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THE HONG KONG POLYTECHNIC UNIVERSITY

SCHOOL OF NURSING

A COMMUNITY-BASED

AND

FAMILY-CENTERED CARE APPROACH

FOR STROKE SURVIVORS IN WUHAN CITY OF CHINA

LI SI JIAN

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNDER THE SUPERVISION OF PROFESSOR SAMANTHA PANG

& PROFESSOR THOMAS WONG

OCTOBER, 2005

PART I



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CERTIFICATION OF ORIGINALITY

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_____(Signed)

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The thesis entitled <u>'A Community-based and Family-centered Care Approach for</u> <u>Stroke Survivors in Wuhan City of China'</u>

submitted by Li Sijian

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Abstract

Stroke is a leading cause of residual disability. Many stroke survivors have to be dependent on their family members, leading to increasing burdens of care after discharge home. This study aimed to explore the kinds of care issues encountered by families living with stroke in Wuhan, China, the different ways in which they deal with these issues, and how such differences impact on the well-being of the families.

Yin's multiple-case (embedded) study design was used. Underpinning this inquiry process was replication logic, in which each family was seen as a single case analogous to a single experiment, and multiple cases were analogous to replicating the study in different families. A protocol that materialized the study proposition was used to guide data collection. The embedded units within each case comprised stroke-related disability, care issues, perceived burdens, coping resources and caring work. The case study was conducted prospectively, so that each family was visited at four time points over a period of six months after discharge. Cases were selected according to the predicted patterns based on the proposition. Eighteen families, including both stroke survivors and their family caregivers, were recruited from three comprehensive hospitals in Wuhan city. Data collection began when the stroke survivors were due to be discharged, and thereafter at one week, one month, three months and six months after discharge, in the survivors' homes. Multiple sources of data were collected over time, including demographic and socio-economic data, the Short Portable Mental Status Questionnaire (SPMSQ), the Barthel Index (ADLs), the Instrumental Activities of Daily Living (I-ADL), the Self Evaluation of General Health (SEGH) and The Center for Epidemiologic Studies Depression Scale (CES-D). At each home visit, field observations and semi-structured interviews with the stroke survivors and family caregivers were conducted. A pilot study of two cases was conducted to refine the study protocol prior to the main study of 18 families.

Overall analysis revealed that optimal family well-being was characterized by (a) mobilization of positive personal coping resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Families who failed in part or in whole to maintain these four features were considered as having functional or dysfunctional well-being. Of the 18 families, seven were able to maintain optimal family well-being

and one remained functional during the study period. Ten families had their family well-being changed over time, with eight families experiencing negative change and two families positive change. The results are informative in enabling nurses to derive culturally-sensitive and community-based care strategies to help families living with stroke in Wuhan, China.

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Chapter One

Introduction

Stroke is the second most common cause of death in China and the most common in Wuhan. With the development of advanced medical technology, the chance of survival with some degree of residual disability is increasing. Organized inpatient (stroke unit) care in multidisciplinary stroke units can reduce these adverse outcomes compared with less organized inpatient care (Stroke Unit Trialists' Collaboration 2001). The stroke unit is a form of an organized inpatient care for stroke patients which is provided in hospital by nurses, doctors and therapists who specialize in looking after stroke patients and work as a coordinated team. Patients who receive this care are more likely to survive their stroke, return home and become independent in looking after themselves (Stroke Unit Trialists' Collaboration 2001, Phillips et al. 2002, Legg et al. 2004a, 2004b). It aims to reduce stroke-related disability for survivors, the burden of care in their families, and the considerable costs for health and social care services (Warlow et al. 2001).

Although the stroke unit is considered as the gold standard of care in developed countries (Legg et al. 2004a), and the effectiveness of its treatment for acute stroke patients is well-documented (Stroke Unit Trialists' Collaboration 2001), in the Chinese context this stroke unit model is practiced only in the form of pilot projects in some hospitals in Beijing (Wang 2001, News 2004). Individuals who experience a stroke are

usually admitted to hospital and cared for by health care providers during the acute stage, i.e. until their medical condition becomes stable. Multidisciplinary team work and planned rehabilitation programs are few, and pre-discharge advice and planning is limited merely to advice regarding medication compliance and regular exercise. The family is the major source of help and support for stroke survivors. No systematic study has been reported in China or in the local community of Wuhan regarding the experience of survivors living with their residual disability and the care experience of family care providers after discharge home.

In China today, the traditional Chinese family virtue of caring and respecting the old is being challenged. While families continue to play a significant role in the support and care of anyone in difficulty or in need, social and economic changes affect the willingness and ability of the family to provide care and support at home (Leung 1997), especially for individuals surviving from stroke after discharge home (Li & Chi 2000). Since the late 1980s and early 1990s, Chinese government policies have started to focus on health care reforms and place an emphasis on developing a community-based health care service. However, community-based health care providers have not given sufficient recognition and responded to the needs of stroke survivors and their families after discharge home. No special home visits or supportive programs have been found that directly aim at assisting families living with stroke in the home care setting, particularly helping them deal with residual disability and the perceived care burdens and psychosocial effects. The following anecdote serves as a trigger for the concerns I would like to raise in this prospective multiple-case study on stroke care phenomenon in Wuhan China.

I was visiting a neurological department in a local comprehensive hospital, which affected me deeply at a time when a patient was waiting for discharge home following stroke. This experience has remained in my mind and motivated me greatly in choosing this topic, which assists me in understanding how family support and family care are changing in present-day China due to unplanned home discharge.

I saw a 76-year old stroke survivor in bed without any movement. His eyes were so lifeless that it seemed that he was still not recovered from the shock of stroke. The family was going to carry him home. His two sons stood silently beside the bed, while his daughter was busy dressing him. After dressing him, they made great efforts to lift him up from the bed. Because he was unable to move independently, the two sons had to carry him in turns, one squatting on his heels waiting, the other son trying hard to hold his father up. He was either too heavy or too weak... When he leaned on the shoulder of his son, his body was almost out of control and swung to one side, his arm suspended and swinging heavily. What was more, his sons could not bear his weight, and looked as if they were going to fall down. Alas! I watched this scene with great astonishment, worrying that he would slip off his son's shoulder. Then, in my mind, another scene emerged: I imagined the son dropping his father heavily onto the bed, and the whole family busying in and out, all around the father. Would any accidents happen

after his discharge home? Who would be the family caregivers? How would they take care of the patient while he was unable to move? What kind of care would they provide for him? What assistance might they need after his discharge home?

The above scenario illustrates that the patient's medical condition of stroke was stable, but functional limitations still remained. His sons and daughter were not well prepared to take care of their father, who needed assistance and depended upon the daily care of the family. Medical costs were high and the family was unable to afford the continuing medical fees for his hospital stay. Only acute medical care was received, and no rehabilitative care or guidance was provided by healthcare professionals before discharge. It is envisaged that home care for survivors following stroke is challenging for those who take on the responsibility of providing care for their loved one who is dependent after returning home.

Numerous studies have been reported in other parts of the world on post-stroke experience of survivors and the care experience of family caregivers. Quantitative studies on the post-stroke experience of survivors have shown the effect of post-stroke residual disability, post-stroke depression and psychological well-being on survivors and how they cope with the problems after discharge home (Gresham et al. 1979, Labi et al. 1980, Dejong & Branch 1982, Skilbeck et al. 1983, Kotila et al. 1984, Wade & Hewer 1987, Kelly-Hayes et al. 1989, Muro et al. 2000, Lincoln et al. 2000, Feibel & Springer 1982, Weddell 1987, Fuh et al. 1997, Beekman et al. 1998, Wyller et al. 1997,

1998, Evans & Northwood 1983, Thompson et al. 1989, Colantonio et al. 1993, Rochette & Desrosiers 2002). These studies have documented that stroke is the major cause of residual disability that most people living with stroke are older adults and experience emotional disorder, such as anxiety, depression, frustration, and despair, and that the pattern of functional recovery mostly happens in the first six months following a stroke, but is still dependent upon the severity of neurological impairment. Social support plays an important role in promoting an optimal functional recovery because the necessary information and emotional support will enhance their personal ability to copy with problems effectively.

Quantitative studies on family caregivers, on the other hand, have primarily focused on the nature of relationship between the caregivers and survivors, the characteristics of caregivers (e.g. age, gender), the characteristics of stroke survivors (e.g. age, personality, and level of activities of daily living), and how these factors affect caregiver's health and psychosocial well-being (Stroker 1983, Silliman et al. 1986, 1987, Wade et al. 1986, 1987, Carnwath & Johnson 1987, Macnamara et al. 1990, Williams 1993, 1994, Anderson et al. 1995, Draper et al. 1995, Segal & Schall 1996, Bethoux et al. 1996, Dennis et al. 1998, Lee et al. 1998, Scholte et al. 1998, Bugge et al. 1999, Nillsson et al. 2001, King et al. 2001, Teel et al. 2001, Morimoto et al. 2001, 2003). These studies report problems related to caregiver burden, anxiety, depression, physical health, decreased marital relationship, social life limitation, and finances. In the qualitative studies on stroke survivors, the study areas have been primarily the experience of stroke, recovery and residual disability, and living with stroke-related disability. These studies are concerned with the perspective of stroke survivors' physical and psychosocial changes over time, and how they deal with such changes by using ways to enhance their body strength and movement (Dolittle 1991 1992, Folden 1994, Haggstrom et al. 1994, Nilsson et al. 1997, Pound et al. 1998, Pilkington 1999, Burton 2000a, 2000, Bays 2001, Hilton 2002).

Finally, the qualitative studies on family caregivers have frequently examined family caregiving experiences, care issues and management strategies of families living with stroke and the impact of stroke on the well-being of families living with stroke. They report that caring for an individual with residual disability and post-stroke depression impacts the family caregivers' lives both positively and negatively (Mumma 1986, Periard & Ames 1993, Folden 1994, Davis & Grant 1994, Jongboloed 1994, Robinson-Smith & Mahoney 1995, Fraster 1999, Eaves 2000, 2002, Brereton & Nolan 2000, Secrest 2000, Pierce 2001a, 2001b, Bakas et al. 2002, Cassels & Watt 2003, Smith et al. 2004).

Gains and satisfaction are frequently associated with the caregiving role, including a sense of fulfillment for the caregiver, increased feelings of closeness between the caregivers and care receivers, and satisfaction resulting from daily caring interaction and communication through personal religious beliefs and expression (Davis & Grant 1994, Subgranon & Lund 2000, Burman 2001, Pierce 2001a, 2001b, Theis et al. 2003,O'Connell & Baker 2004).

Loss has become a recurrent theme that indicates an effect resulting from stroke. These studies reveal that family caregivers experience a loss of independence (Mumma 1986, Jongbloed 1994), lifestyle changes, role changes and emotional changes (Periard & Ames 1993, Robinson-Smith & Maboney 1995, Fraser 1999, Eaves 2000, 2002, Brereton & Nolan 2000), in dealing with multiple care issues (Grant 1996, Dowswell et al. 2000, Burman 2001, Bakas et al. 2002).

However, little attention has been directed towards family dynamics and family functioning after stroke residual disability, because family interpersonal relationships are considered as complex (Evans & Bishop 1987, Evans & Hendricks 1988, Evans et al. 1992, Evan et al. 1994), and stroke itself may often affect not only physical activities, but also psychosocial aspects such as interpersonal relationships, mood, household management, and social inactivity for stroke survivors (Evans & Hendricks 1988). Little has been published also about how a stroke affects family functioning and family well-being living with a stroke patient's transition from hospital into the home care setting over a period of six months, or what factors affect family well-being when living with stroke over time.

1.1 Aim and objectives of this study

The study aims to provide an understanding of the issues encountered by families living with stroke and how these issues impact on the family well-being in Wuhan. The information can provide an insight into the ways in which community-based care can be provided to those families whose well-being is compromised because of inability to cope with the emergent care issues. The objectives were:

- (i) To collect empirical data in order to analyze the care issues encountered by families with stroke survivors in Wuhan;
- (ii) To examine the care issues, perceived burdens, coping processes and the impact on family well-being; and
- (iii) To propose community-based stroke rehabilitation and nursing strategies that can optimize the well-being of both stroke survivors and their family caregivers in Wuhan.

1.2 Research questions

The following research questions are addressed:

- (i) How do family members take care of stroke survivors after they are discharged home?
- (ii) What are the care issues encountered by the family in the first six months after stroke survivors are discharged home?

- (iii) In what ways do stroke survivors and their family members deal with these care issues?
- (iv) Have family caregivers experienced any difficult care situations?
- (v) How do they deal with these difficult care situations?
- (vi) For the families who perceive that they can cope with such situations well,what resources (personal, family and community) have enabled them to doso? And
- (vii) For the families who perceive that they cannot cope with such situations, what resources (personal, family and community) have they utilized and what are the problems they have encountered?

1.3 Significance of the study

Understanding the impacts of stroke on family well-being after home discharge is significant, because it provides an opportunity for nurses to think about what care issues are directly affected by the disease, what effective coping resources can be developed by stroke survivors, how their family caregivers deal with difficulties and problems, how to develop an effective and culturally relevant community-based service, and what key role Chinese nurses can play in assisting families living with stroke and sustaining their high level of family well-being. More significantly, taking account of how stroke survivors and their family caregivers perceive their own well-being in the home setting is important for developing the future role of nurses in helping families cope with stroke.

The provision of community-based health care to support families with stroke survivors is significant in the sense of continuity of care. It can serve as a vehicle for a smooth transition from the hospital setting to a community setting. This type of continuous care approach will help both the stroke survivor and his/her family re-integrate into their normal community and family lives, and enhance their physical, psychological and social well-being as much as possible. As the population ages and health care reform is high on the agenda to address the emerging need for community-based health care services, establishing community-based care on the basis of understanding the needs and care issues of the family for stroke survivors is hence essential. In addition, advancement towards a low-cost, highly efficient and convenient community-based health care service is critically needed in China. The information provided by this research is vital to enable health care professionals to provide appropriate home-based care strategies in addressing the needs of families living with stroke survivors.

1.4 Organization of the thesis

The thesis is organized as follows. This chapter introduces the issues of stroke care and development of the stroke unit model in developed countries, and raises the problems of stroke care in China today by giving a brief description of an anecdotal scenario. The

aims and objectives, research questions, and significance of this study are then proposed.

In Chapter two, the background information to the study of stroke care in China is described, including the epidemiology of stroke, care issues encountered by the family, relevant government policies, and the professional management of stroke care both in nursing practice and research.

Chapter three is a systematic review of the studies on stroke survivors and caregivers after discharge home. Based on the thematic analysis of the previous studies on stroke care in the home care setting, a conceptual framework and study proposition are then constructed to guide the multiple-case (embedded) study.

In Chapter four, the methodology of the multiple-case (embedded) study is delineated including the characteristics of case study research and its application for data collection and analysis.

In Chapter five, profiles of the 18 case studies are presented, containing characteristics of stroke survivors, family caregivers, and the family structures, health care service utilization, and the changes of well-being of stroke survivors and primary family caregivers over time. In Chapter six, the multiple care issues encountered are given, including those surrounding activities of daily living and health problems, and of caregivers'.

In Chapter seven, family dynamics in caring work organization are analyzed. Three major themes are described. They are the cooperative, compromising and disengaged organization of caring work.

Chapter eight delineates personal coping strategies for living with stroke including cultivating the moral self, appealing to spirituality, ascribing positive meaning to life adversities, and acting as a folk healer. It also describes the reasons for failure to mobilize personal coping resources in dealing with multiple care issues.

In Chapter nine, an empirically-based explanation theory of family well-being in living with stroke is proposed. Four constituent elements are characterized by mobilization of positive personal coping resources in dealing with stroke-related disability and daily care hassles, realignment of personal competence to activities of daily living, harmonization of intra-familial relationship, and active and proactive management of care issues.

Finally, in Chapter ten, summary, conclusion, and study implications are presented, including issues of generalization, and the need and strategies for designing organized and planned stroke care community-based health services. The study limitations and suggestions for further study are then discussed.

Chapter Two

Background to the Study: Family Care of Stroke Survivors in China

Stroke is one of the leading causes of residual disability in China. Although the family is the major source of help and support for survivors, no systematic study has been reported regarding the impact of stroke on family well-being after home discharge. This prospective multiple-case study examines the care issues encountered by families while taking care of their members who are disabled after their stroke conditions have stabilized, and how the families utilize various resources in maintaining family wellbeing in real-life context. In order to provide a background understanding of the phenomenon under study, this chapter analyzes the issues of family care of stroke survivors in five aspects. The first focuses on the epidemiological situation of stroke in China, and introduces the severity of stroke with regard to incidence, prevalence and mortality, as well as stroke-related disability. The second part examines the problems and difficult care situations encountered by families living with stroke, and the third how they deal with the issues derived from stroke. The fourth part looks at the policies advocated and action taken by the government, and the last at the existing stroke care practice and research based on an overview of previous studies in present-day China.

2.1 Epidemiological study of stroke in China

Stroke has a huge impact on health service demands owing to the high rates of mortality and incidence (the number of new cases of a disease per year in a defined population), and the fact that it is the most common cause of permanent disability in adults worldwide (The WHO Stroke Surveillance System 2002). Although studies on the length of survival for patients living with stroke have been varied, people surviving from stroke may live with some degree of disability and high rates of stroke recurrence cannot be underestimated.

Stroke ranks as the third leading cause of death in the United States: for example, there are an annual estimated 731,000 strokes and 4 million stroke survivors (Broderick et al. 1998, National Stroke Association 1996). In the People's Republic of China (PRC), stroke ranked as the second leading cause of death after cancer in 2002 (Statistical Yearbook of China 2003). According to the WHO Stroke Surveillance System's (2002) summary, the mortality of stroke in China is predicted to triple between 1990 and 2030 because of its rapidly aging population. Figure 2.1 demonstrates how the number of stroke deaths can be projected by the effect of the aging population. The figure crucially shows that even when there is a small rise in the aging rate of the population, the number of stroke deaths will show a marked increase. When there is a small decrease in the aged population, the number of stroke deaths will still remain stable. Thus with the

population aging, the number of stroke deaths in China will inevitably increase in the

next two decades.



Figure 2.1. Projected number of stroke deaths based on the annual rate of change (%), China, 1990-2030

Source: The WHO Stroke Surveillance System (2002) Truelsen, T. & Bonita, R. *Surveillance of stroke: The WHO STEPwise approach. Summary.* Geneva, World Health Organization. <u>http://www.who.int/ncd_surveillance/steps/stroke/en/flyerStroke2.pdf</u> Retrieved on 13th July, 2004.

Meanwhile, some local studies have been undertaken in Beijing and Wuhan to examine the mortality, prevalence and incidence of stroke. The first comprehensive epidemiological study of stroke was conducted in Beijing from 1986 through 1987 (People's Liberation Army Cerebral Vascular Disease Epidemiology Team Work-PLACVDETW 1993). According to this report, the annual incidence of stroke was 109.74 per 100,000, the prevalence (the total number of cases) 245.58 per 100,000, and the mortality 77.16 per 100,000 annually. Another study reported the average prevalence to be 719.00 per 100,000, and the mortality 116.00 per 100,000 annually (Zhang 1993). Zhang's (1993) report gives higher rates than the PLACVDETW's work (1993) possibly due to the different populations and regions being studied.

In Wuhan city China, stroke is the first leading cause of death (Hubei Statistical Yearbook 2002) and has a high incidence of disability. Qiu et al. (1999) also reported that from 1988 through 1997, the annual mortality of stroke was 185.51 per 100,000. Based on the estimation of the WHO Stroke Surveillance System (2002), approximately one out of four stroke patients is likely to die and the remaining three will survive. For those who survive, half of them are expected to have some degree of residual disabilities resulting in dependency upon their families (the WHO Stroke Surveillance System 2002). The comparison of mortality, survival and disability rates between Beijing and Wuhan as in Table 2.1 was made based on the above estimation.

Table 2.1. Comparison of mortality and disability rate between Beijng andWuhan (per 100,000)

	Mortality	Disability rate
Beijing (Zhang, 1993)	116	174
Wuhan (Qiu et al., 1999)	186	229

Table 2.1 indicates that disability is higher in Wuhan (229 per 100,000) than in Beijing (174 per 100,000). Particularly, in the total population of 7.9 million Wuhanese (Hubei Statistical Yearbook 2002), stroke affects approximately 59,363 (death: 14,840; survival: 44,522) persons annually. Of those 44,522 who survive the stroke, more than

20,000 may have some extent of residual disabilities and be dependent on their families after discharge from hospital. That is to say that there are about 20,000 families newly involved in taking care of persons with stroke-related disability annually, and they may encounter a variety of care issues after discharge home. These figures show that the stroke care situation in Wuhan warrants special attention.

The high incidence of stroke disability cannot be underestimated (Horner 1998) since the decline in stroke incidence has not resulted in a comparable decline in the number of disabled stroke survivors, and a large number of stroke patients will survive many years with chronic physical and psychosocial disability. There have been millions of people who have survived a stroke and lived with varying degrees of residual disability after being hospitalized for acute neurological care, and for whom this has led to a long-term course of recovery. It is indicated that the disability rate resulting from stroke reaches approximately as high as 70% (Wang 1998) to 80% (Nan 1996, p. 208). Meanwhile, an average period of survival with disability would be about seven and a half years (Nan 1996, p. 208).

In addition to high mortality, incidence and disability, the length of survival for patients with stroke has also been reported by WHO (2003) and examined by several studies in Western countries (Rau 1991) and in China (Nan 1996).

More than half of stroke patients have a five- to eight-year survival rate (Anderson 1992, Sacco et al. 1994, American Heart Association 1996). More recently, WHO (2003) has reported that China is home to 20 percent of the world population and *life expectancy* at birth in China is 69.6 years for men and 72.7 for women. When *healthy life expectancy* (HALE summarizes the expected number of years to be lived in what might be termed the equivalent of "full health") is calculated, it is 63.1 years of age for men and 65.2 for women. This suggests that Chinese people may live with some degree of disability in later life for an average of approximately seven years (men: 6.5; women: 7.6). Although there is no formally reported data on the long-term survival of stroke patients in China, it has been suggested that the mean survival time is also about seven years (Nan 1996, p. 208). This means a person may live with disability for about seven years following a stroke.

Long-term stroke recurrence rates in different studies have ranged from 4% to 14% per year (Gandolfo et al. 1986, Hier et al. 1991, Clavier et al. 1994), early (24 months) cumulative recurrence rates between 7% and 14%, and late (48 to 72 months) cumulative recurrence rates between 25% and 37% (Sacco et al. 1982, Bamford et al. 1990, Burn et al. 1994, Gandolfo et al. 1986, Sacco et al. 1991, Clavier et al. 1994). In China, the recurrent rate of stroke, in general, has reportedly ranged from 4% to 14% (Zhang 1993), and 41% (Nan 1996, p. 208). Recurrent stroke is likely responsible for the use of health care services and declining physical condition and health status, leading to further disability.

With the recent developments in medical care and technology, and the increased longevity of the Chinese population (WHO 2003), many stroke patients are expected to survive following acute medical care, and to live with some extent of residual disability in a home care setting for a longer period of time (e.g. about 7.5 years). What kinds of stroke care situation they encounter and how they deal with these care issues are expanded upon in the following discussion.

2.2 Care issues encountered by the family

Financial constraints, the reduced number of available family caregivers, and the burdens of care are issues frequently encountered by families living with stroke in a home care setting.

Financial pressure and constraints

According to Hou et al. (2000) analysis of the costs of stroke care, financial status has become a major issue for families taking care of people recovering from stroke. The items listed by Hou and his colleagues can be categorized into three major parts. The first is the acute care and rehabilitation care stages: medical care in the hospital cost 16,575 yuan, and discharge follow-up (rehabilitation at home, e.g. acupuncture, functional training) cost 25,200 yuan. The second part consisted of continuing care in the outpatient department. Altogether this would be totally about 42,000 yuan. The
third part is the care provided by caregivers (e.g. family members or domestic helpers), which cost 14,400 yuan, and lost productivity to the tune of an estimated 10,201.5 yuan. The total cost on the basis of surviving for 7.5 years would be 66,376.5 yuan (mean cost 8850.2 yuan per year).

Meanwhile, based on Wuhan statistical report (Qiu et al. 1999) and the Hubei Statistical Yearbook (2002), average annual salaries increased from 1996 to 2001, from 5,981 yuan in 1996 to 6,404 in 1997, 6788 in 1998, and 11,280 yuan in 2001. Mean income for these five years was 8,631 yuan. That is to say that one full annual salary is critical for a family if they are to afford both the medical costs during hospitalization and family care after discharge home, with a basic standard of living.

In addition, in this society undergoing a process of economic reform, social structural employment for job opportunities is scarce and this has resulted in a number of workers being laid off (下岗职工) (Deng 2001), but the exact number of these workers has not been reported. Deng (2001) adds that poverty has become more and more widespread and serious. In this sense, some cities have started to set a basic living standard level to ensure an individual's basic needs. For example, the poverty line (低保线) was first set in Wuhan on March 1, 1996. On August 7 of 2001, it was re-adjusted from 120 yuan/person/month in 1996 to 195 yuan/person/month (urban areas) and 143 yuan/person/month (suburban areas) respectively (Tian 2001). From 1996 through 2001, the number of Wuhan residents living below the poverty line rose from about

30,000 to 110,000 (Tian 2001). Tian further stated that even though an increasing number of people are recognized as falling into this category, a large number of residents continue to be excluded because there is no registration system.

As a result, due to the high costs of medical expenditure during a hospital stay in comparison to the annual income for each family, and the potential unemployment status, it is envisaged that the impact of stroke care on the family in terms of financial constraints and pressure would be high.

The reduced number of available caregivers

Du and Yi (2000) stated that family care for the aged is closely related to the number of children. However, due to family planning, the number of small families is on the increase. With the birth of the new family structure and the one-child family planning policy, the ratio of "4: 2: 1" symbolizes the future of the single-child family (Zhang 1999). The trend towards smaller nuclear families will cause an increase in the difficult situations faced by children. One study has shown that the average family size decreased from 4.64 people in 1978 to 4.43 by 1982, and further to 3.74 by 1995 (Leung 1997). On the other hand, on-the-job children represent almost half of this, and they have the double responsibility of caring for their parents and taking care of their own children (Zhao 2000).

According to an investigation in Beijing, the satisfactory degree for social daily care of the elderly is only 2.1%. The gap between the need for care and the support available is becoming larger and larger, and thus the problem is becoming more and more prominent (Zhang 1999, Lu 1999, Zhao 2000). This change will lead to the following two results: an increase in one-member households and a decrease in care provided by children. In other words, decreased family size results in a reduced number of potential caregivers in the family.

Burdens of care

With the development of economic reforms, most middle-aged and young people are at the height of their careers. As a result, they are in a real dilemma and quandary when facing the reality of caring for both their parents and children at the same time as having to work hard in their jobs. An investigation has also shown that most middle-aged and young people significantly lack rest, 45 % of them having absolutely no recreation time. Forty-six percent consider that caring for the old has a great influence on their personal career (Lu 1999).

When Beijing carried out an investigation on "family care and social service during the economic change", it was discovered that the availability of care resources and possible potential resources was not optimistic. When elderly people were unable to do self-care, 90 % of their daily care was given by their spouse or children. Among those caregivers,

28.3 % were unhealthy or very ill. Once this possible resource fell ill, they would change their role from caregiver to care receiver. Furthermore, the children of those senior persons were elderly persons themselves. When taking care of their parents, they felt unable to shoulder the burden of care. Therefore, 25 % of grandchildren had to join the team of family caregivers (Beijing Ageing Committee & Beijing Gerontology Committee 1995).

Pang et al. (2000) report on the situation of family accompaniment during the patient's stay under acute care in the hospital in Beijing (see Table 2.1.). The number of available caregivers was also observed. It was found that the family is still the major source of daily care and assistance throughout the whole process of hospitalization (24 hours, from the acute stage until discharge). In this study, issues of accompaniment are frequently described and of great concern for the family in taking care of stroke survivors. This care mostly refers to the accompaniment of a family member during hospitalization. The rule of general hospitals is routinely that for normal patients, only one family member is allowed to be present (except in serious cases, in which the number must not exceed two). Because of the suddenness and seriousness of an attack of stroke, family members are very much involved in the care of patients during the hospital stay.

Table 2.2. Description of the accompanying persons* and the accompanying hours

Total number of stroke patients (cases)	102
Patients with accompanying persons	91 (89%)
Total number of persons accompanying patient	211
Number of accompanying persons for each patient	1-10
Relationship between the accompanying persons and patient	
Spouse (yes)	46 (45.1%)
Children, relatives or friends (yes)	85 (83.3%)
Domestic helper (yes)	10 (9.8%)
Hours spent per day by accompanying persons	
Two persons for 24 hours (yes)	10%
One person for 24 hours (yes)	70%
One person for 12 to 24 hours (yes)	80%
Average age of the accompanying person (year old)	37.7

Source: Pang, L., Jin, S.G., & Chen, J. (2000) An analysis of the burden of hospitalization accompanying for stroke patients. *Chinese Journal of Health Statistics* 17(2):93-94.

*Definition of an accompanying person: Being able to go to the hospital to care for the patient quite often (more than twice a day, with each visit lasting more than 2 hours).

It is indicated that most stroke survivors (89%) have someone accompanying them, and that this person is usually a family member. The fact is that family members tend to demonstrate love and care by taking care of their sick relatives' bodily functions and meeting their physical needs. This may reflect that the traditional filial responsibility and spousal duty as prescribed to family members continues to play a major role in present-day China.

China is an ancient country with a history of more than 5000 years of civilization, during which showing respect and love to the elderly has long been a traditional noble quality. As early as in the Spring and Autumn Period (770-476 B.C.) and the Warring States Period (475-221 B.C.), the tradition of filial piety was already deeply rooted in the Chinese family. Mencius proposed the famous "love my own elderly relatives and extend the love to others' elderly relatives" (孟子:老吾老以及人之老). "The

Book of Rites" (礼 记) confirms that "all widowers, widows, orphans, childless and the disabled should be taken care of". The emperors of all the feudal dynasties took filial piety as the basis of educating people and strengthening the stability of the country (Tian 1993, Ning et al. 1995) in general.

In the level of the family care, the classic text entitled "Filial Piety" points out that the general idea of this ancient notion is that the role responsibilities between parents and children. It is believed that one's life and body are a gift from one's parents. Therefore one has to show respect to one's parents and the parents should treat their children kindly. Another long popularized saying, the "Twenty-Four Filial" (二十四孝) is one of the most typical examples often quoted by the public to advocate how filial children took good care of their older and frail parents in meeting their physical and emotional needs (Wu 1997).

However, the aforementioned ideal family care has been challenged to different degrees by the social and economic development (Ning et al. 1995). The cultural revolution initiated in 1966, "filial piety culture" was taken as a kind of pure feudal ideology and was heavily lashed, especially during the period of the running wild of the ultra-left. A "big black hat" (戴黑帽子) was smashed on filial piety, and it was looked upon as the opposite of "loyalty", a product of Confucius and Mencius, and filial act was roundly criticized and thrown into the historical waste basket (Ning et al. 1995).

How is traditional filial piety reflected in society today? Positive and negative appraisals exist at the same time. Zhu (1999) reported an investigation of the connotation of "showing respect" among different age groups. In the elderly group, the elderly, this concept has long been deeply rooted. Depending on the order of seniority in the family is considered to be quite natural. The middle-aged group seems to be pragmatic. They seek the harmony of the family and see "filial piety" as a kind of lubricating oil. For the youth group, they stress their inner feelings while somewhat appreciating glorious and romantic ideals. "Filial piety" is expressed by buying a gift for their parents. Zhu (1999) further attempted to distinguish "being filial" from "being not filial" on the ground of the degree of satisfaction to be found in "serving / not serving the elderly". It was discovered that most interviewees tended to view "taking care or not taking care of their parents" as a criterion. It was also found that how one behaves in daily life can give the elderly an impression of "being filial". If they are together all day long, they often tend to find fault with each other, thus the love between them suffers. By contrast, being apart from each other, the elderly will not feel the existence of filial piety, while if they do not stay together, they will miss each other, and when they meet they will have a particular feeling of love. Some of their behavior will thus often make the elderly person feel pleased and grateful.

