much time to do it for 15 minutes at one time. So I feel what the contents in the textbook are easily written, but only the person carrying it out knows where the real problems are! (Pin, senior high, granddaughter)

In addition to the self-care and advanced nursing skills, family caregivers also briefly learned rehab activities, swallowing training information, and nutrition and diet preparation from a physical therapist, physicians and nutritionist. Twelve family caregivers indicated they received rehab services and five did not. However, nine out of the twelve families only received ROM. “He told me how to raise her arms and how to bend her hands. How to move her legs! That’s all! (Lee)” The other three received more rehab training; but the training was all limited to physical training, i.e. muscle training, walking, sitting, and standing. None of the seven alert stroke survivors received self-care training.

Swallowing training was not taught; however, eight family caregivers received recommendations from physicians for feeding their unconscious family member. These recommendations were to give “pudding” or “soft food” and using a small spoon. Seven family caregivers consulted a nutritionist before discharge. The nutritionists recommended commercial formula, such as Ensure, and Glucema, and promoted “commercial formula is the best choice. (Ya)” Only Hua and Quan received instruction on how to prepare an NG diet at home.

I Have Difficulty to Learn

Seven family caregivers described difficulty with learning care skills; including performing NG tube feeding, sputum suction and insulin injection. The reasons for insufficient learning of those complex skills identified from family caregivers were: Lacking enough time for teaching and learning, inefficient teaching ways, and the nurses’ service attitude. For learning self-care skills, most family caregivers learned it right after they had to provide the cares. The lengths of time were from six days to two months for the 13 family caregivers. They usually had enough time to practice those skills. In contrast, for suction and insulin injection, they didn’t learn those skills until one week or less before discharge. They did not have sufficient time to practice the complex skills.

Besides, nurses did not provide sufficient time and effective teaching styles to meet their needs. Family caregivers identified that nurses generally provided one time of teaching and lacked reassurance their understandings. They lacked sufficient opportunity to practice the new skill. Family caregivers described their experiences:

> Actually, they always hurried, so they talked very quickly. They were in a hurry to finish everything, and then they left. But you know, if left me to do the feeding; I couldn't do it even one time! (Hui)
>
> She only roughly describes it. She was too busy! That's impossible for her to recheck whether I did was right or not! (Jin)
>
> We only learned one time (NG feeding). She did not explain clearly. She taught me how to "pull back", but I don't really understand what that term means…..Actually, I didn't quite understand….I had to explore and try it my own way….. It is necessary to learn more times. That means I need more watching and more practice. (Jen)

Family caregivers expressed their fear and difficulties in learning these skills.

> It (suctioning) is very terrible! I can't describe my feelings. Anyway, I feel terrible. I couldn't bear to see my grandmother's struggling and staring at you! I can do it but I could not overcome that feeling. Until now I still couldn't! (Pin)
>
> It was very painful for us to watch the suction process. She is my mother. I felt such suffering too. I never considered learning it! …. But later I thought I had to learn it because I need to do this after going home. (De)

On the other hand, Jen and Ya learned how to perform insulin injection for their mothers. Both learned the injection skill one week and three days before discharge, respectively. Ya considered she was ok with the skill, but Jen felt difficulty in learning insulin injection:

> She used a doll to teach me how to find the eight injection areas and how to pick the right place. She showed me how to withdraw insulin and removing the air out of the syringe …and she emphasized not to inject into muscle tissue. But she did not really show us how to inject my mother and I did not try it…I really don't understand how to find out the eight areas and don't know how to tell muscle and fatty tissues….

Family caregivers all felt nervous and fearful when performing those skills the first time. The following descriptions were family caregivers' first time of performing NG feeding, suction and injection.

> (When feeding from the NG tube) I was not so handy on this and I felt nervous, so when it was almost empty (in the feeding syringe) I folded the tube to avoid the air into (her stomach)! Except for this, I don't feel scared about others (skills)! (Lee)
>
> I don't dare to put the (suction) tube too deep. I was afraid she would have bleeding. Sometimes it happens. I was so fearful! (Ya)
>
> (The first time of performing injection) I felt nervous! At that time, we were not so skilled on removing the air out from the syringe. So we had to try it and did it very slowly! (Jen)

In contrast to the self-care and cleanliness skills, those three particular skills were all invasive to the stroke survivor's body and were more complex. Family caregivers worried about causing suffering or physical damages, such as bleeding, for their stroke survivors. They became emotionally distressed and had difficulty learning the complexity of the skills.

Further Observation and Not Enough Time

Family caregivers indicated they needed to know their stroke survivor's disease and treatment information. However, none of the 17 family caregivers expressed satisfaction with the explanation from physicians and other health care providers. The most common answer from their physicians was "needed further observation!" Physician tended to have passive attitude for providing explanation.

> The answer he gave was very ambiguous! I forget what he told me but I only can be sure of one thing: She doesn't have the three stroke risks, hyperlipedemia, diabetes and hypertension. He only said "need further observation! ... I had to actively ask questions. He wouldn't give you anything if you don't raise questions. … The physicians are not as friendly as before. (Hui)
>
> Never! Except you ask him…My perception is the doctor is only responsible for performing the operation. Only this! He won't give you any details. Never! The family has to find out on our own way…. (Ya)

The physician's service attitude, family having no ideas how to ask questions under an unfamiliar situation, and the limited service time were three possible reasons for the insufficient provision of disease information.

> His attitude was somewhat arrogant. He won't answer everything that we asked. I don't know if it is because of our manner or what... I feel he did not tell us much information. We need to try on our own to understand it. (Quan)
>
> I know as a family member or a patient we have the right to know about what the treatment is for and the medication for. You should give me an explanation. But he didn't. Every time when I asked him, his attitude was always like this way…Then he answered me, "Are you the doctor or am I? You don't trust me?! (Pin)

They needed to actively raise questions to get an understanding and more explanation from their physicians. However, family caregivers indicated they had no ideas how to ask a question because they lacked experience and were unfamiliar with these situations.

> Our brain was empty at that time and we don't know how to ask a question! (Hui)
>
> We were busy learning those care skills. And I had no idea how to ask a question and discuss his disease with the doctor! Actually when we were just home, I still didn't realize his disease condition until the first time of follow-up. I asked him about his conditions! (Quan)

Nevertheless, female non-spouse family caregivers indicated they needed to explain their strokes survivors' disease and treatment conditions to other family members. Unfortunately, in the clinical situation, the physicians only showed up a few minutes each day. They didn't give much time to family members for answering questions. This caused them high pressure.

> When they (other family members) ask me (her disease), I feel it is a pressure for me! At that time I had to wait for her physician to understand her treatments every morning…Otherwise, when they asked me any questions, I only could say I don't know. But I really don't understand my mother-in-law's disease situation….I could not get the clear information from the physician. It makes me feel so helpless! ... He only said needed further observation!
>
> The doctor did not give us any information…They didn't mention anything about his conditions and discuss it with us from the beginning to end. He did not explain what's going on for his disease and treatment! ... We have too many family members and have many conflicting opinions. For making a decision of placing the NG tube, one said yes but the other one said no! …Then I explained what the

> doctor said to them…But when I retell the information to my other family members, I might miss or explain the information unclearly. I feel that’s a very weird thing for me to repeat the information because I don’t fully understand and I don’t know how to explain it well. (Quan)

Thus Quan recommended that the physician should have a formal meeting with the key family members and give a thorough explanation to avoid family members’ misunderstanding.

Lacking clear explanation and stroke knowledge, the family was unclear about how to control stroke risks and preventing a recurrence. Five of eight family caregivers with multi-stroke survivors indicated that they only received briefly knowledge of stroke when their family members had a previous stroke. “Don’t fall!” was the most common recommendation from their physicians. Huo said, “He only reminded me: Don’t let her fall again. The first sentence in hospital was: Don’t fall again…. Watch her diet! Don’t eat too salty and greasy!” “Drink more water; give medication on schedule and less greasy food! (Zu)” Therefore, when asking what the stroke early warning symptoms were and how to prevent a recurrence, family caregivers provided unsure answers. For instance, Chin explained, “Feeling weakness and lacking energy. Then I have to check her blood sugar! Right?!” Zu answered, “(Preventing a stroke) Don’t get out of bed suddenly!”

I Feel Ready to Go Home

Before discharge, seven families received a list of recommended care equipment from discharge planner or nurses. They usually recommended preparing a wheelchair, hospital bed, electric air mattress, suction machine and tubes or other necessary equipment at home. In addition, except Chiou, all of them received a home care service referral. The home care service referral reduced family caregivers’ worry of the tube care at home.

> Because we could not do those (replacing NG tube and Foley catheter), so I worried about how to care for those tubes. In the hospital, nurses take care of this, but after we go home who can do this? When they gave us the information, I felt much relief. (Hua)

After learning the care skills, purchasing care equipment and receiving the home care referrals, family caregivers felt ready to go home.

> Not (feeling nervous) at all! Because my husband (De) took care of her in the hospital, so he knows her condition and I also know it as well. Her situation is very stable ... What you mentioned about the feeding skills and others-we are OK with those. (Siang)

> Because I did those (care activities) everyday in the hospital, so I know what's going on for her. It is Ok with me to go home. (Ya)

Summary

Seventeen family caregivers and eleven foreign care attendants cared for 16 stroke survivors at home from three months to one year. These care experiences included in hospital and at home phases. Four dimensions containing 11 themes emerged from their descriptions. The findings were chronologically presented based on their care experience trajectory along with participant's descriptions. Though stroke disease was a sudden disaster for a family, most family caregivers were highly ready to take on the role. Fifteen of them had been responsible for their stroke survivors' medical issues before the current stroke. Their major reasons for taking on the role were affection, role responsibility, time available, Karma and helping other family members. Affection and role responsibility were two key reasons for all family caregivers. Female caregivers had a higher rate of time available and helping other family members than males. Nine families hired a foreign care attendant to provide physical cares for their stroke survivors. Five family caregivers served as a supervisor only for their foreign care attendant and 12 of them provided part or total care for their stroke survivors. Females had a higher rate of providing direct cares than males. However, daughters-in-law and male caregivers tended to play the role of a supervisor only.

All family caregivers indicated that this was their first time encountering a seriously ill and dependent patient. They also understood they had to provide long term care for their stroke survivors at home. Family caregivers were highly motivated to learn care skills and knowledge before discharge. They learned self-care and advanced care skills from nurse aides and nurses. However, they had less understanding of rehabilitation activities, nutrition, and disease information. Watching and doing were their major ways of learning. They had difficulty learning some complex and invasive care skills, including NG feeding, sputum suction and injection. Caregiver’s feeling unready, lacking sufficient time of teaching and learning, and inappropriate teaching styles were three reasons for their difficulty of learning. Before discharge, most family caregivers received home care service referrals and care equipments recommendation. They described a readiness to take their elder stroke survivors home.

CHAPTER VI

RESULTS: UNCERTAINTY AT HOME

After discharge, family caregivers provided care in the home for their stroke survivors either alone or with hired helpers. This chapter describes the care situation experience in the domains of “Chaos and Panic” and “Surviving Despite Uncertainty.”

Chaos and Panic

In the dimension of chaos and panic family caregivers describe “challenges and difficulties,” and “ways to manage.” All family caregivers received help from other family members on the first day at home. Except for the Fong family, they all had a smooth day at home. Four family caregivers hired a private nurse aide discharged with them. They indicated that because the nurse aides were experienced and handled all of the care activities for them, they felt secure at the first day at home. After the first day, the family caregivers described:

> It was chaos! A series of frustrations! Any care tasks, such as feeding, all became very disordered! (Hui)
>
> Really! I could not get used to the situation...I felt panic because I was not sure if what I did was right or not! I was so nervous! (Bao)
>
> In the hospital, because the nurses were there, if anything went wrong it was OK. I wasn’t afraid. But after being home, I remember the first night at home. I called the emergency room many times. I asked, “Now I am doing …., is that right?” When you find you are not sure of what you are doing is right or not, you will call for assurance. (Ya)

During the first three months, but in particular during the first month, family caregivers talked about how they felt nervous about unexpected care situations. For example, Hua explained how:

> He (Ming) had lots of unexpected situations during the first month. His physician reminded us he might have unexpected situations during the first three months. We need to be careful…The first month he did visit the emergency room very often… (Hua)

And Tsai described how:

> During the first month we didn't know anything at all, so we had no ideas how to manage it, such as the urinary tube problem. …. (Tsai)

The feelings of uncertainty and unknowing stirred up whenever the unexpected situations occurred. Hui explained:

> It was the first time of encountering this and I had a lack of experience, so I was unable to consider many things thoroughly at that time…..At discharge, I thought those (learned care skills and provided information) were enough for us because we didn't realize what our needs would be at home at all…..After going home, we would immediately face many unexpected problems and we would have to find out the way to overcome by ourselves. ..We usually don't know what we need until we face it!

These situations of uncertainty are described more detail in the "Challenges and Difficulties" regarding "giving *care*" and "*what about me?*"

Challenges and Difficulties

Before discharge family caregivers indicated that they had learned essential care skills and felt ready to go home. However, the problems they encountered at home were different from what they had learned to manage in the hospital. For example, they learned how to perform NG feeding while in the hospital, but at home they faced the NG tube frequently being pulled out, bloody drainage and the tube becoming obstructed. Difficulties and challenges were associated with providing care, supervising foreign care attendants and their personal perceived stress or pressure.

Fifteen unexpected challenges and difficulties, due to providing care and supervising foreign care attendants, were identified by family caregivers as shown in figure 3. The number of difficulties or challenges for each participant was from two to twelve. Eight family caregivers had eight or more difficulties during the caregiving process. The most common challenges were diet preparation (n=16), elimination problems (n=13), transportation (n=12), breathing and sputum problems (n=11), and rehabilitation resources (n=10). Those unexpected care situations caused ten stroke survivors have 23 re-hospitalizations and 17 emergency room visits or admissions. Breathing and sputum problems (n=7) were the major reasons for re-hospitalization (figure 4). Inappropriate Foley catheter care (n=7) was the major reason for emergency room admissions (figure 5). During the first month after discharge, the 16 elder stroke survivors had the highest rate of unplanned re-hospitalizations. Emergency room admissions were aggregated during the first three months (figure 5).

Fifteen care difficulties and challenges (figure 3) are clustered into ten major care areas based on the main concern of each difficulty. The ten care areas are described below. When family caregivers faced the problems they tried to solve them, however, their strategies often generated secondary difficulties. Thus in this section, their primary problem, management strategies, secondary problems, and outcomes are depicted in "*giving care*" and "*what about me?*"

Giving Care

Giving care provides a rich description of care situation difficulties in the following ten areas: emotional problems and pain; nutrition; breathing; elimination; lifting, transferring, and bathing; position change and wound care; medication and unexpected situations; rehabilitation therapy and resources; environment barriers and transportation; and foreign care attendant's communication barrier and care ability.

Emotional Problems and Pain

Seven of the 17 family caregivers indicated that their stroke survivors' emotions became unstable after having a stroke. With the exception of Chuan, all of those stroke survivors were cognitively intact. Three family caregivers described their stroke survivors as insecure and lacking hope for themselves.

Figure 3. Difficult Care Situations at Home

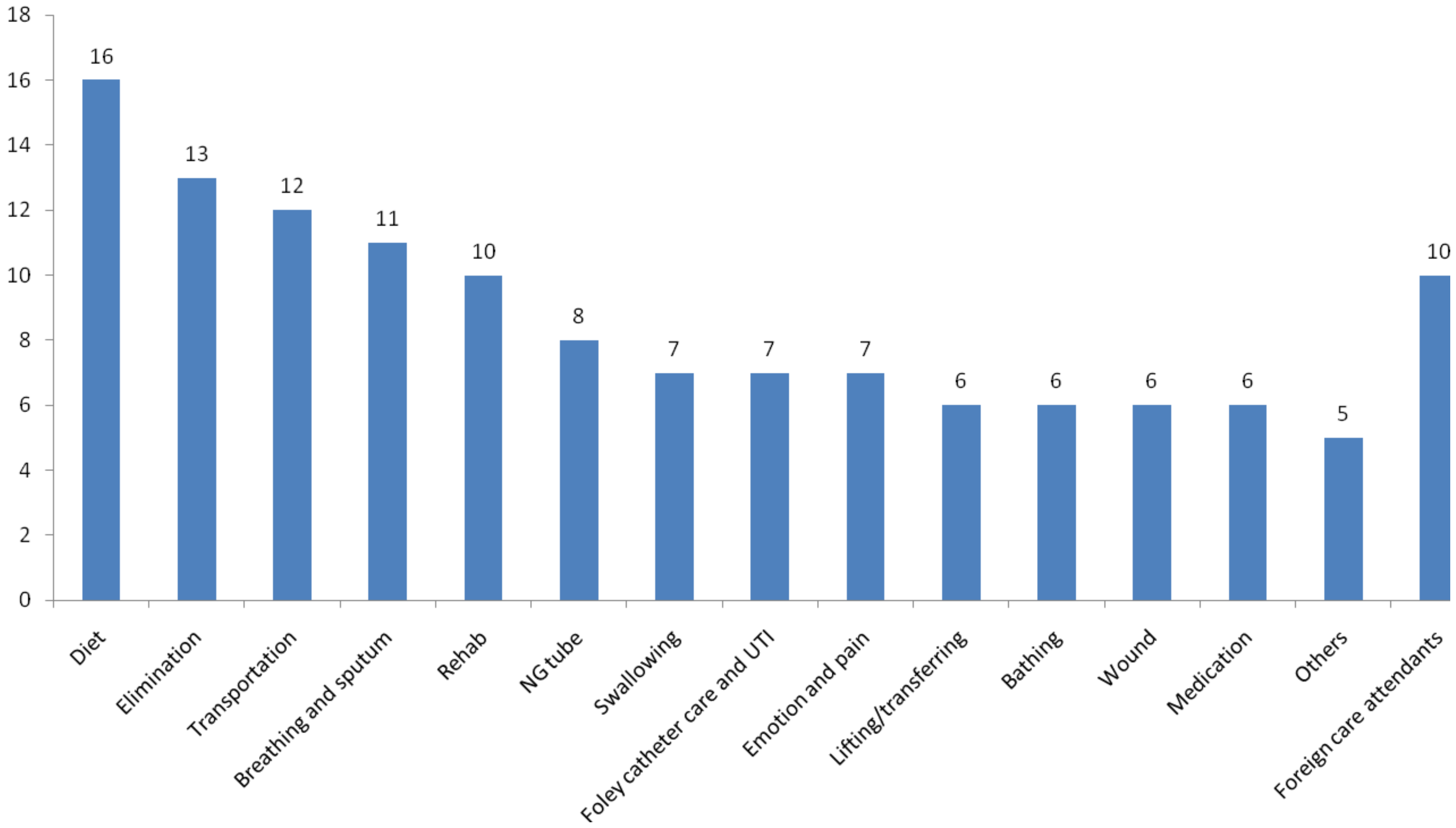


Figure 4: Reasons for Unplanned Re-hospitalizations and Emergency Room Admissions

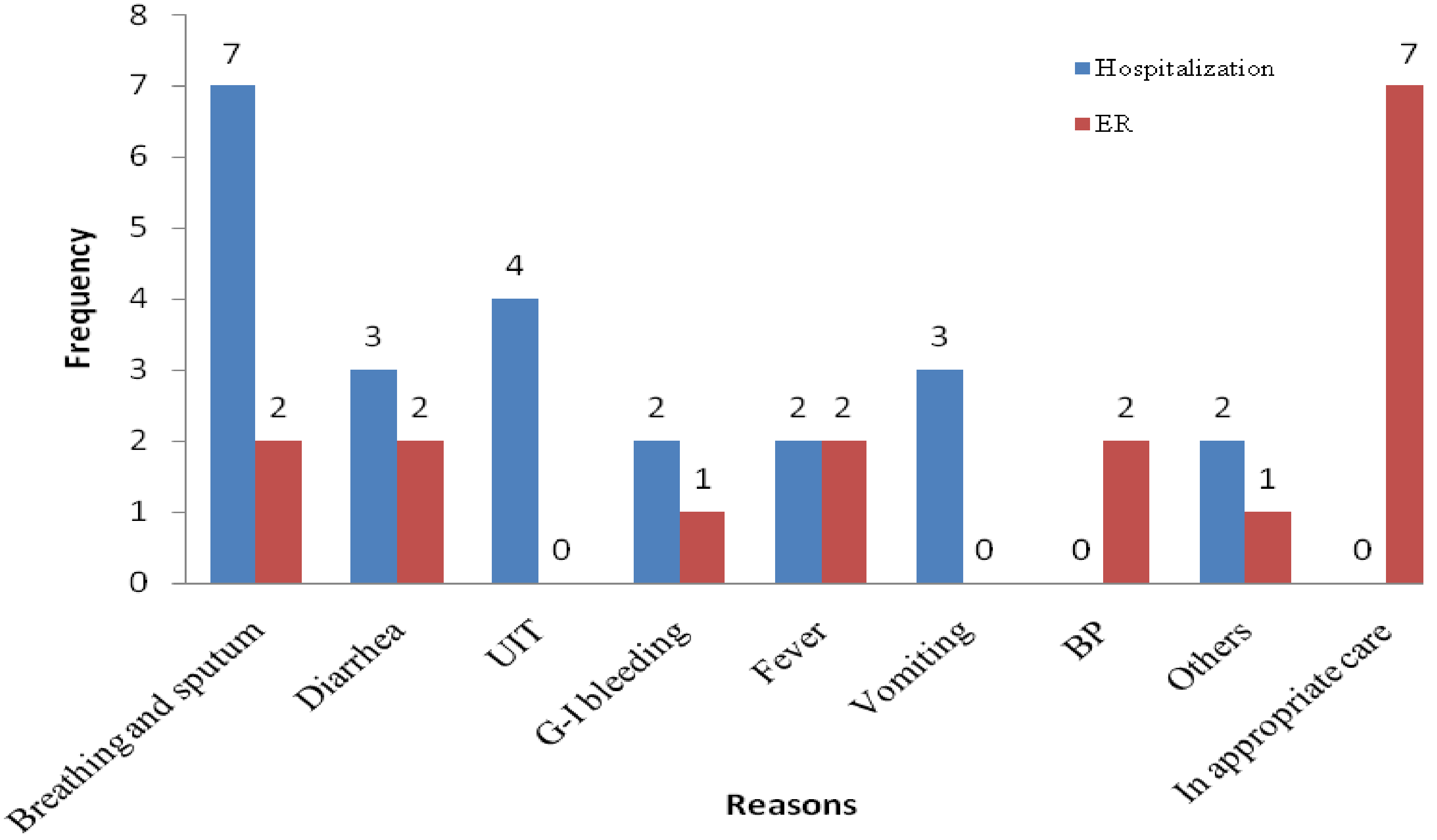
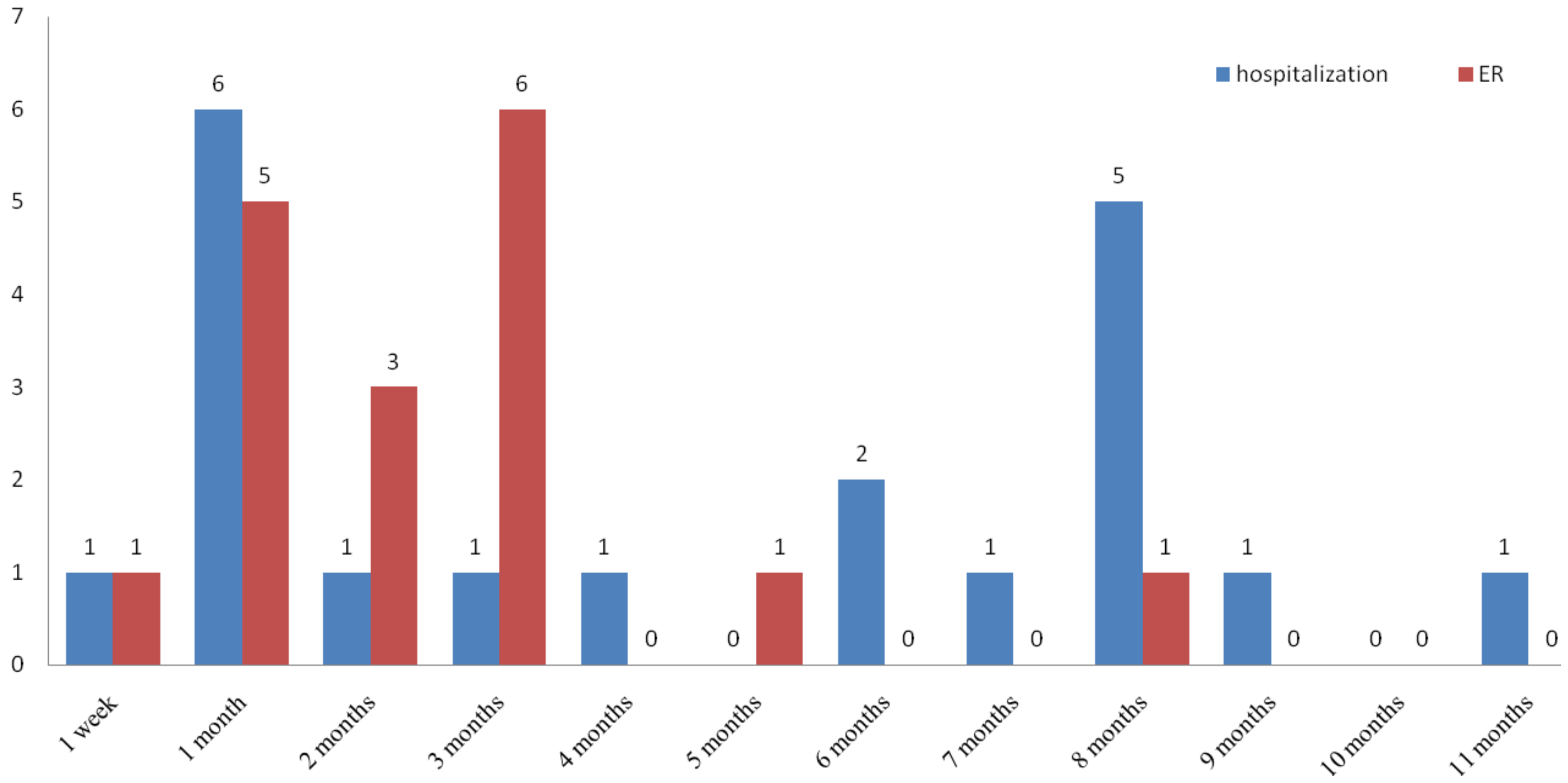


Figure 5: Time after Discharge, Unplanned Re-hospitalizations and Emergency Room Admission



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* Siong had 3 times of rehaopitaliztion due to continuous panting in the 8th month.

* ER: emergency room

> Every day she complains, “I am dying! I am dying!” and she felt depressed “Originally I can walk but now I can’t. What should I do?” We often comfort her but she won’t listen to us….She repeats her complaints over and over within the hour. We have to say the same things again and again. I don’t have any other better ways to deal with her complaints. (Lee)
>
> I asked him “who I am. Do you know what my name is?” Then he said with a very low voice, “I know. You are my wife.” I felt so sad and almost cried. He just stared at me. He couldn’t speak out anything. I know he absolutely won’t be like this. He is not a talkative person. After this stroke and the hospital mistreatment that caused him to be unable to stand. His mood is so heavy. He lacks motivation to say anything now. (Chiou)

Three stroke survivors’ emotion and behavior became out of control and uncooperative with care activities.

> Helping him take a shower is a very difficult thing. He only listens to my daughter, so if she is home it is easy to do. If not, his body is either totally soft or stiff…We almost fall together….then my daughter…She shouted at him what are you doing, dad? … then he becomes very cooperative! (Zu)

The emotional behavior impacted family and stroke survivors. Zong explained:

> My father’s emotions became out of control. When we took him to temple, he spoke abusive language at whoever was there. ..Later he even wanted to kill my mother with a knife… and my daughters were so frightened that they wet their pants.

Post-stroke pain accentuated their emotion condition.

> When we moved her body or hands or legs, she felt pain. Because of pain, she cried and complains a lot. She won’t cooperate with rehab activities. (Hui)
>
> In the early days, his brain condition was not so good. He felt pain at even a tiny movement. Any vibration or percussion caused him having severe pain. So he doesn’t like us to give him chest percussion because the percussion caused his pain... He thought we couldn’t understand his pain at all. Why do we cause him pain on purpose? Why have we treated him like this? (Hua)

The family caregivers were challenged by the emotional problems.

> We had to rub for her all the time. My hands were so sore. This is fine with us. But she kept crying that she was in pain and this almost drove us crazy….I was so stressed! The key point is if she complains of pain or not. Once she feels pain, we are in trouble. (Lee)
>
> Because her emotion was so unstable, Iris was unable to sleep well during the night. My mood was also bad….. Furthermore, my husband, my brother and

> sister-in-law won’t give me a hand. I felt so much chaos! ... Iris and I all felt exhausted. (Hui)

When Zong’s family could not bear Siong’s uncontrollable emotion anymore, Siong was forced to have psychiatric therapy and hospitalized for two months. The family caregivers stated that they had limited understanding about pain. “Does that (the pain) mean her hand and leg are going to atrophy? (Lee)” Lee understood it from the physician’s explanation at a follow-up check and Hui understood the pain from her own mother’s stroke experience.

> My own mother told me, “That (stroke) makes me feel extreme pain! It is really painful! ” Then I understand it is really painful for a stroke person” (Hui)

The first way of dealing with the emotional problem was to verbally comfort their stroke survivors. But this did not work very well. Only three sought help from their physicians (Zu, Hui, and Chuan). The physicians prescribed medications to control their emotions and pain. However, the medications did not work well either.

> Then after she had the medication, she slept all day. She won’t eat anything, just slept. I guessed there must be something wrong. It might be caused by the medication that was too strong for her…. I asked her to have some food again and again. She said “I don’t want to eat. I want to sleep.” Just half tablet. (Lee)

> (After having the medication) Sometimes she won’t sleep until 3 AM and wakes up at noon. She often slept in the daytime but keeps awake in the night time. (Hui)

As a result, the family caregivers dealt with the emotion and pain problems their own way until the emotional problems subsided naturally after the pain disappeared.

> So now I take the medication out. I wouldn’t give her anymore. If she feels pain again, we just rub her. (The pain lasted six months before it subsided.)(Lee)

> I had no choices. I demanded that Iris give her medication earlier to avoid her sleeping during the daytime. (Rou felt less pain after four month.) (Hui)

The other four family caregivers did not seek any advice or help from health care providers. The problems either subsided by their stroke survivors’ condition natural recovery or by continuously enduring the difficult situation. “If he can cooperate, everything should be easy! (Zu)" Regarding the emotional problem and pain, Hui indicated that the health care providers should provide mental rehabilitation therapy for stroke patients before and after discharge.

Nutrition

Nutrition issues included NG tube care, diarrhea, swallowing, and diet preparation. Half of family caregivers experienced the NG care problems at home. Twelve family caregivers said they learned NG feeding and care before discharge. Yet they faced totally different NG care situations at home: frequently pulled out, bloody drainage, and NG tube obstructed. If the stroke survivors were confused, this situation tended to happen more often. Lee described:

> This is the hardest problem for me! One time it (the tube) was accidentally pulled out …. That was early morning! I was so scared. She needed to have her medication and food. She could not eat from her mouth. I was extremely panicked at that time!

And Tsain explained:

> Now she relies on the NG tube to have her food…. One time she pulled the tube out! How terrible it was! I was afraid that if I couldn't find them (the home care nurses), she might starve to death…

When facing this problem, family caregivers' immediate reaction was calling their home care nurses. Yet most home care nurses' work hours are from 8 AM to 5 PM. "Nobody is available after the service hour and during weekends. So I couldn't find them! I feel so insecure! (Tsai)"

If family caregivers did not have timely services, their next step was sending their stroke survivors to the emergency room. Nevertheless, taking a disabled person to the hospital was very difficult. Family caregivers either tried other 24-hour home care agents or learned how to re-tube. Once acquiring 24 hour care assistance, Pin explained how:

> Because my grandma pulls her NG tube out very often, I always call her (the agency home care nurse). She never takes longer than one hour to get here. Having her service, I don't need to drag in lots of people to take my grandma to

> the hospital.

Two family caregivers learned how to replace the NG tubes. The home care nurses recommendation was to apply an unbendable mitten to prevent the elder stroke survivor from pulling out the NG tube. Family caregivers indicated that the recommendation worked well for preventing the NG tube from being pulled out.

Four family caregivers experienced the problems of bloody drainage and blocked NG tubes. Zu described how:

> At the beginning, his NG tube often drained some blood and I had no idea what to do. So I rushed next door (a nursing home) and asked Mrs. D (the nursing home owner) for help. She said: "the color is thin so it is not so serious. You can stop one meal. If the condition lasts, you should send him to the hospital." ….. Otherwise, I was so afraid. After hearing what she said, I felt much relief!

And again when the NG tube blocked, Zu talked about how:

> Now I know how to solve this problem. At the beginning, I was so nervous and hurriedly wheeled him next door (a nursing home). Then they taught me how to deal with this. (When she described this, she pushed a little water with syringe.)… Now it works! Otherwise I was so nervous when I faced this problem for the first time.

At discharge, all of the stroke survivors had NG tube and the nutritionist recommended the commercial formula as their diet at home. However, family caregivers experienced diet issue difficulties, including diet preparation and elimination problems caused by the commercial formulas. Three family caregivers faced the diarrhea and constipation caused by intake of the commercial formulas. They did not understand the reason and felt the issue was hard to deal with. The diarrhea problems caused them to have three unplanned re-hospitalizations and two emergency room admissions. For example, Rou had two serious diarrheas because of having too much probiotics in her diet and lacking sufficient dietary fiber. Hui (Rou's daughter-in-law) did not understand the reason. She described what she learned, "The physician said: Probiotics were good for our intestine, but it also caused diarrhea if having it too much." "She (the nutritionist) told me it might cause by lack of sufficient dietary fiber.” Siu had diarrhea problems after having the commercial formula as well. Pin said,

> I tried different products of milk….I changed her milk (commercial formula), trying many different brands. But she still had diarrhea…Later I assumed it might be an aging phenomena. I changed my grandmother’s diaper again and again….Until one month later I visited the dietitian and she suggested me to use xxx (current commercial formula). Now she is OK. No more diarrheas. (Pin)

Commercial formulas also caused Wen’s and Ji’s hyperglycemia.

> Her blood sugar is very high and unstable. So I switch to xxx (the current brand of commercial formula) because my aunt has diabetes and she has this. Now it is better. (Jen)
>
> When she had the commercial formula, her blood sugar was very high. Thus I don’t think the commercial formula is good for my mother. So I started to prepare her food my own way. (Ya)

Diet preparation and difficulty swallowing were other problems related to eating. At discharge, the nutritionists usually recommended the commercial formula.Yet, family caregivers were concerned about the nutrition and cost. They indicated the ongoing expenditure for purchasing commercial formulas was a burden. Quan expressed, “What I am concerned with is about the expense of buying the diet. It is too high! And the nutrition might not be enough if he only has the commercial formula.” Nine caregivers prepared a home-make NG diet. Yet only two of them learned diet preparation in hospital.

When preparing the NG feeding diet, the first challenge was: how to prepare a right thickness and adequate nutrition diet. Ya described:

> In hospital, the diet easily dripped slowly. It was not necessary to push with a syringe. But my own prepared food was too thick to drip. At that time we didn’t know we could use the syringe to push slowly instead of dripping. We (Ya and her foreign care attendant) stood there over one hour and watched it. But it didn’t flow into at all. Nobody taught me how to prepare an appropriate food! (Ya)

Later Ya searched diet information from books, and learned from friends and other family members that a vegetarian food was the best diet for her mother. At a follow-up visit, she requested a lab check.

> The report showed everything was OK and normal! So I know it is the right way to go. I continue to give her this food…..After my mother had this food, her insulin doses are less than before and her blood sugar is more stable than before.

Tsai described his experience of preparing his mother's food:

> The first month she was so skinny because we didn't know how to prepare her food. The doctor and nurses told us "just giving her the milk (commercial formula)." I bought a whole box of the milk and only gave her this….

The problem was resolved when the "home care nurse visited, she taught us how to prepare her food….One month later, she gained some weight and has more vitality. Now it is much better. Fortunately the home care nurse taught us those things; otherwise, we wouldn't know how to do it. (Tsai)" On the other hand, Quan received instructions from the nutritionist before discharge, but she had difficulty following the instructions.

> The nutritionist gave me one sheet and taught me how to prepare a NG diet at home. She taught me to measure his food by grams. But a common person never uses grams to measure their food when she/he cooks. At that time I thought: should I buy a scale? (Quan)

She went on to explain how:

> We are lucky because one of my hired nurse aides has the experience, so she taught us how to cook it…The process was smooth. We didn't have the exploring stage of finding out the proper thickness. She told me the recipes and how much water… (Quan)

The second difficulty was learning how to prepare a dysphagia diet. Seven elder stroke survivors tried their food from mouth. Except for Ji, the stroke survivors were all cognitively intact. Five family caregivers received instruction from their physicians: give soft food such as pudding. However, soft food did not work for any of the elder stroke survivors. Ya and Chiou explained:

> She couldn't and didn't like to eat it (pudding). I stood there for a long time and she wouldn't try….I tried five or six times and she wouldn't eat it, so I gave up. (Ya)
>
> I fed him porridge with a small spoon and he tried a little bit, but he choked and could not swallow the food. I was afraid that might cause problems for his lungs, so I didn't try anymore. He was unable to swallow. (Chiou)

Zong and Chiou discontinued further trials. The other three family caregivers (Huo, Zu and Ya) all tried on their own ways to deal with this problem. Huo made "Milk cracker mixed with water and it became thick, like rice porridge…. she likes it, it smells so good...If she ate too much at one time, she would choke. Little by little!" And Zu found that to give rice porridge mixed with ground meat and vegetables. "He can swallow most of the food."

Both Mei and Rou were weaned off NG tube after discharge at three and two months, respectively. However, their family caregivers did not learn how to prepare appropriate food. "The physician just said you could give her some rice porridge…But the first time it (the food) was too watery, she choked. (Hui)" Later Lee (Mei's family caregiver) and Hui (Rou's family caregiver) consulted with health care providers. They described:

> The doctor said if she is unable to swallow, you could add some "Kwie EE Bow" (like jello powder which can make the food become colloidal type) in her food. It works. She didn't have any choking. (Lee)
>
> At that time, I suddenly realized that a stroke person could not have liquid food. A thick food is better for swallowing. She (the nutritionist) recommended to me that I buy something to thicken the food…But she did not tell me how much water should be added…She just said, "you could try it at home." I tried it, but it did not work well. At that time I felt so confused…..later I tried many different foods. I found Quaker oatmeal cooked with radish, onion, cabbage and fish was the best food for her.

Another swallowing problem for Rou was chewing. Opening and closing her mouth was the only instruction from the physical therapist. But this did not work well because Rou felt pain and won't cooperate with this activity. "She complained of pain and won't eat anything. (Hui)" Later Hui integrated the training activity into her daily meals.

> I asked Iris about chopping the vegetable into larger pieces then she can chew it. I also let her try some fruit such as banana or kiwi. At first, she refused to chew it because she felt pain when chewing. But I told her, "you have to try it, otherwise you will re-tube the NG tube."….Now she doesn't complain pain anymore and her face shape looked better than before.

In total, all of the families overcame the problems of NG care, diet preparation and elimination. However, before they solved their problems it took time to find the best ways. From Tsai's and Quan's experiences, an experienced persons' instruction can shorten the duration of trials and errors.

Breathing

Eleven elder stroke survivors experienced breathing difficulty and ineffective sputum removal. Family caregivers indicated that breathing difficulties were the hardest caregiving problem to manage. Breathing problems caused six elder stroke survivors to have seven unplanned re-hospitalizations and two emergency room visits. For example, the Fong family faced the serious breathing difficulty right after going home. De described:

> I found she had an unusual breathing pattern from noon to night on her discharge day. At that time, we did not buy the oxygen machine. We didn't know that is necessary equipment…We arrived home around at 11 AM. Until that night, she still had difficulty breathing. I observed her abdominal area…I was so worried. Around one o'clock AM, I borrowed an oxygen tank from a sea diving equipment store. Unfortunately, it was not an oxygen tank. It was a general air tank for sea dive…. So I rushed back to the hospital at midnight and borrowed an oxygen tank…After inhaling around five minutes, she breathed much more smoothly.

Siong had breathing difficulties and was re-hospitalized three times, with one emergency room admission. Zong (Siong's son) described his worry:

> In his recent condition, he keeps panting constantly after going home. I do worry about this… We have to observe his breathing all the way. We count it always. If he pants again, we must call an ambulance and send him to the hospital…. we could handle other non-emergency situations, but for his panting, 30 to 40 times per minutes, we really couldn't handle it.

On the other hand, eight stroke survivors experienced ineffective airway clearance at home. Family caregivers described the common ways of dealing were giving chest percussion, prescribed medications and sputum suction. However, three of them (Ying, Mian, Siu) were re-hospitalized or admitted to emergency room. "I was so nervous, when she (Ying) had sputum. Beth (foreign care attendant) didn't learn suction skill in hospital!

So I sent her to the emergency room! (Huo)” Similarly, only discharged one month, Mian was re-hospitalized for six months due to ineffective airway clearance because Jin (Mian’s daughter) did not know when or how to use the suction machines. Jin explained:

> The physician and other health care providers did not tell me that I have to prepare a suction machine at home. They did not mention that at all! … At that time I lacked experience so I did not prepare anything….When she coughed, I wasn’t aware that she needed sputum suction.…If the doctor told me that I had to rent a suction machine and I learn the suction skill at that time, she wouldn’t have been re-hospitalized and become so serious ill. (Jin)

Yi’s sputum was too thick to suction effectively then caused sputum accumulation. Sputum accumulation produced an offensive odor and caused Yi to be re-hospitalized for three weeks. During this hospitalization, Bao learned how to use a steam inhalator to soften the sputum.

> Nobody told me what possible condition might happen after discharge. I have to manage the problem with my own way. ...At first I didn’t know about giving him steam inhalation. I only gave him oxygen and suction. Really it is not easy to clean his sputum without steam inhalation. The reason for the offensive odor was because the sputum was not completely clean and gradually accumulated…Now I bought a steam inhalator. Now if I cannot give him an effective suction, I will let him inhale some steam. (Bao)

In addition, Mi and Yi had tracheostomy with oxygen supply, their family caregivers also aggressively tried weaning off their oxygen supply machine. When trying this, they did not receive any instructions from any hospital health care providers. Yi succeed but Mi failed. They caregivers (De and Bao) described how:

> Sometimes I turned off the oxygen supply machine….Then I observed his breathing to see if he had any troubles. Sometimes if the oxygen was not sufficient, he took a deep breath. I turned on the oxygen machine. Around a half month later, he no longer needed the oxygen supply. Nobody told me how to do it. I tried it on my own based on my own understanding. (The only one source was the equipment supply store owner who lent her a blood oxygen monitor and told her the normal oxygen level.) Because he lent me the machine, otherwise, I would have no idea how to take off his oxygen supply. (Bao)
>
> I try to take her oxygen supply off every morning and evening, one or two hours each time. .. she can get used to it little by little.… Dr. Lee said she can spontaneously breathe under general air condition. Maybe she is used to breathe under oxygen supply, so when she just came home she could not control her breathing without oxygen supply… (De)

All family caregivers had ongoing uncertainty about how to manage breathing problems, if they did not have a good care plan for their stroke survivors' respiratory system.