An investigation by the Zero-hour Company (Yuan 1999) has shown that among the elderly, 16.1 % are quite worried about being cared for when they become frail, and 28.1% are somewhat worried. It further shows that in urban areas, 91.6 % of sons and

daughters practice filial obedience, and 10 % of the children, in differing degrees, are a negative stimulation factor. Another report (He 2000) points out that in an investigation of 9663 urban elderly people, 25.4% considered that their sons and daughters were not filial. Meanwhile, among 9944 elderly people in rural areas, 29% considered their children to be impious. This reflects the fact that in rural areas the negative factors are higher than in urban districts. It also suggests that the cause of this phenomenon may be associated with personal cultivation and financial condition. He (2000) points out that the incidence of abuse and abandonment in rural areas is serious, with such treatment occurring in about 3 % of cases. It is estimated that among the 72 million elderly people living in rural areas, as many as two million may be being abused or abandoned.

In sum, care issues encountered by families living with stroke after discharge home fall into three main areas: financial constraints and pressure, the reduced number of available family caregivers, and burdens of care. In present-day Chinese society, the traditional values of fostering family harmonization and happiness are cherished in accordance with how family members are expected to act their prescribed roles. As the Chinese popularly saying goes, when the elderly exhibit a good filial example, the younger family members follow suit; when the husband sings, the wife follows accordingly and harmoniously (上行下孝,夫唱妇随). Chinese traditional values are "righteousness prior to profit", and "family prior to individual", e.g. the children take the concept of caring for the elderly as "the foundation of being an upright person". Du & Yi (2000) state that such values are the foundation of family care practice for the elderly, and that this function is expected to sustain successively from one generation to another generation. However, modernization and social economic development have led to changes in the traditional values, and the prescribed family role responsibilities (Leung 1997). Changes in the values and roles lead to unstable caring behavior. An increasing number of cases of elderly people being abused or abandoned by family members have been reported in both urban and rural areas (Du & Yi 2000). What difficult care situation is encountered by the family and how they deal with it in the home care setting deserves more attention in contemporary China.

2.3 Government agenda

The significance of family care has been recognized by our government and reinforced by a series of laws and regulations prescribing family roles and responsibilities. Legislating family responsibility has become crucial to maintaining family stability and harmonization, and addresses the significance of family care. Therefore, a series of laws and regulations has been formulated and promulgated regulating family role responsibilities and emphasizing traditional family values.

Legislating and emphasizing family role responsibilities

Laws to foster family responsibility are written into the constitution. They are the law of marriage and the law for protecting the rights and benefits of the elderly. Bartlett and Phillips (1997) stated that the laws are attempting to reinforce the tradition of family care and support, and to render it obligatory and a legal requirement. The Law of Marriage of 1980, Article 15, and The Constitution of 1982, Articles 45 and 49, prescribe that adult children and spouses have a duty to perform in properly supporting aged parents who may be sick and disabled. The Law for Protection of the Elderly's Rights and Benefits of 1996, Articles 15 and 16, also urge local governments to expand care for the elderly into social and economic planning and investigation. Citizens' responsibility has been stipulated in national law and policy, such as the physical care and the financial support necessary to be provided by the family for the elderly.

These, from the law, ensure that the elderly are cared for by other family members (e.g. spouse, sons, daughters, grandchildren). Leung (1997) stated that the promulgation of these laws can be considered as a government response to the increasing number of reports of abuse or abandonment of the elderly by family members in both urban and rural areas. In order to protect the stability and the rapid development of the social economy, such policies aim to strongly advocate the family's role, a strong sense of social responsibility, the enhancement of family harmonization and happiness, and the traditional Chinese values of family care, with "respecting the old and fostering the young" highly valued.

Bartlett and Phillips (1997) also pointed out that the sole reliance on family care and support is not practical and appears to be more problematic due to the reduction in the

number of potential family caregivers, the constraints on family finances, and the fluctuation in traditional caring virtues. Leung (1997) asserted that the goal of the establishment of new legislation would be to become a "coercive measure to enforce family obligation". He further contended that the government needs to formulate an effective policy to facilitate, support and maximize the competence of family care practice through establishing community-based care services. Health care reform both in hospital-based and community-based services has been proposed in order to improve the quality of care and ease of access, and to bring about a reduction in medical costs.

Health care reform and the need for community-based health care services

With China's transition from a planned economy (from early 1949) to a modern market economy (from the late 1970s until now), the medical care system has been shaken up. The system of free medical care (e.g. free medical service and labor protection service) which has existed for more than 40 years, is undergoing changes, and is facing greater pressure and more difficulty than ever (Zhang et al. 1998). The previous health care system has become inconsistent with the development of social modernization: in particular, it cannot meet the diverse health care needs of the population. Thus, developing a community-based health care system is crucial in China today. The challenges faced by medical health care services and how such health care reforms could be implemented are thus the central concerns in the following discussion. Since the 1990s, corresponding to the new situation, the Chinese government has proposed a series of documents and policies specifically addressing the development of community-based health care service. Responding to The People's Republic of China Disabled Protection Law (1990), The State Council of the People's Republic of China and Secretary Committee for the Disabled (1996) and The State Council of the People's Republic of China (1997), the agenda of the medical reforms has emphasized achieving the goal of developing a community-based service system that is low-cost, has broad coverage and high-efficiency, and is conveniently accessed, so that it can be aligned to each person's health needs. Pilot work on community health care services has been reported (e.g. Beijing, Shanghai, Hangzhou) (Liu et al. 1994, Liu & Hao 1999, Liang 2000, Mao & Zheng 2000, Shanghai Municipal Government 2000, Yi 2004).

The three major reasons why community-based health care services should be encouraged are discussed below, as well as how government policies are proposed and implemented. First, optimizing the distribution and disposition of public health resources is imperative. Public health resources are mostly concentrated in the large and medium-sized cities (e.g. Beijing, Shanghai, Tianjin).

Zhao (2001) has investigated the basic situation of the bed-utilization rate among the large and small comprehensive hospitals under the Minister of Health (MOH). Zhao

points out that the rate in those directly under the MOH is 92.9%, the rate in those under the provinces and autonomous regions and the municipalities directly under the central government (e.g. Beijing, Shanghai) is 82.6%, the rate in hospitals affiliated to medical colleges is 83.9%, that in tumor hospitals is 80.5%, and the rate in other types of hospitals (e.g. comprehensive hospitals at county level) is under 75%. Among these other types, the rate in county hospitals and those above county hospitals is only 59.8%, in still other hospitals it is 49.7%, and in township hospitals, 32.7%. This shows that the majority of patients seeking medical services rush to the large hospital in the city. As a result, large hospitals in large cities have "full house", while medical institutions in rural communities remain quiet. Another study shows that the treatment amounts in the larger hospitals, while the large hospitals in the cities are shouldering quite a heavy burden of treating common and frequently-occurring diseases.

A survey of the top ten diseases of the out-patient department (OPD) revealed these to be the common cold, gastritis, hypertension, coronary heart disease, tracheitis, intestinitis, diabetes, neurasthenia, cerebral thrombosis, and urethritis, and showed that these diseases were the most dependent upon medical treatment (Chu et al. 2003). Consequentially, the OPDs principally dealt with common and frequently-occurring diseases and already clearly diagnosed diseases, which undoubtedly might create a situation of "a giant horse pulling a baby wagon" (大马拉小车) and increase the pressure on large hospitals. As a result, the large hospitals were unable to concentrate on the treatment of emergencies and critical and complicated diseases.

Liu et al. (2004) point out that among the OPD cases in large comprehensive hospitals, 64.8% could be solved at the community level. To achieve reasonable distribution and disposition and to best utilize the existing health care resources, a two-way transmission system should be set up between the large hospitals and the community services, so as to reasonably utilize the existing resources and also reasonably distribute the patient-flow, and ultimately to reach a situation where "mild illnesses are treated within the community, serious ones in larger hospitals (小病进社区,大病进医院)".

Second, it is necessary to lower medical expenditure. In recent years, medical expenditures have shown a trend of rapid increase. According to the Healthcare Statistics Center of the MOH, from 1990 to 1996, the average medical expenditure of OPD patients and hospitalized patients increased yearly to different extents. According to the data from hospitals at the county level and above, the average treatment fee per head was 40 yuan in 1995 and increased to 53 yuan in 1996. The average fee for hospitalization was 1668 yuan in 1995, and increased to 2190 yuan in 1996. The magnitude of these increases all exceeded 30% (excluding the influence of the increase in price), which greatly exceeded the concurrent increases in GDP and price (Zhao 2001).

Another preliminary survey on health behavior seeking was conducted by Chu et al.

(2000b) (see Table 2.3.).

Total

Type of medical unit	Number of people (%)
Hospitals at city level or above	872 (84.50)
Community health care center	72 (6.98)
District hospital	56 (5.43)
Individual clinics	23 (2.22)
Street hospital	13 (1.25)

Table 2.3. Medical help-seeking alternatives

Source: Chu, W., Liu, Q.G. & Jiang, X.L. (2000b) A survey on the satisfaction and intentions of local residents towards community health care service. *Medicine and Society* 13 (1):9-12, 15.

1036 (100.00)

The above observation indicates that the residents attempted to seek medical help in hospitals rather than in the community. 84.5% of residents chose the hospital as their first priority, while only 6.98 % preferred community health service centers. Therefore, the majority of city and township residents sought out large hospitals as their first choice. Chu et al. (2000C) investigation showed that the higher the level of the medical service, the higher the average daily medical expenditure at both provincial and municipal level (179.2 yuan for cerebral thrombosis, 291.0 yuan for tumor).

Third, to meet the requirements of the aging population, a change of disease-spectrum is unavoidable. The aging population is a universal and critical social problem, and old people are the group with the greatest need for medical service. The aging of the population leads to an increase in chronic diseases, non-infectious diseases and disabilities, as well as the increasing utilization of rehabilitation and nursing services, resulting in increases in medical expenditure. Liu and Yu (2002) point out that, according to the National Conference of Health Care Investigation, the two-week prevalence of the elderly above 60 was 1.7 times greater than in the total population, that the prevalence of chronic diseases in this age group was 4.2 times higher than in the total population, and that they had three kinds of illness on average. As compared with the first investigation done in 1993, the two-week prevalence and the chronic diseases prevalence of the elderly had increased significantly. Among the diseases, most were tumors, cardiac-cerebral diseases, diabetes, and elderly mental diseases. However, with the aging process, the ratio of non-infectious diseases and disabilities also increased. The limitation rate of the elderly above the age of 60 was 8.1%, or 2.7 times greater than in the total population, and the disability rate was 25.5%, 3.8 times more than in the total population. Liu and Yu (2002) further point out that according to their investigation of the urban elderly population, their two-week medical help-seeking rate was 23.75%, which was higher than that of the other age groups by 14.44%. Their hospitalization rate was 7.62%, and the rate in the other age groups was only 4.36%. Because most of the elderly had chronic diseases, they had longer length of hospitalization, thereby influencing the bed turnover rate and increasing the utilization of medical and nursing services. Meanwhile, the elderly patients usually had poor health, seriously affecting their quality of life. On the one hand, they were unable to obtain timely medical care. Most of them did not have the benefit of labor insurance or free medical care, so the high expenditure on medical fees made them worried about seeking medical care, thereby causing further deterioration of their health.

A contradiction therefore exists between the vast population of the elderly and the unavailability of medical care and resources, thus making it impossible for the elderly to access basic health care. It has been suggested that the community health center might be better able to meet the needs of old people (such as price, content, function), and to provide timely, convenient and low-cost medical service. This would solve the problem of elderly people's medical care, and ensure more efficient utilization of medical and nursing care (Zhong et al. 2000).

How to implement community health care reform?

The government initiated medical reforms in 1989 to separate the overall fund that is shared by the following three parties: the government, enterprises and individuals. The fund is divided into two parts: social insurance funds and personal accounts. Under the reforms, medical expenses for minor illnesses are paid out of personal accounts, while the social insurance fund takes care of the major costs of serious ailments (Anonymous 2000, He 2000, Ru 2000). Furthermore, a series of policies has been established and nationwide community-based health care services have been undertaken.

Healthcare policies

From 1996 to 2000, a number of documents were issued (Yao 2001). In December, 1996, the document entitled "CPC and State Council: the decision on medical reform and development" proposed:

"To reform the urban medical service system, to develop community health service, so as to form a reasonably functioning health service network that is convenient for people to use."

In December 1998, a decision by the State Council pointed out that

"The distribution of medical institutions should be reasonably adjusted, the medical resources should be better allocated, the health service of the community should be actively conducted, and basic medical services should be covered by the basic medical insurance."

In July 1999, the MOH, together with another ten departments, jointly delivered a document to the provincial government, entitled "Suggestions on the development of an urban community health service". The document made clear the basic principles, the overall objective, and the counterpart measures, and was the first national guiding policy document for the development of community health services.

In February 2002, the council office conveyed the document of the council reform office entitled "The guiding suggestion for the health reform system at the township level", which clearly pointed out its aim:

"To establish a perfect community health service organization, to set up a reasonably arranged medical service system between comprehensive hospitals and specialized hospitals."

The three aforementioned counterpart documents further delineated the fixed subsidy, the profit tax regulation and other economic supportive policies for the development of community health services.

Practice for community-based health care service

To date, to implement the "certain opinions on developing urban community health service", issued by the MOH and other relevant departments, and to respond to this objective, preliminary work on community health care services has been reported in many Chinese cities and provinces (Liu et al. 1994, Liu & Hao 1999, Liang 2000, Mao & Zheng 2000, He 2000, Ru 2000). Some forms of community health care service have successively begun to appear in many cities, including Guangzhou, Shanghai, Beijing, Guandong, Tianjin, Hangzhou (Zhe-jiang), and Wuhan (Hubei province). The basic forms are composed of community hospitals, general practitioners (GP) (全科医生),

community education programs, self-help groups, community health care service centers and other comprehensive community services.

Guangzhou city has suggested a more specific direction and target for the development of the community health service center. The basic principle of the target is to achieve a low-cost, high-efficiency service with broad coverage and universal access for the public. This reflects the fact that Guangzhou city is aware of the significant role of the community health service in promoting both current medical reforms and health service demands (Liang 2000).

In Shanghai, the first elderly community hospital (社区医院或街道医院或区卫生院) was set up in the Jin-an district in 1986. Over the past ten years, due to its important role in wholeheartedly serving local people, it has been honored as a World Health Organization Community Health Research Center, and has become a model service community in China (Mao & Zheng 2000).

Liu and Hao (1999) reviewed the development of community health care services in Beijing, and indicated that they started in 1991 and that their development can be divided into three stages. These are from 1991 to 1993, from 1994 to 1996, and from 1997 until now. The first batch of nine GPs whose quality was confirmed started their work in Zhong-guang-cun (中关村) in 1999 (Huang 1999). They entered into the community and families, serving the elderly and patients with chronic illness and disability. Huang further emphasized that in the beginning, the fee was 50 yuan. After that, a fee of 20 yuan per year included two physical examinations free of charge. For each family visit, 30 yuan would be charged for a doctor and 20 yuan for a nurse. This payment could not be reimbursed.

Some other cities have attempted to establish community-based health care services through qualified family doctors in Beijing (Huang 1999) and family doctors selected by the community in Shangchun (Zhang 2000). These services have been in place since the late 1980s in Shanghai (Mao & Zheng 2000) and the early 1990s in Beijing (Liu & Hao 1999). However, the provision of stroke care that can achieve this goal is still in an experimental stage.

In addition, Tianjin (Dong et al. 1999), Guangzhou (Shen et al. 1999), Nanjing (Wu et al. 2000), Taiyuan (Yang & Li 2000), Qingdao (Chen et al. 2000) have started to conduct various forms of community health service centers within medium-sized hospitals for people with chronic illness. This program includes regular education, videotapes, leaflets, and counseling given by hospital experts.

A recent news item reports that the first self-help volunteer group has been officially formed to help frail and disabled people in Wuhan (Luo & Li 2001). In 1997, my pilot study entitled "Evaluating the effectiveness of a stroke education program in Wuhan city of China" was conducted. The findings indicated that such a program resulted in a satisfactory improvement for stroke survivors and their families. Participants perceived a change from a sense of hopelessness into a sense of hope, from isolation to self-help, from medication and passive role orientation to active participation orientation, and improvement in their physical function (Li & Chi 2000). Recently, a self-help volunteer group has been formed and formally registered to help frail and disabled people in the local community of Wuhan (Luo & Li 2001). This is the first volunteer team group: it has 20 members and will deal with letters and a hotline for disabled persons seeking help and counseling.

More recently, Ren et al. (2001) and Chu et al. (2003) carried out comprehensive studies on the community health service demands of residents in Dalian, and put forward suggestions for its future development. Ren et al. (2001) further indicate that the health demands of residents were ranked in the top five as follows: doctor's home-visits, family wards, contracts between hospital and patient, and regular home-visits (e.g. physical exams and medical guidance).

Chu et al. (2003) investigated the disease-constitution of the community Central OPD and its expenditure. It was discovered that most of the treatment involved common, frequently-occurring, chronic diseases (e.g. gastritis, hypertension, etc.), and that the average payment for each prescription was 36.30 yuan. From this data, it is considered that the community health service is an economical alternative, the single prescription fee being obviously lower than that in the large, comprehensive hospitals, which is 103.04 yuan.

Proposals for developing community-based health care services have also been emerging (Fang 2003, Chu & Jiang 2000a). These were summed up by the following four existing models of community health service: (a) the three-level network type, which revolves between the community health service station, the community health central service, and the district medical center, (b) the family-ward type, in which patients are transferred from the second to third level hospital, and finally stay in a the relevant department of the family ward under hospital, (c) the mutual-supplementary type, in which patients are transferred from the second and third level hospitals, the extension part of the community medical service and community family health service; and lastly (d) the specialized network type, under the information monitor control. The above authors consider the three-level network type to be the ideal model, because of its reasonable allocation of health care resources and effective health functioning.

Fang (2003) further described in his study of the community health care service, and mentioned for the first time the setting up of "a family-centered and community-centered" model, and pointed out that the main form of the family service was family visits, including: (a) diagnosis and treatment of acute patients, (b) care giving after discharge home, (c) management of chronic diseases, (d) management of terminal patients, (e) appraisal of family medical service and family function, and (f) being invited to see the patient. However, the following detailed information was lacking: how to provide concrete and effective family service, how to ensure family care as a unit, and how to set up an overall model of family-centered community service.

It has been argued that the services designed and delivered to support "the family as a unit of care" have grown very slowly as a result of hesitation by local governments (Zhao 2001), and that pilot services and works have been initiated only in some of the biggest cities, like Beijing, Shanghai, Tianjin, Dalian, etc. The development of such services has also been scattered and hindered by a variety of difficulties (Chu & Jiang 2000a). Four major problems are summarized below.

First, Liu et al. (2004) make a new suggestion: "double-direction", meaning that an effective medical service system has to set up a "double-direction" system, so as to reasonably utilize the resources. The "double-direction" system proposes to transfer patients between different types of hospitals according to their illness, such as between upper-level and lower-level hospitals, and between comprehensive and specialized hospitals. Such moves could be vertical as well as horizontal. However, the coordination and cooperation of transferring patients between different hospitals is complicated and needed further study.

Second, as most nurses are working in hospitals doing ordinary treatment and nursing, they do not have the skills for community nursing. They are especially lacking in psycho-social knowledge. At present, the community health service center only has a "form" of combining prevention and treatment, but actually prevention and treatment are disengaged, therefore difficulties occur in the center, and also the chance of cross-infection within the center is increased.

In addition, inside the center, the financial distribution is also unbalanced. For example, the budget for prevention is delivered per head by the Financial Departments, while the Out-patient Departments (OPD) have to assume sole responsibility for its profits and losses. This puts a great deal of pressure on the OPDs, and forces them to concentrate on merely treating diseases, hardly conducting any health education.

Third, manpower is lacking in the community health center. Chu and Jiang (2000a) have stated that the workload for the community doctors and nurses is heavy. On average, every doctor has to serve a population of 3529 local residents, while every nurse has to serve 6204 residents. They have further asserted that this is far from enough as compared with the standard ratio of one doctor for 2000 residents and one nurse for 4000 residents as the community health care service experiences from Britain. Fourth, concerning nursing educational background, the number of individuals who have higher education (i.e., those who are college graduates or above represented only 5.3% of health care providers) working in the community is far more enough (those

who have been trained by two or three years occupied by 37.4% and 38.0% respectively). The quality of service delivery is obviously influenced because there is an absence of knowledge of how to deliver proper and organized community-based health care to meet patients' needs.

Based on the previous studies and experiences, community-based health care has become a major concern and much-studied topic for several reasons. Firstly, the development of community-based care services for stroke survivors and family caregivers is in its infancy. In most cases assistant care service for elderly people with chronic illness and their family members is not available, regardless of the obvious demand (Dong et al. 1999, Chu et al. 2000a, Du & Yi 2000, Zhao 2000, Zhong et al. 2000).

Secondly, the studies that have been reported so far have primarily examined the needs of stroke survivors rather than the needs of the families living with stroke survivors as a whole over time. The health and care needs of the family in the community have not been examined. How to align services to the needs of both stroke survivors and family caregivers is an issue that has not yet been addressed (Qiu & Chen 1997, Zhuo 1999, 2000, Shen et al. 1999, Chen et al. 2000).

Thirdly, the present community health services for people with chronic illnesses are only accessible to those who can afford to pay, because such services are not covered by either public or private health insurance schemes (Liu et al. 1994, Huang 1999, Dong et al. 1999, Chu et al. 2000a). Finally, the current community-based health service is not adequately equipped and prepared (Fang & Yang 1999, Chu et al. 2000a, 2000b, Zhao 2000) to care for these patients after discharge home over a longer period of time.

To overcome these barriers and to achieve the government policy of developing a community-based health care services characterized by "low-cost, high-efficiency service with broad coverage and convenient access by the public" is a great challenge. It is important for health professionals to understand how to plan community-based health care services according to people's health needs and the kind of difficulties they encounter. Taking the perspective that the community is composed of family units, this implies that "health care for everyone" will only be achieved if the well-being of families can be optimized. However, research focusing on the area of the well-being of families with disabled or chronically ill members such as persons with stroke disability needs to be carried out because of the consequential care issues. Therefore understanding how the well-being of families with stroke survivors will be enhanced is important for health professionals if they are to assist families in dealing with their needs and difficulties.

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2.4 Professional management of stroke care in China

The following two parts are concerned with how health care services are provided for the individual living with stroke-related residual disability over time and what are the major research areas for stroke care after discharge home. They are: the practice on a stroke unit model, and an overview of stroke care research.

Stroke unit model

The stroke unit model has only been practiced in the form of pilot projects in some hospitals in Beijing (Wang 2001, News 2004) since early 2000. Many studies have introduced that stroke unit care (organized inpatient care) can be more effective than contemporary conventional care in producing reductions in three areas: mortality, dependence and long-term institutional care following stroke (Wang 2001, Yang 2002, Liu 2003, Wang, 2002, Wu 2003, Wang 2003, Wang 2003, Zhang 2003, Zhao 2003, Ma et al. 2004, Guo, et al. 2004, Zeng 2004). Stroke unit care has also demonstrated some advantages through the following mechanisms: the provision of standardized assessment and early management protocols, prevention of secondary complications of stroke, early active rehabilitation and better coordinated rehabilitation procedures. Wang (2001) further introduces a comprehensive rehabilitation management model for stroke unit care in China. The features of this stroke unit care (organized inpatient care) include the following essential steps with regard to when it is decided that a patient with

stroke will be admitted to: (a) the emergency department for diagnosis, assessment, ICU and acute management (about one week), then transferred into stroke rehabilitation unit for further comprehensive assessment and early rehabilitation management, discharge planning and secondary prevention (several weeks), or (b) outpatient neurovascular assessment, diagnosis, assessment, secondary prevention and follow-up, (c) aftercare management in outpatient neurovascular or inpatient acute and rehabilitation unit; patients will be referred into an outpatient rehabilitation unit, day hospital and family bed, and (d) continuing rehabilitation at home, where family support and community-based service support are necessary after discharge.

In 2003, Beijing initiated its first stroke unit care in ten hospitals (News 2004), following one in Jinan (Hao 2003) and one in Nei-mengu (Wu et al. 2003) respectively. The above studies suggest that the 70% to 80 % disability rate could be reduced by 10 %. However, this still shows that there is disability remaining for 60% to 70% of patients surviving from stroke after discharge home.

Based on the above information, the management of stroke care service has only been limited in medication treatment and the functional recovery in the hospital setting. However, the impact of stroke on the individuals' well-being should not been merely on the physical well-being, but also on the psychosocial well-being. Thus a continuing and long-term care service needs to be addressed.

Overview of stroke care in China

In order to gain an overview of stroke care in China in the past ten years (1994-2004), the literature was systematically searched through the Chinese Professional Journals (CAJ Full-text Database) from 1994 to date. Chinese Journal of Rehabilitation Medicine and the Journal of Chinese Nursing were used as a major source for retrieving articles with themes on contemporary stroke rehabilitative and nursing care issues in China. Using the key words "stroke rehabilitation" and "stroke nursing", 269 articles were found. Of these, 234 articles were the most relevant (Table 2.4.). According to the course of stroke recovery and the nature of the review, the studies are divided into the following five categories in order to understand stroke care phenomenon in China. They are (a) Review, (b) Before the onset of stroke, (c) Study in acute stage, (d) Stroke rehabilitation study in hospital setting, and (e) Transition from hospital to community and home care setting.

Most relevant articl	es	Ν	n (%)
Review	Research on stroke progress and nursing	14	
	Overall progress of rehabilitation medicine	e 8	
	Sub-t	total	22 (9.4)
Before onset of stroke	Risk factors		1 (0.4)
Study in acute	Medical treatment and medication	8	
phase	Time for initial and early rehabilitation	52	
	Sub-t	total	60 (25.6)
Stroke	Approach of Western rehabilitation medici	ine 113	
rehabilitation	Approach of Traditional Chinese Medi-	cine 11	
study in	(TCM)		
hospital setting	Integrative approach	3	
	Rehabilitation nursing	8	
	Sub-t	total	135 (57.7)
Transition	General community care research	6	
from hospital	Stroke care in the community	9	
to community	Community rehabilitation nursing	2	
and home care setting	Sub-t	total	17 (7.3)
	Tota	al 234	234 (100)

Table 2.4. Stroke care research from 1994 to 2004

Source: A review of 269 articles retrieved from Chinese Journal of Rehabilitation Medicine and the Journal of Chinese Nursing.

It is noted that more than half of these studies (135 articles, 57.45%) discuss managing stroke rehabilitation medicine within hospital settings, and most concerns surround the frequently used approaches such as Western rehabilitation, Chinese traditional methods and combining both approaches. The Western approach entails a rehabilitation intervention program including speech therapy, comprehensive cognition, gait and muscular training programs and measurements assessment. Obviously the Western approach to stroke rehabilitation has dominated, as it was described the most frequently (113 articles, 48.3%). Altogether only 17 (7.3%) articles described the transition from hospital to the community and home care setting. This indicates that there is limited research on stroke care after discharge home.

Research on stroke care after discharge home

In order to further understand the situation of community-based care and nursing practice, the following five key words were re-used: stroke, community, rehabilitation, nursing and research based on the above review of 269 articles. Thus a total of three major topics and five nursing articles were identified. They were a questionnaire study (survey) on understanding stroke care issues after discharge home for 60 stroke survivors and their family caregivers; a case analysis and nursing report on summarizing the case experience of 100 cases in a home care setting; and a rehabilitative nursing intervention program.

Feng et al. (2002a, 2002b) conducted a questionnaire survey in Shanghai, involving 60 stroke survivors and their family members. Four major problems were identified: the existence of multiple functional impairments, the lack of rehabilitative training, the lack of modification of the home care environment, and the insufficiency of self-care ability for stroke survivors and caregiving competence for family members. In particular for the stroke survivors, most had more negative affects: 43.5% indicated depression and 48.4% expressed anxiety. Little information could be obtained from the perspective of family caregivers, especially with regard to the kinds of care issues encountered by family caregivers after discharge home over a period of time.

On the basis of these findings, Zhang et al. (2004) have further established a rehabilitative nursing family intervention program for both stroke survivors and their family caregivers following an initial investigation after one month and three months respectively. The program lasted for three months. The findings were remarkable in improving functional status, the stroke survivor's self-care ability and family caregiver's care competence, negative affects for stroke survivors decreased, and the home care environment modified. The study aimed at improving the quality of home care for the survivor survivors. However, these issues are necessary to consider. Such as the lack of the well-defined types of stroke, and how this program implemented, like stroke survivors and their family members as a group or as an individual, in the community center or the survivor's home, or the reasons why selecting the two-month program intervention rather than three- or four- month program. Thus the detailed description of the effectiveness of this home care program for a longer period of time is needed.

Song (2003) summarizes her nursing experiences of taking care 100 cases of stroke survival after discharge home. Three major elements were identified as playing a significant role in an optimal psychological and physical recovery. They are to provide mental health care, guide self-care skills in daily activities of living and functional training, and integrate the therapeutic therapy through combining Western medicine and Traditional Chinese Medicine approach. This study is a major focus on her personal experience of how to improve the quality of nursing care for the stroke survivors after discharge home. However, a systematic study is needed in designing, sampling, data analysis and collection so as to provide a consolidate conclusion in improving the quality of nursing care in the home care setting.

Finally, Zheng and Yu (2003) reported their study of a new rehabilitative nursing technique program. 120 stroke survivors were selected within three months following stroke. Two groups (control group: 50; intervention group: 70) were formed by random selection and the program lasted for two months. The features of this program include an individualized rehabilitative program coupled with an educational video tape, materials delivered to both stroke survivors and family members, and group training activities with family members, medical staff, social workers and voluntary involvement to create a supportive atmosphere. The findings indicate that the progress of functional status following this program was remarkable, and that learning skills and abilities were enhanced through facilitating injured brain function.

In sum, the following areas are discussed in the above studies. First, that stroke-related residual disability remains in the majority of survivors after a stroke; second, that multiple care issues and a perceived burden are encountered by stroke survivors and family members after discharge home; third, that families living with stroke need special skills to manage their care situation and thus need support from health care services; and finally that family harmonization and well-being are influenced by the impact of stroke after discharge home. However, little is known about the impact of

stroke on physical and psycho-social aspects for individuals living with stroke after discharge home over a period of time in Wuhan. Further, most studies were limited to a period of two to three months after discharge home in the aspect of functional status. Thus a longer period of time is needed to further explore their physical, psychological, social and spiritual experiences and difficulties in the home care setting. And no systematic study on both stroke survivors and family caregivers can be found in the above areas. Some topics have been neglected, particularly in the psycho-social aspects for families living with stroke after discharge home. No systematic study has been conducted on the care issues encountered by families living with stroke after the patient's discharge home, and how an effective community-based service can be provided and delivered in a planned way. This perspective case study can be helpful and valuable for nurses working in the community for helping families to deal with difficult care situations. Since most nurses have been educated to work in acute care settings, and they frequently think that families should take all responsibility throughout the whole process of stroke care, not only in acute care but after discharge home in the long run. When families fail to follow the recommendations for care, such as follow-up and the administration of medication, the nurses are critical of the families as "non-adherent" or "non-compliant" in not following the prescribed orders. Nurses usually fail to fully comprehend the complexities inherent in a home care situation and understand the difficulties confronted by families after patients' discharge home.

The findings of this prospective case study is particularly relevant to the local Chinese context with its diverse values, beliefs and ways of thinking, such as the aspects of cultural relevance of care and caring in China, in such a way as to sustain family well-being living with stroke after discharge home. However, this topic has not been addressed in the previously reviewed studies of today's China.

2.5 Summary

Family care of stroke survivors after discharge home is critical as stroke is found to be at high levels in terms of mortality, residual disability and stroke recurrence. And the emergent issues frequently encountered by the family in home care settings include financial constraints (e.g. high medical costs and low monthly income), the reduced number of available family caregivers (e.g. reduced size of family structure), the burden of care (e.g. physical aspects in number of hours to provide care per day, and the marketing mechanisms in the work world that impact on the traditional virtue of taking care responsibilities). Meanwhile, the Chinese government has taken actions to respond to this situation through the formulation of a series of laws and regulations, and instituting health care service reforms. An individual who has suffered from a stroke is admitted to the hospital and in most cases his/her life is saved. But no research has reported an organized care service, particularly for those patients with stroke residual disability after discharge home in the local community of Wuhan.
For the vast majority of Wuhanese in this situation, the family is the only critical source of medical, health and social support for stroke survivors over the course of stroke rehabilitation, especially after discharge home. Given the fact that children working in the modernizing economy are plagued with keen competition, and the push for the young to succeed in society, who would actually be the primary family caregiver at home? How do other family members support the primary family caregiver and share the burden of care? To what extent does stroke-related disability affect well-being of the family in the initial six months after discharge home? What kinds of care issues are encountered in this period? How do they perceive the burden of care and cope with them? Furthermore, what are the coping resources being utilized to deal with the care situation after discharge home by the individual, family and community? All these are questions formed the basis for a search of studies on both stroke survivors and family caregivers after discharge home that have been reported in other parts of the world. The following chapter is a review of these studies.

Chapter Three

Literature Review: Studies on Stroke Survivors and Family Caregivers after Discharge Home

While studies on home care of stroke survivors are in its infancy in China, numerous studies on post-stroke experiences of both survivors and caregivers in home care setting have been conducted in other parts of the world over the past three decades. This systematic literature review aims to identify the kinds of studies that have been conducted in the field of post-stroke home care, and the major issues encountered by families living with stroke as revealed in the research findings. This chapter begins with a description of the search strategy, and this is followed by an exposition of the research findings under the categories of quantitative and qualitative studies on stroke survivors and family caregivers.

3.1 Methods

The relevant research articles in the field of post-stroke home care were identified by searching the 3.1.1 Search strategy

A systematic literature review was conducted in this area of stroke care research, and a couple of methods were used to search the literature published in English. Ovid MEDLINE database from 1966 to and CHNAHL-Cumulative Index to Nursing &

Allied Health Literature from 1982 to March January 2002 and updated in September 2004 using the keywords: stroke, caregiving and home (see Table 3.1)

	Ovid MEDLINE	E (R)	CINAHL			
	<1966 to November We	eek 3 2004>	<1982 to February Week 2 2005>			
#	Search History	Results	Search History	Results		
1	stroke.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	60764	stroke.mp. [mp=title, subject heading word, abstract, instrumentation]	8508		
2	Caregiving.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	2527	caregiving.mp. [mp=titile, subject heading word, abstract, instrumentation]	2348		
3	home.mp. [mp=title, original title, abstract, name of substance, mesh subject heading]	71150	home.mp. [mp=title, subject heading word, abstract, instrumentation]	41781		
4	1 and 2 and 3	25	1 and 2 and 3	33		

Table 3.1. Articles search

Twenty-five and 33 relevant articles were first identified from the Ovid MEDLINE and CINAHL database, in November 2004 and in February 2005 respectively. And another 15 articles were then identified from searching the references of those 58 articles. Thus there were finally 73 relevant to the purpose of this review. Among them, six systematic in order to better understand the experience of both survivors and their family caregivers living with stroke after discharge home. I also extracted attracted the searched literature in my own collection with the major focus of stroke care after discharge home. review articles (Dolittle 1988, Hafsteinsdottir & Grypdonck, 1997, Dorsey & Vaca 1998, Han & Haley 1999, Ouimet et al. 2001, McKevitt et al. 2004) were found. With reference to these previous systematic review reports on stroke care

research, the present review focuses on both quantitative and qualitative studies on post-stroke experience of survivors and care experience of family caregivers. Dissertations and published abstracts were excluded.

The articles were subsequently organized into two broad categories: the post-stroke experience of survivors and the care experience of family caregivers. For the 17 quantitative studies on the post-stroke experience of stroke survivors, three themes were identified. They are (a) stroke survivor's characteristics and post-stroke residual disability, (b) post-stroke depression and the psychological well-being of stroke survivors, and (c) post-stroke coping strategies. The two themes identified from 26 quantitative studies on the care experience of family caregivers are (a) family caregivers' characteristics, health and psychosocial well-being, and (b) the management strategies of families living with stroke. The nine qualitative research articles on the post-stroke experience of stroke survivors are organized under the themes of (a) experience of stroke, recovery and residual disability, and (b) living with stroke-related disability. The remaining 21 qualitative research articles, on the care experience of family caregivers are organized under two themes. These are (a) family caregivers' characteristics, health and psychosocial well-being and (b) management strategies of families living with stroke. These articles came from 49 journals, mainly the journals of rehabilitation, stroke and nursing research. The main features of each study, including the authors and the year of publication, the name of the journal, sampling, research design, and time of evaluation data, are summarized in Tables 3.2, 3.3, 3.4, & 3.5). The following is a review of these studies according to the aforementioned themes.

3.2 Post-stroke experience of quantitative studies on stroke survivors

In order to better understand post-stroke experience for stroke survivors, stroke survivor's characteristics and post-stroke residual disability, post-stroke depression and subjective well-being of stroke survivors, and post-stroke coping strategies are delineated.

Authors (Year of	Name of journal	Sample	Design	Data collection schedule	
publication)		size			
Socio-demographi	ic characteristics and po	ost-stroke r	esidual disabilit	y	
Gresham et al. (1979)	Archives Physical Medical Rehabilitation	148	Cross-sectional	6 months after a stroke	
Labi et al. (1980)	Archives Physical Medical Rehabilitation	121	Longitudinal	Three years after a stroke	
Dejong & Branch (1982)	Stroke	84	Cross-sectional	Assessment was made 2 years after discharge	
Skilbeck et al. (1983)	Journal of Neurology, Neurosurgery and Psychiatry	92	Longitudinal	Assessment took place within the first 3 months and 6 months after stroke	
Kotila et al. (1984)	Stroke	154	Longitudinal	Assessment took place 3 and 12 months post stroke	
Wade & Hewer, (1987)	Journal of Neurology, Neurosurgery and Psychiatry	976	Longitudinal	Assessment took place 3 weeks and 6 months post stroke	
Kelly-Hayes et al. (1989)	Journal of Neurological Rehabilitation	119	Longitudinal	The informants were examined within 48 hours, 119 sustained an initial stroke (10-14 days of being stabilized), 67 survived for 12 months (interval at 3, 6 and 12 months)	
Muro et al. (2000)	Stroke	110-112	Longitudinal	Assessment took place at 3 and 6 months after stroke	
Lincoln et al. (2000)	Disability and Rehabilitation	54	Longitudinal	Assessment took place at 1 and 12 months after stroke	

Table 3.2. St	ummary o	of the quantit	ative studies	of post-stroke	experience of	of stroke
survivors fr	om 1979 f	to 2004				

Authors (Year of publication)	Name of journal	Sample size	Design	Data collection schedule
Post-stroke depres	ssion and psychological	well-being	of stroke surviv	vors
Feibel & Springer (1982)	Archives Physical Medical Rehabilitation	91	Longitudinal	Assessment was completed 10 days, 2 months and 6 months after stroke
Weddell (1987)	Journal of Scandal Rehabilitation Medicine	37	Cross-sectional	Over a 6-month period post-stroke
Fuh et al. (1997)	Stroke	2056	Cross-sectional	Not mentioned
Beekman et al. (1998)	Social Psychiatry Psychiatric Epidemiology	3050	Cross-sectional	Not mentioned
Wyller et al. (1998)	Stroke	1417	Cross-sectional	Not mentioned
Post-stroke coping	g strategies			
Evans & Northwood (1983)	Archives Physical Medical Rehabilitation	67	Cross-sectional	During a two-year period
Thompson et al. (1989)	Social Science Medicine	40	Cross-sectional	The informants were interviewed an average of 9 months post stroke
Colantonio et al. (1993)	Journal of Gerontology	87	Cross-sectional	At 6 weeks after discharge from a hospital
Rochette &	International Journal of	76	Longitudinal	Data were obtained from
Desrosiers (2002)	Rehabilitation Research			informants 2 weeks and 6 months post stroke in their own home

Table 3.2. Summary of the quantitative studies of post-stroke experience of stroke survivors from 1979 to 2004 (Con'd)

3.2.1 Stroke survivors' characteristics and post-stroke residual disability

The high incidence of post-stroke residual disability has been intensively studied since the 1970s by a group of researchers in the Framingham study (Gresham et al. 1979, Labi et al. 1980, Kelly-Hayes 1989). The following discussion focusing on survivors' characteristics through examining age, sex, marital status, lesion of stroke, co-morbidity state, recurrence of stroke, and post-stroke residual disability was delineated by the profiles of recovery in personal activities of daily living and instrumental activities of daily living changed over time. Stroke increases with advance age. The mean age of stroke survivors in the studies was from 60 (Gresham et al. 1979, Dejoing & Branch 1982, Kotila 1984) to 70 and above (Kelly-Hayes 1989, Muro et al. 2000, Lincoln et al. 2000).

Reports on gender differences seem inconsistent. Some reported there were more male (51-55%) than female (45-49%) stroke victims (Dejoing & Branch 1982, Kotila 1984, Muro et al. 2000), but other studies reported that there were either equal numbers of men and women (Skilbeck et al. 1983), or more women (53-60%) than men (40-47%) (Kelly-Hayes 1989, Lincoln et al. 2000).

Marital status is another significant factor to predict the person living in a more or less restricted environment (Dejoing & Branch 1989). They found that 60% percent were married and suggested that an individual's marital status was more important for men than women and might alter the changes of institution among older persons. But in Kelly-Hayes' (1989) Framingham study, it was found that only 28% were married, which implied that the remaining 72% might be living in a more restricted environment, particularly in the case of men.

Living, financial and educational status, and housing facilities and environment are important social environmental factors to affect individuals' independence in instrumental activities of daily living (I-ADL) (e.g. finances, personal care, community activities, leisure activities, transportation) in the community and family ability to provide help to those who are dependent. Dejoing and Branch (1982) reported that 85% were living in the community and 56% were living with spouses (Muro et al. 2000). And 36% of families had an elevator, 95% had a telephone and 51% had central heating (Muro et al. 2000). Furthermore, 60% had at least a high school education, 27% were retired due to age, 53% were receiving social security benefits (Dejoing & Branch 1982), most had a lower level of education, and 24% perceived themselves as insufficient in financial status (Muro et al. 2000). Family informal care at home appears to be the most important source of support and help for stroke survivors after discharge home. However, insufficient income, improper home adaptation and facilities for family living with stroke are crucial.

The brain damage caused by stroke is diverse. The brain lesion was located in the left hemisphere in 40% of cases and in the right in 39%, vertebrobasilar in 10% and 11% could not be defined (Kotila 1984); and of the neurological deficits manifested 52% had no residual functional deficit, four manifested bilateral weakness, and an equal number of cases (34 versus 33) manifested left and right hemiparesis. Finally, others included speech difficulties, hemisensory deficit, hemianopia, dysarthria and dysphasia (Gresham et al. 1979).

Co-morbid states were also shown to be significantly more common in stroke survivors than in controls in the Framinghan Study (Gresham et al. 1979) and affected the personal ability to cope with post-stroke residual disability. Specifically, (a) 14-24% had stroke recurrence (Gresham et al. 1979, Muro et al. 2000, Lincoln et al. 2000), and 13-24% had previous transient ischemic attacks (TIAs) (Kotila 1984, Lincoln et al. 2000); and (b) 30 to 53% had hypertension, 40% had heart disease, 22-16% had diabetes, 14% had a medical history of myocardial infarction, 34% were smokers and 22-24% were overweight and had arthritis (Gresham et al. 1979, Kotila 1984). These studies have proved that hypertension is the strongest risk factor for stroke, and that it is associated with other diseases such as heart disease, diabetes and higher incidence of myocardial infarction.

Only one study reported that the mean length of hospitalization was 26 days (Muro et al. 2000). This mostly depends on the severity of neurological deficits, age and family support.

A number of studies have also examined the severity of the residual disability at one time point or two and more time-points in order to examine the patterns of functional recovery over time.

There were two studies using a cross-sectional design. Residual disability mostly remained as a limitation in three major aspects: household tasks, dependence in activities of daily living (ADLs), and decreased ability to use outside transportation at six months after stroke in the Framingham study (Gresham et al. 1979); 37% of patients were dependent in ADLs (a Barthel score of 60 or less) two years after stroke (Dejoing

& Branch 1982).

Another six studies using longitudinal study designs showed certain patterns of functional recovery. Skilbeck et al. (1983) reported that it was obvious in an early rapid recovery with the first three months in ADL ability and walking, but not significantly after six months. Kotila (1984) made a more detailed observation of the recovery progress at three time-points. At the acute stage, and after three and 12 months, 30%, 69% and 78% respectively were independent in ADL. The findings supported the study of Skilbeck et al. (1983), which showed that the progress of recovery increased rapidly in the initial three months, but would still continue to 12 months after stroke. Kelly-Hayes (1989) also reported in the Framingham Study that the Barthel Index scores improved significantly in the first three months, but plateaued at six months, and declined slightly but not significantly at the end of 12 months after stroke. This study also found a significant improvement in ADL ability (self-care activities) and mobility, but no significant improvement in bowel and bladder function over the first six months, and with a similar decline at the end of 12 months after stroke. Lincoln et al. (2000) indicate that most were independent in personal ADL at one and 12 months, but that there was no significant change in personal ADL over time; however, instrumental ADL was significantly improved in household and leisure tasks, but not in mobility. Muro et al. (2000) only state that there was still 20% residual disability left at six months; no patterns of change in ADL were provided.

Labi et al. (1980) stated further in the Framingham Study that even after post-stroke residual disability improved over time, social activities did not improve. In other words, their household responsibilities did not resume their pre-stroke social activities, such as socialization outside and in the home. Labi et al. (1980) asserted that this group of survivors had achieved satisfactory levels of functional independence in ADLs and mobility, but continued to manifest significant psycho-social disabilities. With this question in mind, post-stroke depression and the impact of stroke on survivors' psychological well-being after discharge home have been examined as follows.

3.2.2 Post-stroke depression and psychological well-being of stroke survivors

A review of the literature on post-stroke depression (PSD) (Dorsey & Vaca 1998, Ouimet et al. 2001) reveals the statement that PSD is a common emotional outcome of stroke and that survivors frequently have emotional distress and mood disturbances, such as anxiety, frustration and despair, which are a reaction to the physical, cognitive, and psychosocial changes resulting from stroke. It is further suggested that the incidence of stroke can be varied because of the difference in the populations studied, different criteria for stroke and depression, time since stroke onset, instruments used to assess depression, and inclusion or exclusion of aphasia, dementia, past psychiatric history (Ouimet et al. 2001).

From two through six months after having a stroke, the incidence of depression

increased from 1.3% (13/91 patients) to 26% (24/91 patients) (Feibel & Springer 1982). The second community-based study conducted by Beekman et al. (1998) reported that depressive symptoms in stroke survivors (27.2%) were approximately 50% increased compared with no self-reported data of having a stroke (14.0%). The third community-based study on post-stroke depression reported that depression in stroke survivors (28/45 stroke survivors, 62.2%) was higher than that in non-stroke subjects (491/1471 non-stroke subjects, 33.4%) among the Chinese rural elderly in Taiwan (Fuh et al. 1997). Early identification of PSD can determine the potential success of adaptation to normal family interaction, which maintains a previous family role, communications and operations (Dorsey & Vaca 1998).

The potential contribution of physical deficit, cognitive deficit and dysphasia to psychiatric disorder for stroke survivors was examined by Weddell (1987). Thirty-seven stroke outpatients receiving hospital-based rehabilitation participated over a period of six months following a stroke. The results indicated that patient mood was related to the critical attitude of a key relative. Patient depression may have been associated with the severity of dysphasia, but no link was found between patient mood and the other measures of cognitive or physical deficit.

The subjective well-being (SWB) of stroke survivors was compared with that of non-stroke subjects (Wyller et al. 1998). Four factors are included in SWB: satisfaction, strength, calmness, and cheerfulness. The findings showed that higher SWB after

stroke was related to female gender, older age, good general and mental health and a firm social network. It suggested that any study on survivor's functioning in activities of daily living following a stroke should by supplemented by the perception of subjective well-being.

Based on the observation of the above studies, stroke is a major cause of residual disability. In addition to physical disability, survivors are likely to experience a variety of psychological changes and problems. Depression is a common reaction following a stroke (Dorsey & Vaca 1998). However, the ability to cope with these changes and problems has become significant for maintaining a person's well-being in the years following the stroke (Evans & Northwood 1983, Thompson et al. 1989, Colantonio et al. 1993, Wyller et al. 1998, Rochette & Desrosiers 2002).

3.2.3 Post-stroke coping strategies

Evans and Northwood (1983) examined the relationship between residual disability and the interpersonal needs of social support during a two-year period identified by 67 survivors after rehabilitation service. It was found that the congruent expression of interpersonal needs (referring to the availability of social support and person's ability to use it) for survivors was important for the adjustment to stroke residual disability. Evans and Northwood (1983) also suggested that social support needs tend to be significant for survivors who have physical limitations, and that such support may promote their optimal level of functional recovery.

Thompson et al. (1989) made a comprehensive analysis by examining four major psychosocial factors and their influence on emotional state at three months after commencement of stroke rehabilitation. These factors included objective circumstances (e.g. age, side of stroke infarction, time since the stroke, financial stress caused by the stroke, severity of physical and cognitive impairment), patients' interpretation of their situation (e.g. meaning, purpose, and fairness in life, perceived control over stroke and a sense of hope for the future), the relationship between the survivor and the primary family caregiver and the perceived social support available to the survivor (e.g. emotional and tangible support, overprotection by the caregiver, and patient and caregiver perceptions of each other), and caregivers' interpretation of their situation as the same domains given to the survivors. Interesting findings suggest that post-stroke depression was mostly related to patient interpretations of their situation and to their relationship with those who provide daily care.

Colantonio et al. (1993) scrutinized the impact of social network on stroke residual disability. This network included marital status, contacts with close friends and relatives, participation in group activities and church membership. The finding showed that the presence of social networks enhanced physical functioning because those who had more social contacts had greater motivation to remain physically active and mobile. Meanwhile, they were able to obtain more information that might enhance their

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personal ability to cope with the problems and changes resulting from a stroke.

The type of coping strategies used following a stroke was explored by Rochette and Desrosiers (2002). These coping strategies included imaginative thinking, distancing, self-controlling, seeking social support, escape-avoidance, positive reappraisal and problem solving. The findings reported that coping did not change between the end of rehabilitation and six months later. However, the utilization of positive-reappraisal and problem-solving strategies was more appropriate at six months following discharge from intensive rehabilitation.

Based on the above observation, the outcome of stroke can be determined by stroke residual disability, post-stroke depression and psychological well-being, and coping with the consequences of the stroke. Of these, social network and family support have become significant in positive adjustment to the physical limitation resulting from stroke (Evans & Northwood 1983). However, the burden of being the primary family caregivers has become crucial to those who care for long-term stroke survivors (Muro et al. 2000). Such issues are prominent and described as family caregivers' health and psychosocial well-being, and management strategies for families living with stroke in the following parts.

3.3 Care experience of quantitative studies in family caregivers of stroke survivors

Table	3.3.	Summary	of	the	quantitative	studies	of	family	caregivers'	care
experi	ience	to stroke su	rvi	vors	from 1979 to 2	2004				

Authors (Year of	Name of journal	Sample	Design	Data collection schedule
publication)		size		
Family caregivers	'characteristics, health	and psych	osocial well-bein	Ig
Brocklehurst et al. (1981)	Social Science Medicine	86	Longitudinal	Assessment was made at 4 to 6 weeks and 1 year post stroke.
Stroker (1983)	Journal of Neurosurgical Nursing	11	Cross-sectional	The mean time of assessment was 6 months post stroke
Silliman et al. (1986, 1987)	Journal of American Gerontological Society, The Journal of Applied Gerontology	89	Cross-sectional	Caregivers were interviewed at the mean time of 11 months post stroke
Wade et al. (1986)	British Medical Journal	324, 235, and 134	Longitudinal	Informants were assessed at three weeks, six months, one year and two years post stroke
Carnwath & Johnson (1987)	British Medical Journal	50 couples and 51 couples in the control	Cross-sectional	Living at home after stroke for between one and three years.
Schulz & Tompkins (1988)	Psychology and Aging	group 140 dyads	Longitudinal	The informants were assessed at 3 to 10 weeks and 6 months post stroke
Macnamara et. al. (1990)	Rehabilitation Psychology	41	Cross-sectional	Informants were interviewed at a mean of 15 months post stroke
Williams (1993, 1994)	Quality of Life Research, Journal of Neuroscience Nursing	29	Cross-sectional	Informants had a mean length of caregiving of 6 vears post stroke
Purk & Richardson (1994)	Families in society: the Journal of Contemporary Human Services	44	Cross-sectional	Discharge at least two months after a stroke
Anderson et al. (1995)	Stroke	84	Longitudinal	Informants were interviewed at 4 and 12 months respectively.
Draper et al. (1995)	International Journal of Geriatric Psychiatry	99	Cross-sectional	Informants had been caregivers for at least 6 months
Kinney et al. (1995)	The Journal of Applied Gerontology	78	Cross-sectional	After 2 years caregiving
Segal & Schall (1996)	Rehabilitation Psychology	38	Cross-sectional	Informants were interviewed at a median time of 6 months post stroke

Authors (Year of	Name of journal	Sample	Design	Data collection schedule
publication)		size		
Family caregivers	' characteristics, health	and psychol	osocial well-bein	g
Bethoux et al. (1996)	International Journal of Rehabilitation Research	9 stroke patients and spouses dyads	Cross-sectional	Informants were interviewed at a mean time of 18 months post stroke
Dennis et al. (1998)	Stroke	246	Longitudinal	At 6 months follow-up interview
Lee et al. (1998)	Topics in Geriatric Rehabilitation	51	Cross-sectional	Not mentioned
Scholte et al. (1998)	Stroke	115	Cross-sectional	Informants were interviewed at a median time of 3 years post stroke
Bugge et al. (1999)	Stroke	110	Longitudinal	Data collected at 1, 3, and 6 months post stroke
Teel et al. (2001)	Nursing Research	83	Longitudinal	Informants were interviewed at 1, 3, and 6 months post stroke.
King et al. (2001)	Research in Nursing & Health	136	Longitudinal	Informants were interviewed in acute rehabilitation hospital and at 6 to 10 weeks after discharge home
Nilsson et al. (2001)	Scandal Journal of Caring Sciences	20 for the T1 and 19 for T2	Longitudinal	1 month and 3 months after discharge
Morimoto et. al. (2003)	Age and Aging	100	Cross-sectional	Informants were not mentioned
White et al. (2003)	Research in Nursing & Health	97 dyads	Cross-sectional	During the first and second year post-stroke
Management strat	tegies for families living	with strok	e	
Stephens et al. (1988)	Psychology and Aging	58	Cross-sectional	Recently experienced a stroke
Grant et al. (2001).	Rehabilitation Psychology	40	Cross-sectional	Recently experienced a stroke
Forsberg-Warleby et al. (2002)	Journal of Rehabilitation Medicine	76	Cross-sectional	Not mentioned

Table 3.3. Summary of the quantitative studies of family caregivers' care experience to stroke survivors from 1979 to 2004 (Con'd)

3.3.1 Family caregivers' characteristics, health and psychosocial well-being

The idea that "a stroke is a family illness" or "a family matter" has drawn increasing attention in the past three decades as evidenced by a number of studies (Brocklehurst et al. 1981, Stroker 1983, Wade et al. 1986, Silliman et al. 1986, Carnwath & Johnson 1987, Silliman et al. 1987, Schulz & Tompkins 1988, Macnamara et al. 1990, William et al. 1993, 1994, Anderson et al. 1995, Draper et al. 1995, Segal & Schall 1996, Bethoux et al. 1996, Dennis et al. 1998, Lee et al. 1998, Scholte op Reimer et al. 1998, Bugge et al. 1999, King et al. 2001, Teel et al. 2001, Morimoto et al. 2003).

Several studies described the characteristics of family caregivers, specifically in terms of age, gender, educational level, family income, their relationship with stroke survivors, religious beliefs, and self-rated of general health. Some studies examined the association between caregiving outcomes (caregivers' physical and psycho-social well-being) and the characteristics of survivors and family caregivers, as well as the impact of stroke-related disability on caregivers at one time or more time points. These studies are discussed as follows.

Stroke occurs primarily in the elderly, but most primary caregivers are younger females. The reports state that more females (63-89%) than males are primary caregivers, and most (59%) have a mean age of less than 65 (from 47 to 61, ranging from 16-89) years old (Brocklehurst et al. 1981, Stroker 1983, Silliman et al. 1987, Schulz & Tomkins 1988, William 1993, 1994, Anderson et al. 1995, Bethoux et al. 1996, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999, Teel et al. 2001, King et al. 2001, Morimoto et al. 2003). However, one study from Taiwan indicated that there were almost an equal number of males and females in the primary caregiver role (Lee et al. 1998).

Educational level varies but most have a high education or above (83%) (Stroker 1983, Silliman et al. 1986, 1987, Wade et al. 1993, 1994, Lee et al. 1998, Teel et al. 2001).

As regards their relationship with stroke survivors, most were spouses (62-85%), and of these there were more wives (54%) than husbands (27%), 9-32% their children (more daughters than sons), and other relatives (e.g. nieces, nephews, and grandchildren). Most of the caregivers (80%-91%) were living with the patient (Brocklehurst et al. 1981, Stroker 1983, Wade et al. 1986, Schulz & Tompkins 1988, William 1993, 1994, Anderson et al. 1995, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999), and a less number (5%) saw each other daily (Brocklehurst et al. 1981). One study from Taiwan indicated, however, that there were more (67%) children (37% sons, 20% daughters, 8% daughters-in-law and 2% son-in-law) than spouses (33%) in taking caregiving role (Lee et al. 1998).

In regard to religious beliefs, most had a religion. Fifty-eight percent caregivers were Protestant, 29.1% were Catholic, and 8.9% belonged to an unspecified group or had no religious preference (5.1%) (Teel et al. 2001).

Deterioration of self-rated general health was indicated, and most perceived their general health as good or above. Ninety percent of caregivers reported their health as fair to excellent, while 10% reported poor health (Lee et al. 1998) at the time of interview. Only one study reported that deterioration in the chief caregivers' health was common during the first year, and 14% of those in employment gave up their jobs because of the patient's stroke (Stroker 1983).

Their working status is usually affected by stroke. It is indicated that 94 (24%) had worked before the stroke. Of those, 72 (77%) were still working at six months, 15 (16%) had stopped, and two (2%) had reduced their work (Wade et al. 1986). And at the mean time of 11 months post-stroke, only 39% were working full- or part-time (Silliman et al 1986). In six months following a stroke, 29% were working full- and 14% part-time, and 25% had retired (Schulz & Tompkins 1988).

The following studies have addressed the consequences of stroke on family members and primary caregivers in cross-sectional and longitudinal studies.

There were 15 cross-sectional studies examining the perceptions of caregiving in gender differences, the positive and negative impact of caregiving experiences, family support and community service utilization, various difficult care situations encountered by depressed spouses, as well as the impact of stroke on caregivers' physical, psychological and social well-being.

Stroker (1983) used an approach of "finding the meaning in the situation" to explore the impact of varied kinds of residual disabilities among family caregivers. Such disabilities included hemiplegia, aphasia, sensory/perceptual deficits, and behavioral problems. It was found that there was a gender difference in attitudes towards survivors, with males experiencing more difficulties than females, such as in the areas of negative attitude toward the survivor, over-commitment, and financial problems because males had greater difficulty with their new roles and responsibilities as care providers in the home care setting.

Silliman et al. (1986, 1987) also identified 101 survivors and 89 family caregivers discharged from a hospital at the mean time of 11 months post-stroke. It was indicated that both positive (e.g. providing care and patient improvement) and negative (e.g. behavior, lifestyle change and functional limitation) perceptions of their caregiving role existed. On the positive side, 84% reported increased self-esteem because they had been able to manage their loved one's illness and 69% reported a closer personal relationship with the survivor, but on the negative, 76% worried about potential difficulties if they became ill, 70% indicated a lack of understanding of the survivor's needs, and 40 to 45% had less time for themselves or their families, went less often to church, and bore greater financial burdens (e.g. increased household and medical expenses). In regard to the use of informal or family supports, most (71%) reported that they received instrumental help (e.g. patient care or household tasks, or emotional support). Only 20-30% of all caregivers obtained financial assistance or information

that might assist them with caregiving. A number of formal services (e.g. health care services) were reported such as visiting nurses, physical therapists, or meals-on-wheels. About half of them expressed a desire for respite care or more help within the home (e.g. household chores or with patient care). No caregivers participated in the stroke club, or other support group, or took advantage of respite services. Three-quarters stated that help from family or friends was more important than help from formal services.

Carnwath and Johnson (1987) examined two groups for spouses between one and three years after a stroke. Couples with a depressed spouse had expressed more difficulties than non-depressed couples affected by stroke. Aspects that spouses described as difficult included: job given up, past psychiatric history, complaint of poor physical health, taking drugs, marital problems, housing problems, dissatisfaction with occupation, fewer visits from friends and relatives, and seen less by neighbors; those cited by survivor included: physical dependence, incontinence, inability to use toilet independently, longer time in hospital, depression and irritability, sleep problems, being troubled by pain, decreased social activities and decreased interests outside house.

Macnamara et al. (1990) used two developmental caregiver strain models to examine caregiver strain at the mean time of 15 months following a stroke. One was derived from work with brain-injured patients, which suggested caregivers experience steadily increasing levels of emotional distress with time; the other was drawn from the observations of chronically ill patients, in which caregivers were considered to experience initially high levels of distress but symptoms of caregiver strain decreased with time. The findings supported the first prediction that caregiver anxiety increased with time after a stroke.

William (1993, 1994) used a convenient sample of 29 caregivers (21 female; 8 male) over a mean time of caregiving of six years. They were found to have moderately few physical symptoms, but considerable emotional distress. Nearly half of primary caregivers had anxiety and depression scores above the level identified. Anger and hostility (40%) were also a salient finding. In addition, the behaviors of stroke survivors were most stressful in three manifestations: irritability, dependence (resulting caregiver confinement) and immature behavior. The author stated that the potential for verbal and physical abuse may exist, particularly in situations when the caregivers feel burdened and angry due to the above three major stressors. And the issue of the relationship between perceived burden and reported hostility for primary caregivers, as well as the stressors caused by stroke was addressed.

The morale of stroke patients older than 60 and their spousal caregivers was explored by Purk et al. (1994). A sample of 44 couples was used, in which stroke survivors required an inpatient rehabilitation stay during the study. At the time of data collection, all had been discharged for at least two months. Length of time since the stroke ranged from six months to four years. Results indicated that morale of caregivers and care receivers were positively correlated. Furthermore, functional independence predicted patient and spouse morale levels. It was suggested that it was important to use a dyadic approach in research and intervention while dealing with stroke patients whose spouses were providing care after discharge home.

Draper et al. (1995) examined 99 elderly caregivers for both stroke and dementia sufferers to predict their subjective well-being and psychological morbidity after the short duration of caregiving for six months. It was found that high subjective burden was related to a worsening in their relationship, being spouses, perceived poor or fair health, having a shorter length of caregiving, caring for more physically disabled survivors, caring for a person with more behavior/mood disturbance. High risk factors of psychological morbidity for caregivers were: female, perceived poorer quality of life, and caring for a person with more behavior/mood disturbance. It was concluded that subjective burden and psychological morbidity for caregivers were closely associated for elder caregivers following a stroke.

The specific stress resulting from a stroke and its impact on caregivers' well-being were explored by Kinney et al. (1995) after two years' caregiving experience. These stress included hassles (daily stresses appraised by individuals) and uplifts (protections from the negative consequences of hassles). The study examined the relationship among these stresses and three indices of caregiver well-being (e.g. restrictions in caregivers' social activities, negative social relationships and depression). The results indicated more uplifts than hassles, and that stroke survivors' characteristics were stronger predictors of both hassles and uplifts than were caregivers' characteristics. Hassles had the strongest association with well-being, with caregivers who reported more hassles also reporting lower levels of well-being.

Segal and Schall (1996) used 38 family caregivers at six months after stroke to examine the relationship between stroke-related disability and life satisfaction and caregiving stress. It was found that life satisfaction/quality of life was lower than for the general population, and directly related to perceived burden by caregivers in three aspects: amount of physical assistance, mobility, and ways of spending time.

Bethoux et al. (1996) used only nine stroke patient and family caregiver dyads to examine factors influencing the impact of stoke on caregivers' quality of life after 18 months after a stroke. Two interviews were performed in different ways: one was structured and the other was an open discussion with the spouses about factors influencing their quality of life. Five major factors including physical and psychological burden, restriction of social activities, financial problems and a worsening of marital relationship were identified.

Dennis et al. (1998) examined the emotional status of caregivers after six months following a stroke. Their results indicated that caregivers' depression was related to survivors' degree of functional disability and their own emotional distress. Anxiety was most related to being female, and was not related to the patients' degree of physical disability. Caregivers suffered more emotional distress if the patients had been dependent before their stroke.

Lee et al. (1998) have examined 51 stroke survivors and family caregivers in Taiwan and the mean of caregiving varied from less than six months to one year. The perceived burden reported that both physical and psychosocial burden existed, such as disturbed sleep, physical strain, sense of confinement, family adjustments, changes in family plans, and demands of time. This implies that respite care may relieve their overall burden and allow them more time to relax.