Elimination

Elimination problems included frequent constipation, and diarrhea caused by intake of commercial formulas (described above), Foley catheter care, and urinary tract infection. Ten stroke survivors had constipation. Family caregivers dealt with the constipation by administering medication, increasing water intake, adjusting vegetable and fruit amount, enema and manual fecal removal. Nevertheless, only three family caregivers indicated that they learned manual fecal removal before discharge. Except for enema and manual fecal removal, the other care skills did not show consistent outcomes for the ten stroke survivors. "I add more water in the milk (NG diet) if her poop looks dry. But it doesn't work well. (Siang)" "When he has constipation, I give him a glass of juice punch. It works very well. (Quan)" Ying continuously had alternative diarrhea and constipation problems. Huo dealt with the problem by adjusting the medication based on Ying's elimination condition.

> A few days ago she had diarrhea for two days, so we went to the emergency room. They gave her a shot. Probably that was diarrhea medication. Then the doctor gave us some medicines. Then her diarrhea was ok. This might be the side effects of the constipation medication prescribed by xx hospital…So I stopped giving her the medication. But the second day she did not poop. So I gave it to her again. This morning she had diarrhea again, so I stopped the drug again and replaced it with the diarrhea medication.

Family caregivers often tried various methods at the same time. Enema and manual fecal removal were the last strategies. But they indicated the last way could not clean the stool completely. Though family caregivers did not talk a lot on constipation problems, they consistently indicated constipation was a very difficult problem.

> He poops every day. But it looks like fecal incontinence. Because he lacks strength to push, so he could not poop it entirely… if I took him to bathroom, I always let him sit on the potty. But he always took a long time. If he could not poop it, I have to manually clean his poop…But I could not remove it completely. Seems there is a lot still in there. His pooping is really a trouble for me… (Zong)

> This is a very difficult problem. Because the prescribed medication does not work very well, so I have to manually clean her poop. Every time when she poops, I am so happy! (Ya)

Inappropriate Foley catheter care, including obstructed urinary catheter and urinary tract trauma, were the major reasons for emergency room re-admissions. Three (Ji, Rou, and Lian) of the seven catheterized stroke survivors encountered the problems. Ya described:

> She couldn’t sleep during midnight … very uncomfortable. …I had no idea! Until the next day around 5 or 6 am, I found my mother didn't have any urine at all and her tummy was so extended. I pressed her tummy and thought there must be something wrong! Later my mother‘s expression was so bitter and she continuously said “I am going to die! I am going to die!” … I tried to call out but I didn’t know where I could call! I thought this should be a urinary tube problem and I should call the home care unit, but it was not office hours yet. … the nurse who came to adjust my mother’s (V-P) shunt function said if there were any problems just call her. … So I called that nurse and told her my mother’s condition. … She answered me, “you ask me the problem, and I also have no idea either. If you think your mother feels uncomfortable just send her back to hospital. My responsibility is only adjusting the shunt function.” … I hung up the phone and called 911 immediately. Then when they moved her body …around 500 cc (urine) ran down in one second! … See, we struggled with this at home for such a long time! At that time I thought someone should have told me about this!

Ya and Tsai faced the bloody urine problem. They expressed “I was so scared and terrible!” Tsai hired a foreign care attendant, Nancy, to provide physical care for his mother. However, Nancy was inexperienced in the care skills. At the beginning, Tsai’s mother, Lian, had some unexpected situations due to inappropriate care and was re-admitted to the emergency room twice.

> At the beginning, the urinary tube was often twisted and sometimes contained blood. The possible reason is: When she held her or moved her, she was not aware of the tube and her action was inappropriate; this caused her urinary tract trauma. I rushed her (Lian) to hospital; the physician said “no serious problems and it’s not necessary to worry. It just is a minor trauma!”

Urinary tract infection was the second reason for unplanned re-hospitalizations (n=7). Seven family caregivers experienced this trouble. Over half of the 17 family caregivers learned and gave more water and cranberry juice to elder stroke survivor to prevent UTIs. In addition, for stroke survivors who were Foley catheterized, family caregivers indicated inappropriate genital clean and care might cause UTIs. For un-catheterized stroke survivors, family caregivers believed frequently changing diapers could prevent UTIs. Yet seven stroke survivors (Foley n=3) had four unplanned re-hospitalizations. Pin described:

> She has the urinary catheter now. Sometimes she also has diarrhea. I clean her genitals by using normal saline and sponge swab…Now I really worry if she isn't cleaned thoroughly that it might happen again.

For the elimination problems, though the diarrhea and inappropriate tube care problems were overcome, constipation and urinary tract infections still bothered family caregivers.

Lifting, Transferring, and Bathing

No family caregivers identified being taught any lifting and transferring skills, which made care activities such as bathing or taking the stroke survivors in and out of their beds, very difficult. All of the 16 stroke survivors relied on their caregivers to lift and transfer them to a wheelchair or chair. Six family caregivers expressed having difficulty with lifting and transferring their stroke survivors. Three family caregivers incurred back injuries when transferring their stroke survivors. Hui explained:

> At first, no one taught us how to assist her into a wheelchair or other place… We didn't learn this skill until we visited the rehab department after discharge. Before the visit I used what I heard and understood from other persons to teach my foreign care attendant…..At that time I had many questions regarding the transferring skill: Why couldn't we have learned this skill before discharge?

Lifting and transferring was an essential skill for giving the stroke survivor a bath at bath time. Types of bath included sponge (n=10), shower (n=2) or both (n=4) (Table 1). For the ten who took a sponge bath only, seven of them were cognitively impaired, four were males, and six were primarily cared for by foreign care attendants. Family caregivers indicated that it was hard for them to lift and transfer their stroke survivors into a wheelchair or a shower chair alone, especially when they cared for male stroke survivors. "I could not bear his weight so I just helped him take a sponge bath. (Bao, wife)" Without a helper they were unable to give the bath alone for their stroke survivors. As a result, most family caregivers chose a sponge bath instead of a shower bath. No family caregivers indicated any difficulty in providing a sponge bath and they considered it was enough for their stroke survivors.

For the six stroke survivors who had a shower and alternating shower and sponge baths, four were cognitively intact. In contrast, five of the six caregivers indicated bathing was a difficult care activity. They expressed that transferring their stroke survivors into a shower chair or wheelchair was the most difficult part. They also worried about causing an accident, such as falls, during the transferring and bathing process. Waiting for helpers was the common way to overcome the difficulty. If their helpers were not available, they provided a sponge bath instead. For example, the researcher observed how Chiou gave a shower to husband (Lin). During the observation, Lin's body was rigid making it very difficult for Chiou to move him out of his bed. Lin was positioned higher than Chiou. During the transferring process, Chiou used all of her strength to lift and move Lin into the shower chair. Chiou indicated that

> His body became harder and harder to move, I fear a fall when I lift him up and moved to the shower chair…Now I won't give him a shower alone, I wait for my son or my daughter to help me.

Inappropriate assistant device also increased the difficulty of taking a shower. Pin and Hui described their situations:

> Helping my grandma to take a shower is the hardest work for me. My father replaced the back part of the wheelchair with elastic bands. But it does not work well. It is hard to clean her bottom area. My father thinks what he does is the best and most convenient. He said "just move grandma into the wheelchair, then wheel her to bathroom and giving her a shower." He thinks it is very easy to do, but he never thinks about how difficult it is for me. Before giving the shower, moving my grandma from her bed into the wheelchair is okay for me and my husband. But after the shower, it is not easy to dry her body thoroughly and her body is slippery, it is not easy to transfer her back to her bed. She almost fell many times! (Pin)
>
> She is not a fat person. And at that time we didn't buy a shower chair with rollers. She was on a stool chair and we (Hui and Iris) had to lift her up and moved her to the bathroom. ……We didn't know we could purchase the shower chair from the

> equipment store at that time. (Hui)

Eventually family caregivers indicated that purchasing a shower chair was not recommended by any health care provider. Rather, “Later, my brother-in-law found one by chance. He asked me: should we buy one? I said: definitely. (Hui)” “The shower chair is a gift from one of my nurse aides. (Lee)” Importantly, they all indicated that having a shower chair made their care easier.

From the distribution of bathing types, stroke survivors’ conscious level and available helpers were two major reasons for their bathing types. If the stroke survivors were alert and helpers were available, their family caregivers tended to give them a shower. In addition, lack of appropriate devices increased the difficulty of taking a shower for their stroke survivors.

Position Change and Wound Care

Proper position change and support was the critical skill for preventing pressure sores. Only six family caregivers identified that they were taught how to change positions and two were taught pillow application before discharge. Three stroke survivors developed pressure sores either in the hospital or at home. Once they had a pressure sore, the wound often worsened and lasted for several months before recovery. For example, Rou developed a pressure sore on her sacrum area two weeks after discharge. The wound lasted two months. Hui described the situation:

> They did teach us how to change position but they didn’t teach us until the day before discharge. What they taught was very rough! At first, we thought those were enough for us…After going home, she soon had a pressure sore…. At that time no one reminded you that this (pressure sore) was a potential developing problem. No one mentioned this! … I only could verbally remind Iris: Be careful! But I didn’t know and didn’t remind her to change her body position frequently. We don’t have the knowledge, so we only can say “be careful!”…

Hui continue explained:

> When I found she had the pressure sore, I went to a drug store and asked the drug store person. She taught me how to care for it and recommended some dressings and ointments. Then I taught Iris how to care for the pressure sore based on my

> own knowledge and understanding. …Until the first home visit, the home care nurse taught Iris how often and how to change her position correctly. So we set the alarm clock to remind Iris. Even at midnight! She also taught us the correct wound care methods! And we changed the dressing very diligently….Now it is healed.

Wen was discharged with a 3x4 cm^2, 3rd degree pressure sore on her sacrum area. Before discharge, Jen did not learn sufficient wound care. She described how:

> We tried many ways. For example, we tried the transparent dressing, but it did not work at all. Because she had urinary incontinence so the wound was contaminated by the urine. The urine seeped into the wound. We also tried different ointment bought from drug store. At last the doctor suggested that we change her dressing whenever she urinated! (After six months her wound was healed.)

Family caregivers stated they did not learn pressure sore prevention and wound care before discharge. When they faced the problem, the home care nurse and the drug store personnel played an important role for providing information.

Medications and Unexpected Situations

The family caregivers also faced medications, skin, and fever problems. The stroke survivors were prescribed three to ten medications to be given two to four times per day. Most family caregivers expressed that they could manage the medications; however, six of them had medication problems. When faced with the problem they all experienced uncertainty and pressure. For example, Ya described controlling her mother's blood sugar problem.

> In the hospital, her blood sugar was very high ....around 300, so the physician gave a certain dose of insulin. But after being home, her blood sugar was decreasing gradually. But I still gave her the same dose of insulin….then her blood sugar became very low. One time, her blood sugar value was around 90. That was before I gave her insulin…. 90 is very low for a bedridden person…At that time, I wondered should I still give her the same dose?!...But no one had told me. Because this was the doctor's order, I don't think I could reduce the dose. We don't understand this! ….Then one physician was just here and told me that "you can adjust the dose. It is not fixed as the order."…then I understand it! It does not mean the order is 10 and I have to give 10, 20 is 20. But nobody told me this before.

Additionally, Ya indicated, “I always focus on keeping the value at 120. He (a traditional Chinese medicine physician) said “a little bit higher than 120 is OK. Don’t worry!” But nobody told us this before. In contrast, the physician always tells you a fixed value. He never tells us a normal range and it is OK if the blood sugar value is in the range. Don’t be scared! He (physician) should provide the safety range.” Ya and Quan also confronted medication unexpected effects. Ya’s mother, Ji, was diagnosed with a UTI and had been prescribed medications at one emergency admission. After taking the medications, Ji became very drowsy, and both her blood sugar and blood pressure were elevated. Ya felt “anxious” and called the pharmacist:

> She said it shouldn’t be this. It might be caused by …. Her answer was so ambiguous. I had no idea what to do. I can say what she said was the same as saying nothing. What I needed was a clear answer: Can the patient continue having the medication or not.

Ya decided to stop the medications and her mother’s condition improved. Chuan had gastric bleeding due to aspirin therapy. He was sent to emergency room for one night. In addition to the gastric bleeding, Chuan had two fevers due to having a cold. Quan described her feeling of dealing about these emergency situations:

> The most difficult thing is to deal with his complications. ….because each time his complication is different. It is kind of unknown. An unknown one is tough to handle. If I know about it, I won’t be afraid. For example, they told me that having sputum might cause a fever. Like this they mentioned to us in the hospital, so we have more understanding if we encounter it. But they did not clearly mention other complications; it is hard for me to deal with.

Other unexpected situations indicated by family caregivers were skin and fever problems. Two (Sing, and Mian) stroke survivors had skin problems (skin rash). Although the problem was not as critical as other problems, family caregivers indicated skin problem were hard to deal with. “She never has the skin problem before. I have no idea about this. I guess it might caused by having too many medications. (Jin)” Seeking treatments from physicians was the only way they could do. In addition, five (Sing, Yi, Sing, Ming, and Chuan) stroke survivors had non-UTI fevers and the fevers caused one hospitalization and one emergency room admission. Similarly, family caregivers also said that not knowing the reason for a fever was most difficult because they were unable to deal with it.

Rehabilitation Therapy and Resources

Ten of the family caregivers indicated they needed further rehabilitation services. Physicians told family caregivers that their stroke survivors needed further rehabilitation therapies after discharge. Yet, physicians didn't offer rehabilitation referrals or teaching. Only Rou and Ming received a rehabilitation referral. Ming's family gave up the arrangement because of the time and transportation problems.

Five family caregivers expressed less motivation to seek further rehabilitation resources. Five possible reasons were identified from family caregivers' descriptions. First, twelve family caregivers stated rehabilitation therapy was range of motion (ROM), which they were trained before discharge and performing at home. "(Rehab activities are) Bending and stretching her arms and legs. That's all! Is there anything else I can do for her?! (Siang)" On the other hand, from caregiving activity observation and family caregivers' descriptions, with the exception of Ya, family caregivers tended to do everything for their elder stroke survivors. "I did everything for him when giving a shower to my father (Zong)." Second, it was not needed because physicians did not recommend rehabilitation therapy, although some stroke survivors were cognitively intact and had paralysis on one side. "The doctor didn't recommend us to a rehab unit for rehab therapy essentially. The only rehab activity for her is doing some range of motions for her hands and legs. (Tsia)" Quan expressed:

> The physician said: "it is unnecessary for him to have rehab therapy…" When I heard this, my thinking was, "his condition is really so bad and he doesn't need a rehab therapy?!" I felt so strange but I didn't want to ask too much!

Third, family caregivers described how they believed that their elder stroke survivors lacked motivation to have the rehabilitation therapy. "She (Mei) is tired of doing that (rehabilitation). She said I am 90 years old. How long I can still be alive?! (Lee)" and

“He should have motivation to do rehab, but he doesn’t. He feels the rehab therapy causes him pain and discomfort. I tend to follow his intentions. Honestly speaking, his current situation is hard to improve... (Hua)” Fourth, family caregivers also didn’t think their stroke survivors were able to perform rehabilitation therapies.

> There is no way that he could do it! He even couldn’t stand up, how he can do (rehab activities)? (Zu)
>
> At that time he was unable to get out of his bed. If he wants to stay in the rehab unit, he should be able to use the rehab equipment. His leg should be able to move…legs and hands…you must have strength to grab those…But he was unable to stand up, so how could he do those activities, such as kicking his leg and grab the bar? (Hua)

Last, family caregivers faced environment barriers, transportation and time consideration.

> Because we don’t have much time! It is impossible for us to take him back to the hospital just for bending his hands and arms. They had arranged the rehab therapy in the outpatient department but we gave up, because it takes a long time and is very inconvenient for us! We have to call an ambulance! So without any other choices, we gave it up! (Hua)

In contrast, Huo, Ya, Hui, Zong, and Tsai expressed a strong need of rehabilitation therapy for their stroke survivors. Of them, three were males (one husband and two sons) and two were females (one daughter and one daughter-in-law) who tended to have higher education level. Four of the five stroke survivors’ were cognitive intact. Except Tsai, the other four stated rehabilitation should include swallowing, walking and recognition training in addition to range of motion. Ya and Hui wanted to promote their stroke survivors’ self-care abilities. The five family caregivers all stated that the first six months was “a golden time” for their stroke survivors’ recovery.

> I always keep her rehab issue in my mind… Because someone told me that the first half year is the golden time for training her swallowing. After the half year, there might be some difficulties in training. (Huo)
>
> I told my mother-in-law that the first half year is your golden time for rehab. You have to tolerate it. My mother also had a stroke. She told me that was painful, but she survived from the process….I told my mother-in-law: You have to bear it. (Hui)

With the strong belief in the importance of rehabilitation, the five family caregivers intentionally figured other rehabilitation activities based on their own understandings.

> I train her cognition and memory. I write some words or numbers and show it to her. Such as I write our four kids' names on four cards then show her first. Later I pick one and ask her what's the name on it and which child's name….things like this. Those strategies pop out of my mind. I use those skills to train her cognition (Huo)
>
> I often talked with her, very often…. I played with her the childhood games she taught us. And I sang her favorite songs to her...... One day I asked her: Mom, do you want some Zong Zi (a pyramid-shaped mass of glutinous rice wrapped in bamboo leaves)? She answered, "No"…And on July 4th, she could say my aunt's name. Now she can sing her favorite songs with us…At first, she only can sing in her mouth, but now she has the voice. She cannot recognize us, but she can sing those songs! (Ya)

Zong demonstrated how he was able to train his father to walks:

> I faced him and put his arms on my shoulder; then I walked backwards to guide him to walk. His left foot could not move, so I used my right foot to hook his left foot and pulled his leg forward. I did this during his way to the bathroom and back to his bed.

The five family caregivers aggressively searched rehabilitation resources. Tsai used acupuncture and Chinese herb medicine as rehabilitation therapy for his mother; however, most expressed it was hard to find an acceptable and accessible rehabilitation resource. They stated that the resources needed to be easily accessed, such as facilities near their houses or an in-home service, and needed to provide continuous therapies. Huo's ideal rehabilitation service was "A van can load necessary rehabilitation equipment…then the therapist can provide in-home service. This is the best one." Chiou also indicated the in-home service was the best one, but she did not think the therapists would like to provide in-home service. "It is too far for them to come here!"

Huo continuously searched for resources from his relatives and friends and he found one resource in Kaohsiung City. However, it took around 40 minutes to go by car. Ya learned of a rehabilitation therapy program in one medical center from a nurse aide. It also took around 40 minutes from their house to the medical center. At the beginning, Ya encountered difficulty getting the service. The physicians could not accept her mother because each physician had an overload of patients. She wheeled her mother back and forth to three doctors' clinics.

> I looked at my mother and thought: we are here but why can't this one (doctor) see us and that one can't either! I was so frustrated and sad. Later one patient told me: "The first doctor is very nice. Try her again!" Overcoming my embarrassment, I wheeled my mother into the first doctor's office again. Then I couldn't control my tears anymore. They burst out from my eyes because I had no idea who could help!

The physician agreed to treat Ya's mother at the last moment. On the other hand, during the hospitalization, Siong (Zong's father) received rehabilitation therapies and had great improvement. Nevertheless, due to the limitation of length of stay, he was discharged. Zong immediately contacted another hospital.

> Transferring to other hospital is ok with me and I also agree to transferring to a specialty hospital for further care ….there should have a specialty hospital, a place for us to go. You couldn't say: OK, the time has run out….I accept this point of needing to transfer…but you should provide a place for us to go. These two segments don't connect very well. That's why he (his father) could not stand up again and his condition did not improve. I am extremely concerned about this, because his left hand and foot were able to move after the therapy in hospital. We had seen the optimistic way; however, there are no further resources over there. How and what can a family do?!

In total, initially ten family caregivers considered rehabilitation therapy necessary. However, some family caregiver considered the rehabilitation was limited to ROM and they had less motivation to seek out further services. Others recognized a "golden time" and the importance of advanced rehabilitations. They had higher motivation to seek out services. Yet, they all faced the difficulty of finding an acceptable and accessible rehabilitation resource.

Environment Barriers and Transportation

Environment barriers also caused difficulty for some care activities. In Taiwan, the current house designs contained many environment barriers (described in Chapter Four). Only Huo installed a ramp at the front door and Zong installed a ramp for assessing the bathroom. “Calling for help” was the way for family caregivers to manage. “I will ask my kids help me to lift her up, if she needs to go outside. (Siang)” In one observation, when Lee gave her mother, Mei, a shower, she and her foreign care attendant had to lift up Mei with the shower chair to step over the uneven surfaces and door sill into bathroom. Bao faced the most difficult environmental barrier. The family was living on the fourth floor of an apartment. There was an elevator in the building, but on the first floor there were 6-steps to walk up before getting into the elevator. This severely limited Yi’s leaving his house and participating with the rehabilitation therapy.

> (Years ago) My husband (Yi) made a portable ramp for my mother. Now he can use it. When he goes down, we can use the ramp. But if we are coming up, my son and grandson have to lift him and his wheelchair up…..They (health care providers) always suggest I take him back to have rehab therapies. It is really hard for me to take him back to hospital and I could not frequently ask my son to take a day off to help me….

In addition to the environment barriers, all families faced the transportation barriers. Eight out of the 16 families had to call an ambulance if the elder stroke survivor needed to leave. The reasons for calling an ambulance as transportation were: “they have a wheel stretcher.” “It is easier to move her.” The other eight families used their own cars, but they needed to wait for other family members for assistance. It usually required two to three helpers to transfer the stroke survivors into a car.

> The most difficult issue is taking him to hospital. Transferring him into the car is the most difficult part. We usually use our own car and we have to move him into the front seat. It is a very hard work. If no one can help me, I couldn’t do it! I try to call a taxi, but we need the driver to help us. They won’t take it. So either my son or my daughter has to help me. My daughter and I hold him together and move him into the car. Sometimes we almost fall together. He almost slips down to the ground! It is really a hard task! Now his body is so rigid…. (Chiou)

Due to the transferring and transportation difficulties, all family caregivers indicated the home care service was very convenient for them. For example,

> It is very good and very convenient for us. We don’t need to take my mother back to the hospital so often. My mother’s condition needs this service. If not, every two weeks we have to call an ambulance to take my mother back to the hospital for replacing tubes. (Siang)

Paratransit is a public and free service for a disabled person; however, none of the families knew about this resource. Three family caregivers (Huo, Hui and Chin) indicated they saw the bus, “but I don’t know what it is for. (Hui)” Three family caregivers (Ya, Jin, and Chiou) received this information about this service either from a nurse aide or home care nurse. They all greatly appreciated the service.

> If she needed to have a follow-up check, we always called an ambulance before… Later a nurse aid told me about the paratransit service. Now we call the paratransit bus. It is really really an excellent service and should be rewarded! Just schedule the time with them, then they pick you up at the appointed time. (Ya)

Overall, all families faced the environment barriers and transportation problems; however, due to lack of the information about the environmental modifications and paratransit service, family caregivers were unable to overcome those problems.

Foreign Care Attendant’s Communication Barriers and Care Ability

Nine families hired a foreign care attendant to provide physical care for their stroke family members. The reasons for hiring a foreign care attendant were: family caregivers were unable to provide 24 hours of care and the monetary concern. Though 14 family caregivers indicated that they had time available for taking on the role, once the elder stroke survivor was home, not all of them were able to provide 24-hour care. They hired a helper as an alternative choice. Yet, the cost of hiring a Taiwanese nurse aide at home was much higher than hiring a foreign care attendant. The nine family caregivers indicated they preferred hiring a Taiwanese nurse aide, but they could not afford the fees of a long-term payment.

Two major problems related to hiring a foreign care attendant were communication barriers, and caregiving capabilities. Four foreign care attendants had difficulty with communication. Family caregivers dealt with the communication problems by speaking slowly, using gestures and finding someone to translate.

> At first I thought that she could understand what I said. Whereas she nodded her head but she did not follow what I said. She could not understand what I told her! (Hui)
>
> Not so fluent, but she understands the basic Chinese. She could not speak as clear as a native speaker. Sometimes we could not understand what she says and have to make a guess. We often communicate with gestures…. (Hua)

Family members were concerned about the foreign care attendant's ability to understand caregiving tasks and expectations.

> We have to communicate with gestures and speak slowly to ensure her understanding. …my younger sister-in-law is an Indonesian. So for the first 3-4 days, she was responsible for communicating with her and making sure that she understood. She also wrote down a schedule of daily care activities on a poster and hung it there (pointing the poster to the researcher). I also asked the manpower agent to confirm what she learned was correct or not and whether she could understand what we taught her. (Quan)
>
> She (the nurse) only demonstrated to Iris once how to do the feeding task. Then Iris showed her once. Actually she really couldn't understand it at all…. I couldn't deal with her language problem, so I call the translator from the Foreign Laborer Agent. I asked her to come to the hospital. Because there were some foreign care attendants in the hospital also, so I told Iris: ask the translator to introduce one experienced foreign care attendant to you and ask her to teach you. I also asked the translator help me to make sure the content of what she learned from other foreign care attendants. Fortunately, there were two foreign care attendants who taught her how to change diaper and how to care in a better way. (Hui)

Another problem was their care capability and care quality. Tsai explained, "I assumed the foreign care attendants are experts on those care skills and understand how to care. I assumed they should have some training in Indonesia." However, this foreign care attendant did not have any elder care experience and except one day of care skill training from Tsai's previous nurse aide. At the beginning, Lian (Tsai's mother) had several incidences of urinary tract trauma necessitating admittance to the emergency room. Tsai found the foreign care attendant did not know how to provide Foley catheter care. Furthermore, Tsai found the foreign care attendant would not tell him about his mother's problems. "We have to find out the problems by ourselves. Possibly, she is afraid that we might consider her care is not good and we might complain to the agent. She is very afraid of the person in the agency because they are all very mean."

Language barriers and insufficient training were two primary concerns of family caregivers regarding supervising foreign care attendants. Seeking help from the manpower agent was the only way for family caregivers to deal with the problems and this was rarely helpful. The next section describes what family caregiver identified as their personal difficulties associate this new role.

What About Me?

All family caregivers described multi-dimensional difficulties related to the new caregiver role including feeling physically tired, emotionally distressed, socially limited and financially strained. In addition, female non-spouse caregivers described a lack of support from other family members.

Personal Impact

All of the 17 family caregivers expressed they were tired, had weight changes and sleeping interruption after taking on the role. The physical tiredness either came from providing direct care or dealing with caregiving matters. Nine of the 17 family caregivers experienced body weight change (two gains and seven lost). Two (Zu and Hui) family caregivers were diagnosed with hypertension after taking on the role. Other physical difficulties were headache, dizziness, and back pain or injury. All of the family caregivers experienced sleep disturbance because of the need to provide care during the night time, with survivor's condition changes and having a new nurse aide or foreign care attendant. Bao explained, "Just at home, he had lots of sputum. During the midnight, whenever he had coughs, I had to get up to give him suction. I was unable to get used to this situation for a while…" Zu described how, "He is very noisy during the night time. Mrs. B (home care nurse) recommended I sleep upstairs. But I am afraid some critical situations might happen during night time." In particular, sleep disturbances occurred, "At the beginning, it did (affect my sleeping). Each time I have a new nurse aide. I have some pressure because I am not sure she could care for him or not…. Such as the foreign care attendant who just was here, I stayed and slept here for ten days. I couldn't trust her care at the beginning… You know the last nurse aide had ten years of experience and she (the foreign care attendant) only had ten days. She had no experiences of the caregiving tasks before. (Quan)"

All family caregivers described psychological impact challenge from caregiving. Lee described, "She (Lee's mother) continuously cried in pain and this almost drove us crazy….I felt it was very stressful! Whenever she feels pain, we are in trouble….Though I feel tired, there is no other choice for me. I cannot escape from this! I have no choice. (Lee)" Chiou felt frustrated and depressed. She said, "I am a very optimistic person. But now I have lost my motivation and ambition. I won't do it anymore." For Jen, there was "no way to escape from caring for her mother. I lack energy, interest and hope…I feel I cannot breathe." Furthermore, all family caregivers indicated they felt hyper-vigilant regarding their stroke survivors' conditions.

> My great happiness is she can interact with us! But sometimes if she looks tired and depressed, I start to worry about her. "Is there anything wrong?" My mood becomes bad. (Ya)
>
> (Because Hui did not live with Rou, her cell phone was on 24-hour.) I know we have an elder at home; I worry that a critical situation might happen. If I turn off the phone and some critical situations happen, what could I do? … Now I find I have a panicky feeling when I hear the phone ring.... It almost drives me crazy. The foreign care attendant always calls me if anything happens; even trivial matters. (Hui)
>
> You (I) must be ready at anytime because he might have a critical condition. You should prepare for any critical situations. Thus the important one is you cannot have a real rest because you always worry and feel anxious about his condition. Of course, I couldn't have a good sleep and the immunity became worse. ….Until now (3 months after the stroke), I still cannot let go of the anxious and nervous feeling. Whenever the phone rings during the night, I jump out of bed and worry, My God! It might that something happened again! I still have some panicky feelings! (Hua)

Thirteen family caregivers felt their social life was impacted regardless if they provided direct care or supervised their foreign care attendants. For example, Zu described:

> I loved to sing songs with my relatives before. But now I cannot. I don’t have time. I am bounded here and I couldn’t go outside. Such like my brother’s daughter got married; I couldn’t attend her wedding ceremony!

The caregiving role also affected caregivers’ jobs. Two of them quit their jobs to provide care. Eight caregivers indicated they either had to adjust their work hours or frequently take days off.

> Everyone! Not only me! At the beginning, we all felt our time schedules were messed up....Now we have one more thing needs to be done. That means we have to take care of him. So we have to incorporate this into our daily life….And we have to deal with any unexpected situations. When it occurs, we might be busy on our own work and we aren’t mentally prepared for the situation. But we need to leave our work and rush to manage his matter. (Hua)

Six family caregivers experienced financial stress from purchasing commercial formulas and/or hiring a Taiwanese helper:

> (Purchasing) the NG diet (commercial formula) it really a burden for me because he needs the diet everyday! It is essential one for his daily life but the diet is not cheap. I feel highly burdened. That’s why we could not give my father seven bottles of NG diet a day. The major reason is expense. Otherwise, it is very convenient. Just open it and feed it. In a long run, the expense is really my family’s burden. … (Zong)
>
> During the first three months, from May to August, each month the expense was around 90,000 dollars (about 3,000 US dollars) on average….Hiring a nurse aide costs around 60,000 dollars each month….Now the pressure is not so high after hiring a foreign care attendant…But each month we still have to pay 3 to 4 thousand dollars for caring for him. (Hua)

The financial stress worsened their mental pressure.

> At first I didn’t feel tired, but now I am tired. Maybe my pressure is too high….tired, really tired. Not only physically tired because of providing care, but also have to worry about this (financial problem). (Bao)

Though not every family caregiver felt monetary pressure, most of them concluded that “Having enough money is the key point. If you feel this (dealing way) is not good, you have to seek other ways. But when you switch to the new way, such as hiring a nurse aide, it costs money. If you don’t have money, nothing can do! (Huo)”

Please Support Me

Spouses and sons had full authority for their stroke survivors. Tsai explained, “I don’t need to ask their opinions (other family members). I can make all decisions.” In contrast, the non-spouse female family caregivers, i.e. daughters, daughters-in-law and a granddaughter, described feeling frustrated, angry and helpless because they lacked authority and support from other family members. For example, the physician told Lee: that her mother, Mei, had a brain tumor and needed an emergency operation. Lee, however, refused to sign the permission and explained: “This is a serious issue not a trivial matter. So I told the doctor I was just waiting for my younger brother to decide. He is the son and has to make the decision. I am only a daughter and married. I don’t have the authority to make the decision. Son is more important than daughter for Mother! (Lee)” Though the four daughters-in-law were responsible for the major caregiving issues, they did not consider that they had authority when making a decision. Siang said:

> Though my mother-in-law is living with us, I still have to let my elder brother-in-law know everything….I have to inform them of everything. I won’t decide anything without their agreement. (Siang)

Hua explained how her brothers-in-laws haven’t disagreed with her decision:

> But this does not mean they support me. The reason is they are all very busy.... Because they don’t have time, they don’t dare to give any objections. That’s the reasons. That does not mean they are all satisfied with my management. The real reason is they don’t want to involve in all of this and don’t have time to think about this issue. But when purchasing anything…..I will call my brothers-in-law before I purchase something. (Hua)

On the other hand, they described the pressure from a lack of support from other family members. For the three married daughters (Lee, Ya and Chin), they indicated that their pressure did not come from their husband’s family members, in contrast, their pressure came from their maiden family members. For example, Ya, who learned to provide a vegetarian NG diet for her mother, explained:

> The bitterest thing is the other family member doesn’t agree with what I do! ...She (her elder sister) considered the commercial formula is the best one for my mother

> and what I prepare is all nonsense! I felt so frustrated! ... Unlike them, I think mother is so healthy now and she is recovering so great! That means what I do is correct! But they always assume the food is like garbage! ... But because I am the person in the first line, I decide everything based on my observation.

Four daughters-in-law all described high pressure of lacking support from their other family members. Hui said,

> (At the early time of discharge) I was in a terrible flurry! My mother-in-law was in a bad mood…I also had to teach the foreign care attendant because she was unable to do anything…Then I called my husband, my brother-in-law, and sister-in-law. Nobody answered me. I was so angry.… I have to face all of those problems alone! …I couldn't manage my emotion very well. I am often mad at my children when I face something unfair and am unable to deal with it. (Hui)

Sometimes she tried to get rid of the responsibility by changing her thinking despite the traditional thinking about a daughter-in-law's responsibility for elder care.

> So I think if I decided not to care for her anymore, just like others, then what can you guys do with me. I developed this thinking in my mind. But I also feel guilty and could not feel easy and rest at all….I am not a heartless person. So I am unable to act like other people who don't take any responsibility! If I am like them, my parents-in-law should be very pitiful. So I take on the responsibility. But I take it on with some complaining.

Hua also complained about her other family members' careless attitude.

> Sometimes it is this way. This is your husband! Your father! You don't actively support, instead I have to tell you what you should do …When he was in the local hospital, I reminded them once. But they had lots of excuses. "Oh! I have a cold and I am afraid pass it on to him." Anyway, they just refuse to come. …so now I don't want to remind them anymore.

Like Ya, Quan felt it was hard to deal other family members' questioning attitude. Her father-in-law often pulled out the NG tube, "When the second time happens, we (Quan and foreign care attendant) start to feel nervous. We couldn't let him have the third time…. Because those (other family members) who are not living here would say: Why? How do you care? Why let him pull it out again? ....My highest pressure comes from other family members. I don't have any pressure from him (Chuan). I can deal with the person who is lying over there; but I couldn't deal with the person who can walk."

As the granddaughter, Pin had high pressure from her father's questioning and misunderstanding her care. When Siu was re-hospitalized due to the fourth stroke, her father said serious words to her, "Grandma might die because of your (bad) care." Pin couldn't control her tears anymore at the scene. She complained that her father didn't understand her care situation.

> Maybe like the home care nurse said, all the people around you only notice you are doing things so easy. They can't imagine the caregiver's pressure. Of course, after I finish everything (caregiving tasks) I go back to my own work! Maybe because eight out of ten times I am in my room when he (Pin's father) sees me, so he thinks I don't provide good care for grandma….Sometimes I wake up around 9 am. Then my father always assumes I haven't done anything for grandma that morning. At that time I have an impulse to tell him: Do you know I have fed her one diet at six and do you know I also did that at 2 am? You don't know about this and just complain about whatever you see and assume I am lazy. You don't see what I have done! You are sleeping when I am working! Anyway, if I am not caring for grandma or doing other household chores instead of staying in my room, he always assumes I am idle on the job.

Another possible reason for the misunderstanding was their expectations for Siu (she was in coma status) were inconsistent.

> He always assumes I should provide good care for grandma and let her "get cured." The question is how can grandma be cured?! You should let me know…Like last time when my grandma had her follow-up check, he asked the doctor: "Can she sit up? And like before, can she talk? Can she eat by herself?" He even asked the doctor: "Is it possible for her to stand up and walk with a walker?" …Anyway he expects that my care will be able to enhance her so that she can sit straight up and can eat by herself as before.
>
> I don't have any wishes. Don't be sick again! No pressure sore! That's it. Then don't spit the milk out again! How could I have any expectations?! It is impossible to improve her situation! The doctor told me: now I understand your pressure.

Pin sought outside resources to reduce her own pressure, such as respite care and free bathing service, but her father didn't appreciate her seeking outside resources. Pin complained:

> I have an urge to tell him: You want me to care for grandma, but you shouldn't hold me back. It causes high pressure on me. What I think is that you should support me in what I have to do. I believe I have done what I have to do for grandma. I don't let her hands and feet become deformed. I don't let her have pressure sore. …The doctor and the head nurse also agree with this. She wants to

> compliment me on the care!

This pressure caused Pin to have severe headaches. Although the doctor had her hospitalized for one week to rest, her headaches did not resolve. Pin explained how:

> I felt the pressure was higher than at home while I was in hospital. My phone rang all day. I had to answer the phone three to four times. "When are you coming back? Nobody can care for grandma.... I said, "why you don't care for her? You are home! Why......" I was so angry!

Pin continued to express:

> At the beginning, I felt high pressure from caring for my grandma. I worried about pressure sores and other things…Now I feel better. I can stand the pressure. In contrast, I could not stand the pressure from my father.

Two daughters-in-law (Hui and Hua) indicated the caregiving responsibility also affected the relationships between family caregivers and their stroke survivors or other family members. Although Rou and Hui had a very good relationship before the stroke, it changed when Hui insisted on hiring a foreign care attendant because she couldn't provide 24-hour care for Rou.

> When she (Rou) found about this, she wouldn't talk with me anymore. As if we will abandon her... At the time of her first evaluation, (after not walking for three months) she unexpectedly stood up and walked from her wheelchair! Originally she was unwilling to walk. That physician shook his head and said she would not be able to pass the test (of need for applying a foreign care attendant). I was extremely angry at her at that time! (Hui)

Rou debilitated further and had multiple falls. She then met the criteria for a foreign care attendant.

> Now she is so resentful at me…So if she is angry, I ask my children to talk with her instead…. She said both I and the foreign care attendant bully her together. (Hui)

In order to avoid conflict, Hui modified her behavior:

> She wouldn't listen to me and wouldn't talk with me. So I couldn't do anything. Okay, you like to lie over there. Go ahead! I am her daughter-in-law. Now if I ask her to do something and she doesn't want to, I stop it immediately because I wouldn't have a conflict with her….I am a daughter-in-law only … Anyway no matter how you do, nothing is right. From the elder person's view, whatever I do

> she is always dissatisfied.

The other daughter-in-law, Hua who cared for her father-in-law, described different problem:

> When he complained to my mother-in-law, she always quarrels with him. Of course he doesn’t feel comfortable. Then they have an argument. ….But I don’t act like her. So he feels more comfortable and not angry when I talk with him. And he always says okay or yes. So in my mother-in-law’s eyes, he only listens to me. She is jealous. She is very angry at this…Yet, the wife should take care of husband. But you are not; instead I am caring for your husband. You don’t feel exhausted at all….You never consider my situation. Instead you make troubles for me. She complains those things to other people. I don’t feel happy about this…. I can’t bear this. But I have no ways to deal this. Actually I am very exhausted, you know! But how can I release my pressure? I am really hurt. But what can I do? I could not argue with her. Like the slang says, “You work so hard and sweat streaming whole body, but the outsiders always have an aversion and never appreciate what you do.” What bad luck I have! It is really hard to do, especially for a daughter-in-law.

Briefly, family caregivers experienced various difficulties and challenges from giving care, supervising foreign care attendants and impact on themselves. They employed various different ways to manage their problems. However, sometimes their strategies caused secondary difficulties. Thus their difficulties were not overcome at one try. Their managing strategies are overviewed in the next section.

Ways to Manage

Family caregivers managed their challenges and difficulties with different strategies including: trying their own ways, and seeking help from others. Each strategy contained various approaches. Family caregivers might employ those approaches one by one or a number of approaches at one time.

Trying My Own Ways

“Trying my own ways” was the most common strategy for family caregivers, including observation, providing verbal comfort, and through trial-and-error. Their previous experience and knowledge was fundamental. For example, Hui had not been taught about the risk for pressure sores; however, “I knew if she continuously rested on the bed, she must have a pressure sore because her aunt had eight pressure sores when she died.” And Quan “learned those (disease conditions) from television and newspaper after he had his earlier strokes….So I know when we care for him, we have to notice if he has sputum or cough. He has fever or not. Has he pooped every day? Is it normal or not?”

Observation was often used before family caregivers tried other approaches. For example, when Mi and Siong had difficulty breathing, their family caregivers employed observation to determine if there was a problem. Observation may last for an extended period, such as when De observed his mother’s severe breathing problem for one day and Ya observed her mother’s pain when her Foley catheter was blocked for the whole night before she called for help. Verbally comforting the elder stroke survivors was the primary approach to deal with their stroke survivors’ emotional problems. Trial-and-error was used to manage all care challenges.

> Previously she often choked when drinking water. Now it is ok for her if she drinks very slowly. We use thin straws and she sips a little bit of water at one time. It works for her! We bought a thick straw for her at first, she choked every time. Now we use the thin one and it works much better! (Lee)
>
> Later I tried him some rice porridge mixed with ground meat and vegetables. He can swallow most of the food….Now he can have regular food. But he still could not swallow water (three months after discharge). (Zu)

Not all trial-and-error approaches succeeded. For example, Siang tried to add water to solve her mother-in-law’s constipation.

> Her diet is prepared by the nutritionist in xx Hospital….She does not have a regular bowel movement. She usually has poop every three to four days. If her stool looks somewhat dry and hard, we add more water…. We decide the water amount based on our observation. If her stool is too dry and hard, we add more water. In general I add 250 cc. If the stool is hard, I will increase to 300 cc. Like baby’s milk, thicker milk can prevent the stool from becoming too hard, right?.... but it does not work very well. She still has constipation. (Siang)

After trying their own ways, some problems were not solved. Some family caregivers accepted the situation and did not try further strategies. For example, Boa gave up doing rehabilitation for Yi. “At first I hope he can walk. But now it is impossible because his leg has weakened. He could not stand up and his feet are curled. He could not step on the floor." Some family initiated seeking further information or help from others.

Seeking Assistance From Others

When family caregivers found their strategies were not helpful or they needed further information, they sought help from other family members or outside persons. They also used the Internet, magazines and books. The resources included their own family members, experts and/or lay persons. Family caregivers might apply those approaches at the same time. However, not all information or help was helpful. Therefore, they either went back to their own way or modified the searched information to deal with their problems. At the least, some problems might be solved, such as diarrhea; but some might still exist, such as constipation.

The first resource for family caregivers was other family members. Other family members primarily provided manpower for bathing or transportation. All family caregivers could receive manpower or transportation assistance from their family members, and their assistance was helpful. The contacted experts included physicians, nutritionists, drug store or care equipment store personnel, nurse aides, and home care nurses. They consulted with physicians about medication, disease, swallowing, emotional and pain problems, but the outcomes were not all satisfactory. Family caregivers had to go back to their own ways. Lee's experience of dealing with her mother's (Mei) swallowing and emotional and pain problems were the typical examples. Regarding Mei's swallowing problem, the physician's recommendation improved Mei's choking problem; however, the emotional and pain problems were not improved. Another example was Siang and De's experience of dealing with Mi's blood pressure. Mi's blood pressure was unstable and tended to be high after one outpatient visit because the physician changed her prescriptions. Her caregivers, Siang and De, were confused and had difficulty dealing with Mi's hypertension. They tried their own way of dealing with this problem. “I gave her the previous medicine because it works much better than the current one.” Later their home care nurse recommended that they talk with Mi’s physician. The second day, De visited the physician but the physician did not change the prescriptions. De described, “I know he won’t listen and accept my opinions. He should accept what I say! I have cared for my mother so long. I know her condition!” The couple continued to control Mi’s blood pressure by their own way and sought further treatments from another hospital. Family caregivers didn’t think their home care physicians were a good consulting person. Thirteen of them indicated, “His visiting doesn’t make any difference for me. He just checks her (my mother) heart and lungs, and then writes his own reports. Rarely says anything. Then he leaves.”

Three family caregivers contacted nutritionists when they encountered nutrition or diet problems. Nutritionists tended to verbally provide the principles of food preparation, but did not provide direct hands-on experiences. Family caregivers needed to try many times to find out the best ways. For example, Hui consulted the nutritionist regarding Rou’s swallowing and diarrhea problems. After the consultation, Hui still needed to try many times to find out the best food for Rou because of her diarrhea.

> She (the nutritionist) told me it might be caused by lack of sufficient dietary fibers…So I purchased many different kinds of diet fiber and mixed it in her diet. Iris and I had many trial-and-errors! Then I found Quaker oatmeal cooked with some vegetable was the best food for her.

Another example was Ya’s experience:

> She taught me how to prepare the food by showing me some leaflets and oral instructions. She taught me how to prepare by showing me: How many grams of rice was one unit….At first, when I prepared my mother’s food, I did use a measure to measure the food. …but later I considered my mother as a normal person. So I used a bowl to estimate her diet...Just consider her as a normal person and how much she needs for one meal. Now I cook her food with one bowel of rice, one bowel of mixed vegetable and mushroom. I use the bowel as the measure. I couldn’t measure it by the gram. (Ya)

From the learning process, Hui complained about the insufficient information and instruction from health care providers. She said, “The physician and nurses often just say one word, and then I have to figure out the way by myself." Hui had great achievements from the care process, such as training Rou's swallowing and preparing appropriate diet to overcome Rou's choking problem, and wound care. But she indicated those achievements were "all dug out from my own trials, not learned from the health providers." From Hui's own experience, she recommended: the nutritionist should have real experience on preparing an appropriate diet for a dysphagia person instead of lip service only.

The drug store persons also provided important information for family caregivers, especially for wound care knowledge and skills. For example, Hui sought wound care information from the drugstore person first before contacting with home care nurse (described in wound care part). Chiou primarily learned wound care from the drug store person.

> (Lin had a small wound and it was unable to complete healing for a long time. Chiou talked with the drug store person.) I told her, I used Beta-iodine solution to clean his wound. The she told me "the Beta-iodine solution kills all germs no matter good or bad ones." She taught me "just using normal solution clean it, then wait to let it dry. Then put the wound dressing on it." Really! It is healed!

Family caregivers also learned care skills, knowledge and information from a nurse aide. For example, Ya learned of the paratransit service from a nurse aide. She also learned properly Foley catheter care from her nurse aide after her mother had a serious urinary tube obstruction. "She showed me how to care for the urinary tube properly, and the most common situations causing the tube blockage. (Ya)" Quan received the instruction of food preparation from her private nurse aide (described in nutrition part). Because the nurse aide knew and demonstrated how to prepare an appropriate NG feeding diet, Quan indicated she did not have any difficulties in preparing the diet.

Home care nurses were the major resources and consulters for family caregivers when they faced difficulties at home. She provided the essential information and services, such as NG care, diet preparation, wound care, and social welfare information. In general, home care nurses' teaching and help demonstrated positive outcomes from family caregivers' descriptions. For example, they provided the timely service of re-tubing NG tube. They taught appropriate diet preparation, wound care, and pressure sore prevention. Home care nurses also introduced social welfare service to family caregivers, such as the paratransit service.

Family caregivers learned information from other family members through sharing of care experiences. For example, Ya indicated she learned a correct rehabilitation concept from one family caregiver:

> She told me: You should let your mother to do those activities by herself as much as possible. This concept is not from a doctor or others (medical staffs), instead it comes from a family caregiver. She told me: you should let her move by herself. Because she had the experience, she shared hers with me. Since then, I started to train my mother to brush her teeth. I felt this (concept) is very important. … (Ya)

After learning this concept, Ya trained her mother's self-care ability, such as brushing teeth every morning and grabbing something. Thus Ya said,

> The experienced family caregiver shared a lot of their experiences with me…so I like to sit in the outpatient waiting area and listen to their experience….I think there should be a family caregiver group. They can exchange their experiences and opinions. This will be more helpful than what nurses teach you.

On the other hand, family caregivers also learned from media and printed materials. They usually pulled what they learned together to find out the best way for their stroke survivors. For example, after consulting the nutritionist, Ya also searched diet information from books, and learned from other family members as well. She prepared a vegetarian food for her mother and the outcome was positive. They also tried Chinese medicines (Huo, Ya, Chin, and Tsai), reflexology massage (De and Jin), and folk treatments (Jin and Ya). Most of them demonstrated good outcomes.

> After she had around ten days of medication, I felt her eyesight was blurred and her reaction was sluggish. Therefore, I started to rub both sides of her first toes (reflexology massage)….The points can stimulate her brain and eyes. At the beginning, her eyes lacked any reactions, but now she can see very far. I feel she has progressed and I believe it (reflexology massage) works. (De)

> (Lian had five bottles of liquid Chinese medication). Her consciousness is still not very clear. Sometimes she is clear and can recognize us. But sometimes she doesn't. If I play a joke with her, she laughs. She has some reactions. We are so happy! …I think this is because of the medicine. (Tsai)

Males and daughters voiced more motivation and aggressively tried various strategies to improve their stroke survivors, such as Huo and Ya aggressively seeking rehabilitation and figuring out their own ways of training their stroke survivor's swallowing.

Some situations, however, were critical or out of their manageability. The common problems included NG being pulled out, GI bleeding, sputum and breathing difficulty, and medication and unexpected critical problems. Family caregivers immediately contacted health care providers, especially home care nurses, or sent their stroke survivors to the hospital. When family caregiver contacted health care providers, they were in an urgent need to get a clear direction from health care providers for their unmanageable situations. Yet, not all of them could receive satisfactory instruction. For example, Ya had two experiences of calling health providers for emergency situations She called for help for her mother's, Ji's, urinary tract obstruction and unstable blood sugar and blood pressure after her mother having medications for UTI. She did not get a clear and satisfactory answer from health care providers (described above).

In addition, the Ou family joined an Emergency Medical Service Network which was provided from their discharge hospital. An in charge person provided answers or instructions through the telephone for unexpected situations. If the patient was in a critical situation, the center would send out an ambulance. Hua described her experience of trying the emergency service system:

> The major advantage is if you push the emergency button, the ambulance comes to help you right away. But nowadays it is very easy to have an ambulance within five minutes no matter if you have the service or not. My major concern is: Should we send him to the emergency room or not. Actually I feel the service doesn't give us much help because we don't get a clear answer or direction when we call. The person's recommendation is based on what you say. So if I describe the situation seriously, he might recommend for us to send him immediately….because the answer person is not a medical staff, so he might not be able to deal some critical situations.

Ya and Hui both emphasized that the person answering the phone should be familiar with their stroke survivors' health conditions. In contrast, they described how home care nurses tended to provide better answers. For example, Ya explained:

> Like yesterday, there was a segment of bloody urine in my mother's urinary tube. When I saw that I was so scared. I called the home care nurse. She said, "Take it easy! You can observe it for a while. Sometimes it happens! If there is no further bleeding, that means it is OK." Then she said, "if she has infection, then…" After listening to what she said, I felt so relieved.

Family caregiver highly recommended that the hospital should provide an emergency consult unit or person. Ya highly recommended a home care nurse:

> She is the first line person and clearly understands the patient's condition because she regularly visits the patient…The hospital should have an emergent contact unit. But if the person never contacts with you before she/he might not be able to give you a helpful direction. Just like the answer from the pharmacist when I called. (Ya)

Nevertheless, not all of family caregivers received timely answers and services from the home care nurses because they were too busy to contact and the limited service hours.

> It is hard to find them. I called them (the home care nurses) many times and I could not find them. I was not sure if they could come or not! …They are all so busy! (Lee)
>
> She is very nice. But I know if I call her, she must tell me: Send to the emergency room. She can only be here during office hours. Everyone wishes she could come if necessary. (Bao)

If unable to receive assistance from health care providers, the most common way of handling unmanageable situation was taking their stroke survivors back to the emergency room. For example, when Lin's NG tube was pulled out and Chiou was unable to contact with the home care nurse. "I called my daughter, 'Hurry! Your father pulled out his tube again!' We sent him to emergency room and replaced the tube."

In summary, when facing difficulties family caregivers assessed if the situation was manageable or not. If they felt able to manage it, they tried their own ways first, including observation, verbally comforting their stroke survivors, and trial-and-errors.

They also sought help or information from others when their own ways didn't work well, including their own family members, experts, lay persons, and media or printed information. However, information often did not work well for their problems. Family caregivers needed to modify what they learned and tried several times to find out the best ways. On the other hand, if family caregivers considered the situation was out of their range of manageability, they sought help from health care providers or sent their stroke survivors to the emergency room immediately.

Managing Personal Pressure

Family caregivers also needed to deal with their own pressure from the caregiving role. They employed various ways to adjust themselves under the challenging and difficult situations. Talking with someone was the common way for all family caregivers. In addition, Chin released herself in gambling; Hui practiced Yoga and Tai-Chi; Chin and Chiou viewed the hardship as Karma; Zu considered it was her fate. Zong and Bao tried to keep optimistic; Hua concentrated on her art work. Family caregivers did not express many strategies of dealing with their personal impact. But they indicated those coping skills made them feel better. Some of their descriptions were:

> If I complain too much and too often about my own matters to others, they feel very bothersome! They are not the garbage can. I have to spend a phone fee also. …Now I go gambling. This is my way to release my pressure. (Chin)
>
> Grin and bear it...I am perfectly happy to do it! Take things calmly! (Zong)
>
> Actually, these are all our own fate. No good relationship, we still can be a friends! (Zu)
>
> I try to keep optimistic. I don't want to think too much. Take one day at a time! .... Otherwise, I should have a hard time… (Bao)

On the other hand, only Zong tried to find outside resources to reduce his financial strain.

> I searched many resources. I contacted the production companies, the nutritionist's office, Genesis Social Welfare Foundation, and the Bureau of Social Affairs to find out any ways that I can purchase NG diet with cheaper price. But they couldn't help me at all!

Unlike dealing with the difficulties from caregiving, family caregivers tended to adjust their own emotions and ways of thinking when dealing with their personal negative impact. The last section describes how family caregivers survived the uncertainty and lack of support for managing these new care situations.

Surviving Despite Uncertainty

After providing care for their stroke survivors from five months to one year, all family caregivers experienced positive gains from the care situations. They also described an ongoing uncertainty about the future of their elder stroke survivors. Two themes emerged from the participants' experiences of their overall perceptions toward their care experiences: I learn, I can and my happiness; I don't know what will happen for the future.

I Learn, I Can and My Happiness

Though family caregivers described the process of learning to care for an elder stroke survivor as primarily filled with uncertainty, chaos, and panic, they all identified positive gains from their experiences in providing care. They described happiness in being able to master the caregiving skills, enjoying their stroke survivors' improvements, finding the meanings from their care situations.

When family caregivers first time faced the care situation, they were "starting from zero." After several months, they were able to provide care for their elder stroke survivors at home. Family caregivers described "I learned those care skills from this experience…I am like a special nurse for my mother-in-law. (Siang)" "I learned everything. The only thing I don't have is the license; otherwise, I also can be a nurse. (Bao)"

In addition, most family caregivers provided attentive care to their elder stroke survivors. They felt achievements from their efforts. For example, although initially overwhelmed, Ya sought out information and care treatment, including preparing vegetarian food, self-prepared vinegar, Chinese medicine, massage and actively talking with her mother. Around two months after discharge, her mother, Ji, unexpectedly chewed a litchi and swallowed it. She also could sing her favorite songs. Ya described:

> I was so surprised and happy. I could not believe it…At first, she looks like a vegetable…she couldn't talk…but now she could interact with me more and more…She can brush her own teeth. This makes me the happiest….Her physician said it is a miracle!

Siong developed a pressure sore when he was hospitalized. After discharge, Zong learned the skills and carefully cared for the wound and the wound was much improved. "They (the health providers) don't think I am able to care for my father's wound, but I did it very well. The wound has improved from 10x12 to 5x6. (Zong)"

Moreover, two family caregivers wisely modified care skills and pillows to improve their care outcomes. Jin described,

> I only use one piece of diaper because it can absorb lots of water. I put it under her head and I can wash her hair very easily and quickly! The student nurse said it is hard to raise a patient's head when washing her hair. After I shared my way with the student, she said your way is much easier. She indicated there is much difference with what she learned in school and my way. After talking with me, she said she learned a lot.

Lin required a position change every two hours. Chiou tried different types of pillows; including traditional and memory foam. She found those pillows were too high, too hot, and didn't easily maintain Lin's position. Later she made several pillows out of pant legs to fit different body regions. Those pillows worked much better than the others.

Family caregivers also indicated some meaningful things from their elder care: Benefiting other family members, being a model for their children, and one way of paying off (Karma). Lee described how her caregiving had helped keep the family together. She described:

> I say if my mother is not here, everyone might walk away. We should never gather here again. That's because my mother is still here, they come back and gather together… She is like the Buddha in a temple. She keeps our family intact. Without her, nobody will come back. Really, if she passes away, they won't come back anymore. (Lee)

They also viewed their stroke survivor's experience as an example to remind themselves and other family members regarding preventing a stroke.

> I pay more attention on my diet and health. This is an example to remind myself. Now I demand my husband not to eat too salty! ....Actually it is a learning opportunity. I used his example to teach my husband and our son. I say, because he refused to do exercise and no food restrictions, he had the stroke. You have the genetics. You should be very careful! (Quan)

Providing care in the home modeled filial piety and Karma. Zong described:

> This experience is an excellent chance for educating my children what filial piety is. I encouraged my children to be involved in the care activities, such as doing range of motion for my father.
>
> Father was not an affable person. Sometime when he blamed you, you would not have a good mood and you wouldn't interact with him…In contrast to the previous situation, now I can massage and do some physical activities for him, and give him a sponge bath. Through the physical contact, I feel the distance between us is lessened. Having one day of care for him is my good fortune…..I hope we can end the Karma from our previous three or five lives. So I use all the time for serving a dedicated care for him.

Based on their experiences, family caregivers drew their conclusions toward the caregiving tasks:

> When facing any problems, we need to actively search out information and try it wisely! .... I appreciate so many different experiences. There are lots of people there to help me to go through the tough time…I am a lucky person…..I believe if I do it, I must have reward; if I learn and do everything diligently, I must gain. If I show efforts, I will have achievements. (Ya)

Losing Hope and Uncertainty for the Future

After providing care for their elder stroke survivors, all family caregivers indicated expectations for their family caregivers. However, except four (Huo, Ya, Hui, Tsai) family caregivers, the rest 13 family caregivers did not comprise high expectation for their stroke survivors.

> I think her current situation is the best one. I do not expect she will be able to recover. (Lee)
>
> Because she suffers so much, she relies on someone else to do everything for her. There is no meaning for her at all….We should have let her go when she was in the hospital! (Chin)

> I wish he could stand up again and walk. I know after a stroke he might not be able to walk easily but I still wish he could stand up again….But for now just let nature take its courses. (Zong)
>
> We prefer that she will pass away peacefully. Her current situation is like a vegetable. Unless a miracle happens we will just care for her until the last day comes! (Jin)
>
> Definitely I still wish he can improve, but I don't think he can. (Quan)
>
> Let nature takes its course! It is impossible for him to recover. He could only get more and more serious. How is that possible for his condition to turn better? (Chiou)

For the other four family caregivers, though they still kept hope for their stroke survivors, they were filled with uncertainty and unknowing for the future.

> I hope she can recover…first she can walk by using a walker; then she can eat by herself and can notice her elimination needs….But honestly, from her current condition, I worry that my efforts and money investments might be in vain. (Huo)
>
> I hope she can sit straighten up and can walk with an assistant device to the bathroom and take a bath…. (When her mother started her rehab therapies) What will happen after she has the rehabilitation is unknown! Now I worry my mother's blood pressure might elevate when having the rehab therapy! If it is too high, she can't take it! Her blood pressure becomes very unstable after having the rehab therapy. (Ya)

Recommendations to Increase Certainty

From taking on the role, family caregivers prepared themselves by learning care skills and knowledge in the hospital. After discharge, they faced unexpected and unknown care situations at home. They dealt with those problems and survived the hardship. Family caregivers provided recommendations for increasing certainty for their future care situations and other new family caregivers; including discharge planning, preferred learning styles, home care service, and social welfare policy.

Discharge Planning

Family caregivers highly recommended that the family caregiver should have good preparation through a well-organized and systemic preparation program before discharge. Two family caregivers provided their ideal way for preparing a new family caregiver:

> Before discharge, I think there should have been a primary health provider in charge to coordinate all the necessary information, provide necessary education and explanation right after each patient's admission. On the other hand, the hospital should have a program of preparation for the family caregiver. The program should be based on the previous family caregiver's and patients' experiences. I think they (nurses) provide care for so many patients; they should have enough experiences to provide systematic information. The program should contain the knowledge of disease, caregiving skills, diet, and possible situations after discharge and social resources. The preparation should be practical and start immediately after admission. ….In other words, provide a set of systematic caregiving information to family members! The content should describe how to manage if unexpected situations happen. If I don't understand, there is a person and a phone number I can call. The person who answers the phone should know the patient; otherwise she might not be able to answer your questions. (Hui)
>
> Nurses should provide a teaching schedule in the hospital. They can let family members know the time and schedule. The training should include all care skills, how to prepare a diet and where we can find the rehab resources. In addition, the stroke knowledge also needs to inform us....after discharge they should let us know where the rehab resources are or if we need a home care nurse…. (Huo)

Hui also emphasized, "The hospital nurses and physician never know what happens at home. They should understand what the real situation is at home. Otherwise, there is a gap between what they said and what we need. On the other hand, the nutritionist should have real experience in preparing an appropriate diet for a dysphagia person instead of lip service only. (Hui)" In contrast, Ya indicated too much information might not be of benefit for family caregivers.

> You (Nurses) might tell me a lot of information. First one, you should … Second one, you have to ...But when we just discharge, we might not encounter the situations as you said. And we might totally forget when we eventually face the situation.

Instead, Ya recommended: "So don't tell us too much. Just give us a business card with a name and phone number that we can contact with if necessary after discharge." Regarding the foreign care attendants, Hui recommended that "the hospital should have translators to help those foreign care attendants learn effectively because hiring a foreign care attendant has become a main strategy for elder care in Taiwan society."

Learning Styles

After acquiring new care knowledge and skills, family caregivers all indicated that concrete learning strategies were the best ways for their learning, such as using an example, video tape, practicing on a real person or a model were most helpful. They desired a need for more than one time of teaching, preferred to learn with a slow pace and emphasized having more chances for practice! Family caregivers indicated an example was the best way for them to learn. Huo and Ya expressed their best ways for learning.

> (Learning what is a pressure sore) Go to the bedside and show me what a pressure sore is. Then tell us how to prevent it after going home. Tell us how to change position, how to do chest percussion and how to clean! Just show us how to do those things. (Huo)
>
> An example! An example can make an impression, for example, using our palm as a measure. Another example is using a bowl! Measure the amount of mixed vegetables in a bowl because in our daily life we are used to a bowl when we are on a diet. And video tape is also a good way. I think watching a video will make me understand. (Ya)

Quan’s learning experience demonstrated learning in a slow pace, with more time of demonstration and practice was the better way to learn. She described:

> Nursing students came to teach us how to change a diaper and other skills. We never experienced those before. The teacher demonstrated for those kids (student nurses) first, then she stood aside and watched how they performed. We also stood aside and watched how they performed feeding, changing a diaper and giving him water. We learned from the teacher and we also practiced it. It is not bad! I felt less pressure. We need someone to show us more times. We are not so clever to learn it in one or two times of teaching!

Hui also emphasized the importance of having real practices before discharge:

> The nurse should an overview first, and then the skills can be applied on a patient. Like position change or massage, we can practice it on each other or a model. For example, I lie down then you practice it on my body like at home settings. Then it’s my turn. This way can increase my retention. (Hui)

Zong highly recommended family caregivers should have enough practice before discharge.

> If it is possible, the family member should practice those skills in the hospital! If any problems occur, there are physicians and they can take over the care. I think

they should learn through practice!

Family members preferred a concrete and hands-on learning style, such as an example or real practice. Reinforcing content with a slow pace was preferred as well as multiple opportunities to practice.

Home Care Service

All family caregivers indicated they needed to spend two to six months to adjust themselves to the care situations. They described high levels of uncertainty about their care being correctly done and they were nervous about new care situations at home, especially during the first month. During this time period, they recommended an accessible and mobile health care service. Hui indicated, “The health care providers should actively contact with families, not just stay there and wait for the family to raise their questions.” Eight out of 17 family caregivers indicated the need to increase the frequency of home care service, especially during the first month. Boa explained:

> It takes me around two to three months to get used to the situation, but I feel panicky and nervous during the first month. …At the beginning, I feel the service frequency is not enough. According to my own feeling, I hope she (home care nurse) can stop by often. And if we have any questions she can come. At the beginning I hope she can visit us frequently because I had some panic. I don’t know if what I do is right or wrong. I feel nervous and need someone to come in to check it… But after a certain time, I have adapted to the situation. That feeling no longer exists. (Bao)

Huo, Zu and Tsai also indicated their needs of home care service at the early stage:

> We need a home care nurse. A half month for one service is too long for us. The best one is once a week. We can pay the service fee! We really need a professional to come in! (Huo)
>
> During the first month we didn’t know anything at all, so we had no ideas about how to manage it, such as the urinary tube problem. ….So the home care nurse should visit frequently, at least once a week. Two weeks is too long. Though most of the time nothing happened, they still can teach us care knowledge when they come. Frequent visits can make the family feel much relief. (Tsai)

On the other hand, Zong indicated once or twice a month service was insufficient for teaching and care, especially for the patients with serious wound problems. Zong highly recommended increasing the service frequency. He said,

> Sometime the care problem requires a continuous care and supervision, such as my father's third degree wound. But she (home care nurse) only visited twice a month. I don't know what she can do for the wound care? My feeling is: Okay! I care for the wound for 28 days, and she did the other two days….Home care service should be a continuous service. With twice a month service the nurse could not provide any meaningful care. The frequency should be increased to at least once a week to provide more helpful care for families.

Family caregivers' recommendations were consistent. They all expected the frequency of the home care services can be increased to once a week during the three months, especially during the first month. Family caregivers also suggested a home care nurse was the best person for an emergency contact person.

Social Welfare Policy

Family caregivers indicated the expense of purchasing the commercial formulas and hiring a nurse aide were two major financial pressures. The strategies for reducing the pressure were preparing home-made NG feeding diet and hiring a foreign care attendant instead (described above). According to Zong's and Tsai's experiences, they recommended:

> This is a good question for further study. Why a person's NG diet can be covered by insurance in the hospital, but after discharge he still has NG tube and his diet is not covered? ….Having some financial support from our government is really good for us. But the subsidized items should be re-considered. The items should be those that are necessary for everyday life. (Zong)
>
> The government social welfare policy is not helpful at all. I feel they write lots of documents, but none of them helps at all….After we got home, the bureau of public health mailed a bunch of information to me regarding the elder care policy. It looks very excellent, Ten Great Policies for Elder Care! But none of it we can use. They say there is subsidy for hiring a Taiwanese nursing aide (10,000 dollars per month for the first year.). However, you know it costs 60,000 dollars per month for hiring a Taiwanese nursing aide. They also require vacations during weekends. The subsidy means nothing. The price is much higher than hiring a foreign care attendant. The policy is not practical at all…..On the other hand, of course they (the government) have their own considerations. We have to pay 2,000 dollars each month to government as the laborer job funds. Because we

> don’t hire a Taiwanese care attendant, so we have to pay the two thousand dollars. We have a heavy burden already, but we are still demanded to pay the extra two thousand dollars. I don’t like to hire a foreign care attendant either, but I couldn’t afford the fees for hiring a Taiwanese care attendant. Not many persons can afford that in Taiwan. The government doesn’t give us financial support; in contrast, they demanded us to pay the two thousand dollars. It really is not a reasonable policy. We are already over burdened. I feel it is kind of a punishment for patients and their families. (Tsai)

In brief, the 17 family caregivers all had positive gains from their care situations. They were proud of themselves for learning and being able to perform the care skills. They were happy to see their stroke survivors’ improvements. They viewed providing care for their family members as a meaningful thing. However, they lacked high expectations and felt uncertainty for their stroke survivors’ future. After dealing with those high difficulties, they all survived despite the hardships. Family caregivers provided various recommendations to increase the sense of certainty for their future care situations and other new family caregivers, including an organized and systematic preparation in hospital, an emergency contact unit or person, concrete learning ways, increased home care service, and the government reconsideration of the subsidized items.

Summary

In summary, at discharge family caregivers felt confident and ready to go home. However, when they started to provide care at home they described uncertainty on how to do the care. On the other hand, although family caregivers learned some care skills before discharge, they faced different difficulties at home. Fifteen challenges and difficulties arose from giving care and supervising foreign care attendants. The most common challenges were diet preparation, elimination problems, transportation, breathing and sputum problems, and rehabilitation resources. The 15 unexpected care situations caused ten stroke survivors to have 23 re-hospitalizations and 17 emergency room admissions. Breathing and sputum problems were the major reason for re-hospitalization. Inappropriate Foley catheter care was the major reason for emergency room admissions. The highest rate of unplanned re-hospitalizations and emergency room admissions were during the first three months. Those difficulties were caused by a lack of health care knowledge, skills, and resources. Problematic skills area included diet preparation, airway clearance, position change, transferring and lifting, wound care, Foley catheter care, and rehabilitation activities. Knowledge deficit was most prominent in the area of pulmonary hygiene, urinary care, pressure sore prevention, swallowing, emotional and pain problems, medication and disease control, understanding possible critical situations and complications, and how to modify the environment and pick appropriate assistive devices. They highly needed rehabilitation resources, transportation services, accessible and mobility home care services, and an emergency contact person.

When encountering the difficulties, family caregivers described “chaos and panic.” Family caregiver employed various strategies to solve their problems. At first, family caregivers assessed their manageability. If they thought it was manageable or uncritical, they tried their own ways, including observation, verbal comfort, and trial-and-errors. Then they sought information and help from health care providers and other lay persons. Yet not all of their learned information was useful or applicable. Family caregivers faced secondary problems caused by seeking resources, such as unreachable home care nurses. Some of their problems were solved, but some were not. In contrast, if the situation was not manageable they contacted health care providers or sent their stroke survivors back to the hospital right away. Family caregivers indicated home care nurses provided helpful services and effective teaching at home, especially during the first month. Therefore they recommended increasing the frequency of in-home care services during the first month and a home care nurse on call for an emergency situation. Home care nurses, however, are not always easy to contact because of their lack of availability, in particular, during the evening and on the weekend.

Family caregivers were motivated to learn information when facing their problems. They preferred concrete learning styles, such as by an example and repeated hands-on experience. The home care nurse was an important educator for family caregivers in the home setting. They provided necessary skills and knowledge and appropriate emergency guides. From the family caregivers' experience, learning from experienced persons, such as a nurse aide, other family caregivers and a home care nurse, could shorten their times of trial-and-errors.

Family caregivers experienced multi-dimension impact after providing care, including physical, psychological, social impact and financial strain. Sleeping interruption and weight loss were the most common physical impact. Needing to provide care during the night time and worrying about their stroke survivors' health conditions were two reasons for sleep interruption. Family caregivers felt tired and had to give up some social activities. Financial burdens included purchasing commercial formula and hiring a local or foreign care attendant. Furthermore, female non-spouse caregivers had more emotional stress because of lacking full authority and supports from other family members. Talking with friends was the common way of dealing with their own caregiving pressure. In contrast to the negative impact, all family caregivers had positive gains from their caregiving process, including mastery of caregiving skills, their stroke survivors' positive progress and benefits to the family. They also viewed the caregiving experience as a meaningful thing for other family members and as a model for their children. All of the family caregivers lacked of expectations and felt uncertainty for their stroke survivors' future. Family caregivers provided recommendations to increase certainty for future care situations, including setting up a systematic and organized discharge procedure, increasing the frequency of home care services, reconsidering social welfare policy and organizing stroke family caregiver sharing group.

CHAPTER VII

DISCUSSION AND IMPLICATIONS

After “taking on the role”, these 17 family caregivers were “learning to care” for their stroke survivors at home. Prior to discharge, they felt ready to provide care at home. Once at home; however, they faced many new and unknown care situations, describing “chaos and panic” due to the care “challenge and difficulties.” They employed “ways to manage” the new caregiver role and personal impact of family caregiving at home. Despite an ongoing sense of uncertainty, family caregivers described “I learn, I can, and my happiness,” regarding learning to be family caregivers. Family caregivers described how the caregiving situation is one of “losing hope and uncertainty for the future.” They provided “recommendations to increase certainty” in the caregiving situation.

Certainty was the organizing construct of the family member descriptions of learning to be a family caregiver. Certainty, according to the Merriam-Webster Dictionary, is a state of being free from doubt. It is a perception of being able to determine meaning or assign probabilities for an event (Mishel, 1990; Penrod, 2001). Ideally, certainty is fostered through patient education (Schumacher & Meleis, 1994). In this chapter, the three research questions (i.e., three learning determinants and care situations), and personal negative impact and positive gains are discussed according to learning and role acquisition theories. Limitations and implications for research, nursing education, practice and health care policy are discussed.

Three Learning Determinants

Education has been indicated as an intervention to increase the certainty for family caregivers through anticipatory preparation (Schumacher, 1995; Schumacher & Meleis, 1994). Kitchie (2003) emphasizes that assessing three learning determinants: Readiness, learning style, and learning needs before providing education is the first step in instructional design and can facilitate learning. The seventeen family caregivers' experiences within the framework of the three learning determinants are discussed below.

Readiness

Readiness to Take on the Role

Readiness to learn is a self-evidence attitude and belief toward learning (Rosenal, 1992). For a family member, motivation to take on a caregiving role is the key determinant for learning. Motivation is willingness and a psychological force that moves a person toward some kind of action, such as embracing learning (Richards, 2003). Family caregivers' motivation for taking on the role has been identified as an antecedent for the quality of caregiving outcomes (Chou, 2000; Lu, 2005). Reasons for taking on the caregiver role influenced family caregivers' motivation and willingness to begin and continue their caregiver role. A sense of responsibility, affection, Karma, paying back, time flexibility, and helping other family members, were reported reasons for taking and continuing a prior caregiving role. A sense of responsibility and affection were the core reasons for these family caregivers. A sense of responsibility was held by spouses, offspring and daughter-in-laws. As found by Hsu and Shyu (2003), in this study, with the exception of one wife (Zu) who had a bad relationship with her husband, other spouses indicated being a family caregiver was because of strong affection and a sense of responsibility for their spouses.

Filial piety is a Chinese virtue and obligation. The most basic standard of filial piety is to satisfy the parents' daily needs and to support them in their old age. A sense of filial piety is positively related to children's willingness to care for disabled parents at home (Chien & Wu, 1999). The nine offspring consistently verbalized a strong motivation, a sense of responsibility and a decision to care for their elder stroke survivors as an obligation.

Traditional Chinese society is patrilineal. Sons are expected to live with and provide care for their parents. The eldest surviving son is the inheritor and holds primary responsibility for care. In this study only one of the three sons was the eldest. Consistent with normative expectations (Chao & Roth, 2000; Holroyd & Mackenzie, 1995; Hsu & Shyu, 2003), three daughters-in-law were delegated by their husbands to take on the role because their husbands were the eldest sons. Cultural and social expectations hold that a daughter-in-law provides all personal care for their parents-in-law as well as all the household tasks (Hsu, Lew-Ting & Wu, 2001). The eldest offspring, however, was not limited to the surviving eldest son or daughter-in-law. Two daughters indicated being the eldest child in the family and having the care responsibility for their parents, though they had younger brothers. In total, six of the 13 non-spouse family caregivers were elder offspring (n =3) or daughters-in-law (n= 3). Four family caregivers (one daughter, three daughters-in-law) indicated they felt forced or semi-forced to take on the role. Consistent with Wu and Lin (1999), in contrast to normative expectation, these daughters-in-law have less willingness to provide direct care. Furthermore, in Chinese culture, the male is viewed as having the power to make decisions, deal with discharge formalities, and communicate with hospital staff members. As such, the male spouses and sons were expected to be the decision maker rather than provide direct care (Shyu, 2000). This may help explain why male caregivers tend to have a lower rate of direct care provision.

Regardless of family role or gender, affection was described as a core reason for family caregivers taking on the role. For spouses and children, affection was related to intimate marriage and parent-child relationships. Similar to Hsu and Shyu (2003), “Paying back” was identified by three sons and one granddaughter. They considered providing care as a form of repaying the benevolence of being raised by their parents or grandparents. Paying back was interwoven with responsibility and a strong sense of affection. Hsu and Shyu (2003) explained paying back was an active motivation that facilitated family caregivers to continue their care. Although all daughters-in-law indicated having strong affection for their parents-in-law as motivating them to continue their role, none described “paying back,” as they don’t have benevolence-raising relationships with their parents-in-law (Hsu & Shyu, 2003).

In this study five daughters (three married and two single) took on the caregiver role. This was unexpected in that in Chinese culture, married daughters are not considered a member of her maiden family nor expected to provide care for their own parents. If a daughter devotes too much of their money, time, or resources to her maiden family, this may cause conflict in her husband’s family (Kao & McHugh, 2004; Kao & Stuifbergen, 1999). The five daughters, however, did not identify any conflict regarding parent care; rather they indicated responsibility and affection as the key determinants for caring for their own parents. They said, “Caring for one’s parents is a daughter’s responsibility.” This changing phenomenon warrants further study.

Karma has been reported as a common reason for taking on the caregiver role in Taiwanese family caregivers (Chao & Roth, 2000; Hsu & Shyu, 2003; Kao & Stuifbergen, 1999). Eight of the 17 family caregivers indicated Karma was a reason for them to take on the role. As also founded by Hsu and Shyu (2003) believing in Karma was a coping strategy to manage caregiving burden and motivate family caregivers to continue elder care. For example, Zong (a faithful Buddhist) considered Karma the primary reason to care take of his elder. He demonstrated a high level of willingness to end the Yin-Guo by serving his father in this life. For other family caregivers, Karma served more like a buffer to alleviate their perceived caregiving difficulties. This was especially apparent for the daughter (Chin) who had a history of bad relationships with her mother. She interpreted her responsibility as Karma.

Family caregivers also considered time flexibility and helping other family members to be two important reasons for taking on the role. Available time meant that the family caregivers had no or less competing cares needs, and adjustable work time or no job. This implied available manpower. Available family caregiving manpower has been reported as the key determinant for caregiving arrangements after discharge. In Chiu, Tang, et al., (1998), when family caregiving manpower is higher than one, the stroke survivors are 33.3 times more likely to be cared for at home than in an institution. In addition, traditional Chinese attitudes toward elder care (filial piety), care receivers' willingness, and quality of long term care facilities still hamper family members' use of institutional care (Chien & Wu, 1999; Chiu, Shyu, Liu, Wang & Chang, 2001; Hu, et al., 1996). Similarly the 17 family caregivers indicated time as a major determinant, yet having the time available did not mean they were able to provide 24 hours of care. For nine of the family caregivers, this meant that they had time to supervise a care helper and/or provide some care. On the other hand, helping family members was one consideration for five family caregivers, especially for wives. This was a core reason for two family caregivers who had a history of bad relationship with their stroke survivors.

Overall, responsibility was a main reason for family caregivers to take on the role in Taiwan society; however, due to the change of family structure and the social concept toward elder care, the sense of obligation to care for the elder in the family is likely to diminish (Chuang et al., 2007). Scholars question how much role responsibility and filial piety will contribute to elder care in the future (Chuang, et al., 2007; Hsu & Shyu, 2003; Kao & McHug, 2004). For these caregivers, affection motivated them to take on the role, especially when the caregivers felt they were responsibly forced to take on the role. Strong affection motivated daughters to take on the role, although it is not consistent with the traditional norm. In role acquisition, the relationship of caregiver and care receiver has been identified as an important factor for family caregivers when they appraise their care situation and the caregiving outcomes (Schumacher, 1995; Schumacher & Meleis, 1994). The findings from this study confirm that the relationship played a key role for Taiwanese family caregivers when taking on the role.

Readiness To Learn

Readiness to learn (Kitchie, 2003; Vanetzian, 1997) occurs when the learner is receptive to learning and is willing and able to participate in the learning process. Adult learners are ready to learn those things when they experience a need to learn in order to cope with real-life tasks or problems (Knowles, 1980; Knowles et al., 2005) and seek out information to overcome a challenging or threatening event (Timmins, 2006). Family caregivers described awareness of the gap between a desired level of care performance and the actual level of care performance. Such care performance gaps exist because of a lack of knowledge and skills (Kitchie, 2003). Family caregivers indicated their need to learn essential information, motivation, and readiness to learn in three critical time periods: before discharge, first month after discharge, and when facing new care situations. Hospitalization and the first month after discharge have been reported as the "golden time" for caregivers to learn new caregiving skills and to establish appropriate caregiving routines (Grant, et al., 2004; Shyu, 2000; Silva-Smith, 2007). On the other hand, Nkongho and Archbold (1996) identified the beginning of caregiving and when facing new situations as opportunities to develop new caregiving patterns. Thus the three time periods are consistent with previous reports.

Consistent with previous reports (Kitchie, 2003; Tiivel, 1997; van Veenendaal, et al., 1996; Vanetzian, 1997), family caregivers who were males, daughters, and who had higher education levels verbalized more motivation to learn and seek out information. Males were more likely than women to seek informal support and preferred employing problem-oriented coping strategies (Ashley & Kleinpeter, 2002). Family caregivers with a higher education level had more resources to search and skills to do so (van Veenendaal, et al., 1996). Daughters who were younger than spouses, described a high level of motivation to take on the role, and provided more hands-on caregiving tasks, necessitating a need to understand the care problems. They demonstrate more motivation to learn and immediately apply more information. Furthermore, stroke survivors' cognitive ability influenced the family caregivers' needs and motivated them to learn more information. The cognitively intact stroke survivors had more emotional problems, challenges with shower bathing, swallowing problems, and were perceived to need more rehabilitation than cognitively impaired stroke survivors. As such, their family caregivers faced more problems and were motivated to seek more resources to manage these problems.

As described in previous studies (Forsberg-Warleby et al. 2004; Kitchie, 2003), the complexity of tasks and individual's emotional status also affects an individual's readiness to learn. Seven family caregivers experienced difficulties in learning NG feedings, sputum suction, and injection skills. Family caregivers indicated those skills were more complex than other self-care skills and they felt fearful about learning these invasive skills. Complex tasks require more cognitive, affective and psychomotor skills to perform (Kitchie, 2003; Neistadt, 1996). Fear can induce anxiety and interfere with the learner's learning ability (Kitchie, 2003). High anxiety has been reported as an interferer for learner's readiness to learn (Kitchie, 2003; Vanetzian, 1997). Female caregivers tend to be more anxious and report more stress than male caregivers do (Forsberg-Warleby et al., 2004; Parks & Pilisuk, 1991).Thus it is important for health care providers to assess family caregiver's readiness to learn when teaching.

In summary, the three time periods, i. e., in the hospital, the first month at home, and when facing new care difficulties, are critical times for family caregiver learning. Family caregivers are motivated and ready to learn new information to overcome their care difficulties. Family caregivers who are male, or a daughter, have a higher educational level and care for cognitively intact stroke survivors described more motivation to learn and seek out information. It is important for health care providers to carefully assess family caregivers' readiness to take on the role and readiness to learn when teaching complex and invasive tasks.

Learning Styles

Caregivers rely heavily on health professionals for necessary information (Rosenthal, et al., 1993; van Veenendaal, et al., 1996; Wiles, et al., 1998). In particular, nurses are viewed as the most appropriate persons to provide information to caregivers (Shyu, & Hwang, 2000; Wiles et al., 1998). In this study, nurse aides and nurses were the primary persons described as teaching care skills and knowledge. Similar to reports in previous studies (Chiu, Pai, Shyu, Chen & Chung, 1998; O'Connell et al., 2003; Rosenthal, et al., 1993; Smith, et al., 2004; Wellwood, et al., 1994), the family caregivers expressed that nurses were too busy to teach, provided rushed one-time instruction and didn't allow the time necessary for family caregivers to learn the information, in particular complex skills such as sputum suction and insulin injection. Nurses consistently used verbal instruction and demonstration teaching styles. Yet, family caregivers indicated they preferred learning with a slow pace, repetition of the information, "hands on" learning, and adequate time for practice.

For both hands on skills and abstract knowledge, family caregivers all preferred a concrete learning style. Concrete learning styles included examples, videos tapes, and hands on practice on a model or a person. They described how an example or real-life experience enhanced their understanding and learning outcomes. Family caregivers indicated that the caregiving tasks, disease knowledge and care situations at home were entirely new for them. They primarily learned their caregiving information by trial-and-error and by seeking out resources. Consistent with experiential learning (Kolb, 1984), the major family caregivers' learning styles were a combination of concrete experience (feeling), reflective observation (watching, listening), and active experimentation (doing). As Garity (1997) reported, their family caregivers' learning styles were predominantly diverger, which emphasized concrete experience and reflective observation; and accommodator, which emphasized concrete experience and active experimentation. Thus family caregivers demonstrated a preference for processing learned new information with a concrete learning style, although it is not the purpose of this study to show how family caregivers learning style changes over time and the difference in learning styles between genders. Further study in these areas is warranted.