Scholte et al. (1998) examined the level and specific nature of the burden by partners of stroke survivors at three years after a stroke. A total number of 155 partners were interviewed. The most frequently perceived burden was the physical care involved in patients' personal activities of daily living. Others were mostly related to emotional burden such as feelings of heavy responsibility, uncertainty about patients' care needs, constant worries, restraints in social life, and feelings that patients rely solely on their care.

Well-being, sense of coherence (SOC), and burnout during the first few months (from one to three months) after discharge home were studied by Nillsson et al. (2001). Ten stroke victims and their spouses participated. Three self-reporting questionnaires were used: the well-being measure (WM), the SOC scale, and the burnout measure (BM). The results indicate that considerable distress is found in both stroke victims and spouses, although individuals with a weak SOC displayed more difficulties in coping with the situation and risk of burnout than did those with a strong SOC.

Morimoto et al. (2003) examined the relationship between caregiver burden and health-related quality of life in family caregivers of older stroke patients in Japan. One hundred subjects were recruited from seven randomly selected out-patient rehabilitation clinics. Findings indicate that increased burden significantly relates to decreased health-related quality of life among stroke caregivers. The prevalence of depressive symptoms among caregivers was twice that of community-dwelling older people.

Relationships between stroke survivors and family caregiver factors and the caregiver's health-related quality of life (HRQL) and overall quality of life were examined by White et al. (2003). Ninety-seven dyads participated during the first and second years after stroke. Caregiver characteristics (e.g. old age, less burden, and fewer physical symptoms) were associated with better HRQL (mental summary scale) in the first year, with similar findings in the second year. Moderate stroke survivor physical impairment and caregiver characteristics (younger age and better HRQL) were associated with better QOL in the first year. During the second year, poorer caregiver physical and mental health and caring for a stroke survivor with communication difficulties were associated with diminished QOL.

In addition, six longitudinal studies examined the association between stroke-related residual disability and caregivers' well-being, the change of prevalence of caregivers depression, perceived burden by family caregivers, and the relationship between physical and psychological health in caregivers over time.

Wade et al. (1986) examined the relationship between stroke disability and caregivers' well-being at three weeks, six months, one and two years based on a community-based sample. At one year after their stroke, 372 survivors lived at home, but 70 lived alone, most (302, 81%) lived with a carer, and 81 had more than one person in the house. The main caregiver was a spouse (257, 85%). The analysis revealed that depression in the primary caregiver was significantly related to a survivor's disability up to one year after a stroke but not at two years. Their mood changes at six months compared with pre-stroke status were an increase in anxiety (43%) and irritability (28%). An interesting finding was that depression was common in the companions of independent survivors: 13 (28%) of the 45 depressed caregivers at six months lived with survivors who were completely independent as measured by the Barthel Index. The authors stated that at that time depression was associated with their poor perception of the survivor's recovery. This finding was supported by the hypothesis proposed by the authors that depression in the caregivers was mostly related to the occurrence of a major and life-threatening illness, and not to the physical stress of caring.

Schulz and Tompkins (1988) also examined the association of stroke disability and its

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impact on caregivers' well-being. The study sample was based on 162 dyads with first-ever stroke, carefully recruited from nine different hospitals. Data collection took place in two time points (T1: beginning seven weeks after the stroke; T2: six months later). The findings showed that depressive symptoms for both primary support persons and stroke survivors were higher than rates in other studies, and the mean level of depression and negative well-being did not change from Time 1 to Time 2. The data also show that the well-being of the family changed from Time 1 to Time 2, suggesting that the factors that play an important role in short-term adaptation are not necessarily consequential in the long run.

Anderson et al. (1995) examined the impact of stroke on caregivers' well-being in Perth, Western Australia at four months and 12 months respectively with a community-based sample. It was found that the assistance of the first three activities of daily living to survivors was dressing (52%), bathing (48%), and feeding (36%) at the one-year follow-up. The most frequently affected areas for caregivers were emotional ill-health (79%), and disruption of social activities (79%) and leisure time (55%), and 25 % described effects on family relationships for reasons including tension, misunderstandings, and feelings of neglect among other family members due to the physical and emotional demands of the patient. In addition, caregivers expressed their frustration and anger, which were displaced onto others and thus creating the tension in the family. Financial and work-related problems were also prominent because the main wage-earner had experienced the stroke. Family caregivers also experienced their own physical symptoms (e.g. arthritis) or were otherwise affected by the management of stroke-related conditions, such as hypertension or cardiac disease. The manifestations of emotional disturbance expressed by caregivers were anxiety (58%), depression (50%), fear (35%), frustration (32%), resentment (29%), impatience (25%), and guilt (10%). They frequently expressed anxiety because of a fear that the patient might fall or experience another stroke when they undertook other work-related activities such as shopping and paying bills, and buying drugs, and left the patient home alone. It was concluded that a high level of emotional disturbance for family caregivers existed in the home care setting after discharge home.

The level of strain experienced by family caregivers at one, three and six months after stroke was examined by Bugge et al. (1999) in Scotland. It was found that 37% of caregivers experienced considerable strain at six months after stroke, and that the indicator of stroke severity was significant at each time point. It was suggested that the interface between patient characteristics and strain, burden, and depression, as well as caregivers' perception of their relationships should be identified and assessed.

The changes in depression, physical health, and contextual and coping factors for family caregivers from acute rehabilitation (T1) to the first six-ten weeks of home care (T2) were explored by King et al. (2001). Coping factors were considered importantly by the authors in two levels: cognitive appraisal and coping skills. In the cognitive appraisal, concerns about stroke recurrence and ability to provide future care, and

satisfaction with social support and availability of support were included. In the coping skills, emotional focused in regard to finding meaning, cautions, seeking social support and avoidance and problems-solving in terms of active problem solving and compromising were examined. The characteristics of the stroke-related disability in the in the study included a variety of serious disabilities, such as aphasia (44%) and incontinence (36%). The results indicate that a decrease occurred in the incidence of depression from 44% to 34% for the family caregivers over the two time points. And new health problems were reported by 16% of primary caregivers at T2. These problems included musculoskeletal, skin. cardiovascular. infectious, and gastrointestinal conditions. Despite health status changes, physical health scores were not significantly different between T1 and T2. Cognitive appraisal of social support was not significant over time. The use of two types of problem-solving coping strategies (the compromising and active problem-solving) increased, but the change was significant only for compromising coping strategy. In contrast, two emotional-focused coping strategies (find the meaning and seeking support) were used significantly, and decreased use of cautious and avoidance coping was not significant. Finally, the strongest predictors of depression were being female and holding negative impact appraisals. Of less significance was poorer health and being employed. Variables that were not related were survivors' comorbidity, appraisal-support satisfaction, and compromising coping.

The relationships of patient characteristics, characteristics of the caregiver, and

caregiver coping resources (spiritual and social support) with the physical and mental health outcomes of the caregiver at one, three, and six months after assuming caregiving responsibilities were explored by Teel et al. (2001). They reported that caregivers have stable perceptions of fatigue, vigor, recurrent sorrow, perceived stress, finances, family support, physical health, and depressive state symptoms at one, three, and six months after the loved one's stroke. The relationship between physical health and depressive symptoms was reciprocal at three and six months. Perceived stress was related to mental health at three and six months. Caregiving ratings of disability at one month paralleled clinical assessment using the Orpington Prognostic scale.

In summary, the above literature consistently documented the common characteristics of family caregivers: more younger females, more spouses and living with survivors, higher educational level, most having religious beliefs, more perceiving financial strain, perceiving poor health status to increase over time, and more family than community support utilization. With regard to the impact of stroke, most studies described a negative impact on caregivers' physical and psychosocial well-being, but one study pointed out that both positive and negative caregiving effects exist. However, risk factors for caregivers' depression and emotional ill-being (e.g. perceived burden or strain, anxiety, anger), included stroke-related residual disability, physical dependence prior to stroke, both male and female caregivers being of advanced age, increased length of caregiving, decreased social activities, occurrence of life-threatening illness such as sudden attack of stroke, adaptation varying from a short- to a long-term run. This information is important for health care providers to give an early assessment and identification for family caregivers' physical and mental health problems in home care settings, and it is further concluded that the reduction of primary family caregivers' depression and their burden in the early stages can be prevented. Thus understanding the ways in which caregivers cope with their stressful situation and enhance their well-being becomes vital in the caregiving process after discharge home.

Taken together, these findings suggest that, to fully understand the caregiving process, future research might explore both positive and negative appraisals made by caregivers across a wider range of illness conditions, and how these patterns may change over time.

3.3.2 Management strategies for family living with stroke

There were three studies that focused on varied coping strategies utilized among family caregivers and their relationship with the impact of stroke on caregivers' well-being.

Stephens et al. (1988) stated that although they examined the association of caregiver coping and its impact on caregivers' well-being, their study was different from previous ones, in that its focus was on coping with specific events appraised by caregivers as stressful instead of on the general caregiving experience. Four-fifths of patients had experienced a recent stroke, and others had experienced a variety of other disabling

conditions. Fifty-eight family caregivers were randomly identified from those recently discharged from a rehabilitation hospital. The mean age of caregivers was 60, most were spouses and the rest were other family members, primarily daughters. It reported that care issues were mostly related to activities of daily living, specifically that 53.4% of the patients required a great deal help with personal hygiene and 69.0% disturbed their caregivers during the night. Findings indicated that younger caregivers, especially those who were women, tended to use escape-avoidance coping strategies more intensively and reported greater depression like more irritability, and more conflict in their personal relationships such as with their families and friends.

The unique contributions of social problem-solving abilities and social support in the prediction of aspects of caregiver adjustment were explored by Grant et al. (2001) in caregivers of patients following a recent stroke. Social problem-solving abilities included problem-solving confidence, personal control and approach-avoidance while social support included the perceived availability of someone to talk to about problems (appraisal), people to do things with (belonging) and material aid (tangible support). The results show that social support was the best predictor of caregiver life satisfaction. Perceived control over emotions when solving problems was the best predictor of caregiver depressive behavior and health. Social problem-solving abilities were associated with caregiver depressive behavior and health, but social support did not mediate these relationships. It is concluded that problem-solving interventions might be most appropriate for the treatment and prevention of caregiver depression and health

problems. Social support programs may be effective for the caregivers' life satisfaction.

Spouses' perception of their future daily life after stroke and the association between this perception and the objective characteristics of the stroke were explored by Forsberg-Warleby et al. (2002) in Sweden. Eighty-three spouses of first-ever stroke victims participated. Sense of coherence (SOC) included three major components: comprehensibility, manageability, and meaningfulness. It was found that the spouses' sense of coherence (SOC) was associated with their satisfaction with life in general, close relationships and their financial situation. Spouses with low SOC were more likely to have a pessimistic view of the future and lower psychological well-being.

Based on the above three studies on management strategies utilized after a stroke for caregivers, different coping strategies have been examined: some suggested that escape-avoidance coping strategies had shown to be related to poor psychosocial adjustment, particularly among younger and female caregivers, and another study suggested that sense of coherence (SOC) appeared to be critical for the spouses' personal coping capacity after stroke. Due to various strategies used among family caregivers, it would help to plan therapeutic interventions with patients' families through adopting effective coping strategies, such as more active and problem-focused method, to assist families in successfully coping with stressful situations in caregiving.

3.4 Post-stroke experience of qualitative studies of stroke survivors' living with

residual disability

Table 3.4. Summary of the qualitative studies of post-stroke experience of stroke survivors from 1979 to 2004

Authors (Year of	Name of journal	Sample	Design	Data collection schedule
publication)		size		
Experiences of str	oke, recovery and resid	ual disabili	ity	
Doolittle (1991,	Journal of Neuroscience	13	Longitudinal	Up to 6 months post
1992)	Nursing, Rehabilitation			stroke
	Nursing			
Folden (1994)	Rehabilitation Nursing	20	Longitudinal	Up to 6 months post
	Research			stroke
Haggstrom et al.	Qualitative Health	29	Cross-sectional	Informants were
(1994)	Research			evaluated at least 12
				months post stroke
Nilsson et al.	Journal of Advanced	10	Longitudinal	Up to 2 months post
(1997)	Nursing			stroke
Pound et al. (1998)	Clinical Rehabilitation	40	Cross-sectional	Informants were
				evaluated 10 months post
				stroke
I iving with stroke	-related disability			
Dillington (1000)	Journal of Neuroscience	12	Longitudinal	Up to 2 months post
Plikington (1999)	Nursing	15	Longitudinai	stroke
Burton (2000a)	Journal of Advanced	6	Longitudinal	Up to 12 months post
~ /	Nursing		C	stroke
Bays (2001)	Rehabilitation Nursing	9	Cross-sectional	Up to 28.89 months post
				stroke
Hilton (2002)	Journal of	5	Cross-sectional	Informants were
	Gerontological Nursing			evaluated at least 12
				months post-stroke

3.4.1 Experiences of stroke, recovery and residual disability

The progressive experience of the bodily recovery of patients who have had a stroke was first explored by Doolittle (1991, 1992). A longitudinal, descriptive ethnography formed the basis of this research, in which 120 interviews were conducted over a period of six months with 13 survivors who had experienced lacunar infarction of the internal
capsule of the brain. Participants were interviewed within 72 hours of the infarct and during the acute and rehabilitation phases of recovery. It was found that patients had a dramatic loss of automaticity during this first six months. Simple activities such as eating became ordeals. Meanwhile, body integration was lost: the affected body parts were referred to as "it" instead of, for example, "my arm". At two to three weeks post-stroke, recovery was experienced in plateaus. Then at seven to 12 weeks, all participants noted waning improvement, but at 15 to 20 weeks, they became daring and experimental. The most dramatic findings were referred to as "transformation by familiar surroundings". Doolittle interpreted this as meaning that patients who had done poorly in rehabilitation centers improved dramatically once they returned home. An example illustrated how one patient was unable to walk more than two steps in the rehabilitation setting, but walked across the room with assistance once she returned home, and eventually walked independently.

Stroke survivors' experience of living with stroke sequelae and their future expectations were described by Haggstrom et al. (1994). Twenty-nine survivors, 60-91 years old, 19 men and ten women, narrated stories about two different photographs, showing a person of the same age and gender as themselves being fed or eating dependently. The stories were analyzed and interpreted by means of a phenomenological hermeneutic method. Four themes were identified: (a) uncertainty, (b) sadness and mourning, (c) gratefulness, hope and satisfaction, and (d) isolation. Based on these four themes, the stores were then condensed into four core stories. The emotional content of each core story was expressed by a metaphor. The stories expressed both optimistic and pessimistic future expectations.

A qualitative study with a grounded theory design was conducted by Folden (1994). The aim of this study was to explore the process of stroke survival and how to manage the multiple functional deficits that follow stroke during the first month after the stroke. Twenty participants between the ages of 65-78 years were interviewed for the first time in the rehabilitation setting within two weeks after the initial onset, and for the second time three-four weeks following discharge from inpatient rehabilitation. The grounded theory method was used to analyze the data. The process identified by the participants was ensuring forward progress, and the endpoint of this process was recovery. Before initiating the core process entitled "Ensuring Forward Progress", participants identified themselves as stroke survivors and accepted that life would be forever different. There were two distinct patterns in identifying themselves as having had a stroke. The first pattern was essentially self-diagnosis, in which they readily identified their symptoms as indicative of a stroke. The second was diagnosis by others, in which they were diagnosed by emergency personnel or a physician. In order to ensure the progress of recovery, the following components were important: accepting that life would be forever different, maintaining hope, preserving energy and increasing personal control over recovery.

The experience of stroke survivors during the acute phase of the disease and the first

few months after discharge was explored by Nilsson et al. (1997). Ten survivors, aged 53 to 81, recently having suffered their first manifest stroke with lasting neurological symptoms, narrated their experiences and gave their views at two different appointments during the first few months after discharge. The analyses of the interviews were formed using a phenomenological hermeneutic method. The emphasis of this study was to uncover the meaning of the living experience through an interpretation process. This interpreting process was carried out in the following steps: naïve reading, structural analysis and comprehensive understanding. The interpretations related to developmental crises (up and down process) included trust vs. mistrust, autonomy vs. shame and doubt, initiative vs. guilt, industry vs. inferiority, identity vs. identity confusion, intimacy vs. isolation, generativity vs. stagnation, and integrity vs. despair.

Subjective accounts of the consequences of stroke were explored by Pound et al. (1998). Qualitative methods were used in the form of in-depth interviews. Forty people participated in the study ten months post stroke: they were recruited from a hospital stroke register in two adjacent health districts in the North Thames Regional Health Authority in London. Interviewees reported a number of ways in which stroke had affected their daily lives, including difficulty with leaving the house, doing the housework, pursuing former leisure activities, inability to walk in the way they wanted, problems with communicating, washing, bathing and dressing, and with confusion and deteriorating memory. In all these areas, people described the loss of social contact that accompanied these changes, and the loss of valued roles which had been embedded in the everyday functions they had previously performed. Particularly people who were over the age of 70 were more seriously affected under the study.

3.4.2 Living with stroke-related disability

Survivors' quality of life experience after a stroke was explored by Pilkington (1999) using a longitudinal, qualitative and descriptive study. Thirteen participants aged 40-91 years, including nine men and four women, were interviewed three times: during their acute stay in hospital, and one and three months after stroke onset. The analysis of a total of 32 interviews was synthesized and created by four themes representing participants' descriptions: (a) suffering emerges amid unaccustomed restrictions and losses, (b) hopes for endurance mingle with dreams of new possibilities, (c) appreciation of the ordinary shifts perspectives, and (d) consoling relationships uplift the self.

Living with stroke was explored by Burton (2000a), who employed a phenomenological approach to understand how stroke survivors experience stroke and recovery. A total of six participants aged 52-81, including two males and four females, were interviewed at initial admission after stroke and at monthly intervals for at least one year. The data illustrate that recovery from stroke involved restructuring and adaptation in the physical, social and emotional aspects of an individual's life. Among

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the issues of physical recovery, the following experiences were highlighted: initial personal experiences of stroke, early recovery, slowing down, and new challenges. As for the issues of emotional recovery, uncertainty, loss of control, anger and frustration were overwhelming. Finally, in terms of the issues of social recovery, changes in roles, isolation, and reflections on their previous life were expressed.

The phenomenon of hope and associated factors in older adults was explored by Bays (2001). Nine stroke survivors, mean age 68, were interviewed at a mean of 25 months (e.g. more than two years) following the onset of stroke. Of these, two had experienced a left hemispheric stroke, and seven had experienced right hemispheric stroke, six were married and living with their spouses, two were widowed and living alone, and one was widowed and living with a daughter. The patterns of hope described by participants were positive anticipation, active participation, forward moving process, inner sense/strength, faith in God, continuing to hope, relative comparison, life-sustaining realistic possibilities, connectedness, previous abilities, and mobility. Factors associated with hope patterns were family connectedness, spiritual connectedness, and goal achievement.

The meaning of stroke in elderly women was explored by Hilton (2002). Five non-institutionalized women surviving from stroke, aged 66 to 80, were interviewed once at least one year following stroke. A thematic analysis was undertaken by using van Manen's method. An overarching theme of transition with transformation was identified. Five sub-themes were created, including deterioration and decline, loss and helplessness, regret, uncertainty and anxiety about the future, and resiliency. Another six interwoven additional themes were also established. Informants experienced numerous changes as a result of stroke that affected the ways they perceived themselves and their lives.

These studies have suggested that the perspective of stroke survivors is different from the biomedical perspective, which frequently emphasizes the fact of progress in terms of bodily strength, movement, and the completion of functional activities and tasks. And many people with stroke would benefit from being able to talk about the changes in their lives and how they coped with them. Innovative proposals are needed to develop ways to help replace the loss of activities, social contact and social roles, and it is vital for nurses to understand the experience of stroke, personal recovery and residual disability, and how they lived with stroke-related disability after discharge home over a period of time. The importance of studying the personal experience of stroke and how they coped with stroke-related residual disability has been well illustrated in the above studies. However, these pitfalls can be carefully avoided in the research design. For example, the participants were limited to survivors suffering from lacunar infarction (Dolittle 1991, 1992) or there was a failure to define the nature of stroke, or the time of the follow-up study was limited to a short period of time (Folden 1994, Nilsson et al. 1997, Pilkington 1999), and most used a cross-sectional study design (Haggstrom et al. 1994, Pound et al. 1998, Bays 2001, Hilton 2002).

3.5 Care experience of qualitative studies of families living with stroke

Table 3.5. Summary of the qualitative studies of the care experience of familyliving with stroke survivors from 1979 to 2004

Authors (Year of	Name of journal	Sample	Design	Data collection schedule
<u>publication</u>	ovnorionco in nhysicol	size	and social of	nongos
Mumma (1986)	Rehabilitation Nursing	30 couples	Cross-sectional	Informants were evaluated at least three months post-stroke
Periard & Ames (1993)	Public Health Nursing	20	Cross-sectional	Informants were interviewed 6 to 24 weeks post stroke (first ever stroke survivors)
Jongbloed (1994)	American Journal of Occupational Therapy	1 couple	Longitudinal	Informants were interviewed over a period of two years
Robinson-Smith & Mahoney (1995)	Journal of Neuroscience Nursing	7 couples	Cross-sectional	Informants were interviewed 6-12 months after discharge post stroke
Fraser (1999)	Journal of Neuroscience Nursing	1 daughter	Longitudinal	Informants were interviewed every two weeks and followed 6 and a half month after discharge home
Eaves (2000)	Journal of Neuroscience Nursing	8 families	Cross-sectional	Informants were interviewed four months after discharge post stroke
Brereton & Nolan (2000)	Journal of Clinical Nursing	7	Longitudinal	Up to 18-month period
Secrest (2000) Pierce (2001)	Rehabilitation Nursing Rehabilitation Nursing	10 8 primary caregivers and 16 secondary caregivers	Cross-sectional Cross-sectional	6 months post stroke Informants were interviewed for the duration of care giving, ranging from 6 months to 11 years.
Cassells & Watt (2003)	Journal of Advanced Nursing	8	Cross-sectional	Informants were evaluated for an average of 4 years of taking care of recipients' incontinence
Smith et al. (2004)	Journal of Advanced Nursing	90	Cross-sectional	One year post-stroke

Authors (Year of publication)	Name of journal	Sample	Design	Data collection schedule			
Care issues and management strategies of families living with stroke							
Davis & Grant (1994)	Advances in Nursing Sciences	8	Longitudinal	Informants were interviewed at the initial follow-up and one week later			
Grant (1996)	Home Healthcare Nurse	10 dyads	Longitudinal	Over a period of 12 months post-stroke			
Burton (2000b)	Journal of Advanced Nursing	1 couple	Longitudinal	Over a period of 14 months post-stroke			
Dowswell et al. (2000)	Journal of Clinical Nursing	30 patients and 15 caregivers	Cross-sectional	13-16 months post-stroke			
Subgranon & Lund (2000)	Journal of Transcultural Nursing	20	Cross-sectional	Not mentioned			
Burman (2001)	Rehabilitation Nursing	13 caregivers	Longitudinal	Six months post-stroke			
Bakas et al. (2002)	Journal of Neuroscience Nursing	15 female caregivers	Cross-sectional	The first six months post-stroke			
O'Connell & Baker (2004)	International Journal of Nursing Practice	37	Cross-sectional	Not exactly provided			
Grant et al. (2004)	International Journal of Rehabilitation Research	22	Cross-sectional	The first month post-stroke			
Impact of stroke on the well-being of family caregiver and stroke survivors							

Table 3.5. Summary of the qualitative studies of the care experience of family living with stroke survivors from 1979 to 2004 (Con'd)

mpact of stroke on the well-being of family caregiver and stroke survivors

Fitzgerald (1989) AXONE 8 spouses Longitudina	Caregivers were interviewed 2 weeks and 5 to 15 weeks post stroke

3.5.1 Family caregiving experience following stroke

Studies on family caregiving experience following a stroke mostly described the changes in physical, psychological and social aspects following a stroke for family caregivers or for both caregivers and stroke survivors after discharge home.

An exploratory, cross-sectional survey conducted by Mumma (1986) described the

losses experienced following a stroke as perceived by both stroke survivors and their

spouses. Sixty middle-aged and older couples were interviewed, in each of which one person had suffered a stroke at least three months prior to participation in the study. Data were collected by using a combination of structured scales and open-ended questions about the perceived losses. Content analysis was undertaken and three major categories of loss were yielded. These were activities, abilities and characteristics, and independence. Meanwhile, views of loss between survivors and their spouses were expressed differently. The loss most often mentioned by survivors being mobility, and the one most mentioned by spouses being traveling.

Perceived lifestyle changes and coping patterns among caregivers of stroke survivors were examined by Periard and Ames (1993). A multiple method approach was used to assess the perceptions of lifestyle changes and coping patterns. Twenty caregivers (18 women and two men) of first-time stroke survivors were interviewed for four to six hours in the early post stroke period, six to 24 weeks after the stroke. In-depth case studies (qualitative approach) were coupled with quantitative analyses. Lifestyle changes were defined as a self-reported alteration (increase or decrease in amount or frequency) in I-ADL. Lifestyle change data were combined from structured and open-ended questions as well as the interviewer's notes and observations. Quantitative analysis revealed that most (95%) caregivers experienced changes in at least one lifestyle category, while qualitative findings revealed two primary changes among caregivers. They were time and confinement, which indicated that the physical confinement and lack of sufficient time prevented them from engaging in activities

such as personal care, leisure, and church or community participation.

The member who experienced the stroke, from the perspective of the persons involved was explored by Jongbloed (1994). The contents of five interviews conducted over two years (namely 5, 9, 14, 20 and 29 months after a stroke) with a woman (aged 55 years) who experienced a stroke and her husband (aged 61) were analyzed with ethnographic research methods. The analysis revealed that a stroke cannot be understood as an individual phenomenon, because the life course of both this woman and her husband were profoundly affected by it. The man's roles as family member, caregiver, home maintainer, and hobbyist required change after his wife's stroke. The woman's experience included her dysfunctional body, dependence, role change, and alternation of retirement plans. The contribution of this study attempted to use the case study to exemplify a couple's experience following a stroke over time in order to view this couple's life within the context of the lives of both the person with the stroke and the partner.

The effects of a cerebrovascular accident were explored by Robinson-Smith and Maboney (1995). Seven couples were selected: all survivors had experienced a stroke six to 12 months earlier and were living at home. Ages for stroke survivors ranged from 60-79 years, while for their spouses it was 62-82 years. Five couples lived alone and two lived with children. All but one couple had children who provided support, such as phoning frequently, paying monthly bills, or providing care during the day. Data

analysis revealed four major themes focusing on physical, psychological, social and marital relationship following a stroke, specifically experiencing physical changes, feeling down and worrying about the future, being restricted and adjusting to limits, and seeking a new balance in the marriage.

The experience of transition for a daughter caregiver of a stroke survivor was explored by Fraser (1999). A phenomenological longitudinal (every two weeks over a six and a half month period after a stroke) case study design was employed. The mother was 64 years old, suffering from a first-ever stroke with residual hemiparesis. The daughter was in her late twenties, married for three years and had a son (aged one and a half years). The eleven unstructured, audiotaped interviews ranging from 30-60 minutes were conducted with the daughter: the data were analyzed by descriptive phenomenological methodology and the following five major themes emerged: (a) the changing relationship, (b) becoming a caregiver then stepping back, (c) enduring emotional turbulence, (d) taking one day at a time, and (e) struggling to hang onto hope.

The experience of stroke from the perspective of rural African American elders and their family members was explored by Eaves (2000). A purposive sample of eight African American caregiving families participated in the study. The eight stroke survivors ranged from 56 to 79 years with a mean age of 67 years, the primary caregivers ranged from 21 to 70 years old with a mean age of 48, and there were ten secondary caregivers aged from eight to 60 years old with a mean age of 32 years. However, the types of stroke were not specified. In addition, half of the survivors (50%) had experienced a prior stroke. The stroke survivors had been discharged from a rehabilitation center within the previous four months. Narrative analysis was used to explain the stroke experience from the perspective of the informants. The findings revealed five themes: discovering stroke, delaying treatment, living with uncertainty, discovering the impact of stroke, and reconstructing life. It was implied that the study may contribute significantly to understanding how individuals and their families live through and respond to the experience of stroke after discharge home.

The experience of family caregivers of stroke survivors over time was explored, with particular reference to the way in which the caregiving role develops and evolves, by Brereton and Nolan (2000) in the United Kingdom. Seven caregivers were interviewed (two males and five females, aged 65 to 84) who were spouses of a stroke survivor. Data were collected at three-month intervals over an 18-month period. A detailed content analysis was undertaken and a constant comparative approach was adopted. From the analysis, four main themes emerged which reflected the uncertain and dynamic nature of family caring. These were: (a) "What is it all about?", (b) "Going it alone", (c) "Up to the job", and (d) "What about me?".

The experience of primary family caregivers of stroke survivors was explored by Secrest (2000). Ten primary family caregivers (ages ranging from 40 to 72, eight being spouses, one a mother and one a daughter) were interviewed by using an existential-phenomenological approach. An analysis of these interviews revealed themes of fragility, vigilance, and loss/responsibility. These themes helped define the essence of the experience, which was a transformation of the family relationship.

The component of stability affecting African American family caregivers' well-being and the functioning of their families was explored by Pierce (2001b). A total of eight primary caregivers (PCs) and 16 secondary caregivers (SCs) were interviewed. Of these caregivers, there were four men (two husbands as PCs and two sons as SCs) and 20 women (three wives and three daughters as PCs and nine daughters, one granddaughter, one daughter-in-law, two sisters, and one friend as SCs). The age range for PCs was 26 to 76 years old and for SCs 22 to 65 years. The majority of survivors were female and all of them were between 58 to 81 years of age. Through data analysis, four themes concerning caring expressions of stability were identified and caring was described as a filial ethereal value, self-contemplation, motivation for a philosophical introspection, filial piety, living in the moment and hoping for the future, purpose, motivation that came from approval by care recipients, and Christian piety.

The impact of care recipient incontinence on their spouses was explored by Cassells and Watt (2003) in Australia. A cross-sectional, descriptive and explorative study design was undertaken by a qualitative approach based on the grounded theory method adopted. Eight home-based caregivers (five males and three females) of spouses with urinary or bowel incontinence, aged over 65 years, were interviewed. The mean age of care-receivers was 77 years. Data analysis revealed a number of categories, grouped under three major themes: underpinnings, processes and consequences. The underpinnings were lifelong love and friendship, and acceptance; the processes were problem-solving and constant watchfulness. The consequences were role change, financial cost, decreased intimacy, emotional responses, sleeping issues and social isolation.

The experience of caring for a stroke survivor one year after stroke in Scotland was explored by Smith et al. (2004). The descriptive study with retrospective and current data indicated that the caregivers' view of such an experience was described. The process of the illness trajectory was explored from the stroke event, the hospital experience and after discharge home. The major themes were described as during the initial period of being diagnosed, during the length of hospital stay: admission, treatment and rehabilitation therapy, unprepared experience after discharge, changing relationships, adjusting to the care role and gaining information.

3.5.2 Care issues and management strategies

The management strategies used by family caregivers to solve home care problems were explored by Davis and Grant (1994). The mean ages were 50 for family caregivers and 52 for stroke survivors. Caregivers were the spouses, parents, and children of stroke survivors. Eight family caregivers for first-time stroke survivors were



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interviewed twice after discharge home: the first interview at the time of the initial follow-up visit and the second one week later by telephone. Qualitative analysis indicated that caregivers of stroke survivors practice situational vigilance, create solutions for problems associated with the functional losses of stroke, construct the reality of recovery for themselves, and seek to find personal meaning in the caregiving experience.

The major problems experienced by stroke survivors and their family caregivers upon returning home were explored by Grant (1996). A total of ten stroke survivor/caregiver dyads were recruited from an acute care hospital setting, a rehabilitation setting and an outpatient clinic in one year following stroke. Data analysis revealed four major themes emergent from the data: loss of the stroke survivor's familiar identity, managing activities of daily living, seeking and mobilizing tangible services, and obtaining emotional/social support.

The application of the trajectory framework for stroke was evaluated based on the retrospective analysis of data generated by Burton (2000b). One stroke survivor and his wife were initially interviewed in hospital and further data were collected at monthly intervals over a period of 14 months. A rich description was demonstrated by the complex path of stroke recovery as the participant's route to home had included three different care environments: emergency, acute and rehabilitation, each with a different intervention focus. Once home, some physiotherapy services continued to be offered in

the hospital environment.