Learning Needs

Accordingly, before discharge, the first month after discharge, and when facing new care situations; family caregivers described changing learning needs. They verbalized a readiness to acquire the knowledge and skills to deal with their stroke survivor care issues and their personal needs.

Before discharge, family caregivers were aware of "needing to perform the care at home," thus they actively sought information to fill the gap. However, they primarily focused on the immediate hands-on care needs, in particular, complex care skills. They learned less care information, such as stroke disease management and treatment, rehabilitation, and nutrition. This is different from Shyu's (2000) findings in which family caregivers mainly focused on learning care receiver's disease condition, symptoms and emergency management. In Shyu's research, participants were family caregivers of frail elders with at least two ADL limitations. In this study however, family caregivers were providing care for totally dependent stroke survivors who had new complex and changing care needs. This was the first time they faced such a seriously ill person and they lacked the experience in these care situations. As Knowles (1980) indicates - adult learners are problem-centered, they prefer to learn what they need to know at the time they need to know it, and apply their learning to a real-life situation. Thus family caregivers tended to focus on basic physical care and the visible care problems like NG, Foley and tracheal tube care. In addition, like van Veenedaal et al., (1996), family caregivers described feeling overwhelmed by learning new skills care. Thus they were unable to anticipate what information they would need in the home care setting.

Although, family caregivers mainly learned physical care skills, they felt “ready to go home.” However, they experienced “chaos and panic” and encountered fifteen “challenges and difficulties” in “giving care” to the stroke survivors as well as self-care “what about me.” They described a sense of uncertainty and a lack of sufficient knowledge, skills and information to deal with their new care situations. The sense of uncertainty was throughout the whole care process as they described “losing hope and uncertainty for the future.” They needed to learn further knowledge and skills to manage their difficulties.

Several family caregivers learning needs in this study are consistent with previous Taiwanese studies, such as learning disease information, physical care skills, nutrition management, medications, managing emergency situation, rehabilitation resources, transportation, and dealing with personal impact (Chen, Lo & Hu, 1994; Chen et al., 1999; Chin et al., 1999; Chiou et al., 2003; Chiou et al., 1998; Chung & Hung, 1999; Hsu & Chiou, 2004 a; Hung et al., 2002; Ling, Su, Liao & Chiou, 2004; Shyu, 2000; Tseng, et al., 2001). Although the learning needs are labeled similarly, the specific content of the learning needs are unknown. Except Shyu (2000), all studies employed a descriptive quantitative study design. Thus only frequencies of learning needs and possible explanations from researchers’ viewpoints were provided. For example, previous studies reported family caregivers needed rehabilitation therapy (Chin, et al., 1999; Chiou, et al., 2003; Hsu & Chiou, 2004 a), but the reported family caregivers’ needs were limited to range of motion. Previous studies did not provide family caregivers’ motivation and difficulties when seeking out the rehabilitation services. These seventeen family caregivers provided new information about their learning needs and strategies for managing their difficulties. For example, family caregivers indicated their difficulties in preparing a diet for stroke survivors who had NG feedings and dysphagia.

Findings not previously reported in Taiwanese family caregiver studies include: a sense of ongoing uncertainty, a need for education in management of swallowing problems, environmental accommodations, applying care assistance devices, and supervising foreign care attendants. A sense of uncertainty (Burman, 2001; Fraser, 1999; Moore, Maiocco, Schmidt, Guo & Estes, 2002; O'Connell & Baker, 2004; Silva-Smith, 2007), management of swallowing problems (Carlsson, Ehrenberg & Ehnfors, 2004; Johansson & Johansson, 2009), environmental accommodations and applying care assistant devices (King & Semik, 2006; Smith, et al., 2004) have been reported in Western studies but these studies do not provide the descriptive detail necessary to inform Taiwanese interventions. Furthermore, the challenges associated with training and supervising foreign care attendants have not been reported. Further study is needed to better identify the management of these challenges and better understand if and how to foster incorporation of this new worker into the traditional Taiwanese elder care system.

The Discrepancies

According to role acquisition, inadequate preparation, insufficient care skills and knowledge, and a lack of incorporation into learning real-life situations often increase family caregivers' sense of uncertainty (Schumacher & Meleis, 1994; Schumacher, et al., 2008) and difficulty of dealing with care problems. In this study, there are discrepancies between what caregivers learned and what they needed to learn. Although feeling ready to go home, they were not prepared to provide care at home and they lacked access to health care providers at home. Consequently, the caregiving process was filled with uncertainty. They mainly employed trial-and-error to manage their difficulties. Nolan et al., (1996) indicate that if a new caregiver develops skills largely by a process of trial-and-error, it is potentially prolongs the novice and beginner stages. In order to increase family caregiver's sense of certainty and manage their difficulties effectively, it is necessary to identify the reasons for causing the 17 family caregivers' sense of uncertainty. Two discrepancies were identified from the findings: problematic preparation and fragmented health care services.

Problematic Preparation

According to family caregivers’ descriptions, problematic preparation consisted of insufficient and inconsistent information between what was learned and what was needed, mismatched teaching and learning styles, and unorganized information before discharge. The insufficiencies and inconsistences are identified in several important care issues, including knowledge of stroke management, rehabilitation, applying environmental modifications and assistive care devices, and complications of long term immobility.

Insufficient and Inconsistent Information

Knowledge of Stroke Management

Family caregivers did not understand the disease process or how to recognize and prevent complications. The recurrence rate of stroke is 32.5%, especially during the first year after the original stroke (Chuang, Wu, Yeh et al., 2005; Tsai, Sun, Chen, Kuo & Hung, 2003). Controlling risk factors, recognizing the warning signs, and seeking immediate medical attention if a stroke occurs is critical (Caplan, 2000 a). Although eight stroke survivors had multiple-strokes, five family caregivers described fall prevention and diet control as the most common discharge education from their physicians. Family caregivers identified a lack of knowledge for controlling their stroke survivors’ blood pressure and blood sugar. Although post stroke pain has been reported in 32% of stroke survivors (Kumar, Kalita, Kumar & Misra, 2009) and in previous studies (Bakas et al., 2002; Bakas et al., 2004; Chien & Shyu, 2000; Chin et al., 1999; Shyu & Chang, 1992; Shyu, 2000; Tseng, et al., 2001), family caregivers struggled with understanding and managing their stroke survivors’ pain and emotional problems. Post-stroke pain and emotional problems were described as the hardest caregiving task.

Rehabilitation

The aim of rehabilitation is to focus on recovery and adaptation to the loss of neurological function. Rehabilitation is meant to reduce disability and to increase independence and empowerment (Caplan, 2000 b; Smith, 1999). During rehabilitation, stroke patients are trained to minimize any handicaps that relate to the neurological impairments that follow stroke. That means that through rehabilitation, stroke patients are expected to regain and/or maintain their normal function, as possible. Accordingly, the majority of physical recoveries occurring within the first three to six months are consistent with reported studies (Chen, et al., 2001; Chuang, Wu, Yeh, et al, 2005; Lin, Chang, Huang, Liu & Lin, 2001). The first three months have been indicated as the “golden period of recovery” after stroke (Lin, Liaw, et al., 1999). All patients should receive rehabilitation (Hanger, 2000) preferably beginning in the first week after the stroke (Caplan, 2000 b). Similarly, Lin, Wei, et al. (1999) recommend that patients with impaired mental status not be routinely excluded from rehabilitation programs. In Musicco, Emberti, Nappi and Caltagirone (2003), stroke patients who initiated the rehabilitation within seven days had better long-term outcomes than did those who initiated rehabilitation after more than one month. Rehabilitation was a team approach, including the patient, patient’s family, primary care physician, neurologist, physical therapist, occupational therapist, speech therapist, social worker, and rehabilitation nurse (Caplan, 2000 b). Family members play a major role in reintegrating the patient back into his or her home and social environment. Educating and training caregivers are important during the rehabilitation process (Caplan, 2000 b), including how to train their stroke survivors’ self-care ability, mobility and mobility safety techniques at home (Galarneau, 1993). This also includes awareness of and appropriate use of assistive devices to facilitate self-care ability, safety transfer and prevent injury, such as specially designed dining set, transfer belt, and transfer board. Particular types of environmental modifications, such as ramps and bathroom modification can reduce the quantity of human help needed by disabled persons (Allen, Resnik & Roy, 2006). An increase in self-care ability of stroke survivors is related to a decrease in family caregiver strain (Chang, Wu & Chuang, 2004; Grant, et al., 2004). Thus independence training is an essential way to decrease the family and caregiver strain.

All family caregivers considered rehabilitation necessary for their stroke survivors. Similar to previous Taiwanese studies (Chiou et al., 2003; Chiu, Kao, Wang & Kuo, 1997; Tseng, et al., 2001), twelve of seventeen family caregivers indicated rehabilitation included only range of motion. This might be because in the hospital family caregivers were educated that rehabilitation was doing range of motion. Five family caregivers identified rehabilitation as more than range of motion and had an awareness of the need for early rehab therapy. They aggressively sought out further rehabilitation for their stroke survivors. In addition, family members faced environment barriers, only three of them had environmental modifications and three had shower chairs. Yet, no home environmental modification or care assistive devices were recommended by health care providers. Family caregivers indicated that the environment barriers and a lack of appropriate care assistive devices increased family caregivers' difficulties when providing care.

Another important issue identified by one family caregiver (Ya) was the concept of the elder "doing by herself." The others described a need to do everything for their stroke survivors. Flick (1999) indicated that family caregivers' overprotection and over assisting stroke survivors might cause the stroke survivors' self-care to decline and increase their depression due to a lack of independence, difficulty with skills, and social isolation. Family caregivers' concepts of filial piety and sick role behavior might be possible reasons for over protecting their stroke survivors. Filial piety emphasizes the child must serves the parents and undertakes all that has to be done (Fan, 2006). Additionally, people in the sick role are excused from other obligations as long as culturally determined conventions of being ill are followed (Christopoulos, 2001).

Taiwanese family caregivers of elder stroke survivors' perspectives about "filial piety," "sick role" and "independence" warrant further study.

Health Prevention and Promotion

A critical area of learning need not identified by family members was prevention of the complications of long term immobility. Dependent stroke survivors often need self-care assistance and most of them become bedridden, especially the severely dependent or unconscious elders (DeWitt, 2003; Faria, 1998). Long term immobility causes complications such as disorientation, depression, thrombus formation, orthostatic hypotension, ineffective breathing, pneumonia, malnutrition, muscle atrophy, joint contracture, osteoporosis, urinary tract infection, renal stones, constipation, and pressure ulcers (DeWitt, 2003; Faria, 1998). Range of motion, frequent turning, use of deep breathing exercises, increasing fluid intake and adequate nutrition with a high fiber diet intake can prevent some of the complications (DeWitt, 2003; Faria, 1998).Consistent with results in Huang, et al. (2006), family caregivers indicated several common complications, including pneumonia and sputum problems, fever, UTI, constipation, and pressure sores, leading to unplanned re-hospitalizations and emergency admissions. However, family caregivers indicated that they only learned UTI prevention, range of motion, chest percussion and position change just before discharge. They described "nobody told me" about how to prevent pressure sores and how to deal with the respiratory and sputum problems. When family caregivers faced those problems they did not know the causes and serious complications resulted. Consistent with previous studies (Chiu, 1998; Chiou, et al., 2003; Shyu, 2000), family caregivers have difficulties in judging and dealing with those emergency conditions causing family caregivers to feel stress when providing caregiving at home.

Theoretically, if family caregivers have sufficient education on health promotion and prevention, then complications and injuries due to providing care would be expected to be reduced, and the stroke survivors' self-care abilities would be expected to increase. Those positive improvements are expected to increase the positive caregiving outcomes and decrease the societal financial investments (Chiu, Tang, Liu, et al., 1998; Chuang, Wu, Ma, et al., 2005; Lin, Lee, et al., 2000; Wu & Chiou, 1997). Early and continued rehabilitation therapy can reduce health care cost and institutionalization. In Chiu, Tang, Shyu, Huang and Wang, (2000), when the ADL scores (based on Index of ADL, Katz) decreased one score, the total home care expenditures decreased 6,537 NT dollars (220 U.S. dollars) per month for home care.

Reasons for re-hospitalizations include sputum problems, UTI and gastric bleeding (Chen et al., 2003; Chou, et al., 2006; Dai et al., 2002). According to Chiu, Hong, Shyu and Chang (1999); Chuang, Wu, Ma, et al., (2005); Chung, et al. (2003), and Tseng (2003), the total hospital expenditures and family costs in hospital are around 223,000 to 334,500 NT dollars (8,260 to 12,390 US dollars) for each stroke episode of 20 to 30 days of hospitalization. Re-admission may reflect unresolved caregiver or stroke survivor problems at discharge or a lack of resources in post-hospital care (Chuang, Wu, Ma, et al., 2005; Shyu, 2000; Williams & Fitton, 1988). Clearly, in this study the lack of health promotion and prevention education was apparent, with caregivers reporting fifteen care challenges causing ten stroke survivors to have 23 re-hospitalizations and 17 emergency room visits or admissions.

Mismatched Teaching and Learning Styles and Unorganized Information

Health educators and family caregivers teaching and learning styles were mismatched. Considering the characteristics of the learners (family caregivers), an educator needs to pay attention to their learning needs and styles (Kitchie, 2003). According to andragogy (Knowles, 1980; Knowles et al., 2005), unlike children, adult learners desire to learn meaningful tasks and knowledge which can be applied and help them cope with problems they are currently facing. The learners have many experiences that become an increasingly rich resource for learning. Experience sharing is an important learning strategy for adults. Thus nurses should assess caregiver needs and their previous caregiving experiences. Following the principles of adult learning (Knowles, 1980) and indicated in Bandura (1977) and Delahaye and Ehrich (2008), several teaching strategies are recommended to increase desirable learning outcomes: Structuring the learning information, dividing the content into several small parts, using easily understood words and avoiding medical jargons, using learners' past experiences as examples, pacing the presentation with learner's ability to process information, practicing new knowledge and skills in various conditions, and reinforcement are ways for enhancing the learning process and outcomes. Family caregivers described nurses and other health care providers primarily employing verbal instructions and a single demonstration. They indicated nurses were too busy to provide sufficient time for teaching and to reassure them of what they had learned. Furthermore, family caregivers indicated that the health care providers lacked real experience concerning caregiving in the home environment. Thus their teaching was not applicable to real home situations. For example, family caregivers described how the nutritionist verbally taught them to measure food by the gram; however this measure is not used in the home. Family caregivers then used trial-and-error many times to find out how to prepare an appropriate dysphagia or NG diet.

Family caregivers indicated the teaching styles were not matched with their preferred learning styles and recommended that the information be organized and presented systematically. Currently the discharge planner is responsible for the discharge preparation; however, a systematic and organized discharge preparation program was not reported by family caregivers. It is not possible to know how discharge information was presented since the observation of the teaching/learning discharge situation in the hospital was not a purpose of this study. As such family caregivers may have been overwhelmed and unable to remember or retain the information. Research to better describe and understand the in-hospital teaching and learning situation is necessary.

Fragmented Health Care Services

The second reason for uncertainty and difficulties at home is fragmented health care services after discharge; including insufficient in-home health care services, emergency contact unit or person, rehabilitation services, and paratransit services. As indicated by Hunt and Smith (2004), when family caregivers face difficulties, being in touch with health care providers can minimize uncertainty. The family caregivers indicated that they needed home care nurses to reassure them about the quality of their care and to provide a timely service when they faced difficulties, especially during the first month. Family caregivers experienced difficulty contacting the hospital health care providers. When home care nurses were accessible and provided timely services; however, their stress and worry were reduced. As in Pierce, Gorden and Steiner (2004), family caregivers also indicated home care nurses had a better understanding about their stroke survivors' condition and their needs in the home environment and they provided better teaching and essential information than hospital-based nurses.

Nevertheless, not all home care nurses were easy to access and home care services were limited to twice a month. Trial-and-error became the major strategy of dealing with their difficulties at home. In addition, family caregivers indicated there was no emergency contact person who was able to provide effective directions when they were feeling incapable of managing their problems. This increased their sense of insecurity, often necessitating hospitalization of their stroke survivors.

Continuous rehabilitation and transportation are two unmet needs due to lack of health and social resources (Caplan, 2000 b; Chuang et al. 2007). In Western studies (Andersen et al., 2000; Britton & Andersson, 2000; Teng, et al., 2003), in-home rehabilitation demonstrated similar outcomes to hospital-based rehabilitation and decreased care expenditures. In this study, family caregivers described a preference for in-home rehabilitation services. Currently there is no in-home rehabilitation service in Taiwan (Chuang et al., 2007). Although there are hospital-based rehabilitation services, family caregivers had difficulties finding and getting the resources due to the limited service beds and rehabilitation providers. Family caregivers indicated that the insufficient rehabilitation resources caused them considerable difficulty finding necessary rehabilitation. In addition, lack of paratransit was a major barrier for family caregivers who were taking their elders back to the hospital for rehabilitation. Importantly, from family caregivers' description, not only were they not aware of the services, but the hospital health care providers were also not aware of paratransit service. The fragmented health care services increased their sense of difficulty and likely contributed to stroke survivors' poor health outcomes.

Family caregivers lacked the sufficient preparation necessary to provide care for their stroke survivors at home because the provided information was insufficient for their needs at home, and teaching and learning styles were mismatched and unorganized. In addition, lack of sufficient and continuing in-home services worsened their situations. Thus family caregivers were unprepared and uncertain about how to deal with their care situations at home. Although there was a discharge planner who was responsible for coordinating information and services, family caregivers indicted that the provided information was under organized and insufficient. They indicated a need for a systematic, well-organized protocol to organize their learning as well as continuing services.

The nursing profession is affected by social and scientific forces; consequently, the role of the nurse is changing, growing, and evolving (Ward-Murray, 2007). The role of the nurse has broadened in response to these changes, from dependent to independent and collaborative, with the recognition that nurses are autonomous and informed professionals (Ward-Murray, 2007). In addition to being a caregiver, nurses are an educator, advocate, and coordinator (Taylor, Lillis & LeMone, 2005; Ward-Murray, 2007). As a caregiver, the nurse conducts independent assessments and implements patient care based on their knowledge and skills. They also collaborate with other members of the health care team to implement and evaluate health care outcomes (Taylor et al., 2005; Ward-Murray, 2007). With greater emphasis on health promotion and illness prevention, the nurse's role as educator has become increasingly important. The nurse assesses learning needs, plans and implements teaching strategies to meet those needs, and evaluates the effectiveness of the teaching (Schmitt, 2005; Ward-Murray, 2007). To be an effective educator, the nurse must have effective interpersonal skills and be familiar with principles of adult learning (Taylor et al., 2005; Ward-Murray, 2007). As an advocate, the nurse helps the patient and his family members interpret information from other health care providers and make decisions about his health-related needs (Ward-Murray, 2007). Although the physician is usually considered the head of the team, the nurse plays an important role in coordinating the efforts of all team members to meet the patient's goals and may conduct a team conference to facilitate communication among team members (Schmitt, 2005; Ward-Murray, 2007). According to Marek, Popejoy, Petroski and Rantz (2006), a nurse care coordination group services demonstrates more positive outcomes for community elders than the non-nurse coordination group.

It is apparent from the 17 family caregivers' experiences, that nurses provided health care, education, and coordinated information. According to Pan, Chin, Hwang and Ko (1993), however, hospital-based nurses spend around 30% of their time providing direct care, including monitoring vital signs, administering medication, assisting in examination and treatment, caring for, and educating patients and family members. How much time nurses contribute to effective care and teaching under the current nursing situation in Taiwan is unclear. The discharge planner provides limited information, such as home care service referral and assistive care devices. Schmitt (2005) indicated there is a different role context between being a caregiver and a coordinator. Nurses need further training in different role expectations. Thus further study is necessary in order to understand nurse’s perception of the role of a caregiver, educator, advocator and coordinator.

Personal Negative Impact and Positive Gains

Negative Impact

Throughout the caregiving experiences, family caregivers describe negative impacts and positive gains. Negative impacts include physical, psychological, social and financial impacts. Those negative impacts have been reported in many previous studies (Chen, et al., 1999; Chien & Shyu, 2000; Chin et al., 1999; Chiou et al., 2003; Chiu, 1998). Sleep interruption has been indicated in previous studies (Chiou et al., 2003; Hsu & Chiou, 2004 a; Wu, 1995) and it was the most common problem for the 17 family caregivers, including eight family caregivers who were supervising foreign care attendants only. However, previous studies only provided the percentage of sleeping problems (Chiou et al., 2003; Hsu & Chiou, 2004 a; Wu, 1995). This study illustrated descriptions of the sleeping problems. For example, family caregivers had significant sleep interruption at three times: during early discharge, when their stroke survivors’ condition was unstable and upon having a new helper or foreign care attendant.

Like previous studies, family caregivers experienced psychological impact (Chiou et al., 2003; Hsu & Chiou, 2004 a) associated with worrying about their stroke survivors’ health condition. Especially, the two daughters-in-law (Hui and Hua) who did not live with their stroke survivors reported high stress from every phone call from their foreign care attendants. Receiving other family support can decrease family caregiver’s strain (Chou, 2000). Similar to other research (Chao & Roth, 2000; Chin, et al., 1999; Chiou, et al., 1988; Shyu; 2000) female non-spouse family caregivers experienced high stress from a lack of other family support and conflict with their family members. In Chinese culture, sons are delegated more power and authority than daughters and daughters-in-law (Shyu, 2000). Lacking full authority female family caregivers indicated they experienced higher pressure than others. Noticeably, daughters and daughters-in-law count around 30% of family caregivers (Chiou et al. 2002; Chuang, Wu, Yeh, et al., 2005; Kuo et al., 2005; Hsu & Chiou, 2004 a; Ling & Chiou, 2004). This is an obvious issue for health care providers and researchers, but has not been reported in previous studies. The Taiwanese non-spouse female caregivers might feel high pressure from their caregiving role and experience burn out more easily.

Social impacts occur with all family caregivers regardless if they provide direct care or supervise their foreign care attendants only. Like previous studies (Chiou, et al., 2003; Chiou, et al., 1988; Chiu et al., 1966), family caregivers often gave up their own hobbies and put their stroke survivors' needs before their own. In addition, financial burden has been reported as a common impact for family caregivers (Chien & Shu, 2000; Chung & Hung, 1999; Ling et al., 2004); however, the issues that accounted for the financial burden were not reported. In this study, family caregivers indicated that purchasing commercial formula and hiring a Taiwanese caregiving helper were two major reasons for causing financial strain. Family caregivers reduced the finance burden by preparing home-made NG feeding diets and hiring a foreign care attendant. Some government subsidized items are expected to reduce family financial pressure. However, from these family caregivers' experiences, the subsidization did not alleviate family financial burden. Further study about what and how the subsidized items are actually meaningful and helpful for families is an area of needed research.

Family caregiving manpower assistance has been reported as a critical area of need in other Taiwanese studies (Chin, 1995; Shyu, 2000; Tseng, 2003; Tseng, et al., 2001; Wu, Chang, Lin & Yao, 1992). In this study, family caregivers rarely indicate this need. A possible reason is in sample selection. These family caregivers identified that having manpower and time available were key reasons for deciding to care for their stroke survivors at home. They all indicated other family caregivers were able to provide assistance when needed. Nine families hired nurse aides or foreign care attendants to fill out their manpower need. Hiring a foreign care attendant is expected to decrease family caregivers' burden; however, from their descriptions, family caregivers only decrease part of the physical impact, not their psychological pressure and social impact. In contrast, hiring a foreign care attendant caused different psychological pressure, such as worrying about the care attendants' learning and care capabilities. Likewise, the foreign care attendants care ability and care issues remain under-explored.

Positive Gains

Family caregivers' experiences are not only limited to negative ones. They all described positive gains from the caregiving experience. Positive gain is defined broadly to include any positive affective or practical return that resulted from caregiving (Kramer, 1997). Reported positive gains include uplifts, positive feelings toward caregiving, personal gain and management of meaning, and finding meaning through caregiving (Farran, Miller, Kaufman & Davis, 1997). Positive gains are indicators for healthy transitions (Meleis, Sawyer, Im, Hifinger Messias & Schumacher, 2000) and negatively related to caregiver burden, and depression (Farran et al., 1997; Pinquart & Sorense, 2004). Uplift is defined as events that make one feel good, make one joyful, or make one glad or satisfied (Kinney & Stephens, 1989). Learning and the ability to perform care skills and see their stroke survivors' improvement were two uplifts for the family caregivers in this study. Stroke survivors' maintaining their health without complications as well as noticeable improvements in their health status were powerful motivators for family members to continue their caregiving.

Finding meaning refers to the subjective appraisal of an anticipated or experienced transition and the evaluation of its likely effect on one's life (Schumacher, & Meleis, 1994). Caregivers use expectations, explanations, and strategies to integrate with the larger context of their lives (Ayres, 2000). On the other hand, Pearlin, Mullan, Semple and Skaff (1990) suggest that finding meaning is a coping strategy that mediates caregiving outcomes. When finding meaning was viewed as a coping strategy, it became a better predictor of depression and caregiver strain (Farran et al., 1997). In this study, family caregivers indicated some positive meanings from their care experiences, such as being a model for children, keeping family members together, and ending Karma, to alleviate their stress.

Family caregiving positive gains have been reported in Western culture studies, but have not been found in Taiwanese studies. These findings broaden the perspectives of Taiwanese caregiving experiences. Kramer (1997) and Schumacher (1995) indicate that understanding family caregivers' positive gains may help health providers to enhance and increase positive aspects and to work more effectively with the family caregivers. However, there are no studies conducted on Taiwanese family caregivers. Further study is necessary to show how family caregivers make meaning from their caregiving process and the benefits from positive gains.

This inductive qualitative descriptive research design provided a comprehensive description of the care situation from the family caregivers' point of view by using their everyday language. It was written in terms understandable by the lay population and informative to research, practice, education and policy (Sandelowski, 2000; Sullivan-Bolyai, et al., 2005). Limitations within the design are addressed followed by implications for research, nursing education, practice, and health policy.

Limitations

Five main limitations are addressed. First, the accuracy of some of the problems faced by family caregivers and the perceived importance of these problems at the time might be questionable due to recall bias for retrospective reports. This is especially true for some of the family caregivers who had been caring for their stroke survivors for around one year. Some of the difficulties and management strategies might be under or over estimated. However, the potential drawback is partially compensated by reconfirming the preliminary analysis and findings with the participants. Second, some situations that caused family caregiver difficulty might be more complicated than participants' description. For example, the teaching/learning process is an interaction between nurses and the family caregivers. The findings only provided the viewpoints from the family caregivers. The teachers' (nurses') viewpoints and hospital context during the learning process are unknown. Third, the new care attendants who did not speak Chinese were unable to be consented and observed. This limited understanding the care situations involving the foreign care attendants. Fourth, while a qualitative descriptive research study does not intend to generalize the findings to other populations, the participants were purposively recruited from Kaohsiung and Ping Tong areas. It is possible that the family caregivers in the southern rural Taiwan areas might have different views and needs than those in the northern, more urban areas. Therefore, the transferability of the research results should be examined carefully before applying to other populations. Finally, this study provides a beginning description of Taiwanese family caregivers' experiences and care situations from hospital to home resulting in implications for further research.

Implications

Research

Family caregiver's general learning and care situations were identified from the family caregivers' perspectives; however, some issues are in need of further study to gain more understanding of stroke family caregivers' three learning determinants. Family caregiver's learning needs were changing at different points in time. In this study, family caregivers' needs before discharge were recalled by family caregivers, instead of collected from their current situations. On the other hand, the nurses' teaching styles and family members' learning styles are only described by family caregivers. The nurse's viewpoints concerning their role in providing care to a family with a stroke survivor is unknown. Thus it is necessary to understand the family caregivers' needs across the different time periods, the congruency of nurses' teaching styles and learner's learning styles and the role context for a nurse. A longitudinal study is recommended.

Taiwanese family caregiver's positive gains are new findings. How a family caregiver makes meaning from their caregiving process and the benefits of positive gains remain unexplored. A phenomenological study is recommended to better understand family caregiver's positive gains and their perspectives.

Additional areas of study includes daughter's and their family members' concept of filial piety, sick role, and care attitudes toward providing care for her own parents; family caregivers' and health care providers' perspectives of independence and rehabilitation; the content of caregiver preparation before discharge; the cost and benefit of providing in-home rehabilitation service; and what and how subsidized items are actually helpful for families. In addition, with changes in Taiwanese long term care, the growing trend of foreign care attendants is a critical area of needed research. In this study, the two major problems related to hiring a foreign care attendant are communication and quality of care. Further, while it is expected that hiring a helper will reduce family caregiver's burden, the family caregiver's psychological pressure was increased. Thus research on care issues related to hiring and employing foreign care attendants in needed. Furthermore, because family caregivers identified that being under-prepared before discharge influenced the stroke survivors' experiencing high rates of unplanned re-hospitalization and ER visits, an interdisciplinary discharge protocol was recommended by participants. Thus it is necessary to analyze unplanned re-hospitalization and ER visits, and test the effectiveness of an interdisciplinary discharge protocol.

Nursing Education

According to Nursing Law (Department of Health, Executive Yuan, R. O. C., 2009), patient education is a major nursing practice role. The nurse is viewed as the best person for providing care skills and information to family caregivers (Shyu & Hwang, 2000). Educational activities occur in the clinical situation every day. However, from the family caregivers' perspective the teaching process was disorganized and did not focus on the learner's needs or effective teaching styles. Currently, educational theory and teacher/learner strategies are not incorporated into nursing education in Taiwan. This study reinforces an urgent need for nurses to learn how to provide effective education. It is recommended that educational theory, principles, and teacher/learner strategies be incorporated into nursing curricula. Additionally, although Gerontological nursing is a popular course in Taiwan, health promotion and prevention, especially the complications due to long term immobility and rehabilitation principles, are needed. Nursing education and care principles must be transferred to the acute care setting.

The nurse has to know what the real situations for family care are in the home. Currently, the nurse education program focuses on nursing care in the acute hospital environment. When students become a member of the hospital health care staff, they may have difficulty understanding home care situations. It is imperative that students and practicing nurses have opportunities to learn about the home care environment. This may include a practicum of home care nursing, through formal nursing education and continuing nursing education offerings. Incorporation of family caregiver learning needs, home care challenges, interdisciplinary practice, and social health resources is recommended.

Practice

Anticipatory preparation facilitates the transition experience from family member to family caregiver (Meleis, et al., 2000). The aim of preparation is to increase the sense of certainty for a family caregiver. Preparation also facilitates implementation of nursing care. It is recommended that an interdisciplinary discharge protocol be developed and tested. Based on participant experiences, components of the discharge protocol follow.

This intervention may include setting up a discharge preparation unit and family caregiver center discharge preparation protocol. When the stroke survivor’s health condition is stable, he/she can be transferred to the discharge preparation unit and then a coordinator or primary nurse should be assigned. Interdisciplinary team work is recommended, including a nurse coordinator, physician, rehabilitation therapist, nutritionist, social worker, and home care nurse. The nurse coordinator could be responsible for coordinating all information and communicating with family caregivers. The nurse coordinator assesses the identified primary family caregiver, the caregiver’s learning needs, readiness to learn, her/his current care capabilities, and preferred learning styles. A home visit could be conducted for a home environment assessment. After collecting necessary information, the team then works with the family caregivers and home care nurse to formulate individualized instruction for each family caregiver. This program may include a group and/or individual educational programs using concrete teaching styles, a slow pace and multiple meeting times for learning and practicing. A home style education classroom setting with simple home environmental modifications, such as a ramp or grab bar, and assistive devices may facilitate discharge instruction and promote transferability to the home care environment. An emergency contact nurse is recommended. Furthermore, according to the aim of rehabilitation, rehabilitation training is begun as early as possible.

Home care visits are recommended once a week during the first month to review family caregivers’ activities and provide vital information. In addition, frequent phone contact is necessary. It is recommended that the home care nurse consider how best to increase the accessibility and mobility of home care services, especially after service hours. On the other hand, female non-spouse family caregivers experienced a higher rate of lack of support from the other family. Health care providers therefore have to become aware of these issues and potential needs of this population. Although not identified in this study, based on Hsu and Chiou (2004 b), a stroke family caregiver group for experience sharing may be helpful.

Health Care Policy

Health policy holds the invisible regulations and direction of the quality of life and care for family and stroke persons at home. Without policy regulation changes, some of the family caregivers' dilemmas will be resistant to change. Along with the rapidly increasing elderly population, long-term care has presented serious challenges to public policy. "Aging in Place" is the guiding principle for elder care policy in Taiwan and it emphasizes maintaining the elder persons' independence, dignity, and quality of life (Wu & Chuang, 2001). According to the United Nations Principles of Older Persons (United Nations Programme on Ageing, 2009), the elders have the right to be able to live in dignity and security and to be free of exploitation and physical or mental abuse. For a dependent elder person, his/her family caregiver plays an important role for protecting and providing her/his dignity, security and quality of life at home (White, Lauzon, Yaffe & Wood- Dauphinee, 2004). Yet, the problematic preparation and fragmented health care services caused family caregivers to face fifteen caregiving difficulties and the stroke survivors had high rates of re-hospitalization and emergency room visits. Furthermore, as family caregiver's described, providing care often negatively impacted them. Caregiving responsibility has been identified as negatively impacting family caregivers' quality of life (Lu, 2005; White, et al., 2004). However, supportive services to help elder persons and their families are seriously lacking in Taiwan (Wu & Chuang, 2001; Wu, et al., 2005). Encouraging home care and financial supportive services to prolong the elders staying in the community have been recommended (Wu & Chuang, 2001).

Studies indicate that in-home services provide numerous advantages and benefits for both family and society, such as increasing the care receiver and caregivers' quality of life, and reducing the re-admission and institutionalization and care expenditures

(Andersen et al., 2000; Liou & Wu, 1999; Teng, et al., 2003). Most of the studies are conducted in Western culture where the context of in-home services is different than the in-home service in Taiwan. From these family caregivers' experiences, they need: more home care service (especially during the first month), in-home rehabilitation services, and rehabilitation specialty hospitals. In-home services should include an interdisciplinary team of health care providers, especially the nurse coordinator, nutritionist and rehabilitation therapists. A cost analysis of in-home rehabilitation versus providing transportation and transfer support for elder stroke survivors should be undertaken to reduce the burden caused by transportation issues. According to these family caregivers' experiences, there is a critical need for rehabilitation services which may include a rehabilitation specialty hospital like a respiratory care center for persons with ventilation problems.

Family caregivers indicated that they need financial support. However, the current subsidized items are not what they need. They indicated their financial burden is from purchasing the commercial formula and hiring a helper. Family caregivers indicated that the diet is a daily item. They recommended the subsidized item should be the daily needed ones like the medication prescription which can be covered by health insurance. While family caregivers indicated that they prefer a Taiwanese helper, the price for hiring a Taiwanese helper is much higher than hiring a foreign care attendant. The current financial support did not alleviate their financial strain. It is recommended that the financial support policy be reconsidered, to include further study to understand the pros and cons of hiring a Taiwanese helper versus a foreign care attendant. In addition, it is necessary to consider the requirements for a foreign care attendant if they are providing care for a debilitated person at home.

Summary

According to role acquisition and learning theories, the family caregivers' readiness to learn, learning needs, and learning styles are identified. Most family caregivers were ready to take on their caregiving role. Although a sense of responsibility was the major reason for almost all family caregivers to take on the role, some of them felt they were forced. Affection and Karma were important for all family caregivers, and especially motivate family caregivers to continue their work when they were forced to provide care or were frustrated and lacked other family members' support. Before discharge, the first month after discharge and when encountering a new care situations were identified as the three times when they were ready to learn. Most family caregivers were ready and able to learn basic physical care skills, but they had difficulty learning complicated skills, such as sputum suction. They needed more time to overcome their fear of learning those skills.

Family caregivers felt uncertainty when they faced new care situations at home. They had difficulty in dealing with their problems. Family caregivers were under-preparation before discharge and they lacked accessible and timely in-home services after discharge. The reasons for under-preparation include problematic preparation and fragmented health care services. The reasons for problematic preparation include the provided information is insufficient and inconsistent with what family caregivers' perceived that they needed, the teaching and learning styles were mismatched, and information was unorganized. After discharge, they needed timely in-home services and an emergency contact person. They needed continuous rehabilitation service, either provided by in-home care or a rehabilitation specialty hospital. A paratransit service was recommended to overcome their transportation problems. While the home care nurse was a key resource for family caregivers after discharge, they were difficult to access and the services time was limited to twice a month. Due to the fragmented health care service, family caregivers had difficulty managing their stroke survivors’ problems, with high rates of complications, hospitalization and emergency room visits.

In this study, there are several new findings for Taiwanese family caregiving experiences: (1) the ongoing sense of caregiving uncertainty, (2) positive caregiver gains, and (3) identified difficulties in managing swallowing problems and training, environment accommodations, care assistive devices, and foreign care attendant problems. Major implications for research, education, practice, and health policy include a need for further studies on understanding the three learning determinants, incorporation of teaching/learning theory as a required course for formal nursing education programs, developing an organized and systemic discharge teaching preparation protocol, and increasing in-home nursing and rehabilitation services.

While stroke continues to be a leading cause of death (Department of Health, Executive Yuan, 2005) and disability among Taiwanese elders (Chuang, Wu, Yeh, et al., 2005) this does not mean that elders’ should be subject to a life of inappropriate care or unnecessary hospitalizations. Elders have a right to quality of life whereby they live in dignity, security and free of exploitation and physical or mental abuse or neglect. Providing elder family caregivers with learning resources at the right time and place to provide this care in the home is consistent and essential to facilitating quality of life and “aging in place” in Taiwan.

APPENDIX A

TAIWAN MAP AND STUDY AREAS

** Study areas are marked with ★

APPENDIX B

IRB APPROVALS

THE UNIVERSITY OF IOWA

Human Subjects Office
340 Medicine Administration Building
Iowa City, Iowa 52242-1101
319-335-6564 *Fax* 319-335-7310
irb@uiowa.edu
http://research.uiowa.edu/hso

IRB ID #: 200805766

To: Chiung-Man Wu

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: Learning to be a Family Caregiver for Severely Debilitated First Stroke Survivors During the Golden Period in Taiwan

---

Approval Date: 07/09/08

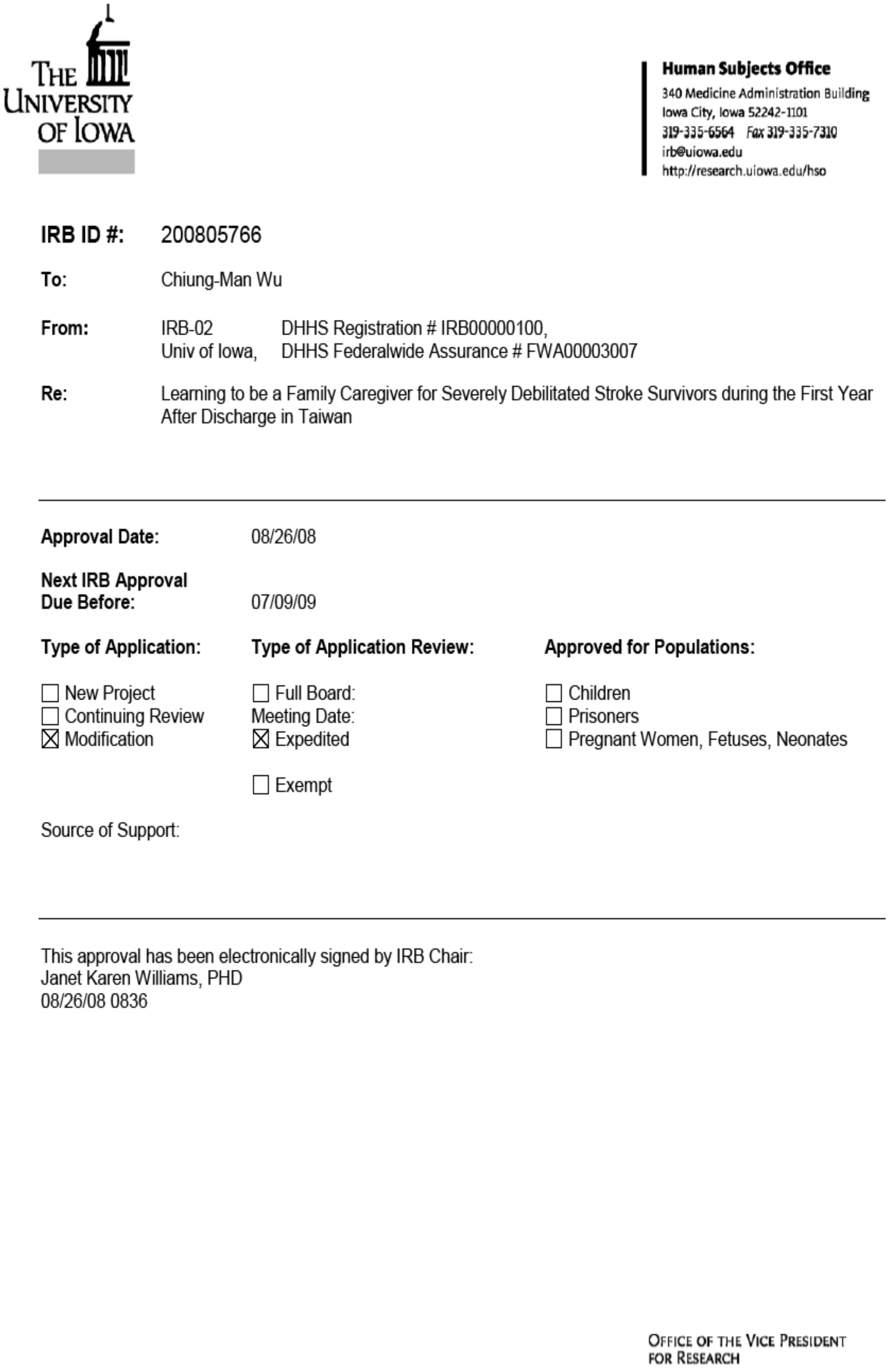
Next IRB Approval Due Before: 07/09/09

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☒ New Project	☐ Full Board:	☐ Children
☐ Continuing Review	Meeting Date:	☐ Prisoners
☐ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support:

This approval has been electronically signed by IRB Chair:
Martha Jones, CIP, MA
07/09/08 2111

OFFICE OF THE VICE PRESIDENT
FOR RESEARCH



THE UNIVERSITY OF IOWA

Human Subjects Office
340 Medicine Administration Building
Iowa City, Iowa 52242-1101
319-335-6564 *Fax* 319-335-7310
irb@uiowa.edu
http://research.uiowa.edu/hso

IRB ID #: 200805766

To: Chiung-Man Wu

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year After Discharge in Taiwan

---

Approval Date: 08/26/08

Next IRB Approval Due Before: 07/09/09

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☐ New Project	☐ Full Board:	☐ Children
☐ Continuing Review	Meeting Date:	☐ Prisoners
☒ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support:

This approval has been electronically signed by IRB Chair:
Janet Karen Williams, PHD
08/26/08 0836

OFFICE OF THE VICE PRESIDENT
FOR RESEARCH

THE UNIVERSITY OF IOWA

Human Subjects Office
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irb@uiowa.edu
http://research.uiowa.edu/hso

IRB ID #: 200805766

To: Chiung-Man Wu

From: IRB-02 DHHS Registration # IRB00000100,
Univ of Iowa, DHHS Federalwide Assurance # FWA00003007

Re: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year After Discharge in Taiwan

---

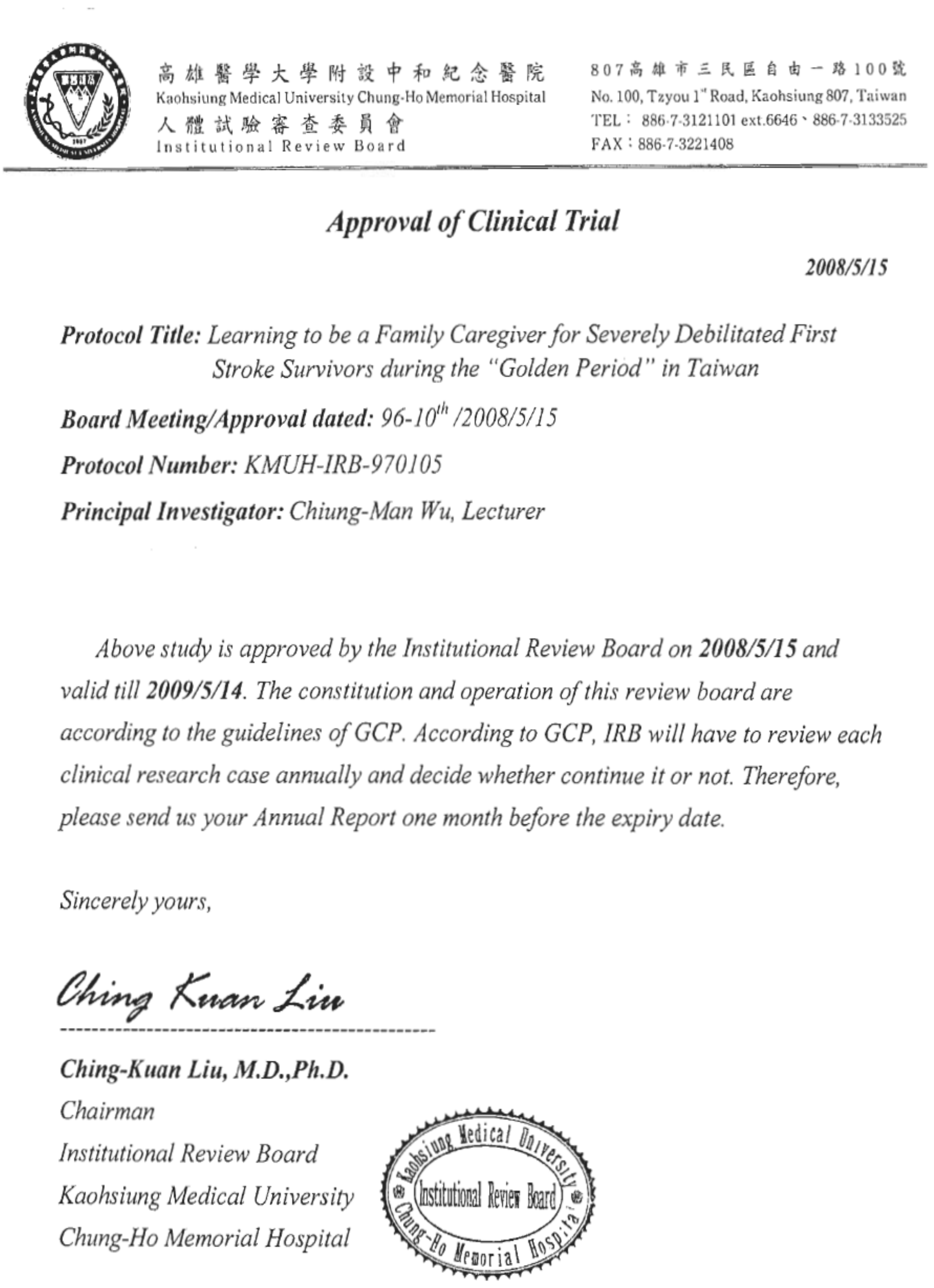
Approval Date: 07/02/09

Next IRB Approval Due Before: 04/20/10

Type of Application:	**Type of Application Review:**	**Approved for Populations:**
☐ New Project	☐ Full Board:	☐ Children
☐ Continuing Review	Meeting Date:	☐ Prisoners
☒ Modification	☒ Expedited	☐ Pregnant Women, Fetuses, Neonates
	☐ Exempt	

Source of Support:

This approval has been electronically signed by IRB Chair:
Janet Karen Williams, PHD
07/02/09 1543



高雄醫學大學附設中和紀念醫院
Kaohsiung Medical University Chung-Ho Memorial Hospital
人體試驗審查委員會
Institutional Review Board

807高雄市三民區自由一路100號
No. 100, Tzyou 1st Road, Kaohsiung 807, Taiwan
TEL： 886-7-3121101 ext.6646、886-7-3133525
FAX：886-7-3221408

Approval of Clinical Trial

2008/5/15

Protocol Title: *Learning to be a Family Caregiver for Severely Debilitated First Stroke Survivors during the "Golden Period" in Taiwan*

Board Meeting/Approval dated: *96-10th /2008/5/15*

Protocol Number: *KMUH-IRB-970105*

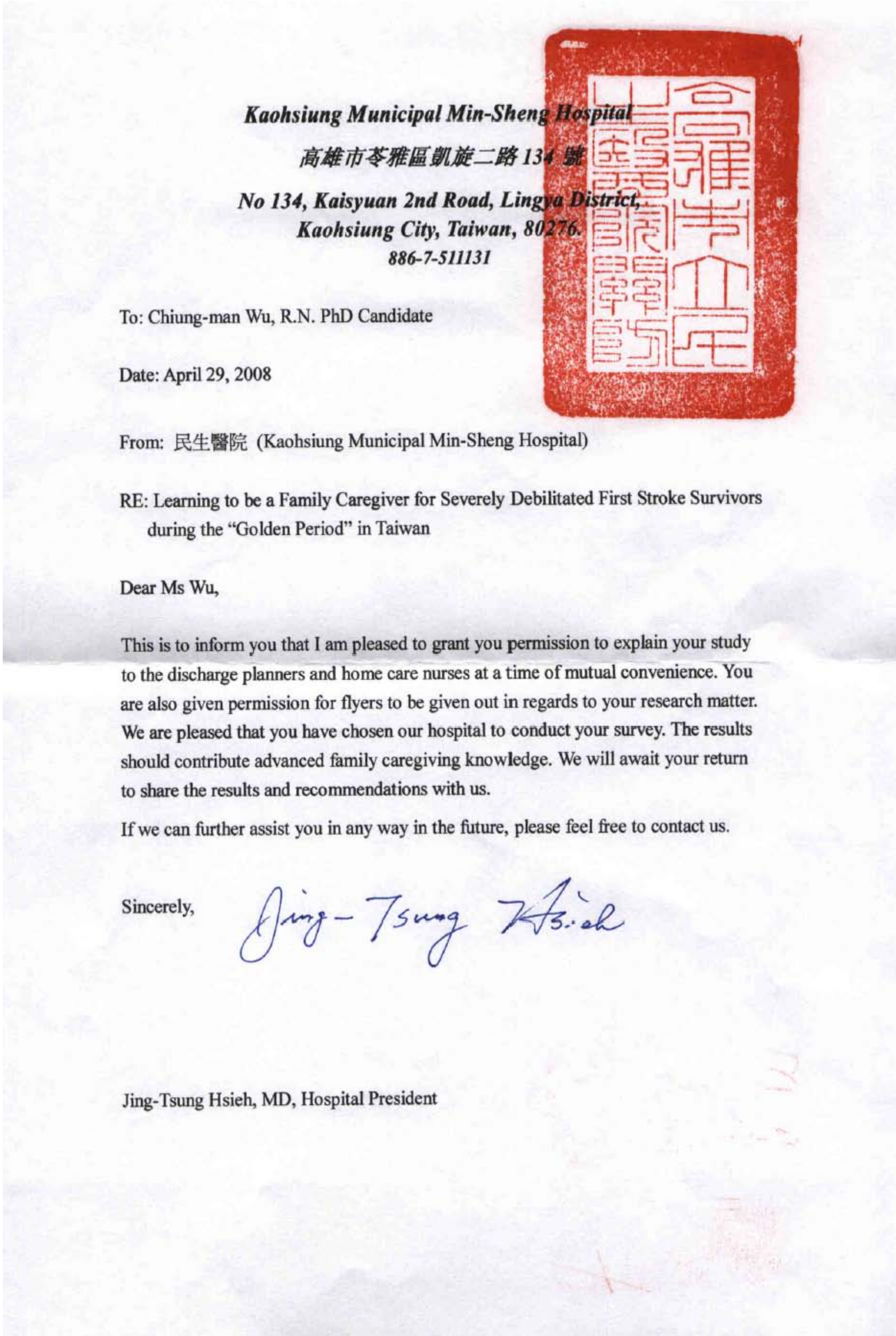
Principal Investigator: *Chiung-Man Wu, Lecturer*

Above study is approved by the Institutional Review Board on ***2008/5/15*** *and valid till* ***2009/5/14****. The constitution and operation of this review board are according to the guidelines of GCP. According to GCP, IRB will have to review each clinical research case annually and decide whether continue it or not. Therefore, please send us your Annual Report one month before the expiry date.*

Sincerely yours,

Ching Kuan Liu

Ching-Kuan Liu, M.D.,Ph.D.
Chairman
Institutional Review Board
Kaohsiung Medical University
Chung-Ho Memorial Hospital



Kaohsiung Municipal Min-Sheng Hospital
高雄市苓雅區凱旋二路 134 號
No 134, Kaisyuan 2nd Road, Lingya District,
Kaohsiung City, Taiwan, 80276.
886-7-511131

To: Chiung-man Wu, R.N. PhD Candidate

Date: April 29, 2008

From: 民生醫院 (Kaohsiung Municipal Min-Sheng Hospital)

RE: Learning to be a Family Caregiver for Severely Debilitated First Stroke Survivors during the "Golden Period" in Taiwan

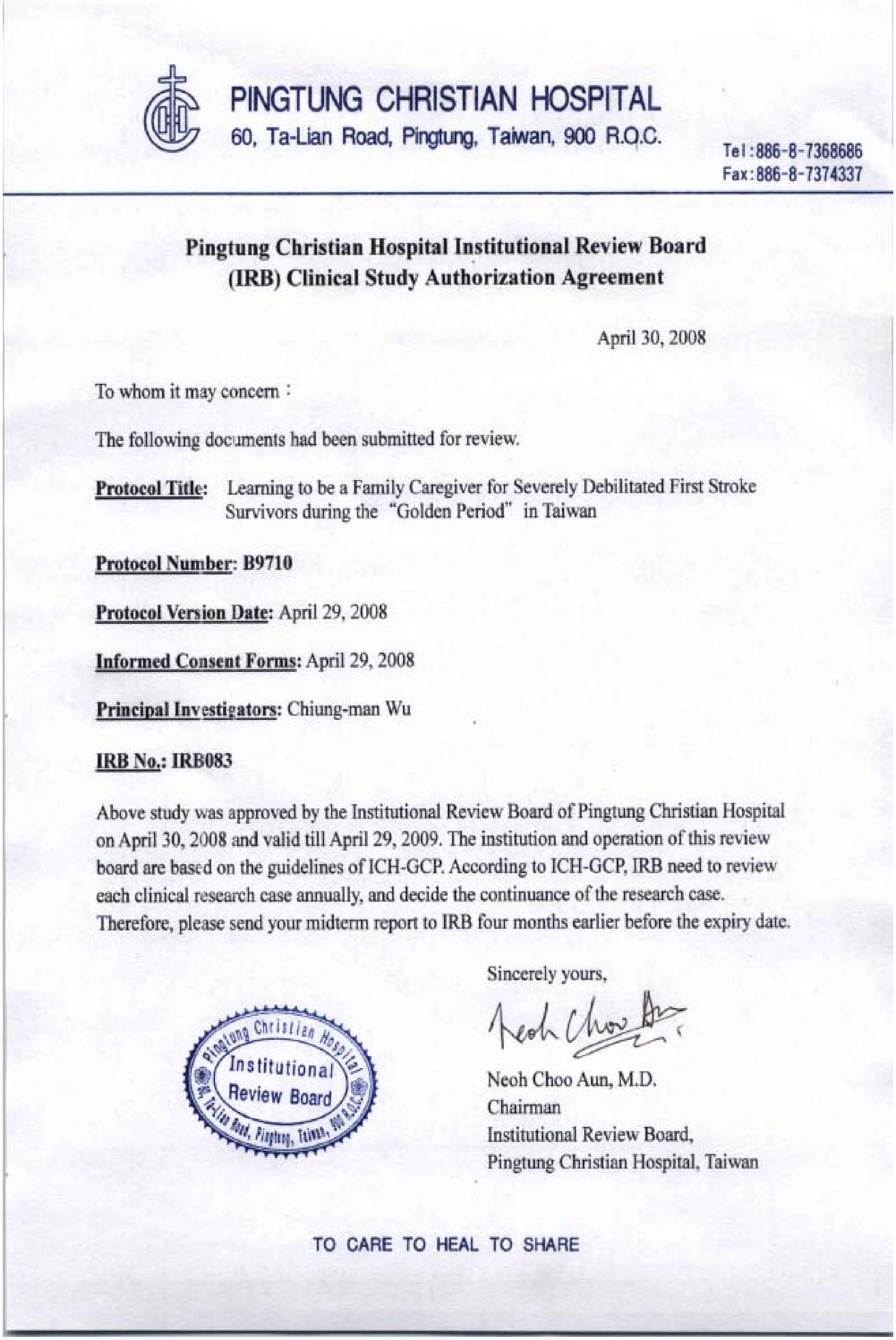
Dear Ms Wu,

This is to inform you that I am pleased to grant you permission to explain your study to the discharge planners and home care nurses at a time of mutual convenience. You are also given permission for flyers to be given out in regards to your research matter. We are pleased that you have chosen our hospital to conduct your survey. The results should contribute advanced family caregiving knowledge. We will await your return to share the results and recommendations with us.

If we can further assist you in any way in the future, please feel free to contact us.

Sincerely, Jing-Tsung Hsieh

Jing-Tsung Hsieh, MD, Hospital President



PINGTUNG CHRISTIAN HOSPITAL
60, Ta-Lian Road, Pingtung, Taiwan, 900 R.O.C.
Tel:886-8-7368686
Fax:886-8-7374337

Pingtung Christian Hospital Institutional Review Board (IRB) Clinical Study Authorization Agreement

April 30, 2008

To whom it may concern：

The following documents had been submitted for review.

Protocol Title: Learning to be a Family Caregiver for Severely Debilitated First Stroke Survivors during the “Golden Period” in Taiwan

Protocol Number: B9710

Protocol Version Date: April 29, 2008

Informed Consent Forms: April 29, 2008

Principal Investigators: Chiung-man Wu

IRB No.: IRB083

Above study was approved by the Institutional Review Board of Pingtung Christian Hospital on April 30, 2008 and valid till April 29, 2009. The institution and operation of this review board are based on the guidelines of ICH-GCP. According to ICH-GCP, IRB need to review each clinical research case annually, and decide the continuance of the research case. Therefore, please send your midterm report to IRB four months earlier before the expiry date.

Sincerely yours,

Neoh Choo

Neoh Choo Aun, M.D.
Chairman
Institutional Review Board,
Pingtung Christian Hospital, Taiwan

Institutional Review Board

TO CARE TO HEAL TO SHARE

APPENDIX C

TOOLS FOR ASSESSING PARTICIPANTS’ ABILITIES TO GIVE CONSENT

Mini Mental State Examination

Care receiver code: ______________________________ Date_____________

Orientation

___ 1. What is the (year) (season) (date) (day) (month)? (5)

___ 2. Where are we (state) (country) (town) (hospital) (floor)? (5)

Registration

___ 3. Name 3 objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until he/she learns all 3. Count trials and record. Trials ____________ (3)

Attention and Calculation

___ 4. Serial 7's. 1 point for each correct answer. Stop after 5 answers. Alternatively spell "world" backward. (5)

Recall

___ 5. Ask for the 3 objects repeated above. Give 1 point for each correct answer.

Language

___ 6. Name a pencil and watch. (2)

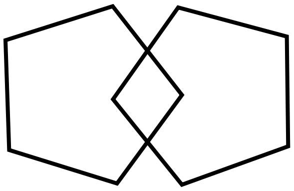
___ 7. Repeat the following "No ifs, ands, or buts" (1)

___ 8. Follow a 3-stage command: "Take a paper in your hand, fold it in half, and put it on the floor." (3)

___ 9. Read and obey the following: CLOSE YOUR EYES (1)

___ 10. Write a sentence. (1)

___ 11. Copy the design shown. (1)



_____ Total Score

Folstein, M. F., Folstein, S. E., & Mchugh, P. R. (1975). Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12* (3), 189-198.

簡式智能量表 (Mini Mental State Examination)

受照顧者編號: ______________ **日期: ________________________**

Orientation:

___ 1. 今天是_______年_______月_______日 星期____ 季節為____季。(5)

___ 2. 這裡是_______醫院______樓______科， 在______縣市。(4)

___ 3. 這棟樓房/建築是做什麼用的?用途是什麼?

Registration:

___ 3. 說出三件東西的名字， 叫病人馬上覆誦□樹木□剪刀□火車 (3)

然後讓個案重複練習此三樣東西的名字 紀錄練習次數 __

Attention and Calculation:

___ 4. 請從100開始連續減7，一直減7到65（5）

93__________; 86_________; 79_________; 72_________; 65_________

Recall:

___ 5. 回想三件東西的名字（次序無關）□樹木□剪刀□火車 （3）

Language:

___ 6. 出示手錶和筆，要病人說出東西的名字□手錶□筆（2）

___ 7. 覆誦： 沒、如、且或但 或 知足天地寬 或 心安菜根香（1）

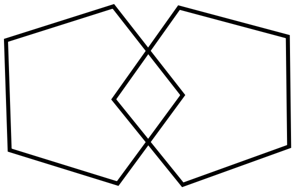
___ 8. 服從命令：□用你的右手拿起這張紙，□將它對摺，□然後置於大腿上面（3）

___ 9. 讀並且執行下列動作：請閉上眼睛(1)

___ 10.寫出一個句子（造句：含主詞、動詞、受詞）或寫出一句話（1）

Spatial:

___ 11.畫出圖形（兩個重疊的五角形）（1）



總分：_______/30

研究同意書簽署能力評估

□照顧者編號:______________ □被照顧編號: ______________ 日期: ____________

說明:

下列第一題可依評估者的主觀判斷決定。詢問參與者 2-5 個問題並紀錄回他的反應。 評估者可以使用不同的陳述方式詢問問題以協助參與者了解。

1. 參與者清醒且可以與評估者溝通? 是 ____ 否 _______
2. 請參與者說出最少兩種參加本研究的潛在性的危險

   ____

   ____

3. 請參與者說出最少兩件將預期發生在參與本研究的過程中的事件。

   ____

   ____

4. 請參與者說明如果他不想繼續參加本研究時，他將如何處理。

   ____

   ____

5. 請參與者說明如果在研究過程中感受到壓力或不愉快時該如何處理。

   ____

   ____

評估者簽名

這是我個人的判斷: 此參與者清醒且可以正常溝通，並對上述問題給予可接受的回答。

____________________________________ ____________________________________

(評估者簽名) (日期)

APPENDIX D

IRB APPROVED DOCUMENTS

FOR IRB USE ONLY
APPROVED BY: IRB-02
IRB ID #: 200805766
APPROVAL DATE: 04/20/09
EXPIRATION DATE: 04/20/10

Learning to be a Family Caregiver for Stroke Survivors You are invited to participate in a research study if you care for to a family member who has had a severe stroke.

The purpose of the study is to learn more about how a family member becomes a caregiver for a stroke survivor. The study will focus on the first year after discharge from the hospital. Based on your experience, our health care providers will have better understanding of the situations and needs for those family members in similar situations. Based on your experience, our health care providers can design a better way to help other family members when they learn to be caregivers.

If you agree to participate, we would like to conduct a three-part interview about your caregiving experience. Also, with your family member's permission, we will collect information about their health problems and self care abilities and conduct one observation session to see how you provide care to your loved one at home. The interviews will include questions about your caregiving experience, what caregiving skills and knowledge you needed to learn, and how you learned the information. You may refuse to answer any of the questions or stop the interview at any time. You or your family member may also refuse to be observed but still participate in the research study. Each visit will be around 0.5-1.5 hours and be scheduled at your convenience. All of your provided information will be kept in a confidential way and will not be released with individual names.

You will be paid for being in this research study. You will not incur any costs.

Thank you very much for your consideration. You may contact us if you need further information by calling Chiung-man Wu, RN, PhD Candidate at (07) 374-7628 or fill out the reply sheet and mail it back in a prepaid envelope.

Reply Sheet

☐Yes, I am interesting to know more about your research.

Name: ________________________________, **Date:** __________________

TEL: _________________________________

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重度中風個案之家庭照顧者於出院後一年內學習成為照顧者經驗

如果您是一位家庭照顧者，且是第一次照顧重度中風的家人，您將被邀請您參加本研究。

本研究是希望了解第一次面臨重度中風的家屬在出院後首一年內如何學習成為一位家庭照顧者的經驗。藉由您的經驗，我們的醫療人員更了解其他有類似經驗的重度中風家庭照顧者真正面臨的情境與需求；並找出更好的方法以照顧未來的中風患者與中風照顧者所面臨的困難與需求。

如果您同意參與本研究 ，我將拜訪您並在您的家中與您會談三次。若您與您的中風家人同意您將有一次的照顧活動被觀察。兩次的會談主要是要了解您在您中風家人出院後的一年內您面臨的照顧情境與感受、您需要學習哪些新的照顧知識與技巧以應付照顧責任，及您如何學習這些新的知識與技巧的方法。照顧活動觀察則是要希望了解您實際的照顧活動過程與面臨的情境。在研究過程中您可以隨時退出研究或拒絕回答某些您不希望回答的問題；您也可以只參與會談但拒絕照顧活動的觀察。每次地拜訪時間可能花費您0.5-1.5個小時，但是拜訪時間可依您的方便性而定。您提供的所有資料將會被嚴謹保密且不會以個人名義呈現在未來發表的任何文章。

參與本研究您不需要任何花費 ，但我將提供禮卷以感謝您的參與。

感謝您花時間思考。如果您希望進一步了解或希望參與本研究，您可與吳瓊滿小姐聯繫 (電話: (07) 374-7628 或填寫下列回覆條 以已附回郵的信封寄回即可。

回覆條

□ 是的，我有興趣進一步了解您的研究

姓名：______________________________，日期：______________

聯絡電話: ______________________________

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IRB ID #: 200805766
APPROVAL DATE: 04/20/09
EXPIRATION DATE: 04/20/10

Family Caregiver Informed Consent Document

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year After Discharge in Taiwan
Research Team: Chiung-Man Wu, PhD Candidate, RN.

I invite you to participate in a research study. The purpose of this research study is to describe the experience of Taiwanese family members who are learning how to become a caregiver for a stroke survivor during the first year after discharge. This information may be used to design of interventions to help family members who are in similar situations learn to become a family caregiver.

I am inviting you to participate in this research study because you are providing care at home to your family member who recently experienced a stroke. Approximately 150 people (50 caregivers, 50 care recipients and 50 foreign laborers) will take part in this study at the University of Iowa.

If you agree to participate in this study, I will schedule three home visits with you at your convenience at your home. Each visit will take 30 minutes to 1.5 hours. The second visit will be scheduled 2 to 4 weeks after the first visit. The third interview will be scheduled after I analyze the first two interviews.

At the first visit, I will ask you about your experience, feelings and needs due to providing care and how you deal with those situations, about your reasons for taking on caregiving role, experience of providing care and associated needs, how you learn and deal the necessary information, and what is the best way for you to learn the necessary information. At the end of first visit, I will schedule the second visit with you at your convenience.

At the second visit, I will ask you if you wish to continue in the study. If you agree, we will discuss the preliminary analysis of the first visit. We will also discuss any changes regarding the needs associated with care situations and learning that might have occurred since the last visited.

If you agree, I will audio record our interview with you. The audio recordings are being made to assist in transcription of the interview narratives. The digital recorder will be locked in a secure box. After each interview, I will download the recording into a password protected computer and two hard drives. After download, I will delete it from the digital recorder. I will be the only one to access the audio transcripts. These audio recordings will be destroyed upon the study's completion. I will ask you at the start of each interview if you agree to the recording. You may be in the study even if you do not wish to be recorded.

In addition, if you, your family member receiving care and your hired foreign laborer (if

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you have one) agree, we will schedule one 30-minute observation of how you provide care to your stroke family member at your convenience. During the observation, I will sit aside and watch. I will not interrupt any activities you, your stroke family member and foreign laborer engage in during this time. I will schedule the observation at a time that works for you and your stroke family member. It could be before or after I conduct the interview with your family caregiver or on a different day.

You are free to skip any questions you would prefer not to answer during the interviews and refuse to have the observation. You may end your participation in the study anytime.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. I will assign a code number that will be used to identify any collected documents, observational and interview information, and recorded tapes instead of your name. All materials collected for the study will be locked in a file box at researcher's home in Taiwan and Iowa.. All electronic information will be stored in a computer and two portable hard drives in password protected files. The list linking your name and your study code number will be stored in a secure area that is only assessible to the researcher. After the study is finished, the link between your name and your study code number will be deleted and any paper materials will be shredded and discarded. If we write a report about this study we will do so in such a way that you cannot be identified.

During the interviews we will talk about providing care to your family member. You may feel uncomfortable answer questions about your caregiving. You may be uncomfortable when I observe your caregiving process. You can skip any questions you do not wish to answer and you may stop the interview or the observation at any time. You may ask me to delete any information that I have collected in my study. You will not benefit personally from being in this study. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. You will be paid for being in this research study. I will give you a $10 coupon that can be used at any 7-11 convenient stores.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

If you have any questions about the research study itself or to report a research related injury, please contact Chiung-Man Wu MSN, (PhD candidate) (07-3747628). If you have questions about the rights of research subjects, please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 52242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your

experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.
You also can contact the office persons from your stroke family member discharged hospital:

( ) The Institutional Review Board, Kaohsiung Medical University Chung-Ho Memorial Hospital, No. 100, Tzyou 1st Road, Kaohsiung, Taiwan, 807, (07) 313-3525.

( ) Jing-Tsung Hshieh, MD, Hospital President, Kaohsiung Municipal Min-Sheng Hospital, No 134, Kaisyuan 2nd Road, Lingya District, Kaohsiung City, Taiwan, 802, (07) 511-131.

( ) The Institutional Review Board, Pintung Christian Hospital, No 60, Da-Lian Road, Pingtung, Taiwan, (08) 736-8686 or Fax：(08) 736-6494

If you agree to be in the study, please tell me now or we can arrange for a time to meet again after you have had a chance to consider your participation. We will schedule the study procedures at mutually convenient times. If you do not wish to be in the study, please let me know now or at any time. Thank you very much for your consideration of the study.

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家庭照顧者參與研究同意書

研究題目:重度中風個案之家庭照顧者學習成為照顧者經驗
研究團隊: 吳瓊滿　護理師，博士候選人

我想邀請您參加本研究。本研究的目的是探討與描述台灣重度中風個案家屬在出院後一年內學習成為一位家庭照顧者的經驗。您的經驗將幫助我們的醫療人員未來規劃更好的措施以幫助其他有類似經驗的中風家庭照顧者。

我邀請您參與本研究的主要原因是: 因為您第一次經驗到在家中照顧您的重度中風家人。大約50位中風病人個案,50位照顧家屬與50位外籍看護工將參加本研究。

如果您同意，我將依您方便的時間到府中拜訪您三次。每次拜訪大約三十分鐘到一個半小時。第二次拜訪將在第一次拜訪後約為二到四週。在第一與二次拜訪結果分析後，我將與您的照顧家人約定第三次拜訪時間。

第一次拜訪時我將與您討論您的照顧經驗與需求、您如何處理照顧過程中面臨的困難與需求、及您學習這些照顧知識與技巧的最好方法。在第一次拜訪結束時，我將依您的方便與您約定第二次拜訪時間。

第二次拜訪您時，我將會再次確定您是否願意繼續參加本研究。若您同意，我將和您分享第一次與您討論的內容，以及了解您在第一次拜訪之後，這段期間您在照顧經驗、需求與學習方式等方面的改變或新的經驗。

如果您同意，我將以數位錄音筆錄製我們的談論內容。錄音的目的是在幫助我正確的紀錄我們的談話內容。此錄音筆將被妥善保管與放置。每次錄音完，我將於當日內將錄音內容轉錄到有密碼保護的電腦與隨身硬碟內。當轉錄到電腦後我將消除錄音筆上的錄音內容。只有我才能取得所有錄音內容。在研究結束後我會將所有的錄音消音。每次錄音前我都會再次確認您的同意。如果您選擇不錄音，您仍然可已參加本研究。

另外，如果您、您的中風家人與外勞(如果您有聘請外勞)同意，我將依您們的方便時間安排30分鐘的照顧活動觀察。可能在與您會談前或後或另約時間。在這過程我將坐在旁邊觀察您或您的外籍看護工如何照顧您的中風家人。我將不會干擾您的照顧過程。

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在與您會談過程，您可以自由選擇回答或不回答某些問題，且您也可拒絕被觀察且可以隨時退出本研究。

我將依法將您的資料作為機密處理。但是稽核者、主管機關、參加本研究醫院與愛荷華大學人體試驗審查委員會皆有權檢視您的研究資料，以確保臨床試驗過程或數據符合相關法律及法規要求，並會遵守保密之倫理。
我將以下列方式嚴謹保密您的所有提供的資料: (1) 您所有的資料將以一個號碼代替，包括面談時的記錄與錄音帶等。(2) 本研究中所有與您個人訊息有關的紙本資料將會被鎖在另一個防火防水的櫃子內並放置在我高雄或愛荷華家中；所有電子檔案將會被存到以三套不同密碼保護的一台電腦與兩個可以隨身攜帶的硬碟。這三組密碼只有我知道。(3) 列有您個人姓名的參與者名單將另外放置在一個安全的櫃子中，只有我才能拿得到此名單。 (4) 在未來，在研究結束後所有的資料將會被銷毀。在我寫成報告時也不會以您的真實姓名呈現且避免被回溯到您的姓名。

當您在談論您的照顧經驗時，您可能在回答某些問題時會感到不舒服。在我觀察您如何照顧家人的過程，您可能會覺得不自在。您也可以跳過可能造成您個人情緒反應的問題或停止會談；並且可以拒絕我的觀察。您也可以要求銷毀所有有關於您的資料。參加本研究，您可能沒有直接的正面受益；但是，我們希望透過本研究，未來能幫助其他與您面臨相同情境的家庭照顧者。

參加本研究是不需付費的。但是，為了感謝您的參與，在第一次與您照顧家人面談後，我將提供300元的7-11便利商店禮券給您與您照顧家人。

參與本研究是完全自願性。您可完全自由選擇參加或不參加本研究。如果您決定參與後，也可以隨時提出退出本研究。如果您決定不參加或之後的任何時間臨時退出，將不會因此影響到您的相關權益。

如果您有任何與本研究有關的疑問，請隨時與: 吳瓊滿 女士 聯絡（聯絡電話：07-3747628）。 如您對參與本研究有任何疑問或相關權益問題，您可以聯絡 Human Subjects 辦公室, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, 或電子信箱 irb@uiowa.edu.

您也可以與下列您中風家人出院醫院的相關人員聯絡:

( ) 高雄醫學大學附設中和紀念醫院人體試驗審查委員會
807 高雄市三民區自由一路100號 電話: (07) 313-3525 或傳真 (07) 322-1408

( ) 高雄市立民生醫院　謝敬崇 院長
802 高雄市苓雅區凱旋二路134號　電話: (07) 511-131

( ) 屏東基督教醫院人體試驗審查委員會
屏東市大連路60號 電話: (08) 736-8686 或傳真 (08) 736-6494.

如果您同意參加本研究，您可以現在告訴我或在您思考後再通知我，未來可拜訪您的時間，將以您的方便性為原則。如果您決定不想參加本研究您，您可以現在或任何時候告訴我。謝謝您的寶貴時間！

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APPROVED BY: IRB-02
IRB ID #: 200805766
APPROVAL DATE: 04/20/09
EXPIRATION DATE: 04/20/10

Care Receiver Informed Consent Document

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year After Discharge in Taiwan
Research Team: Chiung-Man Wu, PhD Candidate, RN.

I invite you to participate in a research study. The purpose of this research study is to describe the experience of Taiwanese family members who are learning how to become a caregiver for a stroke survivor during the first year after discharge. This information may be used to design of interventions to help family members who are in similar situations learn to become a family caregiver.

We are inviting you to be in this study because you have hada stroke and your family member is learning how to care for you at home during the first year after your discharge from the hospital. Approximately 150 people (50 stroke family caregivers, 50 stroke survivors and 50 foreign laborers) will take part in this study at the University of Iowa.

If you agree to participate in this study, I will ask you or your family caregiver your age, other diseases you may have, your educational level, health problems due to the stroke, the medications you are taking, and about the things you are able to do to care for yourself and those that the caregiver must do to care for you,

If you agree to participate in this study, I will schedule three face-to-face interviews with your family caregiver and one 30-minute observation at your home. These visits will occur during the first year of your discharge from the hospital. Each visit may take 30 minutes to one hour and a half. The third interview will be scheduled after I analyze the first two interviews.

The 30-minute observation will occur at a time that works for you, your caregiver and your foreign laborer if you have one. It could be prior to or after I conduct the interview, or on a different day. I will not disrupt your activities during the observation.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. I will assign a code number that will be used to identify any collected documents, observational and interview information, and recorded tapes instead of your name. All materials collected for the study will be locked in a file box at researcher's home in Taiwan and Iowa.. All electronic information will be stored in a computer and two portable hard drives in password protected files. The list linking your name and your study code number will be stored in a secure area that is only assessible to the researcher. After the study is finished, the link between your name and your study code number will be deleted and any paper materials will be shredded and discarded. If we write a report about this study we will do so in such a way that you cannot be identified.

You might feel uncomfortable when I watch how your family caregiver or foreign laboer provides care to you. You may ask be to stop and leave at any time. You will not benefit personally from being in this study. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. You will receive a 10-dollar coupon for use at any 7-11 convenient stores at the completion of the first visit.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

If you have any questions about the research study itself or to report a research related injury, please contact Chiung-Man Wu MSN, (PhD candidate) (07-3747628). If you have questions about the rights of research subjects, please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 52242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

You also can contact the office persons from your discharged hospital:

( ) The Institutional Review Board, Kaohsiung Medical University Chung-Ho Memorial Hospital, No. 100, Tzyou 1st Road, Kaohsiung, Taiwan, 807, (07) 313-3525.

( ) Jing-Tsung Hshieh, MD, Hospital President, Kaohsiung Municipal Min-Sheng Hospital, No 134, Kaisyuan 2nd Road, Lingya District, Kaohsiung City, Taiwan, 802, (07) 511-131.

( ) The Institutional Review Board, Pintung Christian Hospital, No 60, Da-Lian Road, Pingtung, Taiwan, (08) 736-8686 or Fax：(08) 736-6494

If you agree to be in the study, please tell me now or we can arrange for a time to meet again after you have had a chance to consider your participation. We will schedule the study procedures at mutually convenient times. If you do not wish to be in the study, please let me know now or at any time. Thank you very much for your consideration of the study.

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被照顧者參與研究同意書

研究題目:重度中風個案之家庭照顧者學習成為照顧者經驗
研究團隊: 吳瓊滿　護理師，博士候選人

我想邀請您參加本研究。本研究的目的是探討與描述台灣重度中風個案家屬在出院後一年內學習成為一位家庭照顧者的經驗。您的經驗將幫助我們的醫療人員未來規劃更好的措施以幫助其他有類似經驗的中風家庭照顧者。

因為您是中風出院後一年內的個案，且您的照顧家人也是第一次學習如何在家照顧您。大約50位中風個案、50位您一樣的中風照顧家屬與50位外籍看護工將參加本研究。

如果您同意參加本研究，我將詢問您或您照顧家人有關於您的年紀、教育程度、其他疾病、因中風引起的健康問題、服用藥物、自我照顧能力以及您需要家人協助的照顧活動。

如果您同意，我將依您方便的時間到府中拜訪您照顧家人三次及一次約 30 分鐘的照顧活動觀察。這些拜訪時間將在您出院後的一年內。每次拜訪時間約為三十分鐘到一個半小時。

30 分鐘的照顧活動觀察，將依您、照顧您的家人與照顧您的外籍看護工的方便性安排。觀察時段可以在訪談前或後或另定時間。在觀察過程我將不會干擾您的照顧過程。

我將依法將您的資料作為機密處理。但是稽核者、主管機關、參加本研究醫院與愛荷華大學人體試驗審查委員會皆有權檢視您的研究資料，以確保臨床試驗過程或數據符合相關法律及法規要求，並會遵守保密之倫理。

我將以下列方式嚴謹保密您的所有提供的資料: (1) 您所有的資料將以一個號碼代替，包括面談時的記錄與錄音帶等。(2) 本研究中所有與您個人訊息有關的紙本資料將會被鎖在另一個防火防水的櫃子內並放置在我高雄或愛荷華家中；所有電子檔案將會被存到以三套不同密碼保護的一台電腦與兩個可以隨身攜帶的硬碟。這三組密碼只有我知道。(3) 列有您個人姓名的參與者名單將

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另外放置在一個安全的櫃子中，只有我才能拿得到此名單。 (4) 在未來，在研究結束後所有的資料將會被銷毀。在我寫成報告時也不會以您的真實姓名呈現且避免被回溯到您的姓名。

在我觀察您家人如何照您的過程，您可能會覺得不自在。但您有權利拒絕我的觀察。參加本研究，您可能沒有直接的正面受益；但是，我們希望透過本研究，未來能幫助其他與您面臨相同情境的家庭照顧者。

參加本研究是不需付費的。但是，為了感謝您的參與，在第一次與您照顧家人面談後，我將提供300元的7-11便利商店禮券給您與您照顧家人。

參與本研究是完全自願性。您可完全自由選擇參加或不參加本研究。如果您決定參與後，也可以隨時提出退出本研究。如果您決定不參加或之後的任何時間臨時退出，將不會因此影響到您的相關權益。

如果您有任何與本研究有關的疑問，請隨時與: 吳瓊滿 女士 聯絡（聯絡電話：07-3747628）。 如您對參與本研究有任何疑問或相關權益問題，您可以聯絡 Human Subjects 辦公室, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, 或電子信箱 irb@uiowa.edu.

您也可以與下列您出院醫院的相關人員聯絡:

( ) 高雄醫學大學附設中和紀念醫院人體試驗審查委員會
807 高雄市三民區自由一路100號
電話: (07) 313-3525 或傳真 (07) 322-1408

( ) 高雄市立民生醫院 謝敬崇 院長
802 高雄市苓雅區凱旋二路134號 電話: (07) 511-131

( ) 屏東基督教醫院人體試驗審查委員會
屏東市大連路60號 電話: (08) 736-8686 或傳真 (08) 736-6494.

如果您同意參加本研究，您可以現在告訴我或在您思考後再通知我，未來可拜訪您的時間，將以您的方便性為原則。如果您決定不想參加本研究您，您

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可以現在或任何時候告訴我。謝謝您的寶貴時間！

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Foreign Laborer Informed Consent Document

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year After Discharge in Taiwan
Research Team: Chiung-Man Wu, PhD Candidate, RN.

I invite you to participate in a research study. The purpose of this research study is to describe the experience of Taiwanese family members who are learning how to become a caregiver for a stroke survivor during the first year after discharge. This information may be used to design of interventions to help family members who are in similar situations learn to become a family caregiver.

We are inviting you to be in this study because you are providing care to a stroke survivor at home during the first year after she/he discharges from the hospital. Approximately 150 people (50 stroke family caregivers, 50 stroke survivors and 50 foreign laborers) will take part in this study at the University of Iowa.

I will have three face-to-face interviews with the family caregiver who provides care with you. If you agree to participate in this study, I will schedule one 30-minute observation of care activities at the place of your care receiver stay. The 30-minute observation will occur at a time that works for you, family caregiver and your care receiver. I will not disrupt your activities during the observation.

We will keep the information you provide confidential, however federal regulatory agencies and the University of Iowa Institutional Review Board (a committee that reviews and approves research studies) may inspect and copy records pertaining to this research. I will assign a code number that will be used to identify any collected documents, observational and interview information, and recorded tapes instead of your name. All materials collected for the study will be locked in a file box at researcher's home in Taiwan and Iowa.. All electronic information will be stored in a computer and two portable hard drives in password protected files. The list linking your name and your study code number will be stored in a secure area that is only assessible to the researcher. After the study is finished, the link between your name and your study code number will be deleted and any paper materials will be shredded and discarded. If we write a report about this study we will do so in such a way that you cannot be identified.

You might feel uncomfortable when I watch how you provide care to your care receiver. You may ask be to stop and leave at any time. You will not benefit personally from being in this study. However we hope that others may benefit in the future from what we learn as a result of this study.

You will not have any costs for being in this research study. Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, you won't be penalized or lose any benefits for which you otherwise qualify.

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If you have any questions about the research study itself or to report a research related injury, please contact Chiung-Man Wu MSN, (PhD candidate) (07-3747628). If you have questions about the rights of research subjects, please contact the Human Subjects Office, 300 College of Medicine Administration Building, The University of Iowa, Iowa City, IA 52242, (319) 335-6564, or e-mail irb@uiowa.edu. To offer input about your experiences as a research subject or to speak to someone other than the research staff, call the Human Subjects Office at the number above.

You also can contact the office persons from your care receiver's discharged hospital:

( ) The Institutional Review Board, Kaohsiung Medical University Chung-Ho Memorial Hospital, No. 100, Tzyou 1st Road, Kaohsiung, Taiwan, 807, (07) 313-3525.

( ) Jing-Tsung Hshieh, MD, Hospital President, Kaohsiung Municipal Min-Sheng Hospital, No 134, Kaisyuan 2nd Road, Lingya District, Kaohsiung City, Taiwan, 802, (07) 511-131.

( ) The Institutional Review Board, Pintung Christian Hospital, No 60, Da-Lian Road, Pingtung, Taiwan, (08) 736-8686 or Fax：(08) 736-6494

If you agree to be in the study, please tell me now or we can arrange for a time to meet again after you have had a chance to consider your participation. We will schedule the study procedures at mutually convenient times. If you do not wish to be in the study, please let me know now or at any time. Thank you very much for your consideration of the study.