Psycho-social difficulties associated with stroke were explored by Dowswell et al. (2000) one year after stroke. Semi-structured interviews in the homes of a purposively selected sample of 30 patients and 15 caregivers were used 13 to 16 months post-stroke. Information was obtained (sought) from family caregivers on the impact of stroke, services received, perceptions of the recovery process and obstacles to recovery. The findings revealed that patients and caregivers found there were profound ways in which their lives had been affected. Feelings of helpless and frustration were commonly expressed in relation to the changes in social role. Deterioration was another change frequently described in their social lives after a stroke.

The caregiving experience process of Thai caregivers for their elderly stroke relatives was explored by Subgranon and Lund (2000) in Thailand. Grounded theory methodology was used. Eight survivors were dependent in all ADL areas, whereas the remaining 12 required assistance with two to five ADLs. The central idea emerging from the data was maintaining caregiving at home that encompassed these seven contextual situations: (a) caregiving as an integral part of life, (b) caregiving as an unavoidable task, (c) caregiving with love, sympathy, and attachment, (d) family and kinship support, (e) community support, (f) managing treatment, and (g) managing problems and difficulties. Family caregiver expectations of recovery from stroke and the strategies used to manage the stroke trajectory were explored by Burman (2001). Stroke survivors living at home had disability ranging from mild to severe. Thirteen family caregivers, five males and eight females, ages ranging from 28 to 85 years, participated in a semi-structured interview six months after stroke. Analysis revealed one major theme and five sub-themes. The major theme was that family caregivers had no ideas what the recovery of their loved ones would be like and had difficulty making projections about the trajectory. Five strategies were used to manage the stroke trajectory: constructing a positive recovery, reconstituting family life, maintaining family patterns, creating a safety net, and redoubling self-reliance.

The perception of needs, concerns, strategies and advice of family caregivers for stroke survivors during the first six months after hospital discharge was examined by Bakas et al. (2002). Fifteen female caregivers (eight African American and six white American) consented to be interviewed. Five major categories of their needs and concerns were revealed: information, emotion and behaviors, physical care, instrumental care and personal responses to caregiving.

Caregivers' perspectives of their support and educational needs, as well as strategies used by caregivers to manage their caregiver role throughout the three phases of care (acute, rehabilitation and community) were explored and described by O'Connell and Baker (2004). Data analysis revealed that caregivers experienced considerable uncertainty about their role as caregivers and their future, and that they used a number of coping strategies to manage their caring role. These strategies included remaining positive, adapting to change, comparison with others who were worse off, changing their employment status, humor, switching off, and using family support.

The major problems and related feelings experienced by family caregivers of stroke survivors during the first month after returning home were examined by Grant et al. (2004). The three most common problems experienced by caregivers during the first month were safety, difficulty in managing activities of daily living, cognitive, behavioral and emotional changes of stroke survivors in terms of mood swings, lack of motivation, forgetfulness and memory loss, depression and calling the caregiver often. Other problems included the loss of caregivers' independence, confinement, tiredness, and inadequate time to do caregiving tasks as well managing stroke survivor physical symptoms, for example, pain, not eating and skin problems.

3.5.3 Impact of stroke on the well-being of family caregivers and stroke survivors

The effects of caregiving on the spouses of stroke victims were explored by Fitzgerald (1989). A convenient sample of eight spouses of stroke victims was chosen. Interview data were collected over a period of 12 weeks (three months), with each caregiver being seen twice at their homes. Interview data were then analyzed using qualitative methods. Totally twenty-nine different effects of caregiving were found. These were coded into

four major categories: decrease in physical and emotional health, loss of freedom and social activities, marital discord, and change in role. Ten effects of caregiving were placed in decrease in physical and emotional health and loss of freedom and social activities. Six were placed under marital discord, and three under change in role.

These above studies have supported that the family living with stroke experiences physical, psychological and social changes, such as physical loss, insufficient time and confinement in personal care, marital relationship, and role changes within the family (Mumma 1986, Periard & Ames 1993, O'Connell & Baker 2004). It is also asserted that coping with stroke-related residual disability needs a longer period of time, not only for survivors but also for stroke spouses and their children (Ronbingson-Smith et al. 1995, Fraser 1999, Burton 2000b). Furthermore, it has been stated that family living with stroke is not only an experience of physical limitation and loss of independence, but also it is a consequence of positive cognitive and affective responses to an optimal recovery of stroke residual disability. Thus understanding a person's social, cultural, religious, economic context and traditional ways of life is vital (Dowswell et al. 2000, Subgranon & Lund 2000, Pierce 2001). Pierce (2001) illustrates that how well the family could sustain a positive outcome through a caring interaction and situation in family environment and support each other, and Subgranon and Lund (2000) demonstrate how Buddhist and Muslim caregivers uphold their religious beliefs in the commitment to providing good care for their family members living with stroke at home care settings. Finally, it has been suggested that a holistic care approach for both stroke survivors and family caregivers in the community after discharge home is necessary, such as holistic assessment for survivors with incontinence not only focusing on bladder or bowel function, or limited to survivors' residual disability, but also taking into account the needs, concerns and preference of the family caregivers (i.e., primary and secondary family caregivers) in the context. This means that understanding the multiple roles of caregivers, the dynamic nature of the family, and the distressing care situation is important for health care professionals to provide early community-based care service and support in physical and psychosocial aspects such as respite care and telephone contacts.

3.6 Formulation of the study proposition for the multiple-case study of families living with stroke in Wuhan, China

In light of the above studies on stroke survivors and family caregivers after discharge home as well as the background to the phenomenon of stroke care in China, it is found that stroke has become a leading cause of residual disability, and that many stroke survivors are dependent upon their family caregivers to deal with their activities of daily living for the rest of their lives. The family may constantly need support and guidance from health care services in dealing with the emerging demands of care for individuals following stroke in the long term. Yet this kind of care is apparently lacking in the Wuhan community. In this regard, such issues are examined in this prospective multiple-case study. First, to what extent stroke-related disability exists after discharge home; second, what kind of care issues need to be addressed to meet the health needs of stroke survivors; third, what kind of burden is experienced and perceived by the family caregivers; and finally what kind of coping resources are utilized at the personal, family and community levels after discharge home. Such issues form the study framework to provide guidance for designing the present study and collecting the most relevant data.

According to the principle of Yin's case study method (1994), formulating a study proposition for a case study can help the investigator better understand *what* elements may be mostly relevant to the outcome of family well-being, *how* these elements can be interplayed with each other in the process of caring trajectory, and *why* various levels of family well-being would be altered after discharge home over a period of six months. Certain issues have been identified as significant in examining family well-being after discharge home. These are stroke-related disability, care issues, organization of caring work, coping resources, and perceived burden. Figure 3.1 is a diagrammatic representation of possible interplay of the significant issues surrounding families living with stroke contributory to family wellbeing.

Stroke-related disability can be examined by reference to the following factors: stroke illness history, lesion and type of stroke, professional management in the hospital, and the severity of stroke (e.g. multiple deficits and disabilities in cognitive and physical abilities in terms of activities of daily living, and disturbance of psychological status). Cognitive deficit refers to the ability to memorize, think and count. Functional disability is defined as performance of functional status, which is the level of dependence in activities of daily living, such as eating, walking, bathing, etc. The limitation of social activities refers to level of dependence in home care and social tasks, such as handling money, preparing meals, shopping for groceries, using public transportation, etc. The disturbance of psychological status is described by affective components interfered by depressed moods, such as negative and positive affects, somatic symptoms, and behavioral manifestations. Functional disability, cognitive deficit, limitation of social activities and disturbance of psychological status are measured by the standardized structured instruments described in the next chapter.

Care issues are defined by the problems and difficult care situations encountered by the family, and the direct care provided by the family caregiver in day-to-day care tasks and activities.

Caring work is defined as the organization of caring work, which enhances mutual understanding, interaction and communication in each family context.

Perceived burdens are defined as feeling difficulty and emotional disturbance resulting in a negative cognitive and affective response which may made his or her to deal with the post-stroke and care experience extremely difficult or stressful.

Coping resources are defined according to availability, accessibility and affordability in

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the family living with stroke. The concept is divided into three levels: the personal, family and community level. For example, at the personal level, it may include personal background information (e.g. age, gender, health status, socio-economic status, medical insurance); at the family level, it may refer to family background information (e.g. family context in terms of types of family structure, living surroundings, family financial status, available family caregivers, family interpersonal relationships); and at the community level, it may involve what kind of health care services or information can be utilized, or are available, accessible or affordable to assist him or her to cope with the family care situation and deal with the multiple care issues over time.

The well-being of the family is defined as the emotional well-being and a sense of general well-being by both the stroke survivor and the family caregivers, along with observation of the overall family functioning and dynamics as a unit of care. With the focus of this study on the care process over a period of six months, coping resources at three levels that will play a critical role in promoting family well-being will be delineated and analyzed.

In addition, contextual factors refer to the community and social environment in which the family with a stroke survivor is living. It includes background information to the stroke care situation, such as documenting policy and the reviewed Chinese literature described in the chapter two. Although all these factors may shape the process of the illness and care experience, and the outcome of family well-being, it is particularly helpful to examine what factors contribute to the outcome of family well-being and how they interplay in the course of the illness and care experience.

The study proposition is formulated and based on an analysis of the family care of stroke survivors China and the relevant Chinese literature on family well-being and stroke care. It states that the well-being of the family is dependent upon stroke-related disability, coping resources at the personal, family and community levels, perceived burdens, and the organization of caring work. Based on this study proposition, the investigator framed the inquiry process for a better understanding of the experience of both stroke survivors and their care providers and the constituent elements contributing to family well-being.

Specifically, it states that the well-being of the family is dependent upon:

- (i) Stroke-related disability of stroke survivors: cognitive deficit, functional dependence, emotional disturbance and limitation of social activities;
- (ii) Care issues encountered: how both the stroke survivors and family caregivers attempt to deal with difficult care situation;
- (iii) Perceived burden of family caregivers: both the stroke survivors and family caregivers focus on how to interpret their illness and care experience; and

(iv) Coping resources for sustaining a family well-being: what kinds of personal, family and community resources both stroke survivors and family caregivers can utilize in dealing with care issues and maintaining the family well-being (see Figure. 3.1.).





3.7 Summary

Based on a comprehensive analysis of the relevant Chinese and English literature on the post-stroke and care experience of both survivors and caregivers in the home care setting, an overall picture of the impact of stroke has been manifested by the high incidence of stroke-related residual disability, post-stroke depression, and limitation of social activities in survivors, as well as the multiple care issues encountered by the family caregivers and the family in home settings, and how they deal with their residual disability and care issues over time.

Most significantly, the study framework is constructed and a study proposition is formulated. In particular, the study proposition states that the well-being of the family is dependent upon: (a) stroke-related disability, (b) care issues, (c) perceived burden, (d) coping resources (e.g. at the personal, family and community level), (e) caring work organization, and (f) contextual factors.

Based on this proposition, the investigator frames the inquiry process for a better understanding of *what* factors contributory to the well- and ill-being of families living with stroke and *how* these factors interplay with each other in the process of the illness and care experience, and explain the reasons *why* various levels of family well-being would be reached over a period of six months after discharge home. Importantly, the establishment of the theoretical framework and the study proposition frame the procedures of data collection and analysis using Yin's multiple-case (embedded) study design.

Chapter Four

Methodology

In this study, Yin's multiple-case study method was used as research strategy to understand the post-stroke experience of survivors and the caregiving experiences of family members and the way in which these experiences impact on the family well-being over a period of six months. The first part of this chapter discusses the characteristics of case study research, and the second part describes and explains how the investigator adopted the case study method in data collection and analysis.

4.1 Characteristics of Yin's case study method

The case study has been stereotyped as having insufficient precision, objectivity and rigor among social science methods (Yin 1994). Despite this stereotype, case studies have been undertaken increasingly in various settings, such as schools, health care establishments, the military, business and industry, and in a number of disciplines, like psychology, sociology, political science, business, social work, and planning, in economics, in health services and in nursing (Yin 1989, 1993, 1999, 2003, Mariano 2001). The distinctive need for case studies is the desire to understand complex social phenomena, it allows an investigation to retain the *holistic* and *meaningful* characteristics of real-life events, such as individual life cycles, organizational processes, neighborhood change, international relations, and the maturation of industries (Yin 1994).

Furthermore, uses of the different names, such as case study/case study method/case study approach/case study research, as well as case study teaching/patient case studies, appear to be vague and confused (Jones & Lyons 2004). But Yin (1994) asserts that the purpose of the case study for teaching and practice is different from that for doing research.

The purpose of case study for teaching is to build a framework for discussion and debate among students, in which teaching materials are demonstrated by each case in order to help students understand and discuss some particular and important points effectively in class (Yin 1994). The purpose of "patient case studies" is familiar to nursing practitioners in training and that of "patient case histories" routinely described by doctors (Keen & Packwood 1995, Sharp 1998) is to facilitate clinical practice, in which cases are used as a form of record keeping.

Using case studies in doing research, however, is concerned heavily with the rigorous and fair presentation of empirical data, particularly in the form of the proper questions to be asked, the study propositions to be developed, the "case" to be selected, the logic linking of the data to the propositions and the criteria for interpreting the findings to be investigated (Yin 1994, 2003).

Yin (1993, 1994, 2003) also acknowledges that doing good case studies is challenging due to its complexity, especially with regard to analyzing a "combination" of data from different sources, because case studies are based on a combination of quantitative and qualitative evidence, but skills for analyzing this evidence have been the least well developed and documented.

The case study research, however, is a more sophisticated exercise and it contributes uniquely to our knowledge of individual, familial, community, organizational, social, and political phenomena in its contemporary situation. It has been defined by Yin as a serious research strategy which involves "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident" and uses multiple sources of evidence and the prior development of theoretical propositions (Yin 1994, 2003, p. 13).

Based on this definition, the aim of case study research can be defined by three types of study: exploratory, descriptive and explanatory case studies. Exploratory case studies aim to test the feasibility of desired research procedures. Descriptive case studies aim to present a detailed description of a phenomenon within its context. And explanatory case studies aim to present data associated with cause and effect in order to explain which causes generate which effects. These three types of case studies are applied in the present investigation.

Once the aim of the research is determined, the investigator should decide which case study designs must be used. There are single- and multiple-case studies, each of which can contain unitary or multiple units of analysis. The four types of designs are (a) single-case (holistic) designs, (b) single-case (embedded) designs, (c) multiple-case (holistic) designs,

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and (d) multiple-case (embedded) designs. Single-case (holistic) and single-case (embedded) designs focus merely on a single case, but the attention of the former designs is to investigate the overall nature of a phenomenon, such as a program or a family, while that of the latter is to investigate the sub-unit(s), such as two or more issues in the program or a family under the inquiry. On the other hand, multiple-case (holistic) and multiple-case (embedded) designs focus on two or more cases, but the intention of the former designs is to investigate the global nature of a phenomenon, such as two or more programs or families, while that of the latter is to examine the sub-unit(s), such as two or more issues in two or more programs or families, while that of the latter is to examine the sub-unit(s), such as two or more issues in two or more programs or families under investigation. Since this study used a multiple-case study design, the following discussion will focus on the methodological considerations in conducting multiple-case studies.

Multiple-case studies have distinct advantages as compared to single-case studies on the basis of the following reasons. First, single-case studies may be useful as exploratory devices or as the conduct of a pilot case, but the single-case study cannot be considered as a complete study on its own (Yin 1994). Herriott and Firestone (1983) agreed that the evidence from multiple-case studies is often considered more compelling, and the overall study is regarded as being more robust. Second, an individual or single unit (e.g. a family or a hospital) may be addressed in single-case studies, but some research questions call for a multiple-case study approach. This approach is especially useful where comparison of cases is potentially fruitful. Third, in multiple-case studies every case should serve a specific purpose within the overall scope of inquiry. The cases must follow a "replication" logic rather than a sampling logic. Each case must be carefully selected so that it either (a)

predicts similar results (a literal replication) or (b) produces contrasting results, but for predictable reasons (a theoretical replication). The cases should serve in a manner similar to multiple experiments, with similar results (a literal replication) or contrasting results (a theoretical replication) predicted clearly at the beginning of the investigation. When an embedded design is used, each case study must include the collection and analysis of highly quantitative data, including the use of survey or questionnaire, and qualitative data, including documentation, observation and in-depth interview within each case (Yin 1994).

Multiple-case study designs are most useful for investigating complex issues (Yin 1994). As Yin stated, it can involve multiple cases or multiple units of analysis, multiple sub-units of analysis, and the triangulation of data sources (Yin 1994). Combining evidence of different types and from different sources through a process called "triangulation" is an increasingly popular device in health and nursing research (Vallis & Tierney 1999).

Finally, Yin reminded us that case study designs must be kept flexible. That is, the design can be changed and modified after the initial stages of a study, but only under strict circumstances. For example, the selection of cases may have to be revised because of new information about the cases or the initial design may not be feasible to the real-life situation. Thus the use of pilot case studies was highly recommended that as appropriate and desirable as they may show inadequacies in the initial design or may help to describe it (Yin 1994). In short, it is important to recognize that the flexibility of multiple-case studies is in selecting cases different from those initially identified but not in changing the purpose or objectives of the study to suit the cases. Therefore, it is necessary to keep in mind that conducting multiple-case studies is one of the most challenging types of research, and analysis is the most difficult part (Yin 1994). It takes time and cannot be done in a hurried manner, particularly in the process of complex data analysis (Miles & Huberman 1994). Intensive training is recommended and a novice case study researcher is advised to start with something simple and seek guidance in order to complete it successfully and efficiently (Yin 1994).

4.2 Application of case study method in nursing research

Case studies and the case study method have been only prominent as a research strategy in nursing research since the late 1980s, and have been used increasingly in nursing studies because nurse researchers frequently conduct focused investigations in order to improve the quality of care in clinical practice. Examples of using the case study method in the field of nursing were drawn from the Ovid Medline database. Using the key word search of "case study", "nursing", and "research", 16 entries were found, dated from 1966 to August 2004. Three studies had indeed used the case study method. A follow-up search based on these three studies yielded a total number of nine nursing research-based articles using case study research based on these selected articles. The purpose of the review was mostly to determine *how*, *what* and *why* research questions had been asked, and eventually to summarize the natures of the three types of case studies and examine whether they were exploratory, descriptive or explanatory case studies.

An evaluation of pre-registration midwifery education in England was explored using a case study method (Kent 1992). The process of selecting case study sites was reported. In this study, six study sites were selected, with one other site also selected to pilot the research instruments. Each institution was defined as a case, and data obtained from each case included in-depth fieldwork and a survey. The in-depth fieldwork was used to facilitate an understanding of innovative changes in midwifery education, and survey data were collected to give a national picture of pre-registration midwifery education and to assist in providing contextual information. The unit of analysis entailed a curriculum which set out the educational program. The curriculum included teaching materials to deliver the program, and the people involved in the educational process were teachers, students, mentors and other service-based personnel. Thus data from each case was intensive and involved a combination of physical and social elements.

A longitudinal case-study method designed to explore maternal infant interaction in 36 primiparous women from the prenatal period until four months postpartum was used by Tomlinson and Irwin (1993). Data were collected over time at four time points (e.g. in their second trimester of pregnancy and at four months, one year and four years after the birth of the infant). Both standard measures and an intensive semi-structured interview (e.g. multiple sources of evidence, in-depth data) were used over a period of time, and the qualitative and quantitative data were analyzed (e.g. combining both quantitative and qualitative approaches). Finally, an analytical generalization was made. This study was guided by prior development of a theoretical model (e.g. the deductive approach), and *what* and *how* feminine role orientation, or changes in that orientation, related to either family or

marital patterns was examined in detail (e.g. the individual perspective). In this regard, this study focused on family patterns of reorganization, and how the changes in feminine role orientation were related to family or marital patterns.

The relationship between nursing care activities and variations in intracranial pressure (ICP) was explored by Rising (1993) using the case study method. Each patient was seen as a case, and five brain-injured patients with a Glasgow Coma Scale (GCS) score of four or more were selected. Data were obtained from direct observation of the patient's ICP monitoring. Selected nursing activities were recorded: turning, suctioning and bathing. Each patient's condition warranted continuous ICP monitoring with a fiber optic catheter in a neurological intensive care unit (ICU) of two hospitals in the Upper Midwest of the USA. Finally, each case was described and illustrated individually, focusing only on *how* nursing activities affected the ICP. In this study, the study merely examined how ICP changes occurred during and following turning, suctioning, and bathing the patients.

Elderly home-care clients' perceptions of the caring behaviors of the nurse within the context of the nursing relationship were explored by Poole and Rowat (1994). Each client was seen as a case and five clients were cared for over a two- to five-month period. The unit of analysis was the clients' perceptions of nurses' caring behaviors, and data were obtained through one semi-structured interview at the termination of the nursing relationship. Results supported the perception of nursing attributes as caring, consistent with previous research. They also suggested that these nurse attributes form the basis of caring in nursing interventions. A model of caring was proposed. In this study, a

descriptive multiple-case studies design (e.g. five clients) was adopted and only a semi-structured interview was undertaken (e.g. one source of evidence). Qualitative data were analyzed based on caring behaviors in context (e.g. qualitative method and inductive approach). Attention was paid in this study to what community-based elderly people perceived as caring behaviors of a home-care nurse in the context within which nursing occurred.

A support program for nursing service managers suffering from fatigue was explored and described by Poggenpoel and Gmeiner (1996). The study was based on the results obtained from a previous survey that ascertained nursing service managers' views about the problems they were experiencing in their everyday lives (e.g. the individual's perspective). The sample consisted of forty-eight English-speaking and forty-two Afrikaans-speaking nursing service managers (e.g. using a multiple case-study design) from the old Transvaal region. The support program was implemented during two one-day workshops, one with the Afrikaans-speaking group and one with the English-speaking group of nursing service managers. Data were obtained through observation, audiotape recording, written documents and field notes (e.g. multiple sources of evidence). They were analyzed by describing multiple case studies to reflect commonalities and differences between the workshops. This study used a multiple case-study design, the individual perspective (e.g. nursing managers' experience), and in-depth data by using multiple sources of evidence in order to provide a holistic view of the phenomenon. It was limited to describing the operationalization of the support program in two workshops.
An evaluation of the quality of public health nursing in Hong Kong was carried out by Twinn (1997). Each (maternal and child health) center was regarded as a case, and four cases were identified (e.g. a multiple-case study design). Of those, four different centers of individuals were considered as the embedded units of analysis under each case. These were clients, nurses, doctors and administrative personnel. The study focused on the evaluation of the quality of public health nursing through describing how the clients and nursing staff perceived the quality of the service (e.g. individual perspective).

The educational preparation of a group of nurses undertaking a master's degree course for advanced nursing practice was explored by Woods (1997). Five cases were selected, each consisting of a group of people comprising the advanced practice nurse as the key informant and other related persons including a clinical nurse manager, directorate manager, the key informant's consultant preceptor, a lecturer/ coordinator and a member of the key informant's peer group (e.g. a multiple-case study design and the individual's perspective). Data were obtained from interviews, direct observation, documentation (e.g. nursing and medical diaries) and archival records in the form of practice role development diaries (e.g. multiple sources of evidence, in-depth data). Data management and analysis were performed by QSR NUD-IST (e.g. qualitative method, inductive approach) and guided by a prior development of theoretical framework (e.g. deductive approach). This study examined how advanced nursing was practiced by using case study approach.

The practice of case management in community nursing was examined by Bergen and While (2000). Thirteen cases were selected (e.g. a multiple-case study design) and data

were collected through interviews, examination of literature and documentation (e.g. multiple sources of evidence). A prior development of propositions was used to guide data management and data analysis (e.g. deductive approach). This study examined the current and potential relevance and the value of case management to community nursing practiced.

The changing educational needs of community nurses with regard to needs assessment and quality of care in the context of the British National Health Service (NHS) were explored by Cowley et al. (2000). Data were collected from field observation in 134 visits, and 33 interviews were conducted with 33 practitioners (e.g. using a multiple case study, multiple sources of evidence, and the individual perspective). In particular, the role of a prior theoretical framework was emphasized in guiding the process of data collection and helping data analysis. The iterative process was identified at various points where a "policy-practice gap" might arise between policies and practice in both the health service and education. The analytical generalization was made concerning the practicalities of operationalizing into nursing research and the mechanism. This study also confirms that the case study method was an optimal choice in applying a multiple case study design to nursing research while "generalizing to theory". This study attempted to investigate the educational needs of community nurses with regard to needs assessment and quality of care in the context of the NUS and Community Care Act, 1990.

From the above review of nursing research works, all these studies have acknowledged that the case study method is a credible option in nursing research, and proved that it is reliable, because the "what" and "how" research questions could be best answered via this method,

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particularly when the involved factors were the least restricted and the specific focus was on the contemporary phenomenon rather than the historical one. Multiple evidence was collected, such as the use of quantitative or qualitative (e.g. ethnographic or phenomenological) or both approaches (e.g. triangulation), and combining data from standard measures, intensive semi-structured interview, documentary records, written documents, observation, and field notes, involving descriptive statistics, and content analysis and pattern-matching techniques. Furthermore, the application of the case study method in nursing research has a variety of usages, such as in evaluation case studies (Kent 1992, Twinn 1997), descriptive case studies (Tomlinson & Irwin 1993, Rising 1993, Poole & Rowat 1994, Poggenpoel & Gmeiner 1996, Woods 1997, Cowley et al. 2000) and exploratory case studies (Bergen & While 2000). In the present study, multiple-case (embedded) studies were carried out. The following section describes how multiple-case study design was applied in this study.

4.3 Study design

Yin's multiple-case (embedded) study design was used. As Yin (1994) suggests, case study research must be based on a predicted proposition and a clear "logic of design". These two issues were in the investigator's mind when undertaking this study.

The first was strictly adherent to the prior development of the study proposition. This study design used the study proposition derived from the conceptual framework characterized in Figure 3.1 to guide data collection and analysis. Each family was a case. The embedded

units within each case/family comprised stroke-related disability, care issues, perceived burdens, coping resources at the personal, family and community levels, and organization of caring work.

The second was to honestly follow a replication logic, in which each family was seen as a single case analogous to a single experiment, and multiple cases were analogous to replicating the study in different cases. Multiple cases were selected according to the predicted patterns based on the study proposition that they could be contrasted by the different post-stroke and caregiving experience. The use of this design allowed the investigator to address the *how* and *why* questions of different levels of family well-being after discharge home in the context over time.

4.4 Settings

The families living with stroke survivors were recruited from three municipal hospitals covering in three major areas of Wuhan (武汉三镇): Wuchang (武昌), Hanggou (汉口) and Hangyang (汉阳). The nature of these hospitals included: (a) they were comprehensive Western Medicine hospitals combining medical services, teaching and research activities in Wuhan city, and (b) they served the local community in three major areas of Wuhan. Moreover, these hospitals have physical therapy (e.g. electronic, light and magnetic therapy) and traditional Chinese Medicine (e.g. massage, acupuncture) provided in the outpatient department, but no formal or planned or organized stroke rehabilitation services

(e.g. physiotherapy, occupational and speech therapies) were delivered by these hospital-based services. And all of them had an internal neurology ward.

The name of these hospitals is: (a) The Third Hospital of Wuhan; (b) The Fourth Hospital of Wuhan; and (c) The Sixth Hospital of Wuhan. Both the Third and Forth Hospitals of Wuhan, affiliated to the Hubei Medical University, involve a number of teaching and research activities, while the Sixth Hospital of Wuhan, affiliated to the Advanced Wuhan Medical College, was the first to introduce college education for nurses in Hubei Province in 1987.

Initially, only The Third and Sixth Hospitals were chosen. As time went by, more cases were needed to be recruited at the same time due to each case being followed up for a period of six months thus the Fourth Hospital was added in order to increase the number of cases in a limited time.

After selecting these hospitals, personal contact was made with these hospitals' administrative bodies, and physicians and nurses in the neurological unit to gain their permission and co-operation. Ethical issues were also addressed.

Permission was obtained and access was sought from the Departments of Nursing in these three hospitals. The scope and aims of the study were explained clearly to them. Under the management of the Department of Nursing, head nurses were assigned to assist the investigator to approach stroke survivors during the hospitalization. The potential participants were recruited by these head nurses. After the participants agreed to participate, the head nurses phoned the investigator to visit them in the hospitals. Moreover, cooperation was built between the head nurses and the investigator in order to actively recruit survivors in a timely manner, and to inform the investigator that she should approach the stroke survivors before discharge home.

Ethical clearance was obtained from the Departmental Research Committee of The Hong Kong Polytechnic University, and verbal consent was obtained from both stroke survivors and family caregivers during hospitalization.

4.5 Case selection

In order to better understand the characteristics of stroke patients admitted to these hospitals, the stroke case records were carefully reviewed in the previous year, dated from February. 1, 2000 to January 31, 2001. A total of 477 case notes with primary diagnosis of stroke were identified, 171 from The Sixth Hospital and 306 from The Third Hospital of Wuhan. Of these 477 cases, 59.2% were male and 40.8% female, with 88% aged 56 or above. Stroke infarction had affected 68.7% of the cases. Of those, 75.9% had had their first-ever stroke infarction and 23.4% a recurrence. The length of hospital stay ranged from one to 230 days, and 61.4% of patients stayed in the hospital from eight to 40 days (61.4%).

According to this information, stroke survivors to be included in this study were those who were able to be reached, whose medical conditions had became stable, who were able to communicate, and who could live in a home care setting with certain degrees of stroke-related residual disability for a longer period of time; and those with other severe conditions (e.g. aphasia, cognitive impairment) were excluded. Thus the following criteria had to be satisfied: (a) stroke infarction including both first-ever stroke and recurrence of stroke, (b) both family members and stroke survivor agreed to participate, (c) the screening test (the Chinese version of The Short Portable Mental Status Questionnaire-SPMSQ) was performed in order to ensure that cognitive function was not impaired (normal value ranging from zero to two considered as a normal value representing acceptable cognitive functioning) (see Appendix 4.3), (d) unconsciousness, as well as terminal illness or other rapidly progressing medical condition or terminal condition excluded, (e) length of hospitalization ranging from 11 to 40 days, and (f) living within the urban area of Wuhan.

Family caregivers who accompanied survivors during their hospital stay were invited to participate in the study. They were approached by the head nurse or nurse manager, or the investigator during hospitalization, and given information and an introduction to the present investigation. They were invited to participate, and an oral consent was obtained. Both stroke survivors and family caregivers spoke Putonghua or Wuhanese, and were able to respond to questions during the interviews. Even though the stroke survivors had difficulty describing their experience, the family caregivers could assist them in clarifying their ideas and ways of thinking and acting. Family caregivers were both primary and secondary caregivers. Primary family caregivers had unpaid, primary responsibility for the home care of the stroke survivor on a day-to-day basis, and resided with the stroke survivor,

while secondary caregivers might be paid (e.g. a domestic helper) or unpaid (e.g. a daughter or son), and reside or not reside with the stroke survivor after discharge home.

As the study moved along, case selection followed the theoretical sampling. This meant that cases outlined contrasting the post stroke experience and the caregiving experience purposively, and it was envisaged that 18 cases would be used.

4.6 Data sources

Multiple data sources were collected from each case for establishing the chain of evidence in addressing the study proposition (see Table 4.1). This information was collected over time and included a standard questionnaire (e.g. socio-demographic and health information, Short Portable Mental Status Questionnaire, the Barthel Index, Instrumental Activities of Daily Living, the Center for Epidemiologic Studies Depression Scale), semi-structured interviews and field observations.

Stroke survivors' performance in cognitive, physical, emotional and social status and sense of well-being were measured by Short Portable Mental Status Questionnaire (SPMSQ), the Barthel Index (ADLs), the Center for Epidemiologic Studies Depression Scale (CES-D), Instrumental Activities of Daily Living (I-ADL), and Self Evaluation of General Health (SEGH) (see Appendix 3A and 3B), whereas the primary family caregivers' performance in emotional status and sense of well-being were merely measured by CES-D and SEGH to examine the changes in their emotional state and sense of well-being over time. Of these measures, SPMSQ was only used to measure cognitive function in the hospital for stroke survivors, and I-ADL was started to be measured from one month until six months after discharge home because it covered more complex household tasks for survivors in the home setting. In each home visit, both semi-structured interviews and field observations with the stroke survivors and family caregivers and family members were conducted (see Appendix 4A and 4B).