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被照顧者參與研究同意書

研究題目: 重度中風個案之家庭照顧者學習成為照顧者經驗
研究團隊: 吳瓊滿　護理師，博士候選人

我想邀請您參加本研究。本研究的目的是探討與描述台灣重度中風個案家屬在出院後一年內學習成為一位家庭照顧者的經驗。您的經驗將幫助我們的醫療人員未來規劃更好的措施以幫助其他有類似經驗的中風家庭照顧者。

因為您正照顧出院後一年內的中風個案。大約50位中風個案、50位中風照顧家屬與50 位外籍看護工家屬將參加本研究。

我將到府中拜訪主要負責照顧的家屬三次。如果您同意參加本研究，我將安排一次約30分鐘的照顧活動觀察。30分鐘的照顧活動觀察，將依您、照顧家屬與您照顧病患的方便性安排。觀察時段可以在與照顧家屬訪談前或後或另定時間。在觀察過程我將不會干擾您的照顧過程。

我將依法將您的資料作為機密處理。但是稽核者、主管機關、參加本研究醫院與愛荷華大學人體試驗審查委員會皆有權檢視您的研究資料，以確保臨床試驗過程或數據符合相關法律及法規要求，並會遵守保密之倫理。

我將以下列方式嚴謹保密您的所有提供的資料: (1) 您所有的資料將以一個號碼代替，包括面談時的記錄與錄音帶等。(2) 本研究中所有與您個人訊息有關的紙本資料將會被鎖在另一個防火防水的櫃子內並放置在我高雄或愛荷華家中；所有電子檔案將會被存到以三套不同密碼保護的一台電腦與兩個可以隨身攜帶的硬碟。這三組密碼只有我知道。(3) 列有您個人姓名的參與者名單將另外放置在一個安全的櫃子中，只有我才能拿得到此名單。 (4) 在未來，在研究結束後所有的資料將會被銷毀。在我寫成報告時也不會以您的真實姓名呈現且避免被回溯到您的姓名。

在我觀察您如何照顧的過程，您可能會覺得不自在。但您有權利拒絕我的觀察。參加本研究，您可能沒有直接的正面受益；但是，我們希望透過本研究，未來能幫助其他與您面臨相同情境的家庭照顧者。

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如果您有任何與本研究有關的疑問，請隨時與: 吳瓊滿 女士 聯絡（聯絡電話：07-3747628）。 如您對參與本研究有任何疑問或相關權益問題，您可以聯絡 Human Subjects 辦公室, 340 College of Medicine Administration Building, The University of Iowa, Iowa City, Iowa, 52242, (319) 335-6564, 或電子信箱 irb@uiowa.edu.

您也可以與下列您照顧中風個案出院醫院的相關人員聯絡:

( ) 高雄醫學大學附設中和紀念醫院人體試驗審查委員會
807 高雄市三民區自由一路100號
電話: (07) 313-3525 或傳真 (07) 322-1408

( ) 高雄市立民生醫院 謝敬崇 院長
802 高雄市苓雅區凱旋二路134號 電話: (07) 511-131

( ) 屏東基督教醫院人體試驗審查委員會
屏東市大連路60號 電話: (08) 736-8686 或傳真 (08) 736-6494.

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Caregiver Assent Document

Project Title: Learning to be a Taiwanese Family Caregiver
Investigator(s): Chiung-Man Wu, PhD Candidate, RN

I am conducting a research and would like to invite you to participate in this study. A research intends to advance knowledge through systematic investigation. In my research I want to know how Taiwanese family members learn to become caregivers after their loved ones had a stroke.

If you agree to participate in this study, I will schedule three face-to-face home visits and one 30-minute observation. These visits will occur during the first year of your loved one's discharge from the hospital. Each visit may take 30 minutes to one hour and a half. During the first interview, I will inquire personal information about you and your loved one (such as age and educational level), your experience and decision for taking on the role as a caregiver, and your needs. You should feel free to express your thoughts and feelings. There is no right or wrong answer to my questions. If it is alright with you, I will audiotape our conversation for recording purposes and erase my tape after coding is completed. After I complete the first visit, we would schedule our second visit. At this second visit, I will share with you what I gathered from the first visit, and speak with you about your experiences, needs, or learning that might have occurred since the last visit. The 30-minute observation will occur at a time that works for you and your caregiver. It could be prior to or after I conduct the interview, or on a different day. I will not disrupt your activities during the observation. The third interview will be scheduled after I analyze the first two interviews.

There might be risk involved if you choose to participate in this research. It is possible that you may feel uncomfortable when you speak of negative experiences you may have as a caregiver. You may feel uneasy when I observe how you care for your loved one. Please note that you may choose not to respond to my question, not to be observed, or discontinue your involvement in this research all together. There might also be other unknown risks associated with this study that I did not anticipate. Please understand that you may withdraw your participation at any time if so you choose.

I don't know how your participation in this research might directly benefit you or your family. It is my hope, though, through this type of research I could learn from

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you and your family so that your experiences can help those who face similar issues.
After I complete the study, I will write a brief summary of my findings and share it with you.

Your participation in this research is completely voluntary. You may choose to discontinue your involvement later even if you agree now. All you have to do is to inform me of your decision. There is no penalty to your withdrawal.

If you agree to participate in this study, please tell me your decision. You may ask me any questions you have before making a decision.

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照顧者同意書(簡單式)

研究題目:重度中風個案之家庭照顧者學習成為照顧者經驗
研究團隊: 吳瓊滿 護理師 博士候選人

我正進行一個研究且想邀請您參加本研究。研究是用以了解某些事情的一種特別方法。本研究的目的是想了解重度中風個案的家庭照顧者在出院後一年內學習成為照顧者經驗。

如果您同意，我將依您方便的時間到府中與您會談三次及一次約 30 分鐘的照顧活動觀察。這些拜訪時間將在您出院後的一年內。每次拜訪時間約為三十分鐘到一個半小時。第一次會談，我將了解您與您的中風家人的個人資料，如您的年紀與教育程度，您擔負照顧工作的理由、照顧相關經驗與需要、及您認為最好學習照顧知識與技巧的方法。您可以自由的表達您個人的經驗與意見。您的意見沒有對與錯的問題。如果您同意，我將錄音我們的談話內容但錄音內容將在研究完成後消音。在第一次拜訪結束時，我將依您的方便與您約定第二次拜訪時間。第二次拜訪您時，我將和您分享第一次與您討論的內容，以及了解您在第一次拜訪之後，這段期間您在照顧經驗、需求與學習方式等方面的改變或新的經驗。另外，我將依您時間的方便安排三十分鐘的照顧活動觀察。觀察時段可以在訪談前或後或另定時間。在這過程我不會干擾您的照顧活動。在第一與二次拜訪結果分析後，我將與您的照顧家人約定第三次拜訪時間。

選擇參與本研究可能引起您的困擾或不舒服。您可能會因談論一些不愉快的照顧經驗或在我觀察您的照顧活動過程中覺得不舒服與不自在。您可以選擇不回答或不被觀察或退出本研究以避免不舒服感覺發生。除此之外，可能有其他尚未預期到與本研究相關的潛在性危險存在。您有權利在任何時候選擇退出本研究。

參加本研究對您與您家人可能沒有直接的幫助。但是，我希望透過本研究，未來能幫助其他與您面臨相同情境的家庭照顧者。在我研究完成後，我將寫一份簡單的成果給您參考。

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參與本研究是完全自願性。如果您現在決定參加，但是您之後仍可以隨時改變您的決定。不管您的決定如何，都會被接受的。您只要告訴我您的決定即可。

如果您決定參加本研究，請告訴我您的決定。在您決定參加前，您可以詢問任何與本研究有關的問題。

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Care Receiver Assent Document

Project Title: Learning to be a Taiwanese Family Caregiver
Investigator: Chiung-Man Wu, PhD Candidate, RN

I am conducting a research and would like to invite your participation in this study. A research intends to advance knowledge through systematic investigation. In my research I want to know how Taiwanese family members learn to become caregivers after their loved ones had a stroke.

If you agree to participate in this study, I will schedule three face-to-face interviews with your family caregiver and one 30-minute observation at your home. These visits will occur during the first year of your discharge from the hospital. Each visit may take 30 minutes to one hour and a half. During the first interview, I will inquire personal information about you, such as age and educational level. After I complete the first visit, we would schedule our second visit. The 30-minute observation will occur at a time that works for you and your caregiver. It could be prior to or after I conduct the interview, or on a different day. I will not disrupt your activities during the observation. The third interview will be scheduled after I analyze the first two interviews.

There might be risk involved if you choose to participate in this research. It is possible that you may feel uncomfortable when I observe how your family caregiver cares for you. You may choose not to be observed or discontinue your involvement in this research. There might be other unknown risks associated with this study that I did not anticipate. Please understand that you may withdraw your participation at any time if so you choose.

I don't know how your participation in this research might directly benefit you or your family. It is my hope, though, through this type of research I could learn from you and your family so that your experiences can help those who face similar issues. After I complete the study, I will write a brief summary of my findings and share it with you.

Your participation in this research is completely voluntary. You may choose to discontinue your involvement later even if you agree now. All you have to do is to inform me of your decision. There is no penalty to your withdrawal.

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If you agree to participate in this study, please tell me your decision. You may ask me any questions you have before making a decision.

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被照顧者同意書(簡單式)

研究題目: 重度中風個案之家庭照顧者學習成為照顧者經驗
研究團隊: 吳瓊滿 護理師 博士候選人

我正進行一個研究且想邀請您參加本研究。研究是用以了解某些事情的一種特別方法。本研究的目的是想了解重度中風個案的家庭照顧者在出院後一年內學習成為照顧者經驗。

如果您同意，我將依您方便的時間到府中拜訪您照顧家人三次及一次約 30 分鐘的照顧活動觀察。這些拜訪時間將在您出院後的一年內。每次拜訪時間約為三十分鐘到一個半小時。
第一次的會談中，我將詢問您個人資料，例如您的年紀與教育程度。在第一次會談結束時，我會與您與您照顧家人訂定第二次拜訪您的時間。另外，我將依您與中風家人的方便時間安排 30 分鐘的照顧活動觀察。可能在與您會談前或後或另約時間。在這過程我將坐在旁邊觀察您如何照顧您的中風家人。我將不會干擾您的照顧過程。在第一與二次拜訪結果分析後，我將與您的照顧家人約定第三次拜訪時間。

選擇參與本研究可能引起您的困擾或不舒服。您可能在我觀察您的家人如何照顧您的過程會覺得不舒服與不自在。您可以選擇不被觀察或停止參與研究以避免不舒服感覺發生。除這兩點之外，可能有其他尚未預期到與本研究相關的潛在性危險存在。您有權利在任何時候選擇退出本研究。

參加本研究對您與您家人可能沒有直接的幫助。但是，我希望透過本研究，未來能幫助其他與您面臨相同情境的家庭照顧者。在我研究完成後，我將寫一份簡單的成果給您參考。

參與本研究是完全自願性。如果您現在決定參加，但是您之後仍可以隨時改變您的決定。不管您的決定如何，都會被接受的。您只要告訴我您的決定即可。

如果您決定參加本研究，請告訴我您的決定。在您決定參加前，您可以詢問任何與本研究有關的問題。

APPENDIX E

PROTOCOLS FOR DATA COLLECTION

Caregiver and Care Receiver Characteristics

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year in Taiwan

Research Team: Chiung-Man Wu, PhD Candidate, RN; Lisa Skemp, PhD, RN.

A. Caregiver's characteristics: (Code: ____)

1. Gender: ☐ Male, ☐ Female
2. What is your birth date? ____/____/____
   MO DA YR
3. Marriage status: ☐ Single, ☐ Married, ☐ Divorced or separated, ☐ Widower
4. Your religion is: ☐ None, ☐ Buddhist, ☐ Protestant, ☐ Catholic, ☐ Other
5. Highest educational level:
   ☐ Cannot read, ☐ Can read but never attended school, ☐ Primary school,
   ☐ Junior high school, ☐ Senior high school, ☐ Undergraduate,
   ☐ Graduate (state highest degree)

6. Your relationship to care receiver is:
   ☐ Spouse, ☐ Daughter-in-law, ☐ Daughter, ☐ Son, ☐ Other _______

7. Are you working now?
   ☐ No, ☐ Yes, Job position ______________ (Full time____, Part time____)

8. Is there anyone in your family who can help you to care for your care receiver?
   ☐ No,
   ☐ Yes (☐Family member, relationship _________; ☐ Taiwanese helper, ☐foreign laborer)

9. If the helper is hired foreign laborer: length of hire: ________, experience of elder care before: ☐ No, ☐ Yes.

10. How would you rate your overall physical health before you become the care provider: ☐ Poor, ☐ Fair, ☐ Good, ☐ Excellent

11. How would your rate your overall physical health at the present time:
    ☐ Poor, ☐ Fair, ☐ Good, ☐ Excellent

12. Do you have any of problems listed below (multiple choice)?
    ☐ None, ☐ Fatigue, ☐ Headaches, ☐ Sleep problems, ☐ Low energy
    ☐ Weight change (increase or decrease), ☐ Stomach or bowel problems
    ☐ Frequently have a cold or the flu, ☐ Minor infection, ☐ Back pain,
    ☐ Others ____

13. Do you have any of the diseases which are listed below (multiple choice)?
    ☐ None, ☐ renal disease, ☐ DM, ☐ Hypertension, ☐ Depression, ☐ Asthma,
    ☐ Arthritis, ☐ Stomach or bowel diseases, ☐ Heart disease, ☐ Others____

B. Care receiver characteristics:

1. Gender: ☐ Male, ☐ Female

2. Age: __________years old.

3. Stroke incidence: ☐1st, ☐2nd, ☐3rd, ☐>3 ___________

4. Other diseases:
    ☐ Hypertension, ☐ Diabetes Mellitus, ☐ Heart disease,
    ☐ others (please list) _____
5. Health problems due to the stroke:
    ☐ Vision, ☐ Speech, ☐ Limb motor deficit (☐left, ☐right, ☐ both),
    ☐ Cognitive, ☐ Conscious, ☐ Others____

6. Invasive tubes and wounds:
    ☐ No, ☐ NG, ☐Foley catheter, ☐Trachea tubes, ☐ Wound,
    ☐ other (please list)
7. ADL (see Barthel Index)

8. Medications: __________________________

9. Family tree (limited to identify the relationships of family members)

照顧者與被照顧者基本資料

研究題目:重度中風個案之家庭照顧者成為照顧者經驗

研究團隊: 吳瓊滿 護理師 博士候選人; 莉莎·史可門 (Lisa Skemp) 博士

A. 照顧者 (編碼:)

1. 性別: □男， □女
2. 您的出生年月日:___(月)/__(日)/__(年)
3. 您的婚姻狀況是: □單身，□已婚，□ 離婚或分居，□ 鰥寡
4. 您的宗教信仰是: □無，□佛教，□道教，□基督教，□天主教, □其他_____
5. 您的最高學歷是:

   □不識字，□ 識字但未上過學，□小學，□初中，□高中，□大學，

   □ 研究所以上 (____)
6. 您與病患的關係是: □夫妻，□媳婦，□女兒，□兒子，□其他________
7. 您現在仍在上班或工作嗎? □否，□是→全職: □是，□否
8. 您家中是否有其他人可以幫您照顧病患?

   □ 否，

   □ 是 (□ 家人_______，□台籍看護 , □外籍看護工)

9. 外籍看護工聘任時間:___________，是否有照顧經驗: □ 否, □是

10. 在未照顧病患前，您認為您的健康狀況為: □很差，□普通，□不錯 □很好

11. 在照顧病患之後，您認為您的健康狀況為: □很差，□普通，□不錯，□很好

12. 您目前有那些健康問題:

    □無，□覺得暈眩，□頭痛，□睡眠問題，□覺得沒元氣，□腸胃問題，

    □體重改變(增加或減少)， □經常感冒，□輕微感染，□背部疼痛，

    □其他________

13. 您目前有那些身體疾病:

    □無，□腎臟問題，□糖尿病，□高血壓，□憂鬱症，□氣喘，

    □風濕病，□腸胃疾 病，□心臟病，□其他 _______________________

B. 被照顧者

1. 性別: □男，□女
2. 年紀: ________歲
3. 本次為第 _____次中風
4. 除中風外的其他疾病: □高血壓，□糖尿病，□心臟病，□其他____________
5. 因中風造成的健康問題:

   □視力問題，□語言問題，□肢體活動受限(□左 □右□雙側)，□認知問題，

   □意識問題，□其他______________
6. 管路與傷口: □鼻胃管，□導尿管，□氣切管，□傷口, □其他____________
7. 日常生活自我照顧情形(依中文版巴士量表)

   如果被照顧者拒絕參與研究，個案的日常生活自我照顧情形將根據照顧者的描述評估。

   如果被照顧者同意參與研究，個案的日常生活自我照顧情形將根據照顧活動過程評估。

8. 藥物:

   a. ______________頻率 __________使用方法 _______ 作用: ________

   b. ______________頻率 __________使用方法 _______ 作用: ________

   c. ______________頻率 __________使用方法 _______ 作用: ________

   d. ______________頻率 __________使用方法 _______ 作用: ________

   e. ______________頻率 __________使用方法 _______ 作用: ________

   f. ______________頻率 __________使用方法 _______ 作用: ________

   g. ______________頻率 __________使用方法 _______ 作用: ________

   h. ______________頻率 __________使用方法 _______ 作用: ________

9. 族譜

The Barthel Index

Care receiver Code: _____________ Date: ___________________________

GROOMING

0 = needs to help with personal care
5 = independent face/hair/teeth/shaving (implements provided) ______

BATHING

0 = dependent
5 = independent (or in shower) ______

DRESSING

0 = dependent
5 = needs help but can do about half unaided
10 = independent (including buttons, zips, laces, etc.) ______

BOWELS

0 = incontinent (or needs to be given enemas)
5 = occasional accident
10 = continent ______

BLADDER

0 = incontinent, or catheterized and unable to manage alone
5 = occasional accident
10 = continent ______

STAIRS

0 = unable
5 = needs help (verbal, physical, carrying aid)
10 = independent ______

TOILET USE

0 = dependent
5 = needs some help, but can do something alone
10 = independent (on and off, dressing, wiping) ______

FEEDING

0 = unable
5 = needs help cutting, spreading butter, etc., or requires modified diet
10 = independent ______

TRANSFERS (BED TO CHAIR AND BACK)

0 = unable, no sitting balance
5 = major help (one or two people, physical), can sit
10 = minor help (verbal or physical)
15 = independent ______

MOBILITY (ON LEVEL SURFACES)

0 = immobile or < 50 yards
5 = wheelchair independent, including corners, > 50 yards
10 = walks with help of one person (verbal or physical) > 50 yards
15 = independent (but may use any aid; for example, stick) > 50 yards ___

TOTAL (0–100): ______

Mahoney, F. I. & Barthel, D. (1965). Functional evaluation: The Barthel Index. *Maryland State Medical Journal*, *14*, 56-61.

巴氏量表 (Barthel Index)

受照顧者編號: ________ 日期: ________________________ 總分: ________

1.個人衛生(包含刷牙、洗臉、洗手及梳頭髮和刮鬍子)	□5 分：可自行刷牙、洗臉、洗手及梳頭髮和刮鬍子。 □0 分：須別人協助才能完成上述盥洗項目。
2.洗澡	□5 分：可自行完成盆浴或淋浴。 □0 分：須別人協助才能完成盆浴或淋浴。
3.穿脫衣褲鞋襪	□10 分：可自行穿脫衣褲鞋襪，必要時使用輔具。 □5 分：在別人幫忙下，可自行完成一半以上動作。 □0 分：須要別人完全幫忙。
4.大便控制	□10 分：不會失禁，必要時會自行使用塞劑。 □5 分：偶爾會失禁(每週不超過一次)，使用塞劑時需要別人幫忙。 □0 分：需要別人處理大便事宜。
5.小便控制	□10 分：日夜皆不會尿失禁，必要時會自行使用並清理尿布尿套。 □5 分：偶爾會失禁(每週不超過一次)，使用尿布尿套時需要別人幫忙。 □0 分：需要別人處理小便事宜。
6.上下樓梯	□10 分：可自行上下樓梯(可抓扶手或用拐杖)。 □5 分：需要稍微扶持或口頭指導。 □0 分：無法上下樓梯。
7.如廁(包含穿脫衣物、擦拭、沖水)	□10 分：可自行上下馬桶，便後清潔，不會弄髒衣褲，且沒有安全上的顧慮。倘使用便盆，可自行取放並清洗乾淨。 □5 分：在上述如廁過程中須協助保持平衡，整理衣物或使用衛生紙。 □0 分：須別人協助才能完成如廁過程。
8.進食	□10 分：自己在合理時間內(約 10 秒鐘吃一口)，可用筷子取食眼前食物。若須使用進食輔具時，會自行取用穿脫，不須協助。 □5 分：須別人協助取用或切好食物或穿脫進食輔具。 □0 分：無法自行取食。
9.移位(包含由床上平躺到坐起，並可由床移位至輪椅)	□15 分：可自行坐起，且由床移位至椅子或輪椅，不須協助， 包括輪椅煞車及移開腳踏板，且沒有安全上的顧慮。 □10 分：在上述移位過程中，須些微協助(例如：予以輕扶以保持平衡)或提醒，或有安全上的顧慮。 □5 分：可自行坐起但須別人協助才能移位至椅子。 □0 分：須別人協助才能坐起，或須別人幫忙方可移位。
10.行走	□15 分：使用或不使用輔具(包括穿支架義肢或無輪子之助行器)皆可獨立行走 50 公尺以上。 □10 分：需要稍微扶持或口頭教導方向可行走 50 公尺以上。 □5 分：雖無法行走，但可獨立操作輪椅或電動輪椅(包含轉彎、進門及接近桌子、床沿)並可推 50 公尺以上。 □0 分：需要別人幫忙。

Interview Protocol (First time interview)

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year in Taiwan

Research Team: Chiung-Man Wu, PhD Candidate, RN; Lisa Skemp, PhD, RN.

Time of Interview: Date: Place:
Participant code:
Settings:

We are interested in what the caregiver role includes and how you have and are learning this new role.

1. Please describe what it was like when you first found out that your family member had a stroke
   - What kind of stroke did they have?
   - How has this stroke changed the abilities of your elder family member, such as communication, comprehensive, decision making, and self-care abilities?
2. How did you/family decide that you were going to be person responsible for the overall care of your elder?
   - Did you expect to be the person responsible for _____ care?
   - How do you feel about being the person responsible for _____ care?
3. When you realized that you would be responsible for ____ care, please describe your sense of being ready to provide care for your family member?
   - Probe about self expectations, family expectations, medical expecations, prior care provision for elders/children, prior experience with stroke
4. Please describe the care situation when you first brought your family member home.
   - Probe about decision making, hands on care, environmental modifications, caregivers, other family members
   - Probe about learning needs, challenges, benefits, how you learned, what helped, what didn't help
5. Please describe the care situation change as the elder was at home.
   - Probe about decision making, hands on care, environmental modifications, caregivers, other family members
   - Probe about learning needs, challenges, benefits, how they learned, what helped, what didn't help
6. Please describe your experience of managing _____'s health condition changes or critical situations.
   - Probe about decision making, hands on care, environmental modifications, caregivers, other family members
   - Probe about learning needs, challenges, benefits, how they learned,

what helped, what didn't help

7. Please describe a typical day of care for your family member now.
    - Probe about decision making, hands on care, environmental modifications, caregivers, other family members.
    - Probe about learning needs, challenges, benefits, how they learned, what helped, what didn't help
8. What are some of your most memorable experiences in learning to care for your family member?
    - Positive experiences
    - Difficult experiences.
9. Now that you have had the experience of learning to care for _____, you can help us to better understand this process of learning to become a care provider. What would you say is

    - Your ability to provide care, when you first began to care for your elder.
    - your advice to others who are just beginning to take on this care role
    - your advice to health care providers about helping family members learn this new role
    - your advice to the government
10. Is there anything else you would like to tell me to help me better understand how you have or are learning this new caregiver role?
11. How was your experience with the interview?

Caregiving Activities Observation Protocol (Field Notes)

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year in Taiwan

Research Team: Chiung-Man Wu, PhD Candidate, RN; Lisa Skemp, PhD, RN.

Objects:

A description of the home physical environment, persons who are living in the home, stroke family member location in the home.

1. A description of the caregiving activities during the observation.

Participant code: Date: Time: Place:	
Care situation	Reflective Notes

Interview Protocol (Second time interview)

Project Title: Learning to be a Family Caregiver for Severely Debilitated Stroke Survivors during the First Year in Taiwan

Research Team: Chiung-Man Wu, PhD Candidate, RN; Lisa Skemp, PhD, RN.

Time of Interview: Date: Place:
Participant code:
Settings:

Thank you for visiting with me about learning to care for your ________________. First, I would like to discuss the preliminary analysis of the research project. Then we will discuss any of the changes that have occurred since we last visited.

1. Since our last visit, please describe the care situation change as the elder was at home.
    - Probe about decision making, hands on care, environmental modifications, caregivers, other family members
    - Probe about learning needs, challenges, benefits, how they learned, what helped, what didn't help
2. Now that you have had the experience of learning to care for _____, you can help us to better understand this process of learning to become a care provider. What would you say was
    - Your ability to provide care, when you first began to care for your elder.
    - your feelings about being the person responsible for _____ care
    - your advice to others who are just beginning to take on this care role
    - your advice to health care providers about helping family members learn this new role
    - your advice to the government
3. Is there anything else you would like to tell me to help me better understand how you have or are learning this new caregiver role?
4. How was your experience with the interview

第一次訪談

研究題目: 重度中風個案之家庭照顧者成為照顧者經驗

研究團隊: 吳瓊滿 護理師 博士候選人; 莉莎·史可門(Lisa Skemp) 博士

時間::　　　　　日期:　　　　　地點:
受訪者編碼:
環境背景:

問題一: 請您描述您家人中風當時情形與處理過程

- 何種型態的中風
- 此次中風對他各方面的能力的影響，如認知、溝通、理解力、決策能力及自我照顧能力。

問題二: 您與您家人如何決定由您負責您___的照顧責任?

- 您預期擔任這個角色嗎?
- 在決定由您負責照顧____時，請您描述當時對於擔任這個角色的感覺與看法

問題三: 當您了解您需要擔任這個角色後，請您描述當時您對於照顧________在各方面準備程度如何？

- 個人的期望、家庭期望、醫療照護期望、先前老人與小孩照顧經驗、先前對中風的經驗

問題四：請您描述您中風家人第一次回家時當時的照顧情形

- 面臨的挑戰、如何做決策、參予照顧、環境調整、您本身與其他家人參予照顧情形
- 學習需求、挑戰、益處、如何學習這些需要、您如何獲得幫助與獲得哪些幫助、有哪些幫助、有哪些沒幫助

問題五：請您描述回家後到現在照顧情境上有哪些變化？

- 面臨的挑戰、如何做決策、參予照顧、環境調整、您本身與其他家人參予照顧情形
- 學習需求、挑戰、益處、如何學習這些需要、您如何獲得幫助與獲得哪些幫助、有哪些幫助、有哪些沒幫助

問題六：請您描述您中風有特殊情況發生時您的照顧活動

- 面臨的挑戰、如何做決策、參予照顧、環境調整、您本身與其他家人參予照顧情形
- 學習需求、挑戰、益處、如何學習這些需要、您如何獲得幫助與獲得哪些幫助、有哪些幫助、有哪些沒幫助

問題七：請您描述您目前的照顧活動

- 面臨的挑戰、如何做決策、參予照顧、環境調整、您本身與其他家人參予照顧情形
- 學習需求、挑戰、益處、如何學習這些需要、您如何獲得幫助與獲得哪些幫助、有哪些幫助、有哪些沒幫助

問題八: 到目前為止，整個照顧過程中有哪些經驗讓您記憶最深刻

- 正向
- 負向

問題九：目前您已經擁有照顧中風家人的經驗，您可以幫我們更了解如何學習成為一個照顧者。根據您目前的經驗與狀況，

- 您認為您照顧的能力為:
- 您對其他剛開始學習照顧的家人的建議是:
- 您對醫療照護人員對於如何幫助家庭照顧者學習這個新的角色的建議是:
- 您對於政府的建議是:

問題十: 除上述經驗外，您是否有其他照顧經驗可以分享?

問題十一: 您對此次訪問的感覺如何?

照顧活動觀察紀錄

研究題目: 重度中風個案之家庭照顧者成為照顧者經

研究團隊: 吳瓊滿 護理師 博士候選人; 莉莎·史可門 (Lisa Skemp) 博士

目的:

1. 個案家庭硬體環境、家庭成員及照顧中風個案的地點。
2. 觀察時間內照顧者執行照顧活動內容

照顧者編號: 日期: 地點: 時間: _______分鐘	
照顧活動內容	觀察者相關思考內容

第二次訪談

研究題目: 重度中風個案之家庭照顧者成為照顧者經驗

研究團隊: 吳瓊滿 護理師 博士候選人; 莉莎·史可門(Lisa Skemp) 博士

時間::　　　　日期:　　　　地點:
受訪者編碼:
環境背景:

謝謝您提供機會給我訪談您有關照顧您家人的經驗。首先，我想討論上次訪問您後的初步分析結果。然後我想與您討論自上次訪問您後，在這段時間內您經驗到的改變。

問題一:自從上次訪談您到現在，請您描述您照顧上的變化情形

- 如何做決策、參予照顧、環境調整、您本身與其他家人參予照顧情形
- 學習需求、挑戰、益處、如何學習這些需要、您如何獲得幫助與獲得哪些幫助、有哪些幫助、有哪些沒幫助

問題二：目前您已經擁有照顧中風家人的經驗，您可以幫我們更了解如何學習成為一個照顧者。根據您目前的經驗與狀況，

- 您認為您照顧的能力為:
- 您對其他剛開始學習照顧的家人的建議是:
- 您對醫療照護人員對於如何幫助家庭照顧者學習這個新的角色的建議是:
- 您對於政府的建議是:

問題三: 除上述經驗外，您是否有其他照顧經驗可以分享?

問題四: 您對此次訪問的感覺如何?

APPENDIX F

PARTICIPANT DESCRIPTIONS

The Families

Ai Family: Lee and her mother Mei

The stroke survivor and family caregiver: Mei, the stroke survivor, was 90 years old, widowed and had seven married children. Except Lee living nearby, the family caregiver, other children lived in the north of Taiwan. Before this stroke, she was very healthy and had not been told of any chronic diseases. Lee was widowed, 58 years old and a part-time cook. She had two grown children but they lived in other places. She stopped by her mother's house everyday and looked after everything for her mother before the stroke. Considering Mei' willingness and the negative impression toward institutional care, the family never thought about institutional care for their mother. Lee took on the role because "I am the oldest one and I don't need to provide for my kids and parents-in-law (who had passed away). She is my mother." The family hired a foreign care attendant, Ann, to prove physical care for their mother. She was married and had children in her home country, Indonesia. She had been in Taiwan for one year, and she was able to communicate easily Chinese.

The stroke: When Mei had this current stroke, she was sent to a nearby local hospital, and then transferred to a medical center in Kaohsiung for further treatment. Mei was admitted into the intensive care unit (ICU) and the general ward for one week, respectively. Lee said, "At that time, we totally had no idea how to take care of her."; therefore, the family hired a private nurse aid to care for their mother and taught Lee how to care for her mother after one week of instruction. Lee learned how to perform NG feeding, bathing, changing position from the nursing aid. She learned simple rehabilitation activities, such as range of motion, from a physical therapist. Lee learned those skills by watching and doing. However, physicians did not explain her mother's disease and conditions clearly and just said "need more observation." Before discharge, without further information provided, they were only referred to a nearby freestanding home care agent. At discharge, Mei had a swallowing problem and left side paralysis due to the stroke, but her recognition and consciousness were intact. She was discharged with a nasal gastric tube placement. The tube was weaned off after a 4-month placement. Currently she has a soft diet.

The home care settings: Mei lived alone in the first floor of a two-floor townhouse. Her room was a small one with a 3-foot high traditional Chinese style wooden bed and a few pieces of furniture. There was no window but the room was bright enough when the light was turned on and the air was fresh. The indoor environment was very clean and tidy. But like a traditional house, the floors were not even between each room. It was hard to move freely from room to room when Mei was in a wheelchair. Lee and Ann had to lift her up with the wheelchair to walk over any uneven surfaces. The only care assistant device was a shower chair which was a gift from one of their private nurse aids.

Care situations at home: After discharge, the family hired another nurse aid providing physical cares until Ann arrived. The nurse aid taught Ann how to care for in one month. Lee also remained involved in part of the caregiving activities, such as bathing and ROM. But her major role was accompanying her mother and supervising the nursing aid and foreign care attendant. She also had to play the role of a translator between Mei and Ann. Mei only could speak Haka language (one local dialogue), but Ann only could communicate with simple Chinese.

The major care problems for Lee were hard to deal with including her mother’s emotional and pain, NG care and difficulty swallowing. After the stroke, Mei complained of pain for a half year and her emotions became unstable. Her pain and emotional problems caused Lee and Ann to be unable to have a good night sleep leaving them exhausted. Lee did not understand the pain. She talked about the pain and emotional problems with the physician. The physician briefly explained the reasons for pain and prescribed a sedative drug to improve her sleeping. The sedative medication caused Mei to sleep all day; therefore, Lee stopped the medication and comforted her mother’s emotions verbally and continuously rubbed her body to reduce her pain. The problem naturally subsided after six months. The second problem was NG tube dislocation. Mei' NG tube was pulled out once by accident. Lee was scared and sent Mei to a nearby hospital to replace the tube immediately. Another problem was difficulty swallowing. Lee tried to feed her mother some food by mouth at home; however, she did not learn any swallowing training knowledge and skills before discharge. She tried her own way but her mother chocked very often. The problem was not solved until the physician recommended her mixing jello powder with food. Though they were referred to a free standing home care agent, Lee did not feel comfortable with the mobility and accessibility of the home care services. She indicated that the home care nurses were hard to contact and too busy.

Lee felt tired and high pressure from the care role, and was unable to escape from the role. But she viewed caring for her mother was a meaningful thing for her family: caregiving her mother at home provided a chance for her siblings to gather together. She did not have high expectations for her mother's condition because she considered it was very difficult hard to show any improvements for a 90 year old person.

Bi Family: Huo and his wife Ying

The stroke survivor and family caregiver: Ying, the stroke survivor, was 73 years old and a housewife. She and Huo had been married for 51 years and had four married children, two sons and two daughters. They lived in other cities and visited their parents once a week. Ying had diabetes and hypertension with regular control. Huo was 77 years old, a retired junior high teacher. Huo took on the role because of the marriage and strong affection. When Ying had her first stroke, Huo hired a foreign care attendant, Beth, to watch and accompany her. She was married and had two kids left behind in her country. She could understand and communicate with simple Chinese.

The stroke: Ying had a minor stroke in October, 2007. Six months later, a hemorrhage stroke attacked her again. She was sent to a medical center in Kaohsiung city and hospitalized for three weeks, one week in ICU and two weeks in Neurosurgical ward. Beth provided the major care for Ying. But she had no ideas how to care for Ying. Huo hired a private nurse aid to teach her the essential care skills and tasks. Huo went to the hospital every day and managed necessary issues, such as communicating with the physician. Huo hoped Ying could have rehabilitation therapy to improve her condition before discharge. However, because of the regulation, Ying had to discharge after one month of hospitalization. They were referred to a home care unit and discharged to their own home. This stroke caused Ying difficulty swallowing and left side paralysis, but her recognition and consciousness were intact. She was discharged with a nasal gastric tube placement. Before discharge, Huo indicated that the only reminder from medical staff was "Don't let her fall again. Don't eat too salty and greasy!" He felt the health care providers did not provide sufficient information, such as disease information and rehabilitation knowledge.

The home care setting: The family lived in a traditional Chinese style house in a small village, Ping Tong County. Indoors, the surfaces were very smooth with the exception of the doorsill where one needed to step over to get into the bathroom. In the bathroom, Huo installed a hand bar and slip-resistant mat after Ying had her first stroke. In Ying's room, there were two big windows and two beds. One was a hospital bed for Ying and one a single general bed for Beth. The room air and temperature was cozy and no order was present. Everything was clean and tidy. Outsides, as other traditional construction, there was a front step under the eave. Huo also installed a moveable ramp for easily accessing.

Care situations at home: The major care problems for Huo were dealing with Ying's difficulty swallowing, elimination problem, and unexpected disease conditions. He also indicated a high need of rehabilitation services. Regarding Ying's swallowing problem, they only received the advice of “giving pudding or soft food.” “Yes, he did tell me that I have to train her to swallow after going home.” But he considered pudding was too sweet for his wife because of her DM. They tried their own way to deal this problem. The second problem was: Ying suffered incontinence and had alternative constipation and diarrhea. Huo dealt with this problem by adjusting her medications. Ying also had two emergency room admissions after discharge of three months because of chest pain and sputum problems, and diarrhea, respectively. Huo expressed concern because of Beth unlearned suction skills; therefore, he was very worried about any sputum or breathing problems. Huo tried to call for help from the home care nurse when facing care problems. However, he felt it was hard to make contact with the home care nurse. “She was not in her office often and hard to contact.”

The greatest concern for Huo was having rehabilitation services for his wife because he knew that the first six months was the golden time period for rehabilitation. However he did not receive any referrals from health care providers.

> The physician only told me that she needs rehab therapy, but he did not tell me how to do rehab therapy. So I tried to find a physical therapist to help her. He also didn’t refer the rehab services to me! (Huo)

He aggressively sought rehabilitation resources after discharge. He indicated that he preferred an in-home rehab services. After Ying had her second stroke four months later, she started her rehab therapy twice a week in a medical center in Kaohsiung city. It took around 40 minutes to go there by car. Their second son was responsible for the transportation by his own van. It was not easy to transfer Ying into the van. Beth had to hold Ying and use all of her strength to move Ying into the van. Beth accompanied Ying on every trip to rehab therapy. Huo also tried to train his wife’s cognition on his own way. For example, he wrote down their children’s name on flash cards and asked Ying what their child’s name was and order of their ages on the selected card.

Huo indicated the happiest thing was his wife's improvement, though he also had some negative impact, such as lost weight, sleeplessness and worry.

> Of course, I am so happy to see her improvement. She was so weak before; now she can sit straight up and watches TV with us…I know she has improvements. (Huo)

He kept his hope and working on improving his wife's conditions. But he didn't have high confidence for his wife. He worried the improvement might not be as good as his expectations. Based on his experiences, Huo recommended: (1) providing a training program including care skills, diet, rehab resources and stroke knowledge before discharge; (2) the leaflet should provide practical information and be applicable in a real situation and easy to read for lay persons; (3) the health care providers should teach the care skills and knowledge with concrete examples or ways, such as showing a picture of pressure sores, demonstrations with a slow pace and providing practice opportunities; (4) increasing the home care service from twice a month to once a week.

Chow Family: Zu and his husband Sing

The stroke survivor and family caregiver: Sing, the stroke survivor, was 60 years old. He and Chu, his wife, had been married for 35 years and had three grown children, one son and two daughters. Their oldest daughter was married and lived in Taipei. Their son was divorced and had two children. They lived with their son, younger daughter and two grandchildren. Because Sing often violated Zu before, so their relationship was very bad. Sing had hypertension without control and four instances of gastric bleeding history. He had three minor strokes previously; but his self-care abilities were not impacted. Sing still paid no attention to controlling his blood pressure. Zu was 55 years old and a housewife. She had a hypothyroid condition with medication control. Helping their children was the major reason for Zu to take on the role. Her son and daughter helped her bathing for Sing, transportation and some care activities.

The stroke: When Sing had the severe stroke, he was admitted to a nearby local hospital for 15 days. After this stroke Sing had difficulty swallowing and his cognition was impacted, but his limbs and consciousness were not affected. He was discharged with a nasal gastric tube placement. Three months later, he could have regular food, but he still had the NG tube for drinking water and taking medications.

During the two weeks of hospitalization, Zu hired a private nurse aid to care for Sing because she had to look after her grandchildren at home. But Zu and her daughter went to the hospital every day and learned necessary care skills because “we have to do all of those after discharge.” Zu considered the hospitalization time period as the best time for learning care skills. She learned NG feeding, bathing and changing diaper from the nursing aid by watching and doing. Before discharge they received very brief information regarding how to prevent a stroke recurrence. “Drinking more water, having medication on schedule, and less greasy food!” The health provider referred them to the home care unit. But as Zu considered the flexibility of the home care service time, she declined the service and contacted another 24-hour service home care agent. Zu felt ready to go home after learning those care skills.

The home care setting: The Chow family was living in a two-floor townhouse. Indoors, the surfaces were smooth with the exception of the doorsill as one needed to step over it to get into the bathroom. The bathroom was not a big one and without a grab bar. The floor was not slip-resistant. When taking a shower, Sing sat on a small stool and had to grab the faucet to prevent a fall. After the current stroke, Sing’s room was moved from the second floor to the first floor. The room was a Japanese style one. Sing slept on a mattress near the 4-section sliding doors for ease of getting in and out. In order to prevent Sing pulling out his NG tube, Zu bound his hand on the sliding doors. Zu also slept in this room. Each room was very messy and smelly. The family was next to a nursing home for 20 years. Therefore, Zu could get emergency assistants from the nursing home.

<u>Care situations at home:</u> The major care problems for Zu were dealing with Sing's difficulty swallowing and diet preparation, Sing's emotional status, and unexpected disease conditions. Before discharge, "giving pudding" was the only information from the physician for training swallowing. But "I tried pudding and turnip cake, but those were too soft for him. He could not swallow those." She tried her own way "rice porridge mixed with ground meat and vegetables" and it worked well. Three months later, Sing was able to eat regular food, but he was still unable to swallow water.

In addition to their bad relationship, Sing's emotional status became hard to handle after this stroke. He was uncooperative with changing diapers, bathing, and transferring. Zu indicated helping Sing changing diaper and bathing were the most difficult ones.

> His body is always so stiff when I change his diaper. I tell him when you firm your body like this, how I can help you? One time my daughter told him angrily. If so, you don't need the diaper and let your bottom remain soaking there. Then he raised his bottom to let me to change his diaper. He did this purposely to incense and embarrass me.

Sing had one unexpected hospitalization due to urinary tract infection and one emergency admission because of hypotension caused by medication overdose. Zu also faced some unexpected situations, including fever, constipation, frequently NG pulled out, NG obstruction and bloody drainage from NG tube. When facing unexpected problems, Zu asked for help from the nursing home or home care nurses. She felt security after receiving their immediate help. She dealt with those problems by trial-and-error and seeking help from health providers.

Though she indicated she was ready to go home at the discharge, however, she still had around six months of adaptation for the new care situation, especially the first 3 months.

> When we just got home, I was so nervous! I had to feed him every three hours! But later, I found he could be like a normal person…it takes around a half year! I started to feel my life become stable and I can adjust to the task!

She also experienced multi-impact after providing care to Sing, including weight loss, developing hypertension, social and daily life impact and financial stress. She lacked great expectation for Sing. “I just wish he could stand and walk either with a cane or whatever!....But now he only can stand for a while then lay down again…his head always goes this way (drop down)! (Zu)” But she considered, “The pay off for my endurance is my children are so filial piety! They don’t turn bad!” She indicated an accessible home care service was important during the early days at home because everything was under explored.

Duh Family: Jen and her mother Wen

The stroke survivor and family caregiver: Wen, the stroke survivor, was 47 years old. She had four unmarried children, three daughters and one son. Wen had irregular controlled diabetes for ten years. Jen was 27 years old and single. She was the eldest child in the family. Her father was a construction laborer. He never provides any financial support for this family. Jen complained that he never took on any family responsibilities. Therefore, Jen felt she was forced to shoulder all of the family expenditures and responsibilities because she was the eldest child. Her brother and youngest sister, who was a nursing student, shared part of the caregiving tasks with her, such as bathing for their mother.

The stroke: This was Wen’s third stroke. She was admitted to a medical center in Kaohsiung. She had a respiratory therapy with an endotracheal tube and ventilator. She stayed in the ICU for a half month then moved to the respiratory care unit for a half month. During the one month, the physician recommended performing a tracheostomy. But the family refused because they didn’t want her to have one more hole on her body if she died. After her ventilator and endotracheal tube were removed, she was moved to a general ward for one month. At discharge, Wen was in a coma status and had a 3rd degree, 4x 3 cm^2 pressure sore on her sacrum area. She also had a nasal gastric tube placement.

Before discharge, the physician and medical staff did not provide clear explanation of Wen’s disease condition and stroke information. “Need further observation” was physician’s explanation. Jen briefly learned rehabilitation activities, NG feeding and care, insulin injection, changing diapers and clothes, and position change. Those were all new skills for Jen even the essential self-care activities. Nurses employed demonstration and oral explanation when teaching care skills. However, the nurse only taught her one time and used jargons. “She taught me how to ‘pull back’, but I don’t really understand what’s that term means.” She also lacked the reassurance from nurses. Therefore, Jen mentioned many times “I was not quite understood,” and “I had to explore and try it on my own way.” She indicated she needed more time of learning and practice. The nurses played a video tape to teach Jen about how to prevent a fall and how to care for a stroke survivor. But she could not fully understand the content. She indicated she needed a real situation and practice to increase her understanding.

The home care settings: The family lived in a two-floor house. Wen’s room was a big room at the first floor. Jen and one of her younger sister slept with her mother. Indoors, the surfaces were very smooth with the exception of a doorsill where one needed to step over to get into the bathroom. The bedroom and living room looked very messy and smelly. Lots of stuffs piled around the room. There was a yard paved with pebbles in front of the house but it was piled with lots of wood and logs as well. It was not easy to walk on it.

Care situations at home: The major care problems and challenges identified by Jen were dealing with her mother’s diabetes condition (diet, injection and medication), wound care and constipation. The first problem was controlling her mother’s blood sugar. Before discharge, Wen’s insulin was injected with a regular syringe. But only two weeks after discharge, when Wen had her first follow-up check, the syringe was switched to a pen-style one. The physician and nurse did not teach Jen how to use the new syringe in the outpatient department. Jen and her brother studied how to use it without any instructions and tested it on their mother. She indicated that insulin injection was the most difficult one. The physician had educated them how to adjust the insulin doses and deal with hypoglycemia.

> The physician told us that we have to check her blood sugar every day. If her blood sugar is too high, I can increase her insulin units. If it is over 200, increase two Us (Unit); if 290, four Us and if over 300, increase six Us! If the blood sugar is too low, we can give it later or after having her milk.

However, after discharge, her mother's blood sugar tended to be high. Before discharge, they had consulted with the nutritionist several times, but the nutritionist suggested a regular commercial formula instead of diabetes formula. Later, Jen switched half of her mother's diet to the diabetes diet because "my aunt has diabetes and she has this." Her mother's blood sugar became much more stable.

Wen discharged with a 4x3 3rd degree pressure sore on her sacrum area. Before discharge, medical staff did not provide sufficient wound care technique and knowledge. Jen tried various ways to deal with her mother's wound, but those didn't work. Later the physician suggested frequently changing the dressing whenever she urinates. By July her wound was healed. The pressure sore lasted for six months. In addition, Wen had constipation and Jen felt it was an uneasily managed problem. She had to manually clean her mother's stool every two or three days.

Jen considered that she was forced to take on the caregiver role; therefore, she mentioned many times "why it is me?" She felt tired and high pressure from the role responsibility. She wished she could escape from this situation, but "who will and can take care of mother if I escape? Nobody!" Without a better way to overcome her pressure and current situation, she described her life was lacking of energy, uninteresting and hopeless and she could not breathe! For Jen the only positive thing was "I learned all of those skills and I think I can be a nurse! I can do all of those things by myself when the nurses are busy!"

Fong Family: Siang, De and their mother Mi

The stroke survivor and family caregiver: Mi, the stroke survivor, was 67 years old, widowed. She had five married children, four sons and one daughter. She lived with her youngest son (De) and daughter-in-law (Siang), the family caregivers. Her oldest son lived nearby and stopped by frequently. Mi had hypertension with irregular control. De and Siang were 38 years old. They had three teenage children. De was a fisherman. Siang worked at a motel next to their house. Her work time was very flexible. De took on the role because of the responsibility of being a son and he considered this was a way to pay back his mother's raising him. Siang took on the role because "We have an excellent relationship and she treats me very nicely." "We live together, so naturally we have to care for her." De stopped fishing for 4 months to care for his mother. The couple realized that they needed to care for Mi after discharge long-term; therefore, the family hired a foreign care attendant, Faith, to care for their mother. Faith arrived after Mi was discharge one month. Faith was married, had one child in her country, Indonesia. This was her second time in Taiwan. She had elder care experience at home for 16 months previously. Her language was very fluent and she was handy at physical cares.

The stroke: Mi had a severe hemorrhage stroke and lost her consciousness. She had an emergency surgery and treatments for two months in a medical center in Kaohsiung. After two months of hospitalization, she was transferred to a local hospital for one month. After this stroke, Mi became a coma status and right side paralysis. She was discharged with a nasal gastric tube, tracheotomy, and Foley catheter placements.

Siang and De were first time of caring for a serious stroke person and had no ideas how to care for their mother. They hired a private nurse aid to teach them NG feeding and care, change position, chest percussion, bathing and changing clothes. They also learned sputum suction skill from nurses. They learned those skilled by watching and doing. The most difficult skill was learning sputum because they felt pain for watching their mother's suffering during the suction process. "I was so scared when I did the first time of suction. (De)" But later they learned the skill because they had to carry out the skill at home. They felt scared with the first time performing the skill. After learning those skills and the experience of providing care in hospital, they felt ready to go home. Except receiving home care service referral, they did not receive any information from health care providers before discharge.

The home care settings: The family lived in a hilly village in Ping Tong County. The village roads were paved but very bumpy. It was not easy to walk or wheel on the roads. The family's house was a two-floor building. Indoors, there were no barriers except a doorsill at the main door needed to be stepped over. Mi's room was on the first floor. In her room, there was a hospital bed and one single bed for the foreign care attendant. Some care equipment, including a suction machine, an O_2 machine, and medication set orderly. The room temperature and air was cozy and fresh.

Care situations at home: The major care problems at home were lack of necessary care equipment at home, unstable blood pressure and transportation. For Siang she also faced the dilemma of making decisions for her mother-in-law though she was the primary family caregiver. Before discharge, the family did purchase a hospital bed, suction machine and other stuff recommended by one of their relatives. But they did not prepare an O_2 machine or tank at home. They immediately faced a serious problem at the first day of discharge. Mi panted severely because of lacking O_2 supply. Without other choices, De borrowed an O_2 tank from discharge hospital and contacted the medical equipment store during the middle of the night.

Mi's blood pressure was unstable and tended to be high after one outpatient follow-up because the physician changed the prescriptions. The couple was confused and didn't understand the medications. They tried their own way to deal with this problem by giving Mi's previous medication. Later the home care nurse highly recommended that they talk with Mi's physician. The second day, De visited the physician but the physician wouldn't accept De's opinions and wouldn't change the medication. Thus they continued to control her mother's blood pressure by their own way and sought further treatment from other hospitals.

The couple indicated taking a disabled person to the hospital was not an easy task. On the other hand, because their living place was in a remote area, it was hard to travel without a car. Therefore, if necessary, they called 911 and the ambulance became the major transportation for her mother. Thus the couple felt the home care in-home service was very convenient for them.

Siang was the primary family caregiver for her mother-in-law; however, as a daughter-in-law, she lacked real authority to make any decisions. She expressed that she wouldn't make any decision by herself and she informed her eldest brother-in-law and his wife before doing anything.

De kept highly positive hopes. He hoped his mother could wean off the tracheotomy and have food by mouth. He aggressively tried various ways to improve his mother's condition, such as folk treatment and massage. But Siang gradually lost her optimistic hopes and hesitated to say "it is a right decision" about the operation decision. "Her current situation is a suffering for her!" She felt the care process filling her with stress, she felt tired but she was happy about learning the care knowledge and skills. "I feel like a special nurse for my mother!"

Gao Family: Ya and her mother Ji

The stroke survivor and family caregiver: Ji, the stroke survivor, was 67 years old. She had two married daughters. She had regular controlled hypertension and diabetes. Ya, the family caregiver, was 44 years old. She was married and had three teenage daughters. Before taking care of her mother, she was a housewife. Her husband's job was out of the country, so he was rarely at home. The reasons for Ya taking on the caregiver role were daughter's responsibility, affection and Karma. Ya was concerned with not having enough time for providing care; she hired a foreign care attendant to provide physical care for her mother. The foreign care attendant, Grace, was from Indonesia and had been in Taiwan four years. She spoke Chinese very fluently. But four months later, she went back to her country. Ya applied for another one, Gwen. During the waiting time period, she hired a Taiwanese nurse aid to help her. Ya's father and her older sister stopped by every day, but they did not provide any direct care.

The stroke: Ji had a server hemorrhage stroke and she was sent to a medical center and hospitalized for one month. She did not have surgery because the hemorrhage area was near the brain stem, but later she had a ventriculoperitoneal (VP) shunt due to the increased intracranial pressure (IICP). After this stroke, Ji had a difficulty swallowing and left side paralysis. Her recognition and consciousness were impacted. She was discharged with a nasal gastric tube and Foley catheter placements.

Ya understood there were lots of new things that had to be learned. Therefore, she hired a private nurse aid to provide physical care for her mother, and to teach her care of those new skills and tasks. On the other hand, she believed a nurse aid had a better understanding of how to provide self-care activities to a disabled person than a nurse. She watched, took notes and practiced all newly learned skills, including NG feeding, bathing, shampooing, position change, chest percussion, pillow application and manual fecal elimination. Ya also had 3 days of intensive training of suction and insulin injection skills from nurses. She was nervous and afraid about learning those skills. Even though she practiced the suction skill several times, she was still uncomfortable performing it.

Ya complained that the physician did not actively provide enough explanation of her mother's disease and treatments. Before discharge, the discharge planner provided a list of recommended care equipment at home, including a hospital bed, suction machine and tube, and insulin syringes. After learning caregiving skills and purchasing the equipment, she felt ready to go home.

The home care settings: Before this stroke, Ji lived with her husband and their older daughter in their own house. The original living place, a 2-floor townhouse was not easy to get in and out of for Ji's current heath situation. Therefore, she was discharged to Ya's house which was located in the 35th floor of a multi-storey building with a ramp at the first floor and an elevator for access. The indoor environment was very neat and clean. Ji's room was a small air-conditioned one. There was a hospital bed, some built-in furniture, and a television. A small single bed was for the care helper.

Care situations at home: The major care problems for Ya were being unconfident with the injection and problems with insulin dosage right after discharge, difficultly dealing with unexpected critical situations, including urinary tube obstruction and medication problems. Furthermore, she faced her mother's difficulty swallowing, diet preparation, and rehabilitation problems. Transportation was also a challenge when taking Ji to the hospital. After discharge, Ya aggressively tried various ways to overcome the challenges and to improve her mother's health condition. However, she lacked her older sister's supports and felt pressure from her familial disagreements.

Although Ya paid lots of effort on learning new skills and she felt ready before going home; however, she lost her confidence right after arriving home. She called the emergency room many times to make sure that what she did was right. She also faced another insulin problem soon: how to adjust the insulin dosage based on her mother's blood sugar level. She was confused and questioned this for a while. Then she received an explanation from the home care nurse and she understood that the insulin dosage was adjustable, not a fixed one.

An unexpected emergency situation occurred due to inappropriate care for her mother's Foley catheter thereby causing the tube to become blocked. The obstruction blocked the urine and caused Ji to groan for six hours from midnight to the early morning.

Because it was morning time and the home care nurse was not in office yet Ya could not get immediate help, so she called 911. When the rescue person moved Ji's body, around 500 cc of urine ran out at one time. Ya expressed that there should be someone who can tell her how to do this when she faced unexpected situations. After being admitted to the emergency room, Ji was diagnosed UIT and was given some medications. Nevertheless, after taking the medications, she became very drowsy, and her blood sugar and pressure elevated. Ya called the pharmacy, but she could not get a clear answer. Then Ya stopped the medications and her mother's condition improved. "Because I am the first-line person, I know my mother's condition. If she is OK after stops taking the medication, which means my judgment and decision are right."

She was extremely concerned with her mother's nutrition. The nutritionist recommended the commercial formula as the best one for controlling her mother's diabetes. However, Ya questioned her recommendation. On the other hand, her mother's sugar was not well controlled on the diet. Thus she prepared her mother's diet by herself. She experienced a period of difficulty on testing an appropriate thickness food for NG feeding because nobody taught her how to prepare an appropriate food. Therefore, she visited a hospital nutritionist again. In addition, Ya learned a lot of nutrition information from her friends, other family caregivers, and text books. Then she pulled all the information together and prepared an organic vegetarian diet for her mother.

Ya also tried acupuncture, massage and a self-prepared vinegar (which contains various ingredients) to control her mother's blood sugar and health condition. Later she requested a lab check to make sure that what she did was on the right track or not. "The report showed everything was OK and normal! So I know it is the right way to go. I continue to give her those." Her mother's blood sugar became stable after having her prepared food.

She tried various ways to stimulate her mother's recognition and aggressively sought rehab resources to improve her mother's condition as well. She talked and played with her mother. She also tried various foods to train her mother's swallowing. She trained her mother brushing her own teeth because one family caregiver educated her "you should let your mother move by herself." Around two months after discharge, Ji suddenly chewed and swallowed a lee-chi and was able to sing her favorite songs though she still could not recognize her family. "I was so surprised and happy. I could not believe it!" Ji also can brush her teeth every morning as well. Ya could not describe her happiness about her mother's progress. "Her physician said it is a miracle!"

Those improvements motivated Ya to seek more rehabilitation resources. She learned of an excellent rehabilitation therapy program in one medical center from a nurse aid. Ya took her mother to the medical center for further rehab therapies. She was filled with hopes for her mother. She expected her mother "can sit straight up and can walk with an assistant device to bathroom and take a bath." But she still worried some about uncertain situations which happened during the rehabilitation process.

Though Ya had many achievements, Ya had to struggle with the inconsistent care attitude and concepts from her sister. Her sister considered the best care for her mother was following the physician's orders for everything. She extremely disagreed with what Ya did for their mother. This caused Ya a high level of tension and she had some arguments with her sister.

Based on her experience, Ya provided many suggestions. First, she indicated that providing too much information might not be useful before discharge because family caregivers might be able to remember all of the information and in addition, the care situations were so unpredictable and complex at home. She recommended just providing a business care with a name and phone number for contact after discharge. Secondarily, the health care providers have to educate a family caregiver how to adjust the insulin dosage or other medication based on the stroke survivor's situations, not just follow the prescribed dosage. Third, a timely and effectively emergency contact unit or person was highly necessary and helpful for a family caregiver when facing any unexpected situations. She highly recommended the home care nurse was the best person because the home care nurse realized their situations at home. Fourth, because Ya learned lots of information from other family caregivers, she recommended organizing a stroke family caregiver group.

Ho Family: Chin and her mother Yue

The stroke survivor and family caregiver: Yue, the stroke survivor, was 62 years old. She had two daughters and one son. Yue’s husband has a full-time job. Her older daughter had passed away ten years ago. Her son was married with an Indonesian and lived in another place. He rarely visited his parents and wouldn’t take on the care responsibility. Yue lived with her husband and a foreign care attendant. She had hypertension and diabetes without control. Chin quit her job and took on the caregiver role when her mother had the first stroke. She was 37 years old, married, but no children. She lived with her husband in another place, so she had to go back and forth between her own house and her parents’. The major reasons for Chin taking on the role were daughter’s responsibility and helping her father. In addition, she had a bad relationship with her mother before. She explained her current care responsibility for her mother was due to Karma.

After her mother had a second stroke, the family hired a foreign care attendant, Hannah, to care and accompany Yue. Chin was responsible for supervising the foreign care attendant and managing her mother’s medical issues. Hannah was the first time in Taiwan and cared for Yue for around two years. She was able to fluently communicate in Chinese. She went back to her country in October, 2008. Chin hired the second foreign care attendant, Helen. She arrived on October, 2008 and learned care skills and tasks from Hannah in only ten days. She was the first time in Taiwan and had language barriers. Both foreign care attendants were married and had children left behind in their country, Indonesia.

The stroke: Yue had a minor stroke in 1998, and it did not cause any serious physical problems. In 2006, she had the second stroke. In addition, she had a fourth degree wound on her right foot due to poor control of diabetes. She was admitted to a medical center for one and half months. At this discharge, Chin was married. She was sent to her mother's home and one of her relatives cared for her for seven months. Then the family hired Hannah to provide physical care for her at home. After this stroke, the family used Chinese medications to treat Yue's wound and stroke concurrently. Later she could freely walk and go outside. In 2007 November, she had the third stroke. This stroke was a severe one. She needed a ventilator respiratory therapy. She stayed in a medical center for one month. During this month, the physician repeatedly suggested performing tracheostomy. But the family insisted not to perform the surgery because the physician did not provide a clear explanation of the differences and advantages if she had a tracheotomy.

> He didn't indicate the key point. At that time, he only said tracheostomy! Just this word! It is bad for her if she doesn't have the tracheostomy! I asked him how bad?! He only said anyway it is bad for her! He didn't explain if she had the tracheostomy what the benefits for her and what the bad things for her!

On the other hand, the family thought Yue's condition was too serious and she might not be able to survive. They wouldn't like her having one more hole on her body if she died. Due to the limitation of length of stay in a hospital, Yue was transferred to a respiratory care ward (RCW) for further treatment for four months. In contrast to the previous physician, the RCW physician gave the family a very clear explanation about performing tracheostomy. The family agreed to have the surgery.

Because Hannah provided physical care for Yue in the hospital, Chin did not learn any care skills. She was only responsible for communicating with medical staff and sending Chinese medication to her mother. When Yue weaned off the ventilator, she was discharged to home and was referred to a free standing home care agent. After this stroke, Yue was unconscious and had left side paralysis. She was discharged with a NG tube, tracheostomy and a wound on her right foot. Because Hannah was responsible for all physical caregiving tasks, Chin felt comfortable to go home.

<u>The home care settings</u>: The family lived in a three-floor townhouse in Kaohsiung County. Yue's room was in the middle of the first floor and air-conditioned. There was no window but it was bright enough when the light was on. A hospital bed was for Yue and one general bed for the foreign care attendant. An oxygen machine and a suction machine were set next to Yue's bed. All care stuffs were arranged on a shelf. Everything was tidy and very clean.

<u>Care situations at home</u>: The major challenges for Chin were the dilemma of making decisions for her mother in hospitalization, such as performing tracheostomy. She did not have real authority to make a decision. She indicated that before making a decision she had to ask her dad. After discharge, her major problems were training the new foreign care attendant and coping with her own pressure. Because Chin completely relied on Hannah, so she did not learn any caregiving skills until Hannah decided to go back. Chin assumed Hannah could train Helen well before she left and she assumed Helen could perform all of the care skills. However, Helen only had 10 days of training. Helen did not learn it very well and her learning attitude and care manner did not match with Chin's expectation. Chin indicated that she had to teach her again and again and she complained a lot about Helen's cares. She had to supervise her all the time and this made her annoyed.

Chin not only had to take care of her mother, but she still needed to look after her parents-in-law and her husband. She tried her best to balance both sides, but she experienced high stress from the care situations. At first she called her friend to relieve her pressure, but later she discontinued doing this because of the high phone fees. Now her major way for releasing pressure was gambling.

Throughout the whole process, Chin and her father extremely trusted Chinese medication. They never discontinued the medication. They spent around 500 thousand dollars on her mother’s wound and saved her mother’s leg. Chin believed “She doesn’t have amputation and her survival is worthy of our efforts.” However, at the second interview she lost her expectation for her mother.

Inn Family: Hui and her mother-in-law Rou

The stroke survivor and family caregiver: Rou, the stroke survivor, was widowed, 71 years old. She had four children, two sons and two daughters. They were all married except the youngest one. She was diagnosed delusional and controlled by medication. Because of the delusion, Rou’s emotion was unstable. In May 2007, she suffered a fall possibly caused by the psychiatric medication. Thus she was moved to live with her youngest son. She was cared for by her younger son and another son's wife, Hui, the family caregiver.

Hui was 44 years old, had radical hysterectomy two years ago which caused her to be unable to bear heavy chores. She, her husband, and two kids live in another place which was 30 minutes away from Rou’s living place by motorcycle. She had to go back and forth between the two places. The reasons for Hui taking on the role were: good relationship with Rou, responsibility of an eldest daughter-in-law, and Karma. In addition, Hui viewed caring for an elder was a society tradition and an offspring’s responsibility. Rou’s two sons were responsible for transportation and her oldest daughter often bathed for her. But her younger daughter rarely visited her.

Later Hui was aware that she had severe depression. She was diagnosed hypertension as well. In addition, Rou had another two falls when she stayed home alone. Thus Hui insisted in hiring a foreign care attendant to accompany Rou. Rou was against the decision because she worried her children would abandon her if she hired a foreign care attendant. Eight months after Rou’s fall for eight months, the foreign care attendant, Iris, arrived. Rou’s younger son refused to have Iris in his house. Therefore, Rou was moved back to her own house. Iris was married and had a child in her country, Indonesia. She was the first time in Taiwan, so she had difficulty in communication.

The stroke: In May 2008, Rou had a stroke and was hospitalized for six days. Iris cared for Rou in the hospital. Hui went there every day. She was responsible for supervising Iris's work and communicating with health providers. Iris had no experience in giving care to a stroke person before. During the six days of hospitalization, Iris learned new care skills, including NG feeding and care, Foley catheter care, and position change from nurses. But she had difficulty in learning due to language problems. She could not understand because the nurses spoke too fast and demonstrated only one time.

> They (medical staffs) did teach her those (care) skills! But she could not understand the language very well and the nurses spoke everything very fast because they were busy. On the other hand, she didn't dare to ask for a repetition from nurses. Therefore, she did not learn it well. A communication barrier was the possible reason. So I tried to be there if possible because she couldn't understand what the nurses said. I also told her, if I was not there, you had to let them know and please ask them to speak slowly. She could understand if the nurses spoke slowly. But she said she was too shy to say that.

Therefore, Hui called the manpower agent and asked them to find other foreign care attendants to teach Iris again.

The physician did not clearly explain Rou's health condition and treatments. Hui indicated the physician was not friendly and his answers were very ambiguous. "Need more observation" was the physician's explanation. She had to actively ask questions to learn more information. Before discharge, the health care providers referred them to the home care unit and gave Hui a leaflet regarding how to take care of a stoke person at home. She assumed learning those skills and having the information was enough for caring at home.

Due to this stroke Rou had difficulty swallowing and left side paralysis, but her recognition and consciousness were intact. She was discharged with NG tube and Foley catheter placements. Her NG and Foley catheter had been removed after two months and four months placements, respectively.

The home care settings: Rou's house was a one-floor traditional house, located in Ping Tong City. The indoor floor was smooth without any stuff blocking the path. In Rou's room there were two general beds and some pieces of furniture. Everything was neat and clean. Because Hui was concerned with Rou's emotions and their relationship, she refused the researcher contact with Rou. The researcher only viewed the room when Rou and Iris were not home.

Care situations at home: Under other family members' help, the first day after discharge went smoothly. But later the situations became very chaotic and disorderedly. Hui felt very frustrated, helpless and like in the dark. Hui spent three months getting used to the care situations. The immediately faced problems were difficulty of dealing with Rou's diet, bathing, transferring and position change. Before being discharged, the health care providers did not provide any diet information. Thus Hui went to drug stores and searched for a better one for Rou. She mixed multi-brands of milk as Rou's diet. One brand of milk contained Probiotics. The home care nurse assured that the milk was a good quality one, and recommended giving more spoons to increase the total caloric intake. However, Rou had diarrhea after increasing the amount, and she was hospitalized for one day.

The following problem was bathing, assisting Rou into a wheelchair and back to her bed, and position change. At the early discharge, without other family members' help and lacking a shower chair, Hui and Iris had difficulty moving Rou to the bathroom and helping her having a shower bath. Later they purchased a show chair to reduce their difficulty. However, they did not learn how to transfer Rou until Rou had the first time of rehabilitation therapy in the outpatient department. They had to struggle with how to move Rou in and out of the shower chair or wheelchair. On the other hand, Rou developed a pressure sore after discharge for 15 days because of inappropriate position change. Hui indicated that they learned the skill at the day before discharge, and they lacked the knowledge of preventing and caring for a pressure sore. Hui went to the drug store and consulted with the drug store person. Then Hui taught Iris how to care for the wound based on her own understanding. Rou’s pressure sore continuously worsened until the first time of home care visit. The home care nurse taught the correct care skills and knowledge, including position change, the frequency for position change, and wound care. Therefore, Hui set alarm clock to remind Iris to help Rou change position. They changed the dressing very diligently as well. The wound was healed after two months of careful care.

Rou’s pain and emotional problems were hard to deal with for Hui as well. After discharge, Hui demanded that Iris had to continue the rehab activities at home. However, after the stroke Rou felt severe pain when moving her body or extremities. She complained a lot and wouldn’t cooperate with Iris. Hui insisted and verbally encouraged Rou to continue the rehab therapy because she knew the first six months was the golden time for rehab. Regarding the pain Hui discussed this with the physician, but he did not give any answers. After a half year, Rou’s pain was subsided naturally. Furthermore, after the stroke, the physician stopped Rou’s psychiatric medication. She became confused, manic and anxiety driven. The pain and rehab activities worsened her emotional status as well. At the first half month after discharge, Rou often lost her temper and wouldn’t cooperate with care activities. At first, Hui only could verbally comfort her. But later Hui was aware that her own temper also negatively impacted and Iris could not have a good sleep. This condition lasted for one month and made Hui and Iris exhausted. They couldn’t stand it anymore. Hui demanded that her brother-in-law take Rou to see a Psychiatrist. However, the medication did not work very well. After taking the medication Rou’s sleeping was reversed. Without other means, Hui tried Rou’s previous sedative medications to subside her emotional problems.

Regarding Rou’s rehab therapies, the physician only informed the family to train Rou’s speaking, swallowing and chewing functions. Therefore, Hui reminded Rou she had to chew and speak something frequently. But this made Rou very mad. In addition, Hui did not receive any instruction for swallowing training. The physician just recommended giving her some rice porridge. Hui had no idea how to prepare an appropriate food. Thus Rou choked. After consulting with a nutritionist, Hui understood that a stroke person could not have liquid food. After many trials, she finally knew how to prepare appropriate food for Rou.

Another rehab issue was Rou's chewing problem. The physical therapist only reminded that Rou needed to train her chewing function by opening and closing her mouth. But the action caused pain for Rou, so she wouldn't cooperate with this activity. Later Hui incorporated the training activity into her daily diet by chopping the vegetables into bigger pieces and providing some easily chewed fruits, such as banana and kiwi. This trial worked very well. Hui found Rou wouldn't feel hurt anymore and her face shape looked better than before. Hui indicated those achievements were all finding out on her own, not learned from the health providers.

Hui paid a lot of effort to solving and dealing with many care problems. She was very proud of herself because none of her friends providing so mindful care to their mothers-in-law like her. "I believed no other daughters-in-law like me provide such thoughtful care for their parents-in-law." She also viewed this as a good model for her children. However, she lacked support and assistant from her other family members even her husband. In addition, because Hui did not live with Rou, so her cell phone was 24-hours on because she worried about any emergency situations that might occur. Hui felt high stress from the care situations. The caregiving reasonability caused multi-dimension impact on Hui. First of all, Hui and Rou's relationship was negatively impacted because of their inconsistent attitude toward hiring a foreign care attendant, Rou's emotions changed and Hui insisted and pushed Iris to keep working on some caring activities though Rou refused. Under the multi stressors, Hui felt herself almost burned out. She could not have a good sleep and lots of physical sores resulted. She talked with her friends and had Yoga class to release her pressure.

Ju Family: Zong and his father Siong

The stroke survivor and family caregiver: Siong, the stroke survivor, was married, and 67 years old. Zong had seven married children, three sons and four daughters. Zong lived with his wife and his youngest son’s family, Zong, the family caregiver. Siong was not an affable father because he had a violent tendency. He often punished his children with a stick. Therefore, he didn’t have a good relationship with his wife and children except the youngest one. Siong had diabetes controlled by insulin injection. He also had heart disease and had a coronary artery bypass graft (CABG) operation. Zong, 36 years old, married and had one son and two twin daughters. He graduated from the university and was a medical technician in a medical center. His wife was a nurse. He was a very faithful Buddhist, so he deeply believes Karma was the major reason for his caregiver role. Another reason for him to take on the role was because he was the only child having good relationship with Siong. His brothers assumed he had to take care of their father. Zong’s mother also cared for Siong during the day time.

The stroke: In February 2007, Siong suddenly lost his left ear’s hearing due to a minor stroke, but it was recovered later. However, his emotions became out of control and very violent on all family members. He even tried to kill his wife and his granddaughters were too frightened to control their urine by his unreasonable behavior. Zong’s family could not bear this situation anymore. Siong was forced to have psychiatric therapy and hospitalized for two months; then he was transferred to another hospital. However, after one week admission, Zong found Siong’s left side was paralyzed due to a new stroke, but the health care providers did not notice this change. He could not forgive the health care providers’ overlooking this for a while. Siong was re-admitted to a medical center for three months, including two months in rehab unit. After having the rehab therapy, Siong was able to move his left side. Due to the limitation of the length of stay, Siong was discharged with NG tube placement and referred to a free standing home care service. After this stroke, Siong had left side paralysis, swallowing and cognitive impact. He also had a 10 x 12 cm^2, second degree pressure sore on his sacrum area.

Siong had six months of a steady period at home. During the time period he was clear, had a NG placement and a pressure sore. He needed someone else to perform daily activities for him. In March 2008, Siong had a coma due to hypoglycemia at home; then he was re-hospitalized for two months. After having critical treatment, Siong's consciousness was back to clear status, but his reaction became very sluggish. However, after discharge for only one month, he had a severe gasp and was re-admitted to the emergency medical intensive care unit (EMCU) for ten days. Later he had other two difficult breathing situations and was re-admitted to the emergency room and hospital. At the last time of hospitalization, because he could not get rid of a ventilator, he was transferred to the respiratory care ward (RCW).

Zong was a health care provider, so he felt at ease in learning care skills. He learned wound care by watching how a physician and nurses performed the skill. He felt able to deal his father's care situations at home except his father's breathing problems, which were out of his management abilities.

<u>The home care settings</u>: Siong was hospitalized during the two interviews, so the interview places were in the hospital's meeting room and Zong's office. From Zong's description, their house was a townhouse and Siong's room was on the second floor. Zong had to carry his father up and down stairs. A portable ramp was installed to access the bathroom.

<u>Care situations at home</u>: The major care problems for Zong were lack of sufficient rehab therapy and resources, caring for his father's wound, elimination, breathing problems and financial burden. After discharge, he immediately contacted another hospital for his father's rehab therapy, but he never got an answer from the hospital. The only thing he could do was performing rehab activities, i. e. range of motion, for his father at home. He purchased a rehab bicycle and trained his father walking based

on his own way. Except muscle power training and walking, Zong did not train his father's self-care. Regarding the swallowing, the physician only informed Zong to start with pudding and a litter water in order to avoid choking in the hospital. Zong tried it but "he could not swallow those." The rehab outcomes were not as good as Zong's expectation; then his father's conditions gradually worsened. From the whole process, Zong highly recommended the health care system should provide a rehab specialty hospital for a stroke person after discharge.

Siong developed a pressure sore in the hospital when he had the second stroke. After discharge, Zong carefully cared for the wound and it was much improved. He was very proud of his wound care outcome because it was improved from 10x12 cm^2 to 5x6 cm^2. Elimination was another bother for Zong. He tried glycerin ball enema and prescribed medication, but those didn't work well. Manually fecal stool removing was the way for solving this problem.

Siong's breathing problem was the most difficult one for Zong. He indicated he was unable to handle his father's breathing difficulty. The only way was sending his father back to the hospital. After his father was transferred to RCW, he had some relaxation and less worry. Another challenge for Zong was the financial burden. Zong felt purchasing commercial formula was the highest financial pressure for his family. He recommended the subsidized items should be reconsidered as the items for daily life instead of care equipment.

Zong very positively viewed his caregiver role. He viewed this was a great chance to serve his father intimately. He also thought his caregiving work could end the Karma between him and his father. He also viewed this experience as an excellent chance of learning life meanings and educating his children what a filial piety was. He encouraged his children involving the care activities, such as doing range of motion for Siong.

According to his experience, Zong also made recommendations for home care services. He highly recommended the service frequency should be at least once a week, especially for the person having a wound. He also recommended that family members need to prepare and practice necessary skills before discharge.

Kuo Family: Bao and her husband Yi

The stroke survivor and family caregiver: Yi, the stroke survivor, was 61 years old. He and his wife, Bao, had three grown children, two sons and one daughter. They lived with Bao’s mother and two unmarried sons. Bao’s mother, 90 years old, needed self-care assistances due to aging. Their daughter was married, had two sons, and lived upstairs. Their older son, 35 years old, was a part time care attendant. He was the major bread earner of this family. His income was only around 600 US dollars/month. Their younger son was mentally retarded and needed self-care assistance. Bao was 60 years old, and had diabetes controlled with insulin injection. She was responsible for providing care for her mother, younger son and Yi. The reasons for her taking on the responsibility were their strong affection and Karma. Their daughter and older son helped with some care activities, such as feeding, and giving a sponge bath for Yi.

The stroke: Yi had uncontrolled hypertension. In September 2007, he had hemorrhage type of stroke at home. The stroke was very serious, so he lost his consciousness at the onset. He had NG tube, Foley catheter and ventilator respiratory therapy and treated in ICU for one month. At the onset, the physician suggested and provided necessary explanation of performing a brain surgery. But Bao refused because Yi’s condition was too serious so she thought the surgery wouldn’t able to make much improvement.

After one month, the physician recommended performing a tracheostomy surgery, but Bao declined again because she worried Yi might not be able to survive. Because of the limitation of length of stay, Yi was transferred to a free standing respiration care ward

(RCW). However, the RCW did not provide good care. Yi developed a pressure sore after 10-day admission. Bao decided to transfer Yi back to a nearby hospital and perform the tracheostomy surgery because the physician told her: just don't let him feel so painful!

After the surgery, Yi stayed in RCW for one month then he was moved to the general medicine word and stayed for another month. During the two months in the hospital, Bao learned essential care skills: NG feeding, sputum suction, Foley catheter care, and tracheostomy care. Her motivation for learning was "need to provide those cares at home." She also learned how to replace NG tube from a nurse because Yi often pulled out the NG tube in the hospital. She expected this situation should happen at home, too. "Watching" was her major way to learn.

Yi discharged with NG tube and Foley catheter placements, and tracheostomy with oxygen supply. His right side was paralyzed and recognition and consciousness were impacted as well. Yi was re-admitted to the hospital three times after discharge nine months, due to spasm and sputum accumulation, gastric bleeding, and fever. He had emergency surgery at the second time of hospitalization because of his gastric bleeding. He also had two emergency room admissions because of fever and urinary problem.

<u>The home care settings</u>: The Kuo family lived on the fourth floor of an apartment. There was an elevator. But on the first floor before reaching the elevator there was a 6-step stair. So it required walking up and down the stair. The elevator only can fit a wheelchair, not enough for a bed. This was a big barrier for Yi to get in and out of his house. Therefore, Boa had to ask her son and other people to help her if necessary.

The Kuo's house had one living room, three bedrooms, kitchen and bathroom. The indoor settings were very simple. The room air and temperature were cozy. Yi, Bao and their younger son slept in a big bedroom. There were a hospital bed facing the door for Yi, and two general beds for Bao and their younger son. There were some pieces of furniture with damaged marks made by their younger son. A television was set at the top of a closet, so Yi could watch TV with ease when lying on his bed. A half-size door was installed in order to preventing their younger son from walking outside the room.

Care situations at home: At the early time at home, Yi had lots of sputum and required frequent suction. This affected Bao's sleep and made her tired. The major care problems at home for Bao were uncertainty that what she did was right or not during the early discharge and financial burden. "I feel panic and nervous during the first month." Those unsure conditions occurred when Bao provided care for Yi: replacing NG tube, wearing oxygen supply machine, weaning Yi's Foley catheter, and dealing with sputum problem.

After discharge, Yi frequently pulled out his NG tube; Bao tried to replace it. But she was fearful of inserting it in the wrong place and this did happen once. She avoided replacing the tube as much possible. On the other hand, Bao very aggressively tried to take away Yi's oxygen supply machine and Foley catheter. However, she did not receive any instructions from health care providers or home care nurses. The only one source was the owner of an equipment supply store who lent her an oxygen monitor and taught her how to use it and the normal oxygen level. Later Bao tried to remove Yi's Foley catheter twice. But this time she gave up after two trials. Another major problem was: Yi's sputum was ineffectively cleared and caused sputum accumulation. Sputum accumulation produced an offensive odor, so Yi was re-hospitalized. Bao learned how to use a steam inhalator to soften the sputum at this hospitalization. She indicated she had no idea about this potential problem and how to deal with it because nobody told her. The smell disappeared after he had a new tracheal tube. Those unsure situations all happened in the first three months after discharge.

Bao very much appreciated the home care services. But the services were only offered during regular office hours. After the service hour, the home care nurse only provided consultation by phone. If any unexpected situations occurred, the only way was going to the emergency room. According to Bao's experience, she indicated that the frequency of home care service was not enough. She hoped the home care nurse could come in often, especially at the first one month because she felt nervous and panic and was unsure that what she did was right or wrong. The time period of adaptation for Bao was around one to two month.

Financial burden was another problem. The family had 900 dollars per month of subsidization from the government, but that was not enough for a family's monthly expenditures. The fees for caring for Yi only were around 500 dollars per month and the NG diet cost around 200 dollars each month. Without further income to reduce the financial stress, Bao felt mentally and physically exhausted. Under such high pressure, she tried to remain optimistic and took one day at a time.

Bao was very proud of herself regarding learning so many care skills and knowledge. She considered herself capable of being a nurse if she had a license. In contrast, Bao lacked great expectation for her husband.

> At first I hope he can walk. But now it is impossible because his leg has weakened. He could not stand up and his feet are curled. He could not step on the floor….Now his IQ is not as good as before. He only stares at me. I could not help it. It is hard for him to have any improvements.

Lu Family: Jin and her mother Mian

The stroke survivor and family caregiver: Mian, the stroke survivor, was 91 years old and widowed. She had seven children, four sons and three daughters. They were all married expect Jin, the family caregiver. Mian had arrhythmia with regular medication control. Jin was 50 years old and single. Mian lived alone before this stroke. Jin came back every day and took care of everything for her, including her diet and medication; therefore, she naturally took on the role when Mian had the stroke. Another reason for Jin taking on the role was affection and role responsibility. She quit her job and moved back to take care of her mother.

The stroke: In August 2007, Mian had an infraction type of stroke. Because she lived alone, around 20 hours passed when Jin found her mother had lost consciousness.

She was admitted to a nearby hospital. Mian had NG tube, Foley catheter, and endotracheal tube with a ventilator treatment in ICU for 12 days; then she was moved to a general ward for 18 days. After one month hospitalization, she was discharged with NG tube. Her consciousness was in coma status and right side was paralyzed.

When Mian was moved out from ICU to the general ward, Jin had to provide cares for her mother. She felt hard pressed to care for her mother because this was her first time of encountering a seriously sick person. But she was aware that she had to care for her mother at home, so she must learn. She learned NG feeding, chest percussion, and range of motion from nurses. Nurses taught her by oral instruction and demonstrating one time. But the nurses did not recheck her performance because they were too busy. Her major way of learning ways was by watching and doing. She also learned from hearing, watching and discussing with other family members. Jin learned as many care skills as she could. But she did not learn sputum suction skill at the time of hospitalization.

However, after one month at home, Mian had difficulty breathing due to ineffective sputum cleanliness and was re-hospitalized in two hospitals for two and four months, respectively. In the first hospital, she stayed in ICU for one month then was moved to a general ward. She had ventilator respiratory therapy during the two months. The physician recommended performing a tracheostomy surgery, but the family refused. The family considered “she is so old. We don’t want her to have any cuts on her body. Just give her medication. We don’t want any further therapies. If she had any critical situation, we would give up any rescue interventions. We had signed it. Just medication! If it can save her, that’s great! If not, we want her to naturally pass away!”

Then the family transferred Mian back to a nearby hospital to continue her therapy. In the second hospital, she was in ICU for one month, then in general ward for three months. She still had endotracheal tube, ventilator and NG tube. But her endotracheal tube was removed after a six month placement. Jin was so excited about this. But Jin still hesitated to learn sputum suction skill because she could not overcome her fear feelings. She did not learn it until her mother was ready to go home. She learned it because she had to do it at home. She described her first time experience of performing suction, “At first I was afraid to do, so I did it (sputum suction) very slowly! But after having the first time experience, I had my confidence at the second time.” After a half year of hospitalization, Mian was discharged with NG tube placement and Jin felt ready to go home!

<u>The home care settings</u>: Mian’s house was a one-floor old house. Her room was in the middle and air-conditioned, and had a big window. The temperature and air were comfortable. There was a queen size bed, a chest drawer and a closet. The settings were very simple but organized. Everything was neat and clean. Jin slept with her mother at the same bed. From the observation, the bed was not suitable for Jin performing care activities. She had difficulty in changing her mother’s position. She experienced some back pain because of the bed. They once considered buying one hospital bed, but the door was not wide enough for moving the bed into Mian’s room.

<u>Care situations at home</u>: At the first time of discharge, Jin did not feel comfortable caring for her mother for a while because she was not familiar with care situations. On the other hand, the health providers did not recommend preparing a suction machine at home and she did not learn suction skill. Therefore, when Mian had sputum Jin was unable to deal with the problem effectively. She only could tap Mian’s back. Because of sputum accumulation, Mian was readmitted to hospital. Jin felt very sad about her oversight. In contrast, she felt very comfortable at the second time of discharge because she had experience. Mian’s condition was very smooth at home except one instance of diarrhea, constipation, and skin rash. But Jin didn’t think those were hard to manage.