Concepts						
Data Source	Stroke-related	Perceived	Care	Caring	Coping	Family
	disability	burden	issues	work	resources	well-being
Standard						
questionnaire						
-Survivor	ADLs, IAD-L			SHI_1	SHI_1	CES-D ₁ , SEGH ₁
-Primary family caregivers				SHI_2	SHI ₂	CES-D ₂ , SEGH ₂
Semi-structured						
interviews:						
-Survivor	Y	Y	Y	Y	Y	Y
-Primary family	Y	Y	Y	Y	Y	Y
caregivers						
-Other family	Y	Y	Y	Y	Y	Y
members						
Field observation						
-Survivor	Y	Y	Y	Y	Y	Y
-Primary family caregivers	Y	Y	Y	Y	Y	Y
-Other family members	Y	Y	Y	Y	Y	Y

 Table 4.1. Collection of multiple sources of evidence in establishing a chain of evidence in addressing the study proposition

Y: Yes:

ADLs: the Barthel Index;

I-ADL: Instrumental activities of daily living;

 $CES-D_1$, $CES-D_2$: The Center for Epidemiological Studies Depression Scale for survivor and primary family caregiver; $SEGH_1$, $SEGH_2$: Self Evaluation of General Health for survivor and for primary family caregiver;

SHI₁, SHI₂: Socio-demographic and health information for survivor and primary family caregiver.

4.6.1 Standard questionnaire

Socio-demographic and health information (SHI)

Socio-demographic and health information was collected from both the stroke survivors and the primary family caregivers to capture the demographic characteristics (e.g. age, gender, educational level, personal income, living condition, and relationship between the survivor and family caregivers), general health status (e.g. eye sight, hearing ability), and health care service utilization of the survivor (e.g. availability, accessibility, satisfaction), both during the hospital stay and after discharge home.

The survivor's and the primary family caregivers' perception of general health status was determined by the self-evaluation of general health: scores ranging from one to ten, one being for the worst self-rated general health and ten being for the best.

Health care services utilization during the hospital stay included health conditions, health care cost and use of medicine, while health care service utilization after discharge home included money spent, sources of health care information, and types of services utilized at one week, one month, three months and six months. Scores of satisfaction of health service utilization ranged from one to ten, one being for the least satisfaction and ten for the most.

The survivors and caregivers were asked about the hospital, rehabilitation and community services that they had received after a stroke. A list of services was provided (Appendix 3A

& 3B), and for each service they were asked to report whether they had received the service during hospital stay and after discharge home at one week, one month, three months and six months.

Short Portable Mental Status Questionnaire (SPMSQ)

The SPMSQ developed by Pfeiffer (1975) is intended to offer a rapid method of screening for cognitive deficit in the elderly. It detects organic intellectual impairment and determines its degree. It consists of only ten items which can be easily administered by trained interviewers. Items included in the SPMSQ are through, in terms of the realm of cognitive functioning which they cover. It has been widely used not only because of its convenience but also because of its high validity and reliability (Kane & Kane 1981). It is also modified and used in Hong Kong in order to fit into the local context (Chi & Boey 1992, Chi 1998), and in Wuhan China (Guo 1998). A correct answer in the SPMSQ scores one point, while wrong or missing answers score zero. The range of total scores is from zero to ten. The number of errors is counted, with unanswered items treated as errors (Fillenbaum 1980). The following criteria were established: zero to two errors = intact functioning, three to four errors = mild impairment, five to seven errors = moderate intellectual impairment, and eight to ten errors = severe impairment. Pfeiffer took more than four errors as indicative of "significant impairment" (Pfeiffer 1975). One more error is allowed if the respondent has only a grade school education, and one less error is allowed for those with education beyond high school. The SPMSQ has been compared to clinical rating in numerous studies. Four-week test-retest reliabilities were 0.82 and 0.83 (Pfeiffer 1975). Correlations reported between the SPMSQ and MSQ (The Mental Status Questionnaire) include 0.88 (Fillenbaum 1980), 0.76 (Fillenbaum et al. 1990), and 0.84 (Haglund & Schuckit 1976).

The Barthel Index (ADLs)

The Barthel Index was originally developed by Mahoney and Barthel (1965) and further revised by Granger et al. (1977) in a stroke care program, and is used in clinical practice as a means of assessing the degree of independence in patients with neuro-muscular or musculoskeletal disorders.

The Barthel Index consists of ten items, each of which is rated in terms of whether the patient is unable to perform the task, requires help, or can manage independently. The Barthel Index is a rating scale which takes two to five minutes to complete (Collin et al. 1987) or can be self-administered in about ten minutes (McGinnis et al. 1986). Instructions for scoring on the Barthel Index are provided (see Appendix 4.3A and B). Dependent scores zero on all items, and other scores are intended to reflect the amount of help or assistance needed. For example, independence in bathing scores only five because it is a relatively infrequent activity, while walking scores 15, and there are another three items dealing with incontinence and the ability to use the toilet (total score 30). Furthermore, full independence using a wheelchair scores five, and someone who is able to walk only with assistance scores ten. Patients are given an overall score out of 100. Scores range from zero to 100, in steps of five, with higher scores indicating greater independence. An overall

score is formed by adding the scores for each rating, and suggests the amount of time and assistance a patient will require (Mahoney & Barthel 1965).

Several authors have proposed guidelines for interpreting Barthel scores (Shah et al. 1989, Lazar et al. 1989). For the ten-item modified version, Shah et al. (1989) suggested that scores of 0-20 indicate total dependency, 21-60 severe dependency, 61-90 moderate dependency, and 91-99 slight dependency. On reliability for the modified ten-item version, Shah et al. (1989) reported alpha internal consistency coefficients of 0.87 to 0.92. Wade and Hewer (1987) also reported obtaining validity information between 0.73 and 0.77. This rating has also been examined and translated by the Minister of Health in the People's Republic of China (1998).

The Barthel index scale was adopted in the present study to reflect the performance of personal activities in daily living, aiming particularly at examining the severity of disability for stroke survivors and the progress of recovery after discharge home through a six-month period.

Instrumental Activities of Daily Living (I-ADL)

The instrumental activities of daily living (I-ADL) are a modified version of the instrument known as the Physical Activities of Daily Living from OAR Multidimensional Functional Assessment Questionnaires (Kane & Kane 1981). It measures the functional health of a person in terms of his/her capacity to perform higher levels of self care tasks (e.g. using the

telephone, transportation, and managing money) and encompasses some complex activities, such as doing simple and heavy housework, which are sensitive to variations of mood and emotional health.

Items in the I-ADL include activities in terms of home management, such as cooking, cleaning, and shopping. In more detail, self care tasks, such as using the telephone, doing simple housework (e.g. washing, cooking), doing heavy housework (e.g. cleaning, moving furniture), going out (e.g. shopping, visiting friends and relatives, transport), and managing money are also included.

I-ADL has also been used in Chinese populations (Chi & Boey 1992, Chi 1998). Ten items were included and the total scores were 30. Guidelines for interpreting the scores are: each question uses a 0-to-3 response scale. One indicates most independence, two means more dependence, and three means complete dependence.

I-ADL was selected because of its wide usage among the elderly population in the community setting (Chi & Boey 1992) and to examine the ability for independent living in the community and social activities after discharge home.

Center for Epidemiological Studies Depression Scale (CES-D)

The Center for Epidemiological Studies Depression Scale (CES-D) is a depression screening instrument which has been widely applied in epidemiological studies, including

a community-based study between chronic diseases and depression in older persons (Bisschop et al. 2004). The scale consists of a 20-item, self-reporting depression scale developed to identify depression in the general population (Radloff 1977). This scale addresses four different factors. The first is depressed affect, and items that load on this factor include: "bothered by things that usually don't bother me", "I could not shake the blues", "I feel depressed", "I felt lonely", "I had crying spells" and "I felt sad". The second factor is positive affect and includes the items: "I felt as good as other people", "I felt hopeful about the future", "I thought my life had been a failure", "I was happy" and "I enjoyed life". The third factor is somatic complaints and includes the items: "I did not feel like eating", "I had trouble keeping my mind on what I was doing", "My sleep was restless", "I felt like everything was an effort", "I talked less than usual" and "I could not get going". The final factor is interpersonal relationships and includes the items: "People were unfriendly" and "I felt that people dislike me". Each item is rated on a 1-4 scale or a 0-to-3 response scale, depending on the frequency of symptoms the week prior to the administration of the scale. Therefore, the range of answers is 0-60. A score of 16 or greater is considered indicative of clinically significant depression (Radloff 1977).

Radloff (1977) reported alpha coefficients of 0.85 for general population samples and of 0.90 for a patient sample; split-half reliability ranged from 0.76 to 0.85. Radloff also reported consistent results of factor analyses across three samples. This suggests that the scale as a whole has high internal consistency (Davidson et al. 1994).

The CES-D is a useful screening scale for depressive symptoms in community samples of older adults. The one shortcoming to this scale, as Bisschop et al. (2004) states, is that it requires responding to a spectrum of four responses over the previous week compared to a simple yes-no format as is found in other symptom-screening scales. However, this scale is still valuable both for community studies and in clinical screening efforts.

A Chinese version showed an alpha reliability of 0.92 (Rankin et al. 1993). The CES-D has also been used in various studies in China (Chi & Boey 1992, Chi 1998).

4.6.2 Interviews and field observations

Semi-structured interviews and field observations were conducted. The interview guides for the survivors were: What are their major concerns at present? How do they deal with them? And what kind of difficulties have they encountered in dealing with them? (See Appendix 4.3A) Meanwhile, the interview guides for the primary family caregivers were: Please say something about what happened to them and what they think about it. Specifically, how do they actually take care of stroke survivors? What kind of care issues do they/have they encountered? How do they perceive these care issues? Do they feel difficulty in coping? How do they deal with the issues? What kind of resources do they utilize, etc.? (See Appendix 4A).

Field observation notes of the interview process were undertaken for any observed focus under the investigation, including home environment, living condition, performance of physical ability, family interaction, attitudes of participants, their interest and expression, etc (see Appendix 4.3 and 4.4). All these served to provide a basic understanding of each family in its own context.

4.7 Data collection schedule

A protocol that materialized the study proposition was used to guide data collection. The distinct advantage of using the study protocol is that it is intended to increase the reliability of the case study research and guide the investigator to collect the most relevant data being studied (see Figure 4.1). The major contents of the schedule for data collection included time points for home visits and preparations for data collection.

The case study was conducted prospectively, so that each family was visited at four time points over a period of six months post discharge. This period was selected because the major functional recovery typically seen in stroke survivors occurs within a six to 12-month time frame (Kelly-Hayes et al. 1989, National Stroke Association 1992) and most recovery from stroke occurs in the first six months. Thus data were gathered through a series of four interviews with each family: at one week, and one month, three and six months after discharge home, in their home settings. These time intervals were considered clinically significant in the previous reviewed articles.

Good preparation was made before each home visit. This included having sufficient resources while in the field: (a) note book and pen for field notes and observations, (b)

blood pressure monitor for informing participants of the importance of change of blood pressure over time and sustaining a follow-up visit, (c) tape recorder and batteries for audio-taped speech to be transcribed verbatim, and (d) camera for pictures which could be taken as a memento and given to families in the next interviews in order to establish mutual rapport. These pictures might also be used by the investigator to illustrate stroke care in real-life situations. However, in this case, all characters' faces would be disguised.

Figure 4.1. The study protocol



4.8 The pilot case study

An exploratory pilot study was conducted with two families. Replication logic was followed, the hospital was accessed, two families were selected based on the prior development of criteria, multiple sources of data were collected, and the study protocol was applied. These two cases were not included in the main study of the 18 families.

The duration of each face-to-face interview was approximately 45-60 minutes. All pilot case study data were collected during a two-month period (from April to June, 2001). Information from the two pilot cases was tape-recorded and transcribed and two home visits were determined because the desired procedures were obtained. These desired procedures included a brief description of two pilot cases, and modified procedures for the main study.

4.8.1 Description of two pilot cases:

Mrs. X, 71 years old, first ever stroke, widow living with her son. She was taken care of by her three adult children and one daughter-in-law during hospitalization. After discharge home, she was living with her son's family and cared for by a 24-year-old female domestic helper. Her score in ADLs (the performance of functional status) was 65, and that of I-ADL was dependent (she was dependent upon her living in the community). The CES-D score was ten, which showed that she was fearful of depending on others. Her self-evaluation of general health score was two, indicating dissatisfaction with her health. Her son was absent while paying visits.

Mr. Y, 70 years old, first ever stroke, living with his spouse, Mrs. Y, 70 years old. Both of them were retired workers; total income was 800 yuan. Mr. Y had no free medical coverage due to his work unit's poor financial status. His son and daughter paid him frequent visits during hospitalization, and his wife was responsible for his meals during his hospital stay. After discharge home, he was cared for by his wife completely. His ADLs score was 70 and his I-ADL was more than three. He was dependent on his wife in activities of daily living, but his CES-D scores were normal, which showed that his emotional status was stable. His score in self-evaluation of general health was two, indicating that he was dissatisfied with his current health. His wife's CES-D score was five, indicating that she had a poor appetite and suffered from sleep disturbances while taking care of her husband all day long. Her SEGH score was three, indicating that she was not satisfied with her current health status.

These two pilot cases might represent the most complicated issues of the real cases, such as living with a child and a spouse respectively, having residual disability and multiple care issues encountered by two families after discharge home. Therefore almost all relevant data collection issues would be compared with the illness and caring process.

4.8.2 Modified procedures for the main study

The previous procedures based on the protocol were modified in order to conduct the main study successfully. The major areas included the refined items, lessons to be drawn as follows and reminders for the main study.

Refined items

(a) Interview rearrangement. The case selection criteria were refined in item four, which involved both family caregivers and stroke survivors being interviewed separately at the same time. This was changed by interviewing them together due to their feeling uncomfortable or unwilling to be interviewed separately.

(b) Site selection. It was previously decided to select two hospitals. However, regarding the time constraints and the need to recruit more cases at the same time, three hospitals were chosen. Thus the Third Wuhan Hospital was added because it had similar characteristics to the previous two ones and was also located in Wuchang.

(c) Evaluation of time schedule. The five home visits were reduced to four, since the first home visit was easier for the families to accept at one week following discharge instead of two days (immediately after discharge home). Thus, the home visit at two days following discharge was omitted. They were one week (T1), one month (T2), three months (T3) and six months (T4).

(d) Ethical issues: During the pilot period, seeking written consent created some anxiety for both the investigator and the participants. It is not very common for researchers to

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seek written permission in our local community, since this might cause participants to think they are being considered as 'the subjects of an experiment' or 'the subject of research': such a role would be un-welcome and rejected by participants. However, it is common for hospital staff to seek verbal permission during the hospital stay, since doctors and nurses in the hospital are observed to carry out their duties and become familiar with stroke survivors and their family members: respect and trust in each other are established. Therefore, oral permission was obtained instead of the written form. Furthermore, permission to take photos during the interviews was also obtained from those who agreed. In return, copies of all photos taken were given to the families they were pleased to receive them as a souvenir.

Lessons drawn from the pilot case study

Building trust between the hospital staff, stroke survivor and family members was essential to the success of this study in both settings.

(a) During the initial time in the hospital, access to the neurological ward was considered important to obtain appropriate cases. However, selecting which units (Department of Medical Affairs or Department of Nursing) was problematic due to administrative issues. Through a couple of times of contact, winning the support and cooperation of the chief of the Department of Nursing was a key element, as the chief had a strong sense of desire to promote the development of nursing research in the clinical setting. With her understanding of the significance of this study, two nurses were assigned to coordinate this work, undertaking duties such as reporting to the investigator by telephone in a timely fashion when new stroke patients were admitted, bedside introduction of the study to stroke patients and their family members, and necessary note-taking with regard to patients' conditions. This assisted the investigator to build a rapport with patients and their families, and paved the way for the subsequent home visits.

(b) In the home setting during the initial time, relieving worry and anxiety for the family members was also essential for successful home visits. Such worry and anxiety were frequently expressed concerning the identity of the investigator, the motives for the home visits and the intention of the investigation. For example, the first visit was paid after a phone call. However, as soon as the investigator arrived, the letter of introduction and hospital working card were immediately requested to prove the identity of the investigator. The investigator was embarrassed and astonished by this sudden request, since a detailed explanation had been given before paying this home visit. In such a situation, one subject further doubted the investigator's intentions and the reasons for the home visit. He asked, "From where did you make the phone call? It seems this number is different from the hospital's...are you a salesman from a drug company, here to promote your medication or advertise your facility or something else? ...". Such questions were unexpected prior to the home visit. This indicated that it must be clarified with patients and their family members before paying a formal home visit.

(c) During the interview, sensitive questions were to be avoided since both the stroke survivor and their family members were sitting together. In particular, while the stroke survivor was answering questions, the daughter-in-law seemed to be very alert and sensitive while discussing financial issues or family relationships. In order to avoid any conflict or uneasiness among family members, and to ensure the success of follow-up

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visits, a warm atmosphere should be created and any misunderstanding should be eliminated.

(d) Planning the home visits. Before each home, reviewing the survivor's severity of stroke and other related illness conditions was necessary. In the day of the each home visit, considering family acceptance and timing was also taken into consideration. During the process of each interview, timing was carefully managed in order to avoid distractions because of being tired or busy with their housework tasks.

(e) Difficult situation. An important point in home visits is how to deal with difficult situations in interacting with the stroke survivor and family caregiver. For example, when the investigator was asked to eat food, biscuits, fruit, and particularly when offered gifts or money, she had to be careful to accept or decline while protecting both the stroke survivor's and family member's words and feelings. It was necessary for the investigator to establish a rapport and a collaborative relationship with the family. On the other hand, it was difficult to determine what is appropriate in such a situation. Total refusal to accept anything might have damaged or destroyed the mutual relationship and success of further home visits.

Reminders for the main study

Based on this experience, the following points needed to be borne in mind:

(a) Continuous help should be sought from the Department of Nursing, a suitable nurse should be assigned for coordination and assistance, and nurses should be rewarded in a timely fashion for their help.

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(b) The investigator's identity and intention should be introduced actively and openly, and any questions should be answered accurately and in a timely fashion.

(c) The investigator should be aware of any sensitive issues within the survivor's family, and protect and respect their relationship.

(d) The investigator should cope with their emotional status and not force them to talk. Choose a proper time to visit them and find something interesting for them to talk about, and

(e) The investigator should cope with any interference during the interview, such as TV noise, or strangers coming and visiting. Tell them the purpose and importance of the study patiently and that their information was particularly valuable for improving health care service.

4.9 Data collection procedures for main study of 18 families

The case-selecting criteria were modified on the basis of the pilot case study. From June 8, 2000 to January 30, 2001, those survivors who had suffered cerebral infarction and been discharged home accompanied by family primary caregivers were recruited in the study. They were all living in the urban region of Wuhan and thus convenient to follow up; there were 74 in total.

Through observation during hospitalization, it was found that 50 of the initial subjects did not meet the selection criteria of this study because of the following reasons: TIC, cerebral infarction with cerebral hemorrhage, aphaxia, incontinence, unconsciousness, dead during hospitalization, no need for caregiver, serious dermatosis, home located in distant suburbs, taking medicine for mental disturbance, duration of hospitalization exceeding 60 days. A further four were unavailable later (one left no address, one had moved to his/her daughter's home, one refused to take part, one gave no response when the investigator knocked at the door), and another two were missing during follow-up (one had moved away and lost contact, one had become worse and been re-hospitalized).

Twenty stroke survivors met the criteria and agreed to participate in the study. Both stroke survivors and family caregivers were interviewed together because they would perceive mutual trust in the investigator and thus find it easier to express themselves comfortably.

It took about two hours (120 minutes) on the average to conduct an interview with each family, the longest being three hours, and the shortest one hour. With the permission of the family member(s), the contents of the interview were tape-recorded. Right after the interview, the investigator transcribed verbatim the tape into a written-form record. On the investigation forms and the evaluation tables, the basic data and the scores of both the survivors and the caregivers were entered separately. (For the survivor, cognitive, emotional and physical status and scores were recorded, while the emotional status and scores of the caregivers were recorded as well): on the basis of the above data, the cognition, emotional status and disability of the survivor and the emotional status of the primary caregiver could be evaluated. All the interviews and written-form records were made by the investigator alone. Data were audio-taped and transcribed verbatim after interviews.

Of the 20 survivors, two ended their participation after the initial two visits. The contact of one family was lost due to moving into another place and the other was re-admitted to the hospital due to stroke recurrence. Thus eighteen families finished the four visits at the end of June, 2001. Of those, four were from the Fourth Hospital of Wuhan, and seven from the Sixth and Third Hospital of Wuhan respectively. After finishing the 18 case studies, all interviews were audio-taped and transcribed verbatim. Based on Yin's (2003) views of analyzing case study evidence, both quantitative and qualitative evidence were analyzed by constantly examining, categorizing, tabulating, testing and recombining in order to address the initial proposition of the study. These methods were utilized throughout the case-based and cross-case analyses as described in the following.

4.10 Case-based analysis

Case-based analysis is an initial step to examine the individual cases before the work of cross-case analysis starts (Huberman & Miles 1994). In the present study, the following parts were included in the case-based analysis in each of the 18 cases: (a) characteristics of survivor, primary caregiver and family and health care service utilization, (b) examination of the study proposition, and (c) evaluation of family well-being. A template for presenting the multiple data sources of each case is provided in Table 4.2. (see Appendix 4: a detailed description of the 18 cases).

Characteristics				
Survivor	1.	Demographic information		
	2.	Medical conditions: onset, physical examination (PE), past		
		history, diagnosis, length of hospital stay		
	3.	Others: educational level		
	4. 7	Observation notes while discharge		
Primary caregiver	5. 6	Demographic information of primary caregivers		
Family		members and surroundings		
	7.	Observation notes while interviewing		
Health care service utilizat	ion			
During hospital stay		Medical care services used		
	2.	Medical coverage		
After discharge	3.	Health care services utilization and		
	4.	Cost for services utilization per month.		
Examination of the study r	orop	osition		
Care issues		Activities of daily living		
	2	Health problem		
	<u>-</u> . 3.	Caregivers' need		
Coping resources	1.	Cognitive		
	2.	Affective		
Organization of caring work	1.	Family dynamics		
Evaluation of family well-h	bein	g		
Evaluation	1.	Statistical analysis and time-series analysis		
	2.	Summary of the case		
	3.	Determination of the type of family well-being and changes of family well-being from one week to six months after discharge home		

Table 4.2. Template for presenting the multiple data source of each case

4.10.1 Characteristics and health care service utilization

Information on characteristics of stroke survivor, primary caregiver and his/her family was delineated in order to understand the family well-being in its own context. This information was obtained from their socio-demographic and health information (SHI) is illustrated by following examples (Table 4.3.1).

Table 4.3.1. Characteristics and health care service utilization of Mr. A's Family

Stroke survivor characteristics

Mr. A, 58. Hospitalized on July 28, 2001, because of 'weakness of right limbs appeared during rest, especially right upper limbs, with oppressive pain in the whole head at the time when admission'.

P.E.: BP:162/96mmHg, conscious, left naso-labial sulcus shallowed, tongue moving to left, deep and superficial sensation decreased in right limbs, muscular tonus of right upper limbs, grade III, right lower limbs, grade IV, no signs of pathological reflect.*CT scan: left brain-stem infarction.

Past history: Several stroke attacks in the past (September, 1999; June 2000; July 2001); hypertension in the past, the highest being 190/100mmHg, took (xin-tong-ding) Nifepine, diabetes, type II (for 9 years). Chronic bronchial asthma (for 32 years).

Diagnosis: left brain-stem infarction (right hemipares).

Length of hospital stay: 15 days, 3300 Yuan for hospitalization fare, 80% compensated by public health service. Observation: He was cared for by his wife and he left the hospital on foot with a stick. His educational level: middle school. Mr. A's salary was 460 RMB.

Primary caregiver and family characteristics

Mr. A and A's wife lived together. A's wife, 58, primary education, a retired textile worker, shouldered the burden of care of the whole family.

A's son, 32, not living together, was the dean of a primary school, daughter-in-law, three months pregnant, had two abortions in the past, was resting at home. Being the dean, the son was very busy, and had to take particular care of his wife. The son had a meal once a day in his parents' home, and gave them 300 RMB per month.

A's wife salary was only 290 RMB. Because her working unit belonged to a government-run enterprise which was broke, wages had not been available for one year, only she had only got paid recently. Their family income each month: 1050 RMB. Educational level: middle school.

They lived on the 5th floor, and the flat was assigned by their working unit. They shared the flat with another elderly couple's family. The neighbor's husband had hemiplegia after stroke, the wife died suddenly of cerebral hemorrhage later.

There were 3 rooms for Mr. and Mrs. A and they had their own toilet and kitchen. One room was the room for their son's marriage although the son had bought a new house, this room was kept specially for him. The room was well decorated, with an erecting-style air-conditioner, a big double-bed with a high-quality silk cover. A dining table and a big sofa were in the middle room which had a broad window toward the south, keeping room very bright in anticipation of their son's frequent visits. Turning to the room of the elder parents, there were no windows at all, only two doors, and it was dark. Mr. A hated darkness, and due to his asthma attacks he always complained that the poor ventilation was causing him to choke.

Heath care service utilization

Affordability: the family was experiencing a great financial burden (asking for loan). From 1999 to 2000, Mr. A was hospitalized for 3 times (2 strokes, 1 heart attack), and their medical payment reached 12000 RMB, which had to be paid out of their own pocket in advance and could not compensate in time (their unit paid compensation only twice a year at certain times). Mrs. A sighed with emotion they had spent all the money they had saved for so many years and still they had to borrow 3000 RMB from their relatives, and another 3000 RMB from their son. Once they started talking about financial problems, they expressed sorrow and sighed with deep feeling. In the 6 months at home, 4470 RMB had been spent (T1=300, T2=800, T3=70, T4=3300).

Health care service utilization included: General dispensary : common medicine (constipation, external use) and medication consulting; clinics of their units : I.V transfusion, acupuncture, common medicine); private clinics and OPD of the hospital : (Important medicine) emergency (uncomfortable at night); hospitalization (admitted to the provincial traditional hospital due to his afraid of being infected or condition worsening)

4.10.2 Examination of the study proposition

Based on the information regarding characteristics and health care service utilization, qualitative data regarding care issues, cognitive and affective responses and organization of caring work was analyzed by qualitative content analysis. Qualitative content analysis and the application of this strategy are described and presented in the following discussion.

Qualitative content analysis

Qualitative content analysis was adopted in the present study to analyze the qualitative information, including semi-structured interviews, field observation and notes obtained from stroke survivors and family caregivers based on the study proposition. The following concepts are important to examine in the present multiple-case study, which is mostly based on the stance of Graneheim and Lundman (2004). They are unit of analysis, a meaning unit or a sub-unit of analysis, condensing and abstracting. In the process of abstracting, code, sub-category and category were included.

The unit of analysis was previously defined as well-being of the family living with stroke. Thus each family's well-being living with stroke was considered as one unit of analysis.

Within each unit of analysis, there were sub-units or embedded units of analysis based on the study proposition. The sub-units of analysis examined in this study included care issues encountered by the family living with stroke, perceived burden reflected by both cognitive and affective response, and caring work organization.

Condensing or condensation refers to a process of shortening while still preserving the core meaning of the text.

Finally, abstracting or abstraction emphasizes descriptions and interpretations on a higher logical level. Examples of abstraction include the creations of codes, sub-categories and categories.

Application of qualitative content analysis

Qualitative content analysis was adopted to examine the care issues, perceived burdens and caring work organization as experienced by the stroke survivor and family caregiver. Following is an illustration of a meaning unit, condensed meaning unit, code, subcategory and category to examine how care issues were analyzed using this method (see in Table 4.3.2).

 Table 4.3.2. An illustration of a meaning unit, condensed meaning units, code, issues and category

A meaning unit	Condensed meaning unit	Code	Issue	Category
"Everyone gives me the same advice, take better meals, yes, but who does the shopping, who does the washing, cooking?"	I know I should eat better, but I was unable to go downstairs and go shopping.	Difficulty in preparing meals	Eating and meals Mobility issues	Care issues surrounding activities of daily living
"Now my top concern is the weakness of my limbs. I can't hold things firmly, I can't stand steadily, that's my biggest problem!"	I have problems with my arms and legs.	Difficulty in holding, standing	Mobility issues	
"I slipped on the stairs, and hurt my face; I also slipped on the floor, and hurt my handonce I slipped on the floors and spilt the water in the spittoon all over my body. I know it is because I don't have enough strength in my injured limbsdo you think the strength can be regained?"	I have slipped many times and hurt my body	Falls	Safety issues	

4.10.3 Evaluation of family well-being

Evaluation of the family well-being at different time points is presented including: (a) statistical analysis and time-series analysis, (b) a summary of the case, and (c) determination of the type of family well-being and changes of family well-being over time (see Table 4.4.1, 4.4.2 and 4.4.3).

Category	Scales	T1	T2	T3	T4
Mr. A					
1	SPMSQ	0			
2.	CES-D	6	28	47	47
3	ADLs	35	60	75	80
4	I-ADL	-	25	24	26
5	SEGH	3	2.5	2.5	2.5
A's wife					
1	CES-D	0	0	0	0
2	SEGH	6	6	4.5	3

Table 4.4.1. Statistical and time-series analysis for Mr. A's family

T1: discharge from the hospital at one week; T2: discharge home after one week; T3: discharge home after three months; T4: discharge home after six months.

Table 4.4.2. Summary of Mr. A's family: examination of the study proposition

Prognosis

Mr. A, 58, medical conditions were severe, blood pressure was high (180/90mmHg); besides infarction, he had complications (coronary heart disease, hypertension, several episodes of stroke recurrence, asthma, diabetes).

Family background

The couple was living together, and their only son came back home to eat with them. They were a modified nuclear family. There had 80% free medical care coverage, but their financial burden was still very high.

Health care services

A number of health care services had been used.

Stroke-related disability

Functional status showed improvement over time, but completely dependence upon family members after discharge home. After one month, he had depression. Meanwhile, his self-evaluation of general health was remained low (2), and his wife gave the scores of his evaluation of general health as decreased over time.

Care issues

They include constipation, mobility (walking), sleeping disturbance due to fear of death, physical discomforts (leg pain and numbness, swelling and skin rashes) and medication concerns.

Responses to illness indicated by survivors

1) His predominant thought was his wish to get everybody around him. Mr. A insisted on his authority as a father and husband. The father should dominate the family. However, in the later stages, things went in the opposite direction. Because the original father was no longer the center of the family was no more the original father, the focus shifted instead to the daughter-in-law and grand son; he perceived that they were not fulfilling their prescribed filial son and filial wife roles (e.g., either children or spouse not acting according to their prescribed role, traditional value of getting return from children);

2) Being treated unfairly by heaven;

3) Perceived burden of illness;

4) A number of negative affects (emotional disturbance) included guilty, worry, irritability, fear (death, high BP and stroke recurrence, constipation and cancer, being ignored and sneered at by neighbors), self-pity, hopelessness, isolation, demanding, immature feelings, accusation, upset, over-dependent and self-protection and other concerns.

Organization of caring work

At first the husband sang and the wife followed, and the atmosphere was harmonious. But one month later, with the change in the family affairs (daughter-in-law pregnant), Mr. A's temper flared up, and family conflicts emerged. At this stage, the wife and son still tried to comfort him and exercised tolerance so as to maintain peace in the family. Six months later, with the birth of the new-born baby and some other factors, the family conflicts became more serious. The son tried to avoid his father, and the wife spent much more time in the hospital taking care of the mother and child. Mr. A seemed to be isolated, his anger and rage burst out, and he even used harsh words, beat his wife, and shouted that he wanted a divorce. Ultimately, his wife and son started to strike back, they argued with him at high pitch, and the family relationship was close breakdown.
Table 4.4.3. Determination of the type of family well-being and a change of family well-being over time

Type of family	From optimal to dysfunctional
well-being	

Statistical and time-series analyses

Statistical analyses were undertaken to evaluate the family well-being by using the structured questionnaire results at different time points for profiling the changes in general health, functional level and emotional state of stroke survivor and the general health of the family caregiver.

Both the scores obtained from the stroke survivor and primary family caregiver, and their family situations were recorded and summarized based on the structured questionnaire at one week, one month, three months and six months after discharge home.

Measurements of the survivor's well-being included evaluation of the survivor' cognitive status (SPMSQ, for screening purposes only), emotional status (CES-D), the survivor's performance of functional status (ADLs), instrumental activities of daily living (I-ADL), and self-evaluation of general health (SEGH). Measurements for the primary family caregiver involved evaluating the primary caregiver's emotional status (CES-D) and self-evaluation of general health.

A summary of the case

A brief summary of each case was made by combining both the quantitative and qualitative information. The quantitative data came from the structured interview questions and produced a basic understanding of each family's stroke care situation. This information was summarized by the characteristics of the survivor (e.g. age, gender), the primary family caregiver and their family members (e.g. age, gender, type of family structure), and the well-being of the survivor's family (e.g. physical performance of ADLs, emotional status, social activities regarding I-ADL, and self-evaluation of general health).