Jin viewed caring for her mother like caring for a baby, and viewed “having the suffer thing as having a diet supplement." Jin provided attentive care and tried various ways to comfort her mother as much as possible. She massaged her mother from head to toes, did range of motion three times a day, prepared a rich food for her mother and invented a convenient and economic shampoo. Because of her diligence and efforts, she has many achievements from the caregiving experience. She was proud herself of learning so many care skills and her mother didn't have any deformities. She also invented an easy way of shampooing her mother's hair with one piece of diaper. A nursing student learned the convenient way and highly appreciated her convenient technique. But she did not have great expectation for her mother because of her age.

Ma Family: Pin and her grandmother Siu

The stroke survivor and family caregiver: Siu, the stroke survivor, was 79 years old and widowed. She had five married children, two sons and three daughters. She lived with her eldest son, eldest daughter-in-law, and her granddaughter's family, Pin. She did not have any chronic diseases except stroke. Pin, the family caregiver, was 33 years old, married and had one boy and one girl. She was a housewife before caring for her grandmother. Her reasons of shouldering the role were strong affection with her grandmother, paying back for grandmother's nursing her, and helping her father. After deciding to take on the role, she and her family moved back to live with her grandmother and her parents. Her husband and her sister-in-law helped her with some care tasks, such as bathing and suction.

The stroke: In 1999, Siu had her first stroke, a hemorrhage type, and was hospitalized for 20 days. After this stroke, her left side was weakened. But she still could take care of herself and moved with a walker. In 2001, she had a second minor stroke. Later she developed dementia and fell frequently. Therefore, she was sent to a nearby nursing home for one and half years. She had one minor stroke again in the nursing home. Her offspring often visited her but she looked unhappy and cried whenever her family visited her. In October 2007, her eldest son decided to take her back and Pin agreed to care for her. At the discharge, she was clear and could eat by mouth, but needed self-care assistance. Four months later, February 2008, she had vomiting and fever and was hospitalized for one week. She was diagnosed having the fourth stroke. In April and May, 2008, Siu was re-hospitalized twice due to UTI and vomiting. Then she had NG tube and Foley catheter placements. In September, 2008, she was re-admitted to the hospital again for one week because of ineffective coughs and sputum accumulation. Siu's health condition was gradually degenerated. She became unconscious after the second time of re-hospitalization in April, 2008.

The health providers in the nursing home did not teach Pin any care skills and knowledge. She only searched some care information from the internet and checked with her good friend, whom she called her "younger sister." She tried her own way to figure out how to perform daily activities by observing other nursing staff performing care skills. During the four times of re-hospitalizations, Pin learned some advanced care skills from nurses, such as NG feeding, chest care, range of motion, and suction. Nurses taught those skills by oral instruction and demonstration. Pin preferred to learn those skills demonstrated step by step with a slow pace. She also indicated that during the hospitalization was the best chance for learning. She learned those skills by watching and practicing. However, she had difficulty to learn sputum suction skill. She could not overcome her fear feelings of watching her grandmother's struggling when performing the suction skill. Most of the time, her husband did it, though she indicated she could do it. Regarding her grandmother's disease and treatments, the doctor did not explain clearly. Pin did not appreciate the physician's service attitude at all. Therefore, she transferred her grandmother to her sister's service hospital. She felt much better. She also felt at ease to receive and learn care information and skills from health care providers. The nurses passed some leaflets on stroke disease and care information, such as chest percussion. However, she did not think the content was helpful because it was inconsistent with the real situations.

The home care settings: The family lived in an old two-floor house located in a small village, in Ping Tong County. A big yard filled with gravels was right in front of the house. There were many rooms in the house, but the researcher only looked around Siu's room, kitchen, bathroom and living room. Like other traditional houses, there was a door sill between each room. The bathroom was small and without any grab bar installation and ramp for assessing. Siu's room had two big windows and was air-conditioned. The room air was comfortable and not smelly. Siu's bed was a hospital bed with an electronic air-mattress on it. Everything was organized and clean. Pin did not sleep with Siu during the night time.

Care situations at home: Pin experienced several difficulties from her care experience, including dealing with Siu's unexpected situation (NG tube care, fever, urinary tract infection, and vomiting), constipation and diarrhea, bathing and transferring, sputum problems, and struggling with the pressure from her father; and various negative impacts on her.

After discharge, Siu pulled out her NG tube very often. At first, Pin contacted the discharged hospital home care unit, but the home care nurse was unable to come in right away. She contacted another free standing home care agent. The home care nurse could replace the NG tube in 30 minutes to one hour. Pin very much appreciated the highly accessible in-home service. Pin solved most of her problems by asking and gaining help from the home care nurses. Thus she overcame most of the problems except three difficulties: bathing, preventing the urinary tract infection and struggling with the pressure from her father.

Pin indicated bathing was a tough work for her. Though her father modified a wheelchair as a shower chair, it did not help much during the bathing process. She experienced back injury due to inappropriately lifting her grandmother from the bed into the wheelchair. The home care nurse introduced a free bathing service. She felt that was very helpful and she could have some relaxation.

Siu had diarrhea problems after having the commercial formula. At first, Pin tried various products but it did not work. Therefore, she assumed it might be one of aging phenomena and dealt with the diarrhea by changing her grandma’s diaper again and again. The problem was unsolved until one month later; the dietitian recommended the current commercial formula. The other problem was preventing urinary tract infection. Before Siu had Foley catheter placement, Pin was very careful to prevent Siu from developing a urinary tract infection. She changed her diapers every two hours or whenever the diaper was wet. But the urinary tract infections still happened and caused Siu to be hospitalized three times. During the hospitalization, the physician and nurses educated her using cranberry juice and how to clean the Foley catheter and genital area. But she still worried the infection would happen again. She highly felt uncertainty and unable to prevent the urinary tract infections.

After Siu went back to home around a half year later, she had been re-hospitalized three times because of a recurrent stroke, vomiting, fever and UTIs. Those events made Pin’s father question her care quality. Her father’s questioning caused high pressure for her. She complained that her father misunderstood her care situations. She also complained that her father’s expectation for the grandmother was impractical, such as her father expected her grandmother could walk and speak under her care. However, Pin did not have such expectation for her grandmother. Pin considered it is hard for her grandmother to improve. Her father didn’t even appreciate her seeking outside resources, such as respite care, home care assistant service and free bathing service. Pin expected her father should support what she did. This pressure caused Pin to have severe headaches. The doctor understood her pressure, so recommended that she be hospitalized for several days as a rest for herself. But she did not really get rid of the pressure. Her phone rang all day and she had to answer the phone frequently. She felt higher pressure than at home.

Pin indicated she could stand the pressure from caring her grandmother, but she could not stand the pressure from her father. She expressed that if she had a chance to make a decision again, she would say no! But she viewed caring for her grandmother was a meaningful thing and a model for her children.

Niu Family: Tsai and his mother Lian

The stroke survivor and family caregiver: Lian, the stroke survivor, was 80 years old. She had two daughters and three sons, but her eldest son has been dead for several years. She had regular control hypertension and cholesterol. She lived with her youngest son until she developed some dementia symptoms which caused some safety concerns. Therefore, she was moved to live with Tsai, her second son and the family caregiver. After moving in to Tsai's house one month later, she fell and caused a femur fracture. She had surgery and stayed in the hospital for 19 days. After this fall she was unable to walk and was restricted to a wheelchair. She was accompanied by a Taiwanese nurse aid at home because Tsai and his wife had no time to care for her. Simultaneously, Tsai filed an application of hiring a foreign care attendant to care for her.

Tsai, the family caregiver, was 51 years old, married. He had two grown children, one daughter and one son. They were university students and not living at home. Tsai was the surviving eldest son for Lian. He viewed caring for his mother as his responsibility because his elder brother had passed away. He also strongly believed Karma was the reason for taking on the role. His elder sister-in-law was living next to Tsai's house. She looked after Lian's husband, and provided transportation for Lian. Tsai's two older sisters and younger brother visited their mother very often.

The foreign care attendant, Nancy, arrived after Lian discharged nine days. Tsai hired another nurse aid to take care for Lian until Nancy arrived. Nancy was married and had children in her country, Indonesia. This time was her second time in Taiwan, so there were no language problems for her. But she did not have elder care experience previously. Nancy learned care tasks and skills from the nurse aid in only one day.

The stroke: In March 2008, Lian had the 2nd fall. This time only some medication were prescribed for her. After taking the medications for less than two weeks, she had bloody stools and lost her consciousness. Lian was sent back to the hospital. After four days of treatment, because the hospital lacked proper treatment equipment the physician recommended transferring Lian to another medical center in Kaohsiung. At the medical center, the bleeding spot was located and she was diagnosed a hemorrhage type of stroke as well. She stayed in the ICU for around twenty days and in the general ward about ten days.

During the hospitalization, there was no available manpower in Tsai family, so he hired a nurse aid to take care of his mother. He did not learn any nursing skills during the one month in hospital. His major responsibilities were making decisions and communicating with health care providers. But he did not fully understand his mother's medication and disease conditions. Because of the limitations of hospitalization, Lian was discharged to home after one month of hospitalization. Before discharge, the health providers referred them to the Ping Tong Long Term Care Service Center. In addition, the nurses verbally provided brief food preparation and a list of care equipment and stuff the day before the discharge. Tsai didn't feel confident after having those preparations because he did not have enough time to prepare. During the hospitalization, physicians did not have any treatment for her stroke. The physician only reminded Tsai that she needed rehab therapy after going home. But they did not provide any rehab referrals. At the discharge, Lian was unconsciousness, had NG and Foley catheter placements. Her extremities were not affected by the stroke.

The home care settings: Tsai's house was a two-floor townhouse. There was a front yard. The indoor surface was smooth and no uneven surfaces. Lian's room was in the middle of the first floor. There was a big window in Lian's room, and the air was fresh. There were two general beds for Lian and the foreign care attendant, a television and a cabinet for keeping care stuffs. The settings were very simple and organized.

Care situations at home: The major challenges and difficulties at home identified by Tsai were supervising foreign care attendant, searching rehab resources, nutrition problems and lacking timely home care service. Tsai was unable to care for his mother at all. Therefore, he hired a nurse aid to care for his mother at home until the foreign care attendant arrived. He expected the foreign care attendant could provide good care. However, Nancy did not have any elder care experience and training before. This was out of Tsai's expectation. He assumed the foreign care attendants had training before being in Taiwan and were able to care. However, Nancy only had one day of learning from the private nurse aid. Therefore at the beginning, Lian had urinary tract traumas due to inappropriate care and was re-admitted to the emergency room. At the same time, Tsai found Nancy rarely informed them about his mother's problems and he had to find out by himself.

Another issue for Tsai was the urgent need to find rehab resources for his mother because the physician told him the first six months was the golden period for recovery. He tried acupuncture therapy and herbal medicine for six months. After having those treatments for one month, Lian opened her eyes and could interact with Tsai and other family members. Tsai was very excited about his mother's improvement. Except acupuncture and herb medicine, Tsai did not search for any other rehab activities for his mother because the physician did not encourage them to seek a rehab unit.

Nutrition and diet was another problem. The nutritionist recommended the commercial formula as the best food for Lian. Thus the first month, Lian only had the commercial formula, but she was very skinny. Until the home care nurse visited, she taught Tsai how to prepare a NG diet for his mother. Lian's nutrition condition was improved. Tsai indicated during the first month, they had many problems and they did not know how to manage them. He highly recommended that home care nurse should visit once a week during the first month.

Ou Family: Hua and her father-in-law Ming

The stroke survivor and family caregiver: Ming, the stroke survivor, was 71 years old and married. He had four married children, three sons and one daughter. He lived with his wife in a townhouse in Kaohsiung city. His youngest son's family lived next door. Ming had uncontrolled hypertension and arrhythmia.

Hua, the family caregiver, was 47 years old, married, and had two adolescent children, one boy and one girl. She was Ming's eldest daughter-in-law. Hua lived with her parents-in-law for around 15 years then moved to the current living place. She ran an art studio alone so her time schedule was flexible. The reasons for her to take on the role were: the responsibility of an eldest daughter-in-law and affection. But she couldn't afford a 24-hour care for Ming, so the family hired a foreign care attendant, Olive, to care for him at home. Before Olive arrived, they hired a private nurse aid to care for Ming. Olive arrived two month after Ming discharged from hospital. She was at her early 20s, unmarried. She had been in Taiwan over one year but her previous work was caring for a child. She only learned the caregiving tasks and skills with the private nurse aid in three days. Her language was not fluent enough. Ming complained her speaking was not understandable. The family had to communicate with her with gestures to enhance her understanding.

The stroke: In 2006, Ming had a minor stroke but his self-care ability was not affected. After one year he was back to his normal life. In May 2008, he had the second stroke and was sent to a local hospital for three weeks. The family was not satisfied with his treatment outcomes; they decided to transfer Ming to his previous visiting hospital, a medical center. Ming was admitted to the ICU for two weeks then moved to the general ward for ten days. The family hired a nurse aid to care for Ming because Hua didn't have time and didn’t know how to care for him. Therefore, Hua did not provide direct care. Her responsibilities were accompaniment, purchasing necessary stuffs, supervising the nurse aid and making necessary decisions. The physician arranged rehab therapy for Ming in the outpatient department. However, due to the transportation problem and time consideration, the family did not take Ming back to the hospital for rehab therapy.

Before discharge, the discharge planner provided a list of recommended care equipment for renting or purchasing and referred them to the home care unit. Hua felt those were enough for going home, especially the home care service referral. The referral reduced her worry about NG care at home. This stroke caused Ming’s left side to be paralyzed and dysphagia, but his consciousness and cognition were intact. He discharged with NG tube and Foley catheter placements.

<u>The home care setting:</u> Hua was concerned about her relationship with her mother-in-law, so she refused the researcher to visit her father-in-law. The real home care settings were not observed. From Hua’s description, Ming’s house was a townhouse and his room was at the first floor. She purchased a hospital bed, an electronic air mattress, and wheelchair when Ming discharged to home.

<u>Care situations at home</u>: Several major challenges and problems at home identified by Hua were: dealing with unexpected critical situations, and Ming’s emotional problems. She also experienced physical and psychosocial impact due to the role. During the first month after discharge, Ming had three unplanned hospitalizations due to G-I bleeding, UTI and abdominal pain. He also had two emergency room admissions due to hypertension and fever. The family joined an Emergency Medical Service Network which was provided from the discharge hospital. This was not a formal regular service for a stroke person at home; instead it was part of an ongoing experiment study. The system included a service center in the hospital and a terminal installed in patient’s home. If any unexpected situations occurred, the family could push an emergency button. An in charge person in the service center provided answers or instructions through the

telephone. If the patient was in a critical situation, the center would send out an ambulance. Hua didn't consider the system as helpful because she could not receive clear directions from the consulting person when facing emergency situation. She concluded that the best way was to go back to hospital if necessary.

Ming needed chest percussion and sputum suction during the first month. But those care activities caused him to feel pain and un-cooperative with care activities. Ming complained about his feelings and pain to Hua. Hua described, "I can understand and accept his emotions. For a common person, it is very normal to feel depressed when facing the situation. I am ok with his emotions. I can understand his feelings. He needs to talk with you." But her understanding and comforting for Ming provoked her mother-in-law's jealousy and annoyance, and worsened their relationship. Her mother-in-law assumed her husband should listen to her; however, Ming only said Ok or yes to Hua. She grumbled to other people. Hua was very bothered by this and she felt hurt by her mother-in-law's behavior.

Hua experienced multiple impact due to the caregiving role, including job, and psychological stress, as well as impact on her daily life and health daily. Hua ran her own business and she had a flexible schedule, but the caregiving job still affected her job. She had to stop her work whenever Ming had unexpected conditions. Another influence was psychosocial and physical stress on her and her daily life. She worried and had to be ready for any critical situation anytime. The stress affected her sleeping and health. The impact took around three months for Hua to adjust herself to the care situation.

With her caregiver role, she handled all of the matters for her father-in-law. Her other family members never disagreed with her. But she didn't think she had the absolute authority to do this. The reason was other family members were too busy to manage Ming's problems. Thus Hua always called and reported to her brothers-in-law before purchasing something and making a decision. In addition, she also lacked support from other family members. Hua did not have great expectation for her father-in-law. She considered Ming's situation was too serious, so it was hard for him to improve.

> I hope he can go outside with a wheelchair. That's all that I expect. If he can do this, that sounds good for him! Because his condition is so severe! ....of course I hope he can live longer, but we have a mental preparation!

Pan Family: Chiou and her husband Lin

The stroke survivor and family caregiver: Lin, the stroke survivor, was 74 years old. He did not have any chronic diseases but he smoked before this stroke. Chiou, Lin's wife and the family caregiver, was 57 years old. She had diabetes controlled with oral medications. They had four children, three daughters and one son. Two daughters were married. Their daughter was concerned with Chiou's health situation, so they did think about institutional care for Lin. Thus Chiou and her daughters visited some long-term care facilities. But Chiou decided to take care of her husband at home because she did not appreciate the instructional care at all. The major reasons for her to take on the role were their strong affection, Karma, and financial concern. Their good affection was the key reason for Chiou to take on the role.

The stroke: In November 2007, Chiou and Lin visited their relatives in Zhe Jiang, Mainland China. Lin had a hemorrhage stroke over there. He was sent to a nearby hospital for one day; then transferred to another hospital for ten days. Chiou was not satisfied with the treatment and Lin's condition looked very serious. Chiou hoped he could go back to Taiwan alive. She decided to take his husband back. They had a three days hard journey by ambulance, boat and airplane from Zhe Jiang back to Taiwan. The third day they flied back to Taipei and Lin was admitted to one medical center for 40 days. Their eldest daughter was a soldier. Because of the political issues, she could not visit Mainland China. She pleaded to her colleague in planning the transferring journey. During the transferring process, Chiou requested a physician and a nurse accompany with them. She spent lots of money for the journey. She said, “I have no choices. We want to go home!” “Without my eldest daughter’s back up, we couldn’t be home!”

His situation recovered very well. He was clear but had a little difficulty speaking and swallowing. Lin also had rehab therapy for ten days. Due to the limitation of the length of hospitalization, Lin was transferred back to a nearby hospital in Ping Tong for further rehab therapy of one month. His progress was very positive. He could stand and walk except for left side weakness. He still had a NG tube for feeding and having medications. However, only seven days after discharge Lin started to pant. He was re-admitted to a nearby hospital again. In the emergency room, a nurse withdrew arterial blood from his left femur artery for blood gas check. His left leg swelled seriously right after the withdrawing and the situation inflated to whole left side few days later. The physician denied the swelling was caused by the blood withdrawal. Nevertheless, Lin was unable to stand up again due to this issue. His skin near the external genital organs was festered. The situation was not improved after 15 days of treatment. The physician recommended transfer to one medical center in Kaohsiung City and he had 14 days of treatment. At this discharge, Lin had NG tube placement and urinary bag. He was clear but very frustrated about his physical disaster due to the medical mistreatment. Chiou was extremely resentful at the mistake.

Chiou provided cares for Lin in the hospital. She learned bathing, NG feeding and care, change positions, chest percussion, sputum suction, wound care, range of motion and how to applying urinary bag and manual fecal stool removing during the long term of staying in hospital. The daily activities care skills were not difficult to learn for Chiou. But she felt some difficulties to change Lin’s clothes at the beginning. She learned NG care and feeding, changing position and chest percussion primarily by watching, doing and thinking. The major reasons motivating Chiou to learn those skills were “need to do at home”, and the health care provider’s uncomfortable service manner and attitude. She indicated nurses never actively taught her how to perform those skills because they were always busy and they wouldn't response to calls for a long time. After learning those skills and 4 months of care experience in the hospital, Chiou thought there was no difficulty for her to care for Lin at home.

At the first time discharge, Lin's condition was very fine. He was clear and could walk except his left side was weakened and he needed NG feeding. The health care providers did not provide any necessary information. After being home, Chiou found the traditional bed was extremely inconvenient for feeding and care. Therefore, Chiou purchased a hospital bed when the second time discharged. The second time of discharge, the health providers did not give the necessary information, including equipment and home care service referral, either.

<u>The home care setting:</u> The family lived in a rural village, Ping Tong County. It took one hour from Kaohsiung City. Their houses were two buildings: the old one was a two-floor building at the front and faced a small country road; the new one was a two-floor one right behind the old building. After they moved into the new home, the old building was used as storage only. Lin's room was on the first floor of the old building. This room was a living room before. There was a French window in the front and a rear door connected to their previous kitchen and their new house. Though it looked old, the room air and temperature was cozy and fresh. From Lin's bed, he could view outside through the window. Chiou said, "Because our room only has one window, the air ventilation is not so good and it is somewhat dark. So I prefer he stays in this room. He can look outside and see some neighbors." There was a hospital bed with an electronic air mattress for Lin, and a wood board covered with straw mat as Chiou's bed. There were a suction machine and many care stuffs orderly kept in two cabinets and one small table. Everything was neat. Right behind Lin's room there were their previous kitchen, a small bathroom and an open space connecting to their new house. There was a one-foot step needed to walk up from the open space to their new house. On the right side of the house, a half-person high wall surrounded and separated their house from a farm. Chiou usually

gave a shower to Lin at the open space if the temperature was warm. If not, her son had to help her lift Lin up to the step and wheel him to the bathroom in their new house.

Care situations at home: Chiou indicated several difficulties and challenges at home, including, NG tube care, transportation, transferring, bathing, and skin care. At first, Lin often pulled out the NG tube at home. Because the hospital did not refer home care service to them, so when this happened she had to take Lin back to the hospital for replacement. However, taking Lin back to the hospital was the most difficult problem for Chiou because Lin's body was so rigid and it was hard to transfer Lin into a wheelchair and then into their own car. Chiou had to ask her son or daughter for help. Later a medical equipment store person introduced a home care agent to her. After receiving the home care service, Chiou felt much more relaxed. In addition, the home care nurse introduced paratransit service to her. Now she felt greatly relieved from the stress.

But according to the regulation, only twice a month of home care services can be reimbursed from the National Health Insurance. If more than two times of services, the family has to pay off the fees. Lin often replaced his NG tube over two times per month. Chiou concerned the service fees and sometimes the home care nurses could not provide timely service. Therefore, Chiou decided to learn it. She watched how home care nurses did it and tried it at home alone. She worried that some accident might happen, so she avoided replacing the tube as much as possible.

In addition, Chiou also indicated bathing and assisted Lin transferring was difficult because Lin's body was rigid. She indicated that his body became harder and harder to move and she feared a fall during the process. She had to wait for her son or daughter to help her.

Lin did not have any serious wounds, but because his skin was too fragile so he often had scratches or small wounds when Chiou transferred him to the wheelchair or shower chair. Chiou learned wound care information from the staff in a medical equipment store. She showed various gauzes and wound ointment to the researcher and explained how to pick a better dressing and ointment based on the skin condition. “If he has a scratch, just apply this (transparent) dressing. It can protect his skin.” “Have a wound! Use this first (wound ointment), then when it is almost recovered just use the dressing (another one)!” Because her wound care was so excellent, so a health station nurse introduced a family member to visit her and learn how to care for a wound.

From this experience she concluded that whenever facing problems, asking someone to learn useful information was important. She did her best to take care of her husband. She purchased care materials as best as possible if she could afford them. She said, “Money can die, people can’t die.” Furthermore, Chiou indicated many caring ways modified by herself to improve the care outcomes. For example, Lin required a change of position every two hours and needed pillows to support his position. Chiou tried various types of pillows; but those were not easy to support his position. Therefore, she made different size of pillows from used pants to fit different body regions. Those pillows worked much better than the others.

After long-term care, Chiou had severe back and shoulder pain. She worried she might not be able to provide care for her husband any further. In addition, she did not have any expectations for Lin. She didn’t think Lin was able to make any improvement.

Ran Family: Quan and her father-in-law Chuan

The stroke survivor and family caregiver: Chuan, the stroke survivor, was 76 years old, and had four married children, two daughters and two sons. He had hypertension that was not well controlled. Quan, the family caregiver, was 42 years old. She was Chuan’s eldest daughter-in-law. She took on this role because of the responsibility of the eldest daughter-in-law, and good relationship with Chuan. But she wouldn’t quit her job to provide 24 hours of care for Chuan. Therefore, they hired a foreign care attendant, Rachel, to take care of Chuan. Before Rachel, the family hired a nurse aid to provide care for three months. Chuan’s wife, elder daughter, and youngest son visit him frequently and they also shared the caregiving responsibilities. His youngest son was responsible for picking up medications from the hospital.

Rachel was married and had two children. She was the second time in Taiwan, but she was inexperienced caring for a stroke person. She learned the majority of caregiving tasks and skills from the private nurse aid for ten days. Rachel could not communicate fluently in Chinese. The family members had to communicate with gestures and spoke slowly to ensure her understanding. In addition, Chuan's second daughter-in-law was an Indonesian. At the first 3-4 days after discharge, she was responsible for communicating with Rachel to ensure her understanding. She wrote down a schedule of daily care activities in Indonesian on a poster and hung it on a wall. Quan also asked the manpower agent to confirm her care abilities.

<u>The stroke</u>: Chuan had two strokes in 2002. The first one was a minor stroke and did not cause any health concerns or self-care problems. At the second stroke, he had some significant impact: his right side was weakened, his mouth was askew to one side and his extremities were uncoordinated. Those functional impacts caused Chuan's speaking unclearly and difficulty walking. He still could do all self-care for himself, but other family members had difficulty of understanding his speaking. They had to guess what he said. In May 2008, Chuan had the third stroke and was hospitalized in a medical center for two weeks. At this hospitalization, he was diagnosed with diabetes. During the first two days of admission, Chuan was clear but had difficulty swallowing. At the third day, he choked and caused aspiration phenomena. He became confused and had a NG placement. He discharged with a NG tube placement.

During the two weeks of hospitalization, his family members took turns taking care of him for one week. Later they hired a private nurse aid to care for him because the family members had to work. Quan and other family members learned care skills, including bathing, changing diapers, NG feeding and care, sputum suction and range of motions. She learned the basic caregiving skills primarily from student nurses and their teacher. She appreciated the learning process because she had more instances of demonstrations from students and their teacher and the pace was slow. She felt little pressure from the learning process. The nurse taught the NG feeding and suction by demonstration and oral instruction. She felt nervous and had difficulty the first time of performing the NG feeding skill. “A little bit nervous because she (nurse) said: don’t let the (NG) tube empty, otherwise the air could go inside! Now I am skilled at it so I feel better.” After having aspiration pneumonia, Chuan needed suction to clean his sputum. However, Quan and other family did not learn the skill in the hospital because but after going home,

> They taught me how to suction but I just watched. I didn’t learn it. This is a more difficult skill for me, so I just took a look. And I didn’t have motivation to learn it because my other family members all ran away every time the nurse mentioned about learning suction. So do why I have to learn that? At least one of you should learn it with me. No! All of them ran away! So I decided not to learn! Ok, let none of us know how to do it.

Quan still needed to perform suction skill. She learned the skill from her private nurse aid. She described her first time experience: “I was afraid of inserting the suction tube too deep and damaging his throat or pulling out his NG tube.”

Quan only learned range of motion as rehab therapy. The physician didn’t think Chuan needed any rehab therapies and didn’t refer further rehab therapy either. In addition, Quan didn’t think the physician explained Chuan’s disease and health situations very clearly. Thus she didn’t thoroughly understand her father-in-law’s therapies and disease conditions. Some possible reasons were identified by Quan: the physician’s arrogant attitude, lack of sufficient time for asking questions because they were busy learning how to do the care, and the family had no idea how to ask questions in an unfamiliar situation. Before discharge, the discharge planner provided a list of recommended care equipment, social welfare information and home care referral. The home care referral reduced her worry about the NG tube care. Quan felt ready to go home.

Furthermore, they still hired a nurse aid providing care at home, so Quan felt less stress at the early discharge.

The home care settings: Before the third stroke, Chuan lived with his wife in his own house and his room was on the 3rd floor. With consideration of a convenient care environment, Chuan was discharged to Quan's house. He stayed in the living room, on the first floor. There was a hospital bed next to a big window. A suction machine and some caring stuff were organized and set on both sides of the bed. Next to Chuan's bed, there was an L-shape sofa as the foreign care attendant's bed. A TV set was on the opposite side, so Chuan could watch TV from his bed. A big cabinet separated the living room from their kitchen. The room was air-conditioned and the air and light were comfortable.

Care situations at home: The major challenges identified by Quan were family communication and decision making, Chuan's emotion and NG tube care, diet preparation, and pressure from other family member. When Chuan had aspiration pneumonia, the physician recommended placing a NG tube. However, the physician did not provide clear explanation to family members. Quan had to re-explain the situations again to other family members. Quan felt it was very weird for her to retell the information because she didn't fully understand the situation as well. She recommended that the physician should give a thorough explanation to the key family members through a family meeting to avoid any misunderstandings.

Chuan's consciousness was unclear and his emotions became unstable after this stroke. Thus he often pulled out his NG tubes. Quan put an unbendable mitten on his hand to prevent his NG from being pulled out again. His frequent pulling out of the NG tube caused high mental pressure for Quan because other family members would question their care. She was unhappy with other family members' attitude and questions. Regarding the diet, Quan considered the expenditures for purchasing the commercial formula and was concerned about the nutrition. Thus she prepared the diet by herself. A nutritionist passed one sheet and taught Quan measuring the food by gram verbally. Quan wandered how she could measure the food by gram every time. On the other hand, in general family members often experienced a time period of testing on how to prepare an appropriate thickness food for NG feeding. But she didn't experience this because one of her private nurse aids taught her how to prepare the food at home.

Chuan's first critical situation was gastric bleeding just after one week discharge. The bleeding was due to aspirin. Chuan was admitted to the emergency room for one night. Two other unexpected situations were having a fever due to a cold. Quan indicated that before discharge medical staff noticed that he might have a fever because he had some sputum; but they did not notice that aspirin might cause gastric bleeding. Quan expressed that dealing with unexpected situation was the most difficult one because of the unknowing. She indicated that if the situations had been told before discharge, she would have been more prepared to deal with. Quan viewed her father-in-law's stroke experience as an example for her own family regarding how to prevent a stroke. However, Quan lacked great expectation for Chuan.

APPENDIX G

SUMMARY FOR PARTICIPANTS' CHARACTERISTICS AND CARE SITUATIONS

Table G-1: Stroke Survivors' Characteristics and Care Situations

							Hospitalization		
Name	Gender	Age	# of stroke	Type	Previous disease(s)	Control	Length of stays$^{\$}$	ICU*/ Ward and RCW	Cared for by
Mei	F*	90	1	I*	Unknown	n/a	2 wks*	1 wk /1wk	CG +FL
Ying	F	73	2	H *	HT*, DM*	+	28 days	1 wk / 3 wks	FL
Sing	M*	60	4	I	HT	-	15 days	0/15 days	CG
Wen	F	47	3	H	DM	+	3 mths*	2 mths / 1 mth	CG
Mi	F	67	1	H	HT, DM	-	3 mths	1 mth /2 mths	CG+FL
Ji	F	67	1	H	HT, DM	+	1 mth	15 days /20 days	CG+FL
Yu	F	62	3	I	HT, DM	-	5 mths	0/ 5 mths	FL
Rou	F	71	1	I	Unknown	n/a	6 days	0/ 6 days	FL
Siong	M	67	2	I	DM, HD*	+	2 mths	0/ 2 mths	CG
Yi	M	61	1	H	HT	-	3.5 mths	1mth /2.5 mths	CG
Mian	F	91	1	I	Arrhythmia	+	1 mth	12 days/ 18 days	CG
Siu	F	79	4	I	HT	-	1 wk	0/1 wk	CG
Lian	F	80	1	I	HT	+	1 mth	20 days/ 10 days	FL
Ming	M	71	2	I	Arrhythmia	-	1.5 mths	1mth/ 15 days	FL
Lin	M	74	1	H	Smoking	-	3 mths	2 mths / 1 mth	CG
Chuan	M	76	3	I	HT, DM	-	2 wks	0 / 2wks	FL

* F: female; M: male; I: Infarction, H: Hemorrhage; HT: Hypertension, DM: Diabetes Mellitus, HD: Heart Disease; RCW: respiratory care ward or unit; wk: week, mth: month; NA: Nursing aid; CG: family caregiver; FL: foreign laborer; ICU: Intensive care unit; NG: nasal gastric tube; FP: diet is prepared by family caregiver. CP: canned prepared food

$ Transfer: stroke survivors experienced transfer for current stroke; Length of stay: the total length of stay for current stroke in hospitals, including the length in respiratory care ward and /or in rehabilitation unit.

** +: affected or placement or having this problem; - : non-affected or without this placement or problem n/a: not applicable

Table G-1 continued

	Impact due to stroke				Major care problems at home				Diet	Improved
Name	Swallow	Lim	Recognition	Consciousness	NG*	Foley	Trachea	Wound		condition
Mei	+**	Left	-**	Clear	+	-	-	-	P*	NG
Ying	+	Left	-	Clear	+	-	-	-	R*	
Sing	+	None	+	Clear	+	-	-	-	P+R	
Wen	+	Both	+	Coma	+	-	-	+	R	
Mi	+	Right	+	Coma	+	+	+	-	R	
Ji	+	Right	+	Confused	+	+	-	-	P+R	Swallow, speaking
Yue	+	Left	+	Confused	+	-	+	+	R	Wound
Rou	+	Left	-	Clear	+	+	-	+	P	NG, Foley, Wound
Siong	+	Left	+	Clear	+	-	-	+	P+R	Wound
Yi	+	Right	+	Confused	+	+	+	+	P+R	Wound
Mian	+	Right	+	Coma	+	-	-	-	P+R	
Siu	+	Left	+	Coma	+	+	-	-	R	
Lian	+	None	+	Confused	+	+	-	-	P+R	
Ming	+	Left	-	Clear	+	+	-	-	R	
Lin	+	Left	+	Clear	+	-	-	+	R	Wound
Chuan	+	Right	+	Confused	+	-	-	-	P	

* F: female; M: male; I: Infarction, H: Hemorrhage; HT: Hypertension, DM: Diabetes Mellitus, HD: Heart Disease; RCW: respiratory care ward or unit; wk: week, mth: month; NA: Nursing aid; CG: family caregiver; FL: foreign laborer; ICU: Intensive care unit; NG: nasal gastric tube; FP: diet is prepared by family caregiver. CP: canned prepared food

$ Transfer: stroke survivors experienced transfer for current stroke; Length of stay: the total length of stay for current stroke in hospitals, including the length in respiratory care ward and /or in rehabilitation unit.

** +: affected or placement or having this problem; - : non-affected or without this placement or problem n/a: not applicable

Table G-1 continued

Name	# of medicine	Caregiving equipment and assistant devices	# of unplanned hospitalization	Reasons & length of stay	# of ER admission	Reasons
Mei	6	Bathing chair, wheelchair	0		0	
Ying	5	Hospital bed, wheelchair	0		2	• Chest pain and sputum • Diarrhea
Sing	7	Wheelchair	1	UTI/ 1 week	1	• Hypotension
Wen	9	Air mattress, suction machine, wheelchair	1	• Brain tumor /3 months	0	
Mi	5	Hospital bed, air mattress, suction machine, O_2, Steam inhalation machine, wheelchair	1	• Sputum/ 2 days	0	
Ji	7	Hospital bed, air mattress, suction machine, O_2, Steam inhalation machine, wheelchair	0		1	• Foley catheter obstruction • UTI
Yue	3	Hospital bed, air mattress, suction machine, O_2	0		0	
Rou	6	Wheelchair, bathing chair	1	• Diarrhea/ 1 day	1	• Diarrhea

* F: female; M: male; I: Infarction, H: Hemorrhage; HT: Hypertension, DM: Diabetes Mellitus, HD: Heart Disease; RCW: respiratory care ward or unit; wk: week, mth: month; NA: Nursing aid; CG: family caregiver; FL: foreign laborer; ICU: Intensive care unit; NG: nasal gastric tube; FP: diet is prepared by family caregiver. CP: canned prepared food

$ Transfer: stroke survivors experienced transfer for current stroke; Length of stay: the total length of stay for current stroke in hospitals, including the length in respiratory care ward and /or in rehabilitation unit.

** +: affected or placement or having this problem; - : non-affected or without this placement or problem n/a: not applicable

Table G-1 continued

Name	# of medicine	Caregiving equipment and assistant devices	# of unplanned hospitalization	Reasons & length of stay	# of ER admission	Reasons
Siong	9	Hospital bed, air mattress, suction machine, O_2, Steam inhalation machine, wheelchair	4	• Hypoglycemia /2 months • Pant 3 times: 1month/17days/1month	1	• Pant
Yi	7	Hospital bed, air mattress, suction machine, O_2, Steam inhalation machine, wheelchair	3	• Sputum and spasm /20days • Gastric bleeding/ 26 days • Fever/14 days	2	• Fever/ UTI
Mian	5	Suction machine, O_2, wheelchair	2	• Pant and sputum/ 6 months • Diarrhea/ 1 week	0	
Siu	7	Hospital bed, air mattress, suction machine, wheelchair bathing chair	3	• Vomiting/ 1 week • UTI/ 1 week • UTI/ 1 week	0	

* F: female; M: male; I: Infarction, H: Hemorrhage; HT: Hypertension, DM: Diabetes Mellitus, HD: Heart Disease; RCW: respiratory care ward or unit; wk: week, mth: month; NA: Nursing aid; CG: family caregiver; FL: foreign laborer; ICU: Intensive care unit; NG: nasal gastric tube; FP: diet is prepared by family caregiver. CP: canned prepared food

$ Transfer: stroke survivors experienced transfer for current stroke; Length of stay: the total length of stay for current stroke in hospitals, including the length in respiratory care ward and /or in rehabilitation unit.

** +: affected or placement or having this problem; - : non-affected or without this placement or problem n/a: not applicable

Table G-1 continued

Name	# of medicine	Caregiving equipment and assistant devices	# of unplanned hospitalization	Reasons & length of stay	# of ER admission	Reasons
Lian	6	Air mattress, wheelchair	0		3	• Hematuria • Hematuria • Hematuria
Ming	Unknown	Hospital bed, air mattress, suction machine, wheelchair	3	• Gastric bleeding/ 1 week • UTI/ 1 week • Abdominal pain/ 1 week	2	• Blood pressure • Fever
Lin	5	Hospital bed, air mattress, suction machine, O_2, wheelchair, bathing chair	1	• Pant & sputum/ 1 month	0	
Chuan	10	Hospital bed, air mattress, suction machine	0		1	• Gastric bleeding

* F: female; M: male; I: Infarction, H: Hemorrhage; HT: Hypertension, DM: Diabetes Mellitus, HD: Heart Disease; RCW: respiratory care ward or unit; wk: week, mth: month; NA: Nursing aid; CG: family caregiver; FL: foreign laborer; ICU: Intensive care unit; NG: nasal gastric tube; FP: diet is prepared by family caregiver. CP: canned prepared food

$ Transfer: stroke survivors experienced transfer for current stroke; Length of stay: the total length of stay for current stroke in hospitals, including the length in respiratory care ward and /or in rehabilitation unit.

** +: affected or placement or having this problem; - : non-affected or without this placement or problem n/a: not applicable

Table G-2: Characteristics of family caregivers

Name	Role *	Gender	Age	Married Status	Religious	Relationships	Education level	Quality of Relationship	Care before
Ju	S+P*	F *	58	Widower	Buddhism	Daughter	Primary	Excellent	Yes
Huo	S	M*	77	Married	Taoism	Husband	Junior college	Excellent	Yes
Zu	P	F	55	Married	Taoism	Wife	Primary	Poor	Yes
Jen	P	F	27	Single	Buddhism	Daughter	University	Good	Yes
Siang	S+P	F	38	Married	Taoism	Daughter-in-law	Junior high	Excellent	Yes
De	S+P	M	38	Married	Taoism	Son	Junior high	Excellent	Yes
Ya	S+P	F	44	Married	Buddhism	Daughter	Junior college	Excellent	No
Chin	S	F	37	Married	Taoism	Daughter	Senior high	Poor	Yes
Hui	S	F	44	Married	Taoism	Daughter-in-law	Senior high	Excellent	Yes
Zong	P	M	36	Married	Buddhism	Son	University	Excellent	Yes
Bao	P	F	60	Married	Buddhism	Wife	Primary	Excellent	Yes
Jin	P	F	50	Single	Buddhism	Daughter	Junior high	Excellent	Yes
Pin	P	F	33	Married	No	Grand daughter	Senior high	Good	No
Tsai	S	M	51	Married	Buddhism	Son	Junior college	Excellent	Yes
Hua	S	F	47	Married	Taoism	Daughter-in-law	Senior high	Good	Yes
Chiou	P	F	57	Married	Taoism	Wife	No formal education	Excellent	Yes
Quan	S	F	42	Married	Taoism	Daughter-in-law	Senior high	Good	Yes

* Role indicates the family member's role in the caregiving situation; S: Supervising the hired foreign laborer; P: Providing direct cares; F: female; M: male; FL: foreign laborer; FM (1): the number of other family members who can help.

Table G-2 continued

Name	Current Job	Job impacted	Health before	Health after	Disease	Helper (numbers)	Discharge to 1st interview
Ju	Part time	Yes	Good	Good	No	FL*	3 months
Huo	Retired	No	Excellent	Excellent	No	FL	2.5 months
Zu	Housewife	No	Excellent	Good	Thyroid	FM* (2)	4 months
Jen	Part time	Yes	Excellent	Excellent	No	FM (2)	6 months
Siang	Full time	Yes	Excellent	Excellent	No	FL+ FM (1)	20 days
De	Full time	Yes	Excellent	Excellent	No	FL+FM (1)	20 days
Ya	Housewife	No	Good	Good	No	FL	5 months
Chin	Housewife	Quit	Fair	Poor	No	FL	4 months
Hui	Housewife	No	Fair	Fair	HT	FL	4 months
Zong	Full time	Yes	Excellent	Excellent	No	FM (1)	11 months
Bao	House wife	No	Good	Good	DM	FM (2)	9 months
Jin	No	Quit	Excellent	Excellent	No	No	11 months
Pin	Housewife	No	Poor	Poor	No	FM (1)	11 months
Tsai	Full time	Yes	Good	Good	No	FL	5 months
Hua	Full time	Yes	Good	Fair	No	FL	2 months
Chiou	Housewife	Yes	Excellent	Poor	DM	FM (2)	7 months
Quan	Full time	Yes	Good	Good	No	FL	5 months

* Role indicates the family member’s role in the caregiving situation; S: Supervising the hired foreign laborer; P: Providing direct cares; F: female; M: male; FL: foreign laborer; FM (1): the number of other family members who can help.

APPENDIX H

TYPICAL HOUSE MODELS IN TAIWAN

A. Traditional House Building (San-Ho-Yuan)

B. Townhouse

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