The qualitative data was obtained from the semi-structured interviews and field notes, and analyzed by qualitative content analysis that resulted in rich descriptive and explanative information regarding care issues, their perception of the post-stroke and the caregiving experience, and organization of caring work over time by the type of family well-being.

Determination of the type of family well-being and changes of family well-being over time

Based on the above statistical information and a summary of each case, the type of family well-being and the change in family well-being over time for each case were determined. Based on the findings of the case-based analysis, cross-case analysis was undertaken.

4.11 Cross-case analysis

Cross-case analysis was conducted among the 18 families, and consisted of the following procedures: (a) statistical analysis, (b) time-series analysis, pattern-matching techniques and triangulation, and (c) explanation building technique. The characters included in the 18 cases are presented in Table 4.5. The codes as presented in Table 4.5 are used as pseudonyms for the survivors and family caregivers thereafter in this thesis.

Types of	Case	Survivors	Primary	Other family members
well-being	ID		caregivers	
Dysfunctio	1	Mr. A	A's Wife	A's Son and A's Daughter-in-law
nal	2	Mrs. B	B's Daughter	B's Husband and B's Helper
	3	Mrs. C	C's Husband	C's Son and C's Daughter-in-law
	4	Mrs. D	D's Son	D's Helper, D's Daughters, and D's
	5			Daughter-in-law
		Mr. E	NA	E's Sons, E's Daughter, and E's
				Daughter-in-law
Functional	6	Mr. F	NA	F's Daughter, F's Younger and F's Elder
	7			Son
	8	Mrs. G	G's Daughter	G's Daughter-in-law and G's Son
	9	Mr. H	H's Wife	H's Helper, H's Daughter, and H's
				Son-in-law
		Mr. I	I's Wife	I's Son and I's Daughter-in-law
Optimal	10	Mr. J	J's Wife	J's Son and J's Daughter-in-law
_	11	Mrs. K	K's Husband	K's Son and K's Daughter-in-law
	12	Mr. L	L's Wife	L's Daughter and L's Son-in-law
	13	Mr. M	M's Wife	M's Younger and M's Elder Son
	14	Mrs. N	N's Husband	N's Son
	15	Mrs. O	O's Daughter	O's Husband and O's Son-in-law
	16	Mr. P	P's Wife	P's Son, P's Grandson, and P's Daughter
	17	Mr. Q	Q's Wife	Q's Son and Q's Daughter-in-law
	18	Mr. R	R's Wife	R's Daughter

Table 4.5. Characters included in the 18 cases

NA: Not available

4.11.1 Statistical analysis

Statistical analysis of the socio-demographic characteristics, general health, functional level and emotional status by the levels of family well-being was undertaken by the following steps. First descriptive statistical analysis was used to examine the distribution of demographic characteristics using the frequency, mean and standard deviation. Second, the association of stroke survivors' performance and emotional status by different levels of family well-being was tested using nonparametric statistics (e.g. the chi square test, Kruskal-Wallis test, Mann-Whitney U test and Friedman test for comparisons of ranked scores between and among the groups).

The Kruskal-Wallis test was used to compare the differences between the three types of family well-being (e.g. optimal, functional and dysfunctional) in terms of the characteristics for stroke survivors, family caregivers and family, health care service utilization, and well-being of the family. This test was also used to compare changes over time in physical performance of ADLs, changes of emotional status (CES-D) over time, changes of four domains of emotional state over time, changes of instrumental activities of daily living (I-ADL) among the three types of family well-being over time, and changes of self- evaluation of general health. The Mann-Whitney U test was used to compare the differences between the two types of family well-being (e.g. optimal with functional, optimal with dysfunctional and functional with dysfunctional) in emotional status (CES-D) and self-evaluation of general health (SEGH). After the Kruskal-Wallis and Mann-Whitney U tests were done, the Friedman test was conducted in order to compare the

differences between the three types of family well-being in ADLs, I-ADL, CES-D and SEGH.

Third, Spearman's correlation coefficients were calculated for the scores on measures that were given to both survivors and family caregivers at one week, one month, three months and six months after discharge home. The Spearman's correlation was used to measure the strengthen of the relationship between: (a) physical performance of activities of daily living (ADLs) and characteristics of stroke survivor (e.g. age, gender, relationship with primary family caregiver), as well as primary family caregivers (e.g. age, gender) over time; and (b) emotional status in survivors (CES-D) and characteristics of stroke survivor (e.g. age, gender, relationship with primary family caregivers), as well as primary family caregiver), as well as primary family caregivers (e.g. age, gender) over time; and (b) emotional status in survivors (CES-D) and characteristics of stroke survivor (e.g. age, gender, relationship with primary family caregiver), as well as primary family caregiver), as well as primary family caregiver (e.g. age, gender, relationship with primary family caregiver), as well as primary family caregiver (e.g. age, gender, relationship with primary family caregiver), as well as primary family caregiver (e.g. age and gender) over time. The value of the Spearman's correlation coefficient varies from -1 to +1, with -1 or +1 indicating a perfect negative or positive relation and zero meaning there is no relation. The significance level was set at p<0.05.

4.11.2 Time-series analysis, pattern-matching techniques and triangulation

Time-series analysis, pattern-matching techniques and triangulation were used to make a constant comparison among the 18 families in order to identify the commonalities and differences based on the study proposition.

Time-series analysis

Time-series analysis allows the investigator to characterize a pattern over time, analyze unique fluctuations of a variable through time and predict future changes in the individuals (Jensen 1990).

The more intricate and precise the pattern, the more the time-series analysis will lay a firm foundation for the conclusions of the case study. Simple and complex time series involve not merely rising or declining trends, but some rise followed by some decline within the same case. This type of dual pattern, across time, would be the beginning of a more complex time series. The strength of the case study strategy would not merely be in assessing this type of time series but also in having developed a rich explanation for the complex pattern of outcomes and in comparing the explanation with the outcomes (Yin 1994).

Pattern-matching techniques

The procedures for pattern-matching are based on the discussion made by Campbell (1975). It compares an a priori predicted pattern derived from theory with an observed empirically based pattern. If the patterns coincide, the results can help a case study strengthen its internal validity. If the patterns coincide (as in this situation), a theoretical replication across cases has been made. If the patterns are consistent with each other, the findings can assist a case study in enhancing its internal validity.

In other words, the initial theoretical proposition was compared to the findings of the first case. On this basis, the proposition was revised, then compared to the findings of the second case again. As Yin suggests, this process was iterative and repeated in a circle with the details of the next cases further revision was made when discrepancies appeared between the prior theoretical framework and the results. The revised assertions were subsequently compared with the results of the second, third...and eighteenth case, the results were repeated and further modifications were made. The result of the iterative process led to further constant revision and comparison with the initial proposition, and led to an expansion of the theory.

Triangulation

Denzin (1989) described two types of methodological triangulation. One is within-method and the other is between-method triangulation. Within-method triangulation means the combination of more than one similar data collection strategy in one study to measure the same variable(s) as described previously combining multiple sources of evidence, while between-method triangulation refers to the use of both qualitative and quantitative approaches in a particular study to investigate the same unit. In the following discussion, between-method triangulation was presented.

Application of time-series analysis, pattern-matching technique and triangulation

Application of time-series analysis, pattern-matching technique and triangulation are presented in this study by the following tables (see Table 4.6, 4.7 and 4.8).

In this study, the major proposition was studying what factors contribute to changes of family well-being. A certain pattern of family well-being would be predicted by stroke-related disability, care issues, organization of caring work, and coping resources based on the study proposition. After a comprehensive comparison across cases, the results showed that family well-being was actually produced by the predicted factor—those who could mobilize positive personal coping resources and others who failed to mobilize these positive personal coping resources.

In Table 4.6 compares various kinds of care issues encountered by the three types of family well-being in different levels of physical performance of activities of daily living (ADLs) and social activities (I-ADL) at different time points (from one week-T1 to six months-T4). Qualitative content analysis revealed that there were various kinds of care issues encountered by the 18 families, and this information was closely related to the quantitative information obtained from the survivors' physical performance and social ability with different scores. The lower scores might be closely related to the higher level of dependence and the burden of care, and vice versus. Thus combining both the qualitative data on category and the quantitative data on ADLs and I-ADL among the 18 cases, the shared and different care issues across cases emerged.

	Type of family well-being								
ADLs		Optimal	ŀ	Functional	Dys	sfunctional			
		(n=9)		(n=4)	(<i>n</i> =5)				
	Case	I-ADL	Case	I-ADL	Case	I-ADL			
>85	Mr. L	T2: 0, T4: 0	Mr. G	T2: 12, T4: 12	Mrs. B	T2: 21, T4: 13			
	Mrs. O	T2: 25, T4: 26	Mr. F	T2: 8, T4: 2					
	Mrs. K	T2: 0, T4: 0							
	Mr. Q	T2: 13, T4: 11							
	Mr. P	T2: 5, T4: 5							
	Mrs. N	T2: 25, T4: 26							
35-85	Mr. R	T2: 25, T4: 26	Mr. I	T2: 27, T4: 27	Mr. A	T2: 25, T4: 26			
	Mr. M	T2: 21, T4: 21	Mr. H	T2: 25, T4: 28	Mr. E	T2: 16, T4: 15			
	Mr. J	T2: 16, T4: 15							
<35					Mrs. C	T2: 27, T4: 29			
					Mrs. D	T2: 25, T4: 29			
					Mrs. D	T2: 25, T4: 29			

Table 4.6. Examination of care issues based on levels of residual disability and by type of family well-being

ADLs scores range from 0 to 100; the higher the score, the more the independence is the survivor. I-ADL scores range from 0 to 30; the higher the score, the more the dependence is the survivor living in the community. I-ADL scores of the survivor assessed from one month (T2) to six months (T4) are presented in the table.

In Table 4.7 compares family dynamics in the organization of caring work based on the five types of family structures by the three types of family well-being among the 18 families. Qualitative content analysis revealed that there were different categories in the three types of family well-being, and this information appeared to be related to the five types of family structure according to the quantitative information. Combining both the qualitative data regarding the family interaction and the quantitative information in terms of the five types of family structure was used to examine shared and different family dynamics on evolving family role responsibilities. Ultimately three patterns of organization of caring work among the 18 families emerged.

	Type of family well-being (N=18)						
Types of family	Optimal	Functional	Dysfunctional				
structures	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)				
Nuclear	Mrs. N and her husband	*Mr. H and his wife					
(<i>n</i> =3)	Mr. R and his wife						
Modified	Mr. P and his wife	Mr. I and his wife	Mr. A and his wife				
nuclear			*Mrs. B and her				
(<i>n</i> =4)			daughter				
Extended	Mrs. K and his husband	Mrs. G and her daughter	Mrs. C and her husband				
(n=8)	Mr. L and his wife		*Mrs. D and her son				
	Mr. M and his wife						
	Mrs. O and her daughter						
	Mr. Q and his wife						
Modified	*Mr. J and his wife		Mr. E and his grandson				
extended							
(<i>n</i> =2)							
Living alone		Mr. F					
(n=1)							

 Table 4.7. Five types of family structures by type of family well-being in organization of caring work

*Those who had domestic helpers to assist the family in providing care

Table 4.8 examines personal coping resources mobilization among the 18 families based on different time points, emotional status, and self-evaluation of general health from the stroke survivors and the primary caregivers. It is found that both positive and negative affects existed among the 18 families, and this information was obtained from the quantitative data (CES-D). The positive and negative affects were different from one to another because personal coping resources utilization was varied, and this information was obtained from the qualitative data. Combining the quantitative and qualitative data revealed that those who had positive affects (e.g. satisfy each other) attempted to use more positive personal coping resources, while those who had negative affects (e.g. mutual dissatisfy) had failed to use positive personal coping resources.

						Type of f	family	well-b	eing						
ADLs		Opti	imal				Func	tional			I	Dysfur	nction	al	
		(n =	=9)				(n :	=4)				(<i>n</i> :	=5)		
	Case	Т	CE	SE	SE	Case	Т	CE	SE_1	SE_2	Case	Т	CE	SE_1	SE_2
	(family)			1	2	(family)					(family)				
>85	Mr. L	T1	0	5	5	Mr. G	T1	0	4	5	Mrs. B	T1	2	2	4
	(wife)	T4	0	6	6	(daughter)	T4	0	5	5	(daughter)	T4	14	2	NA
	Mrs. O	T1	27	2	5	Mr. F	T1	0	7	3					
	(daughter)	T4	0	4	5	(alone)	T4	0	7	NA					
	Mrs. K	T1	0	5	5										
	(husband)	T4	0	6	6										
	Mr. Q	T1	0	4	3										
	(wife)	T4	0	4	4										
	Mr. P	T1	0	3	5										
	(wife)	T4	0	5	5										
	Mrs. N	T1	0	2	5										
	(husband)	T4	0	4	4										
35-85	Mr. R	T1	35	2	4	Mr. I	T1	0	3	3	Mr. A	T1	5	3	6
	(wife)	T4	15	4	5	(wife)	T4	0	7	3	(wife)	T4	45	2	3
	Mr. M	T1	0	2	4	Mr. H	T1	19	2	4	Mr. E	T1	6	2	4
	(wife)	T4	0	3	4	(wife)	T4	38	2	4	(grandson)	T4	11	3	NA
	Mr. J	T1	0	2	2										
	(wife)	T4	0	4	3										
<35											Mrs. C	T1	7	2	6
											(husband)	T4	19	2	4
											Mrs. D	T1	5	2	5
											(son)	T4	48	2	NA

 Table 4.8. Personal coping resources based on residual disability by type of family well-being

Ca: case; T: Time; CE: CES-D; SE₁: SEGH for S; SE₂: SEGH for PSP; NA: Not available

4.11.3 Explanation-building technique for an examination of how the study

proposition is presented in this multiple-case study

Explanation-building technique is a special type of pattern-matching technique (Yin 1994). Mariano (2001) has suggested that the procedures of explaining-building search for explaining phenomenon through the development of a series of causal links. Mariano (2001) further contends that 'interpretation of the data is the expectation', which is similar to Yin's view that the final explanation or interpretation is a result of a series of iterations (Yin 1994). The procedures of explanation-building consist of identifying the prior proposition, comparing findings from the first case with the modified proposition, comparing the subsequent modification with additional cases, and repeating the process as necessary until a solid un-contended explanation/interpretation is produced. Thus an iterative process (Yin 1994) would take place. The utmost goal is to analyze the case study data by building an explanation about the case (Yin 2003).

In this study, explanation-building technique was used to identify factors which can explain the phenomenon of family well-being living with stroke in an optimal, functional and dysfunctional type among the 18 cases. After an iterative comparison of commonalities and differences among the 18 families based on pattern-matching and time-series techniques, four characterizations from the case study data emerged. These four features were: (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Among the 18 families, nine families could meet these four features at six months as categorized by optimal family well-being, four could fulfill two or more of these features as categorized by functional family well-being, and finally five families could not fulfill three or more of these features as categorized by dysfunctional family well-being. At the same time, three patterns of changes of family well-being evolved (see Table 4.9).

It was concluded that three contrasting results were replicated among the 18 families, and these were described as three types of family well-being: optimal, functional and dysfunctional well-being. In each contrasting result, the same findings were replicated by nine, four and five families respectively at six months after discharge home. That is to say, three theoretical replications took place across families. Of those, nine families with optimal, four families with functional, and five families with dysfunctional well-being were literal replications.

Patterns of T1 T4 N Cases change Positive Functional Optimal Mr. R 1 change Dysfunctional Optimal Mrs. O 1 Negative Optimal Functional Mrs. G, Mr. H, Mr. I 3 change Optimal Dysfunctional Mr. A, Mrs. B, Mrs. C, Mrs. D 4 Functional Dysfunctional Mr. E 1

Q Mr. F

Mr. J, Mrs. K, Mr. L, Mr. M, Mr. P, Mr.

Table 4.9. Three patterns of change of different types of family well-being from T1 toT4

T1: 1 week after discharge home; T4: 6 months after discharge home

Optimal

Functional

Optimal

Functional

Remain stable

7

1

4.12 Discussion

Discussion of the methodology used in the present investigation is presented focusing on the following three major points: (a) non-parametric tests, (b) reflections from filed work, and (c) data completeness and confirmation,

Non-parametric tests

Non-parametric tests were applied in the present study, and these tests had both advantages and disadvantages. It is applicable because they do not require parametric assumptions because data are converted to rank-ordered data (Gibbons, 1993). Examples of non-parametric tests are: Kruskal-Wallis (KW) test, Mann-Whitney U (MW) test, and Friedman's test. Handling of rank-ordered data is considered as the strength of non-parametric tests (Gibbons 1993).

However, non-parametric procedures are criticized for the following reasons: (a) unable to estimate the population: Because non-parametric tests do not make strong assumptions about the population, a researcher could not make an inference that the sample statistic is an estimate of the population parameter (Gibbons 1993), (b) losing precision: Edgington (1995) asserted that when more precise measurements are available, it is unwise to degrade the precision by transforming the measurements into ranked data, and (c) low power:

Generally speaking, the statistical power of non-parametric tests are lower than that of their parametric counterpart except on a few occasions (Tanizaki 1997, Freidlin & Gastwirth 2000).

Reflections from field work

Conducting a multiple-case study required the investigator to be deeply immerging into the setting and situation, with total physical, emotional and social involvement. This was particularly challenging for a single and novice investigator working in the field, subject to feelings of loneliness and lack of sharing with others caused by the experience of the participants living with stroke. The following is an example demonstrated by the investigator's field notes, which recorded the investigator's emotional experience during an interview.

This was the last interview for Mrs. C's family. I was looking around their room, and the only thing of value was a TV set working 24 hours non-stop. Thoughts flashing across my mind: a helpless husband, a helpless wife, a helpless family! Same as for me, a helpless visitor. In the course of all the visits, I have never encountered such a situation----such deadly silence, helpless and hopeless silence. I was clearly conscious of their existence, while they seemed not to be aware that I was in front of them. When I tried to raise a question, there was no response, only the faint sound from the TV set, a very choking sound. The air around us seemed to be frozen. The couple just sat there; it seemed that they were absolutely blocked and isolated from the human world. Many a time, I tried to break the ice, but the end was the same: three pairs of eyes gazing at each other and then immediately looking away. They attempted to answer me with their desperate eyes, as if to say: "no words because of no hope...".

The TV screen still flashed and waved; I didn't know how to end this visit. My heart began to tremble: I was shocked and ashamed of my powerlessness, my desperation and sorrow. In the end, I couldn't help but blurt out the only words hanging on my lips: "What on earth can I do for you?" To my surprise, they replied to me simultaneously, "Thank you, we really have nothing to trouble you with any more!" I was astonished. A family in such a difficult situation, could not even maintain basic living standards, and they did not have any thing to ask for!

Again, I looked at Mrs. C: our eyes met, she blinked, but her trembling lips did not utter a word. It seemed she wanted to say something, but tried to hide it. How could I guess what she was thinking? Looking at her watery and cool eyes, the sight of her pierced my heart. I stood up slowly and attempted to be released by saying good-bye. Suddenly, Mrs. C spoke to me with effort: "Wait, I will knit a wool cap for you if you come next time ...". Oh my word that was what she once promised me the first time I met her. I was astonished again by her clear memory.

Grief and sorrow remained at the bottom of my heart on my way to visit the next patient's home, because I asked myself again and again, "What is their future? How will their life be?" Their hopeless living circumstances and helpless sight always floated before my eyes and stayed in my heart. The everlasting TV programs reflecting the outside world became a sharp contrast with their living room surroundings: people in the world with different fortunes and futures, as well as a different way of living. I was murmuring: that is life and reality. No need to be too sad, just hold up my head, face the reality and go straight forward!!

This was a record of my personal feelings, thoughts and worries after finishing home visits. Sometimes it was quite difficult for me to detach myself from the situation and their experiences. In order to overcome this sense of helplessness, sharing this experience with other families living with stroke allowed me to vent my feelings and obtain emotional support through understanding and listening to them. This experience was valuable for me in allowing me to gain an in-depth understanding of families living with stroke, as well as providing me with constant support and driving me to complete my study in its entirety.

Data completeness and confirmation

The quantitative data yielded much information on the characteristics of the stroke survivors and the primary family caregivers, the features of the family context of living with stroke, the community-based health care services existing around the family living with stroke after discharge home over a period of six months. However, as regards the care issues encountered, *how* the families deal with these care issues or difficult care situations, and *why* the above important factors shape different patterns of family well-being, little information was obtained. To understand the phenomenon of changed family well-being holistically and comprehensively over time in living with stroke, more intensive and

in-depth information were needed. Therefore, a qualitative data set obtained from qualitative methods (e.g. chart review, semi-structured interview, direct observation, documentation and field notes) could assist the investigator to produce a rich description and explanation of the kind of care issues encountered, *how* families experienced and coped with the situation, *what* perception of the post stroke and caregiving experience constructed could shape the process of the organization of caring work over time. This qualitative data enabled the investigator to delineate specific facets of family well-being living with stroke-related residual disability after discharge home over time.

Qualitative information with "thick" description of each case based on prior development of a theoretical framework provides a meaningful method of investigating the contemporary phenomenon of the post stroke and caregiving experience for maintaining family well-being living with stroke after discharge home over a period of six months. By definition, the aim of this "thick" description of each case or vignette is to converge with detailed, dense, rich and specific information from the structured questionnaires (e.g. health survey and instruments), the semi-structured interviews, field observations and field notes. The case study approach is an ideal approach which allows the investigator to use a wide variety of evidence and address a broader range of issues than other strategies (Yin 1994, 2003). It has a primary goal of collecting rich data leading to an in-depth analysis of the contemporary phenomenon in its real-life situation, and making a more convincing and perceptive conclusion because of its unique features based on several different sources of information "following a corroboratory mode" (Yin 1994, p. 92). A variety of data collection methods are utilized by structured questionnaires including health survey, standardized instruments, in-depth interviews and direct observation, which allows the investigator to converge the lines of inquiry using a variety of analytic techniques so as to examine constituent factors contributing to family well-being and investigate its changes over time.

The case study approach aims to capture the care issues encountered by families and to examine the relationship between factors (e.g. stroke-related disability, care issues, perceived burden, coping resources—at the personal, family and community levels, organization of caring work) and their impact on family well-being. Two questions are important to bear in mind: (a) what factors contributing to family well-being, and (b) how these factors interplay each other within each family context? The focus of the case study is the search for commonalities experienced by families with similar illnesses, like a person following an infarction stroke. Since ill- and well-being of the family happen within a total real-life family situation in the Chinese context, the case study approach is vital to understand how individuals within the family as a whole unit interact and understand themselves and the meaning of the shared post stroke and caregiving experience in its context.

The advantage of using thick description is that it helps the investigator better understand the post stroke and caregiving experience with the families living with stroke over time, and to capture the feelings and the experience of the families' and survivor's real-life situation so as to gain a whole picture of the phenomenon under inquiry. Combining both quantitative and qualitative data was optimal to achieve the goal of completeness and confirmation of data analysis.

Therefore, the significance of combining both quantitative and qualitative data can provide complementary data sets which give a more complete picture than merely using quantitative or qualitative data. Quantitative data provides the investigator with knowledge of the characteristics of families living with stroke after discharge home over time, the features of family context, and to what extent health care services are utilized by families living with stroke after discharge home over time. Quantitative data also tend to assist the investigator in gaining an overall understanding of the situation for families living with stroke over time. On the other hand, qualitative data tend to provide the more detailed and in-depth information for describing what care issues are encountered, how the families experience and deal with these situations, and explaining why caring patterns emerge differently and the patterns of family well-being change over time. In this sense, qualitative data is crucial for attempting to provide intensive and detailed information for interpreting the earlier statistical data results in tackling the important issues of personal lived experience and meaning, such as what care issues were experienced and how they interpreted such experiences through their words and observed behaviors. It was also important to give meaning to why their caring work could be altered from one pattern to another over time (cooperative, compromising and disengaged caring patterns), as well as the patterns of family well-being (e.g. optimal, functional and dysfunctional family well-being).

4.13 Summary:

The characteristics of case study research are delineated through comparing the difference between case study teaching and case study research. The examples of case study method applying in nursing research are then followed. The focus of this Chapter presents the detailed procedures of the present study including: case selection, data sources, data collection schedule, data collection procedures for main study of the 18 families, case-based and cross-case analyses. Figure 4.10 summarized this process.





Chapter Five

Profiles of 18 Case Studies

This chapter presents the profiles of 18 case studies in two parts. The first part describes the socio-demographic characteristics of the case studies in terms of (a) stroke survivor characteristics, (b) primary family caregiver characteristics, (c) family characteristics, and (d) the use of health care services. The socio-demographic characteristics of these families by the three types of family well-being over six months after stroke are then compared. The three types of family well-being are optimal, functional and dysfunctional. The second part presents the findings of the standard measures for profiling the changes of the stroke survivors at the four time points: in one week (T1), one (T2), three (T3) and six months (T4) after discharge home by the three types of family well-being in terms of (a) activities of daily living (the Barthel Index, ADLs), (b) emotional status (the Center for the Epidemiologic Studies Depression Scale, CES-D), (c) self-evaluation of general health (SEGH), and (d) dependence level in instrumental activities of daily living (I-ADL). The family caregivers' self-evaluation of general health (SEGH) by the three types of family well-being is then tabled. Statistical analyses for any difference in these standard measures by the three types of family well-being and the association between socio-demographic characteristics and these standard measures over six months after discharge home are discussed.

5.1 Stroke survivor socio-demographic characteristics

Table 5.1 shows the characteristics of the 18 stroke survivors. They are described by age, gender, marital status, education level, working status, and religious beliefs.

			Ту	pe of family we	ll-being		
		Total	Optimal	Functional	Dysfunctional	Chi ²	P-value
		(N=18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)		
		n (%)	n (%)	n (%)	n (%)		
Age	Mean±SD	67.3±9.5	65.8±11.1	75.3±3.3	63.8±6.9	5.06 [§]	.08
	Range	44—82	44—82	71—79	56—73		
Gender	Male	11 (61.1)	6 (66.7)	3 (75.0)	2 (40.0)	0.89	.350
	Female	7 (38.9)	3 (33.3)	1 (25.0)	3 (60.0)		
Marital	Married	13 (72.2)	8(88.9)	2 (50.0)	3 (60.0)	13.00	.002
status	Widowed/separated	5 (27.8)	1 (11.1)	2 (50.0)	2 (40.0)		
Education	Middle school level	9 (50.0)	3 (33.3)	1 (25.0)	5 (100.0)	8.11	.088
level	or below						
	High school level or	9 (50.0)	6 (66.7)	3 (75.0)	0		
	above						
Working	Retired	16 (88.9)	7 (77.8)	4 (100.0)	5 (100.0)	25.0***	.000
status	Unemployed	2 (11.1)	2 (22.2)	0	0		
			_				
Religion	Buddhism	1 (5.6)	0	0	1 (20.0)	14.22***	.000
	No religion	17 (94.4)	9 (100.0)	4 (100.0)	4 (80.0)		

Table 5.1. Characteristics for stroke survivors

Chi²: Nonparametric Chi-Square Test. [§] It is tested by Kruskal-Wallis Test. *P<.05, **P<.01, ***P<.001

The mean age of the 18 stroke survivors was 67 years (ranging from 44 to 82 years). Eleven (61.1%) of the stroke survivors were men, thirteen (72.2%) were married, nine (50%) had middle school level education or below, sixteen (88.9%) were retired and the majority (94.4%) had no religious beliefs. Among the three types of family well-being, the mean age in the dysfunctional type was the lowest (63.8 years), 60% were women and 40% men, and 40% were either widowed or separated. In the functional type, the mean age was highest (75.3 years) and the widowed or separated occupied 50% and in

the optimal type, the mean age was 65.8 years, which was in the middle of these three types. Among these factors, the Kruskal-Wallis analysis showed no significant difference in the 18 families by age. The Chi-Square analysis revealed no significant difference in the 18 families by gender, marital status and educational level. However, it revealed significant difference in the 18 families by working status and religious beliefs.

5.2 Primary family caregivers' characteristics

The primary family caregivers are depicted according to the characteristics of age, gender, relationship with stroke survivor, education level, working status, religious beliefs, and health conditions.

			Typ				
		Total ¹	Optimal	Functional	Dysfunctional	Chi ²	P-valu
		(N=17)	(<i>n</i> =9)	(<i>n</i> =3)	(<i>n</i> =5)		e
		n (%)	n (%)	n (%)	n (%)		
Age	Mean±SD	56.4±17.1	61.3±13.6	66.3±15.9	41.4±16.0	5.33 [§]	.070
	Median	58.0	65.0	75.0	37.0		
	Range	19—80	37—80	48—76	19—58		
Gender	Male	5 (29.4)	2 (22.2)	0	3 (60.0)	2.88	.090
	Female	12 (70.6)	7 (77.8)	3 (100.0)	2 (40.0)		
Relationship	Wife	9 (52.9)	6 (66.7)	2 (66.7)	1 (20.0)	12.71	.013
with stroke	Husband	3 (17.7)	2 (22.2)	0	1 (20.0)		
survivor	Daughter	3 (17.7)	1 (11.1)	1 (33.3)	1 (20.0)		
	Son	1 (5.9)	0	0	1 (20.0)		
	Grandson	1 (5.9)	0	0	1 (20.0)		
Education level	Middle school level or below	8 (47.1)	3 (33.3)	2 (66.7)	3 (60.0)	7.56	.109
	High school level or above	9 (52.9)	6 (66.7)	1 (33.3)	2 (40.0)		
Working	Employed/Working	1 (5.9)	0	0	1 (20.0)	19.00***	.000
status	Retired	12 (70.6)	7 (77.8)	3 (100.0)	2 (40.0)		
	Unemployed	4 (23.5)	2 (22.2)	0	2 (40.0)		
Religion	Buddhism	1 (5.9)	1 (11.1)	0	0	13.24***	.000
-	No religion	16 (94.1)	8 (88.9)	3 (100.0)	5 (100.0)		
Health	No. of health						
conditions	problems					3.82	.58
	0	5 (29.4)	1 (11.1)	0	4 (80.0)		
	1	12 (70.6)	8 (88.9)	3	1 (20.0)		
	Health problems						
	Coronary heart disease (yes)	1 (8.3)	1 (12.5)	0	0	13.24***	.000
	Kidney problem	2 (16.7)	2 (25.0)	0	0	9.94	.002
	(yes)	2(167)	1 (12 5)	1 (22 2)	0	7 1 2	008
	Muscular skalatal	2(10.7) 3(250)	1(12.3) 1(12.5)	1(33.3) 2(66.7)	0	7.12 Q Q/	.008
	problem (yes)	5 (25.0)	1 (12.3)	2 (00.7)	0	7.74	.002
	Others (yes)	4 (33.3)	3 (37.5)	0	1 (100.0)	1.88	.390

Table 5.2. Characteristics of the primary family caregivers

Chi²: Nonparametric Chi-Square Test. [§] It is tested by Kruskal Wallis Test. **P*<.05, ***P*<.01, ****P*<.001

¹18 families had 17 primary caregivers and one family living alone but had secondary caregivers.

The characteristics of primary family caregivers by family well-being are presented in Table 5.2. They included 17 primary caregivers, of whom 12 were spouses (wives: 9, 52.9%; husbands: 3, 17.7%), four children (daughters: 3, 17.7%; son: 1, 5.9%), and one was a grandson. Their ages ranged from 19 to 80 years (mean, 56 years), and 64.7% were female. Half of them had middle school level education or below, and the

remainder had attended high school or above. 70.6% were retired, and 94.1% had no religious belief. It was also observed that 58.9% had one or more chronic health problems. The most common health problems found among the primary caregivers were coronary heart disease (10.0%), kidney problem (16.7%), anemia (16.7%), muscular skeletal problem (25.0%), and others (33.3%). The most common chronic health problem was muscular skeletal problem. This suggests that the primary caregivers' own physical conditions may be compromised by their managing care issues for the stroke survivors.

Among the above these factors, the Kruskal-Wallis analysis showed no significant difference in the 18 families by age. The Chi-Square analysis revealed no significant difference in the 18 families by gender, marital status and educational level. However, it revealed significant difference in the 18 families by working status, religious beliefs and coronary heart disease for the primary family caregivers.

5.3 Family characteristics

Family characteristics are portrayed by types of family structure, living status, types of housing, family income, perceived financial constraints, financial concerns, who to depend on when sick, and perceived dependability.

Table 5.3. Family characteristics

		Total	Optimal	Functional	Dysfunctional	Chi ²	P-value
		(N=18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)		
		n (%)	n (%)	n (%)	n (%)		
Types of	Nuclear	3 (16.7)	2 (22.2)	1 (25.0)	0	5.33	.255
family	Modified nuclear	2 (11.1)	1 (11.1)	1 (25.0)	2 (40.0)		
structure	Extended	8 (44.4)	5 (55.6)	1 (25.0)	2 (40.0)		
	Modified extended	4 (22.2)	1 (11.1)	0	1 (20.0)		
	Living alone	1 (5.6)	0	1 (25.0)	0		
Living with	Spouse	5 (27.8)	2 (22.2)	2 (50.0)	1 (20.0)	9.78	.044
	Spouse and children / Children /	12 (66.7)	7 (77.8)	1 (25.0)	4 (80.0)		
	Living alone	1 (5.6)	0	1 (25.0)	0		
Type of housing	Assigned by the	13 (72.2)	7 (77.8)	4 (100.0)	2 (40.0)	3.56	.059
nousing	Privately owned	5 (27.8)	2 (22.2)	0	3 (60.0)		
Family income	Mean±SD Median Range	913.9±407.8 850.0 200—1800	900.0±360.6 900.0 200—1600	1015.0±568.8 900.0 460—1800	858.0±435.5 800.0 420—1500	0.15 [§]	.928
Perceived	Frough	6 (33 3)	2(222)	2(50.0)	2 (40 0)	0.00	1 000
financial	Lust enough	6 (33.3)	6 (66 7)	2 (30.0)	2 (40.0)	0.00	1.000
constraints	Not enough	6 (33.3)	1 (11.1)	2 (50.0)	3 (60.0)		
Financial	Worry	11 (61.1)	6 (66.7)	2 (50.0)	3 (60.0)	7.00	.030
concerns	Some worry	2 (11.1)	2 (22.2)	0	0		
	Not worry	5 (27.8)	1 (11.1)	2 (50.0)	2 (40.0)		
Whom to depend on when sick	Spouse Children or relatives	10 (55.6) 8 (44.4)	6 (66.7) 3 (33.3)	2 (50.0) 2 (50.0)	2 (40.0) 3 (60.0)	10.89	.012
Perceived	Ves	15 (83 3)	6 (66 7)	4(1000)	5 (100 0)	8.00	005
dependability	No	3 (16.7)	3 (33.3)	0	0	0.00	.005

Chi²: Nonparametric Chi-Square Test [§] It is tested by Kruskal Wallis Test.

Family characteristics are presented in Table 5.3. There were five types of family structure. They were (a) nuclear, which indicated couples living with or without children; (b) modified nuclear, which denoted couples living without children, but eating together; (c) extended, which designated two or three generations living and eating in the same household; (d) modified extended, which meant two or three generations living in the same household but eating separately; and (e) living alone,

which specified the single adult living alone. Among these five types of family structure, twelve families were extended (8, 44.4%) and modified extended (4, 22.2%) families. Most were living with their spouse and children (17, 94.4%).

Thirteen families (72.2%) were living in houses assigned by their working unit. The mean family income was 913.90 RMB (ranging from 200.0 to 1800.0) per month. Twelve families (66.6%) expressed their perceived financial strains and 13 families (72.2%) were worried about their financial status. Seven stroke survivors (55.6%) perceived their spouses to be the person on whom they were mostly dependent when they were sick, and 15 of them (83.3%) found that they had someone to be dependent on at home. However, of those perceived as dependable, no one mentioned their daughter-in-law or son-in-law.

Among the three types of family well-being, the extended family type of structure was prominent (5, 55.6%) in the optimal group; and the other two (functional and dysfunctional) groups varied remarkably, including almost all types of family structures. The mean family income was the lowest in the dysfunctional type of family well-being (858.00, ranging from 420.0 to 1500.0) and the highest in the functional type (1015.0, ranging from 460.0 to 1800.0). However, the optimal type was found in the middle (900.0, ranging from 200.0 to 1600.0).

As shown in Table 5.3, the Kruskal-Wallis analysis showed no significant difference in

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the 18 families by family income. The Chi-Square analysis indicated no significant difference among the three groups by types of family structure, living status, types of housing, perceived financial constraints, financial concerns, who to depend on when sick and perceived dependability.

The findings suggest that although there are diverse types of family structure, the extended type of family structure is still the major form among the Chinese. This may reflect the current situation of Chinese families which still retain the Chinese tradition of having a big family and living with their family members; however, nuclear families and those living alone family deserve more attention in the functional and dysfunctional family well-being groups.

5.4 Health care service utilization

Health care service utilization after discharge home is summarized in Tables 5.4 and 5.5. The number of services received by stroke survivors is diverse, particularly after discharge home. Health care service utilization includes health care service and information utilized during the hospital stay and after discharge home.

5.4.1 Health care service utilization during hospital stay

Health care service utilization during hospital stay is depicted by the medical

conditions of the survivors, length of hospital stay, health care cost and use of medicine. Health care service utilization during hospital stay is presented in Table 5.4. The aspects of the stroke conditions, side of brain lesion and affected side of residual deficits are included. Ten survivors had recurrent stroke (55.6%) and the remainder had their first ever stroke. As for the side of brain lesion, seven (38.89%) had left brain lesion, six (33.33%) had right and five (27.78%) had both sides affected. Meanwhile, in the affected side of residual deficits, ten (55.6%) had the weakness of the affected limb, six (33.3%) had hemiparesis, and two (11.1%) had hemiplegia. This suggests that the majority of them were confronted with the problems of mobility in the home care setting.

It was also observed that 15 (83.3%) survivors had two or more chronic health problems. The common health problems found among the survivors were hypertension (94.4%), coronary heart disease (50.0%), diabetes (27.8%), asthma (11.1%) and others (38.9%). Of these problems, hypertension was the most crucial problems encountered in the survivors and it may be responsible for the stroke recurrence and the need of the long lasting adherence to the anti-hypertensive medications (detailed description about the issues of medication provided in Chapter six).

The mean length of hospital stay for the 18 survivors was 24 days (ranging from 9 to 61). Among the three types of family well-being, the longest length of the stay was found in the functional type (30 days, ranging from 14 to 61) and the shortest in the

optimal type (22 days, ranging from 9 to 50).

The mean medical expenditure was 7035 yuan (ranging from 2030 to 20000). Among the three types of family well-being, the highest expenditure was found in the functional type (8583, ranging from 2030 to 20000) and the lowest in the optimal type (6222, ranging from 3000 to 10000).

Regarding medical coverage, 61.1% (11 stroke survivors) had 50% or more free medical care, and 38.9% (seven survivors) had less than 10%. This suggests that most of them had enjoyed free medical care. Among the three types of family well-being, there was higher number (60%) in the dysfunctional type who had little free medical care and medical insurance than that in the optimal (33.3%) and the functional (25%) types of family well-being.

Finally, for the use of medicine, 94.4% selected Western medicine and 5.6% used integrative medicine (e.g. combining both Western and Traditional Chinese medicine). There was no rehabilitative medicine used during hospitalization for the 18 stroke survivors. This suggests that there is a lack of organized stroke care in the hospital service.

As shown in Table 5.4, the Kruskal-Wallis analysis showed no significant difference in the 18 families by the length of hospital stay and medical expenditure. The Chi-Square analysis showed no significant difference among the three types of family well-being in the aspects of the episodes of stroke, side of brain lesion, affected side of residual deficits, number of co-morbidities, types of co-morbidities, medical coverage, and the medical conditions. However, it revealed significant difference in the survivors suffering from hypertension and in use of medicine in the 18 stroke survivors.

				Туре	of family well	-being		
			Total	Optimal	Functional	Dysfunctional	Chi ²	P-valu
			(<i>N</i> =18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)		e
			n (%)	n (%)	n (%)	n (%)		
Medical	Stroke	First onset	8 (44.4)	4 (44.4)	1 (25.0)	3 (60.0)	.22	.637
condition	conditions	Recurrent stroke	10 (55.6)	5 (55.6)	3 (75.0)	2 (40.0)		
	logical	Side of brain lesion					.33	.846
	impairment	Left	7 (38.89)	4 (44.4)	2 (50.0)	1 (20.0)		
	and	Right	6 (33.33)	3 (33.3)	1 (25.0)	2 (40.0)		
	functional deficits	Both	5 (27.78)	2 (22.2)	1 (25.0)	2 (40.0)		
		Affected side of					17.11	.001
		residual deficits						
		Hemiplegia	2 (11.1)	0	0	2 (40.0)		
		Hemiparesis	6 (33.3)	3 (33.3)	1 (25.0)	2 (40.0)		
		Weakness	10 (55.6)	6 (77.7)	3 (75.0)	1 (20.0)		
	Health	No. of co-morbidities					9.11	.028
	conditions	1	3 (16.7)	1 (11.1)	0	1 (20.0)		
		>=2	15 (83.3)	8 (88.9)	4 (100.0)	4 (80.0)		
		Types of						
		co-morbidities		0 (100 0)	4 (4 6 6 6)	4 (22.2)		
		Hypertension (yes)	17 (94.4)	9 (100.0)	4 (100.0)	4 (80.0)	14.22***	.000
		Coronary heart disease (yes)	9 (50.0)	4 (44.4)	2 (50.0)	3 (60.0)	0.00	1.000
		Diabetes (yes)	5 (27.8)	4 (44.4)	0	1 (20.0)	3.56	.059
		Asthma (yes)	2 (11.1)	1 (11.1)	0	1 (20.0)	10.89	.001
		Others (yes)	7 (38.9)	3 (33.3)	2 (50.0)	3 (60.0)	7.00	.030
Length of l	nospital stay	Mean± SD	24.00±14.29	21.78±13.33	30.00±21.92	23.20±10.18	$0.67^{\$}$.716
(day)		Median	18.5	18.0	22.5	22.0		
		Range	9—61	9—50	14—61	13—38		
Health care	e cost	Medical expenditure						
		Mean±SD	7035±4421	6222±3.32	8583±7881	7260±3753	$0.18^{\$}$.913
		Median	6000.0	6000.0	6150.0	10000.0		
		Range	2030-20000	3000-10000	2030-20000	3000-10000		
		Medical coverage						
		=<10%	7 (38.9)	3 (33.3)	1 (25.0)	3 (60.0)	4.67	.198
		50% or above	11 (61.1)	6 (66.7)	3 (75.0)	2 (40.0)		
Use of med	licine	Western medicine	17 (94.4)	8 (88.9)	4 (100.0)	5 (100.0)	14.22***	.000
		Integrative medicine	1 (5.6)	1 (11.1)	0	0		

Table 5.4. Health care service utilization during hospital stay

Chi²: Nonparametric Chi-Square Test [§] It is tested by Kruskal Wallis Test. **P*<.05, ***P*<.01, ****P*<.001 Hemiplegia means paralysis of one lateral half of the body resulting from stroke. Hemiparesis refers to muscular weakness or partial paralysis restricted to one side of the body. Medical coverage refers to percentage to be reimbursed by the work unit. Integrative medicine: using Western medicine meanwhile, Traditional Chinese medicine used as well.

5.4.2 Health care service utilization post-discharge

Health care service utilization after discharge home is portrayed by informal health information, use of health services, self-prescribed therapeutics, money spent on health care service-seeking, and satisfaction with health care service utilization.

In Table 5.5, most families used medical consultants (77.8%) and access to government hospitals via the out-patient department (61.1%); drug stores were mostly used in community-based health care services (55.6%), most used a self-exercise regime (44.4%) and active joint help with their family caregivers (55.6%). In the previous six months, the mean amount of money spent on seeking health care services was 1521.70 yuan (ranging from 20.0 to 5000.0). Most of the self-report on satisfaction with health care service utilization were scored as very unsatisfied (44.4%) and unsatisfied (33.3%). It is noteworthy that no one family gave a "very satisfied" rating to health care service.

The Kruskal-Wallis analysis revealed no significant difference among the three types of family well-being by the money spent on seeking health care services in the past six months after discharge home. The Chi-Square analysis showed no significant difference among the three types of family well-being according to source of health care information, use of the general out-patient department, emergency room, community-based health care services and satisfaction with health care service utilization. However, it revealed significant difference in the use of the hospital-based services regarding specialized out-patient department, admission to the in-patient department, the out-patient department of the traditional Chinese medicine (TCM), and the use of the community-based services, regarding special clinic and traditional Chinese medicine clinic.
Table 5.5. Health care service utilization after discharge home

				Type of f	amily well-being	5		
			Total	Optimal	Functional	Dysfunctional	Chi ²	P-value
			(N=18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)		
			n (%)	n (%)	n (%)	n (%)		
Informal	Medical co	onsultants (yes)	14 (77.8)	7 (77.8)	4 (100.0)	3 (60.0)	5.56	.018
health	TV progra	m/radio/ newspaper	7 (39.9)	5 (55.6)	1 (25.0)	1 (20.0)	0.89	.346
informa-	promotion	(yes)						
Tion	Books/jou	rnals (yes)	5 (27.8)	3 (33.3)	2 (50.0)	0	3.56	.059
	Street proi	motion (yes)	5 (27.8)	2 (22.2)	1 (25.0)	2 (40.0)	3.56	.059
	Peer shari	ng (yes)	6 (33.3)	3 (33.3)	1 (25.0)	2 (40.0)	2.00	.157
	Advice (fa	amily members	9 (50.0)	7 (77.8)	1 (25.0)	1 (20.0)	0.00	1.000
	/relatives/f	friends) (yes)						
Use of	Govern-	General OPD (yes)	11 (61. 1)	6 (66.7)	3 (75.0)	2 (40.0)	0.89	.346
health	ment	Specialized OPD	1 (5.6)	0	1 (25.0)	0	14.22***	.000
service	hospital	(yes)						
	1	Emergency room	2(11.1)	0	1 (25.0)	1 (20.0)	10.89	.001
		(yes)						
		Admission to	1 (5.6)	0	0	1 (20.0)	14.22***	.000
		inpatient (ves)						
		TCM OPD (herbs.	3 (16.7)	0	3 (75.0)	0	14.22***	.000
		acupuncture.						
		massage) (yes)						
	Commun	Drug stores (yes)	10 (55.6)	4 (44.4)	3 (75.0)	3 (60.0)	0.22	.637
	ity-based	General Work	4 (22.2)	2 (22.2)	0	2 (40.0)	5.56	.018
	•	clinic unit		. ,				
		(yes)						
		Private	7 (38.9)	4 (44.4)	2 (50.0)	1 (20.0)	0.89	.346
		(yes)						
		Special clinic (yes)	2 (11.1)	1 (11.1)	1 (25.0)	0	20.33***	.000
		TCM clinic (yes)	2 (11.1)	1 (11.1)	1 (25.0)	0	25.00***	.000
Self-presci	ribed	Over-counter	2 (11.1)	0	1 (25.0)	1 (20.0)	10.89	.001
therapeutic	es	medication (yes)						
		Self-prepared	2 (11.1)	1 (11.1)	1 (25.0)	0	10.89	.001
		medicine (yes)						
		Self-prescribed	8 (44.44)	4 (44.4)	4 (100.0)	0	0.22	.637
		exercises (yes)						
Money sne	ant on	Mean+SD	1522+1618	1537+1378	1138+1237	1802+2437	0.288	872
health care		Median	890	1000	825	1002-2437	0.20	.072
service-see	, aking	Range	20 5000	100 3250	100 2800	20 5000		
501 VICC-800	Ang	Runge	20-5000	100-5250	100-2000	20-5000		
Satisfactio	n with	Very unsatisfied (1-2)	8 (44.4)	6 (66.7)	2 (50.0)	0	1.00	.607
health care	e service	Unsatisfied (3-4)	6 (33.3)	1 (11.1)	0	5 (100.0)		
utilization	(1—10)	Satisfied (5-7)	4 (22.2)	2 (22.2)	2 (50.0)	0		

Chi²: Nonparametric Chi-Square Test; TCM: traditional Chinese Medicine; [§] It is tested by Kruskal Wallis Test. **P*<.05, ***P*<.01, ****P*<.001 ¹Scores ranged from 1 to 10 (1 represent the worst and 10 represents the best).

5.5 Stroke survivors' well-being

Well-being of the 18 stroke survivors is shown by (a) their changes of the functional (ADLs), emotional (C-ESD) and psychological status (SEGH), and social activities (I-ADL), and (b) the major components for determining the changes in well-being of the 18 stroke survivors.

5.5.1 The changes of stroke survivors' well-being

The changes of stroke survivors' well-being are presented by their physical performance in ADLs, emotional status (C-ESD), psychological status (SEGH), and social activities (I-ADL) by the three types of family well-being at the four time points in Table 5.6.

Time	ADLs		Ту	pe of family well-	-being		
	(0—100)	Total	Optimal	Functional	Dysfunctional	KW	P-value
		(N=18)	(n=9)	(<i>n</i> =4)	(<i>n</i> =5)	(<i>df</i> =2)	
T1	Mean±SD	57.8 ± 28.7	67.2 ± 29.1	55.0±27.1	43.0±28.0	3.96	.138
	Median	45.0	45.0	45.0	35.0		
	Range	20—100	35—100	35—95	20—90		
T2	Mean±SD	67.5 ± 25.0	75.6±23.1	70.0±21.2	51.0±27.6	2.82	.244
	Median	60.0	70	62.5	55.0		
	Range	20—100	45—100	65—100	20—90		
тз	Mean+SD	76 9+25 3	817+214	85.0+15.8	62 0+35 1	1 22	244
15	Median	82.5	95.0	87.5	75.0	1.22	.244
	Panga	20 100	50 100	65 100	20 100		
	Kange	20—100	50-100	05—100	20-100		
T4	Mean±SD	78.9±26.5	85.0±19.8	87.50±15.5	61.0±38.1	1.99	.371
	Median	87.5	95.0	92.5	80.0		
	Range	20-100	50-100	65—100	20-100		

Table 5.6. The functional performance in ADLs by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

KW: Kruskal Wallis Test.

Barthel index: Scores are ranged from 0—100. The lower scores the higher dependence. 100 represents independent living in activities of daily living

As shown in Table 5.6, comparison of scores of functional performance in ADLs by the three types of family well-being showed that the scores of the optimal group were higher (67.2: more independent) at one week (T1) after discharge than those of the dysfunctional group (43.0: more dependent). Although the overall scores by the three types of family well-being increased over time, lower scores were observed by the dysfunctional group (61.0) than those by the functional (87.5) and the optimal group (85.0) at six months (T4) after discharge home. There was no significant difference existed in the three types of family well-being according to the Kruskal-Wallis analysis at the four time points.

Changes in emotional status (CES-D) by the three types of family well-being over time are illustrated in Table 5.7.

Time	CES-D		Ту	pe of family well-	being	KW	P-value
	(0—60)	Total	Optimal	Functional	Dysfunctional	(<i>df</i> =2)	
		(N=18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)		
T1	Mean±SD	5.8±10.2	6.9±13.8	4.3±8.5	5.0±1.9	3.59	.166
	Median	0.0	0.0	0.0	5.0		
	Range	0—35	0—35	0—17	2—7		
T2	Mean±SD	7.3±10.3	3.3 ± 6.7	6.5±13.0	15.0±11.3	6.84	.033
	Median	0.0	0.0	0.0	14.0		
	Range	0—27	0—17	0—26	3—27		
т2	Maan SD	0.0 \ 15.1	24+69	92165	22.0+18.0	7.40	025
15	Median	9.9±13.1	5.4 ± 0.8	8.5±10.5	25.0±16.9	7.40	.023
	Denera	0.0	0.0	0.0	10.0		
	Kange	0—46	0—16	0—33	4—40		
Т4	Mean+SD	10 6+16 6	17+50	95+190	27 4+17 7	9.83	007
14	Median	0.0	0.0	0.0	19.0	2.05	.007
	Range	0-48	0-15	0-38	11-48		
	Runge	0 40	0 -15	0 -50	11 -40		

Table 5.7. Emotional status (CES-D) by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

KW: Kruskal-Wallis Test.

CES-D: Scores are ranged from 0—60 (0 representing the best and 16 being the mean cut-off for depression). Higher scores represent greater emotional disturbance.

As shown in Table 5.7, no significant difference existed in the three types of family well-being among the 18 case studies in Kruskal-Wallis analysis. However, a significant difference was found by the three types of family well-being at one (T2), three (T3) and six months (T4) after discharge home.

Changes of the four domains of emotional status by the three types of family well-being over time are indicated in Table 5.8. These four domains of emotional status are categorized by negative affects, somatic symptoms, behavioral manifestations, and positive affects.

Time	Domains	Type of family well-being								
11110	Domanis	Total	Ontimal	Functional	Dysfunctional	кw	<i>P</i> -value			
		(N=18)	(n=9)	(n=4)	(n=5)	(df=2)	I -value			
Negati	ive affects (N_	_33)	(11-2)	(n-1)	(n = 5)	(uj=2)				
T1	Mean+SD	3 6+6 0	36+60	2 5+5 0	2 5+5 0	3 63	163			
	Median	0.0	0.0	0.0	0.0	0100	1100			
	Range	0-21	0-21	0-10	0-10					
	8-		0 -1	0 10	0 10					
T2	Mean±SD	4.8 ± 7.01	2.3±4.6	4.0 ± 8.0	10.0±8.6	6.53	.035			
	Median	0.0	0.0	0.0	8.0					
	Range	0—19	0—11	0—16	2—19					
	U									
T3	Mean±SD	5.9 ± 9.0	2.1±4.2	5.3±10.5	13.2±11.4	6.51	.039			
	Median	0.0	0.0	0.0	8.0					
	Range	0—27	0—10	0—21	3—27					
T4	Mean±SD	$6.4{\pm}10.1$	1.0 ± 3.0	6.0±12.0	16.4 ± 10.7	10.23	.006			
	Median	0.0	0.0	0.0	11.0					
	Range	0—28	0—9	0—24	6—29					
Somat	tic symptoms	(0—6)								
T1	Mean±SD	0.5 ± 0.9	0.3 ± 1.0	0.5 ± 1.0	0.8 ± 0.4	4.30	.117			
	Median	0.0	0.0	0.0	1.0					
	Range	0—3	0—3	0—2	0—1					
T 2		0.0.1.0	04.00	0015	2010		0.0 4			
12	Mean±SD	0.9 ± 1.2	0.4±0.9	0.8±1.5	2.0±1.0	6.66	.036			
	Median	0.0	0.0	0.0	2.0					
	Range	0—3	0—2	0—3	1—3					
Т2	Moon+SD	1 2+1 7	0.4+1.0	0.8+1.5	30+14	8 00	018			
15	Median	1.2 ± 1.7	0.4±1.0	0.8 ± 1.3	3.0±1.4	0.09	.010			
	Range	0.0	0.0	0.0	1-6					
	ivange	00	0—5	0 5	1 0					
T4	Mean+SD	1.1 ± 1.5	0.3 ± 0.7	0.8 ± 1.5	2.6 ± 1.3	9.05	.011			
	Median	0.0	0.0	0.0	2.0	2.00				
	Range	0—4	0—2	0—3	1—4					

Table 5.8. Domains of emotional status (CES-D) by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

Time	Domain		Ту				
		Total	Optimal	Functional	Dysfunctional	KW	P-value
		(<i>N</i> =18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)	(<i>df</i> =2)	
Behavi	ioral manifesta	ations (0—9)					
T1	Mean±SD	0.5 ± 1.5	0.7 ± 2.0	0.8 ± 1.5	0.0 ± 0.0	1.19	.552
	Median	0.0	0.0	0.0	0.0		
	Range	0—6	0—6	0—3	0		
т2	Mean+SD	03+08	0.1+0.3	0.8 ± 1.5	0.4+0.5	1 43	490
12	Median	0.0	0.0	0.0	0.0	1.45	.470
	Range	0.0	0.0	03	0.0		
	Runge	0 5	0 1	0 5	0 1		
Т3	Mean±SD	0.9±1.9	0.1±0.3	1.3 ± 2.5	2.0±2.7	1.93	.380
	Median	0.0	0.0	0.0	0.0		
	Range	0—5	0—1	0—5	0—5		
T 4	MarrieD	1 2 2 5	0.1.0.2	15.20	28.28	2.14	242
14	Mean±SD	1.2±2.5	0.1±0.3	1.5±3.0	2.8±3.8	2.14	.343
	Denera	0.0	0.0	0.0	0.0		
	Kange	0—7	0—1	0—0	0—7		
Positiv	e affects (0—1	2)					
T1	Mean±SD	1.3±2.8	1.9 ± 3.8	1.0 ± 2.0	0.6±0.9	0.10	.952
	Median	0.0	0.0	0.0	0.0		
	Range	0—9	0—9	0—4	0—2		
-							
12	Mean±SD	1.6±2.4	1.3±2.8	1.0 ± 2.0	2.6±1.7	2.68	.262
	Median	0.0	0.0	0.0	3.0		
	Range	0—8	0—8	0—4	0—4		
Т3	Mean+SD	1.9 + 2.8	0.8+1.6	1.0 + 2.0	4.8+3.4	6.14*	.05
	Median	0.0	0.0	0.0	5.0		
	Range	0—8	0—4	0—4	0—8		
	-						
T4	Mean±SD	2.2 ± 3.6	0.3±1.0	1.25 ± 2.5	6.4 ± 4.2	11.21	.004
	Median	0.0	0.0	0.0	6.0		
	Range	0—11	0—3	0—5	1—11		

Table 5.8. Domains of emotional status (CES-D) by type of family well-being at 1 week (T1), one (T2), three (T3) and six (T4) after discharge home (Con'd)

KW: Kruskal-Wallis Test. *P<.05, **P<.01, ***P<.001

The Kruskal-Wallis analysis showed that changes were significant in the three domains of negative affects, somatic symptoms and positive affects at one (T2), three (T3) and six months (T4) after discharge home, but not at one week (T1). Changes in behavioral manifestation were not significant at the four time points.

Changes in dependence level in instrumental activities of daily living (I-ADL) by type of family well-being over time are compared and demonstrated in Table 5.9. The Kruskal-Wallis analysis revealed no significant difference by the three types of family

well-being at the four time points after discharge home.

Table 5.9. Instrumental activities of daily living (I-ADL) by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

Time	I-ADL	_	Ty	pe of family well-	-being		
	(0—30)	Total	Optimal	Functional	Dysfunctional	KW	P-value
		(<i>N</i> =18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)	(<i>df</i> =2)	
T2	Mean±SD	17.6±9.3	$14.4{\pm}10.5$	18.0±9.4	22.8±4.4	1.44	.491
	Median	21.0	16.0	18.5	25.0		
	Range	0—27	0—25	8—27	16—27		
T3	Mean±SD	17.2 ± 9.6	13.9±10.2	17.8±9.8	22.8±7.0	1.93	.380
	Median	18.5	15.0	18.5	24.0		
	Range	0—30	0—24	7—27	15—30		
T4	Mean±SD	17.3 ± 10.5	$14.4{\pm}11.0$	17.3 ± 12.5	22.4 ± 7.8	2.34	.310
	Median	18.0	15.0	19.5	26.0		
	Range	0—29	0—26	2—28	13—29		

KW: Kruskal-Wallis Test.

I-ADL: Scores ranged from 0—30. Less than or equal to 5 indicates normal; 5 or more indicates inability to live independently in the family and community.

Changes in self-evaluation of general health (SEGH) for stroke survivors are presented by type of family well-being over time in Table 5.10. The Kruskal-Wallis analysis by the three types of family well-being showed no significant difference in SEGH at the four time points.

Time	SEGH		Ту	pe of family well-	-being		
	(1—10)	Total	Optimal	Functional	Dysfunctional	KW	P-value
		(<i>N</i> =18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> = 5)	(<i>df</i> =2)	
T1	Mean±SD	3.1±1.4	3.0±1.3	4.0±2.2	2.4±0.4	1.66	.436
	Median	2.5	2.0	3.5	2.5		
	Range	2—7	2—5	2—7	2—3		
T2	Mean±SD	3.5 ± 1.7	3.9 ± 1.3	4.5 ± 2.5	2.1±0.2	8.94	.011
	Median	3.0	3.0	4.0	2.0		
	Range	2—8	3—6	2—8	2-2.5		
тз	Mean+SD	3 3+1 0	37+05	3 9+1 <i>4</i>	2 3+0 7	7.04	030
15	Median	3.5	4.0	43	2.3 20.7	7.0-1	.050
	Range	2-5	3-4	2-5	23		
	Itunge	2 3	5	2 3	2 3.3		
T4	Mean±SD	4.1±1.8	4.4±1.0	5.4±2.5	2.3±0.7	8.55	.014
	Median	4.0	4.0	6.0	2.0		
	Range	2—7	3—6	2—7	2-3.5		
	-						

Table 5.10. Self-evaluation of general health (SEGH) by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

KW: Kruskal-Wallis Test.

SEGH: Scores ranged from 1-10 (1 representing the worst and 10 the best situation).

5.5.2 The major components for determining the changes in well-being of the 18 stroke survivors.

The major components for determining the changes in well-being of the 18 stroke survivors are examined by (a) the comparison of the changes in self-evaluation of general health (SEGH) and emotional status (CES-D) by the three types of family well-being, (b) comparison of changes among ADLs, I-ADL, CES-D and SEGH in stroke survivors by the three types of family well-being, and (c) the association socio-demographic characteristics and these standard measures at the four time points. Comparison of changes in self-evaluation of general health (SEGH) and emotional status (CES-D) in stroke survivors by type of family well-being over time

Comparison of changes in self-evaluation of general health and emotional status by type of family well-being is presented in Table 5.11. The Mann-Whitney U analysis showed that there was no significant difference between the optimal and functional, functional and dysfunctional types of family well-being at the four time points, but there was significant difference in the changes of SEGH and CES-D between the optimal and dysfunctional types of family well-being at the four time points.

Table 5.11. Comparison of changes in SEGH and CES-D by type of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

	Type of family well-being									
-	Optimal vs. fu	inctional	Functional vs. Dys	functional	Optimal vs. Dysfu	inctional				
	Mann-Whitney <i>P</i> -value		Mann-Whitney U	P- value	Mann-Whitney U	P- value				
	U Test		Test		Test					
SEGH										
T1	12.50	.370	4.50	.167	20.50	.780				
T2	15.00	.628	3.00	.059	0.00**	.002				
T3	15.00	.624	3.50	.078	3.00**	.006				
T4	11.50	.301	3.00	.060	1.00**	.003				
CES-D										
T1	17.50	.917	5.00	.211	10.00	.075				
T2	16.50	.754	3.50	.104	5.00	.013				
T3	16.50	.754	3.00	.081	4.50**	.010				
T4	15.00	.462	3.00	.081	2.00**	.002				

*P<.05, **P<.01, ***P<.001

Comparison of changes among ADLs, I-ADL, CES-D and SEGH in stroke survivors

by the three types of family well-being over time after discharge home

Comparison of changes among ADLs, I-ADL, CES-D and SEGH in survivors by the

three types of family well-being over time is presented in Table 5.12 using the Friedman analysis. There was also no significant difference in ADLs in the dysfunctional type, but there was significant difference in ADLs within the overall, optimal and functional types of family well-being (P<0.05) from one week (T1) to six months (T4). That means that there is a significantly functional improvement occurring in the optimal and functional types of family well-being and no significantly functional improvement found in the dysfunctional type of family well-being.

There was also no significant difference in I-ADL among the optimal, functional and dysfunctional types of family well-being at the four time points. However, there was a significant difference in CES-D in the dysfunctional type of family well-being (P<0.05), and this was not found in the optimal and functional types of family well-being at the four time points.

Finally, there was a significant difference in SEGH in overall and the optimal type of family well-being (P<0.05) at the four time points, but none in functional and dysfunctional types of family well-being at the four time points.

 well-being at one week (T1), one (T2), three (T3) and six months (T4) after

 discharge home

 ADLs

 I-ADL

 CES-D

 SEGH

Table 5.12. The comparison of ADLs, I-ADL, CES-D and SEGH by type of family

	AD	LS	I-ADL		CES-D		SEGH	
Type of	Friedman	P-value	Friedman	P-value	Friedman	P-value	Friedman	P-value
family	Test		Test		Test		Test	
well-being								
Optimal	16.27**	.001	3.90	.140	5.40	.150	15.96**	.001
(<i>n</i> =9)								
Functional	10.94*	.010	0.29	.870	3.00	.390	3.86	.280
(<i>n</i> =4)								
Dysfunctional	6.25	.100	0.00	1.000	13.08**	.004	2.40	.490
(<i>n</i> =5)								
Total	32.39***	.000	2.23	.330	6.15	.110	13.62**	.003
(<i>N</i> =18)								

*P<.05, **P<.01, ***P<.001

The association socio-demographic characteristics and these standard measures at the

four time points

The association between the functional performance in ADLs and the socio-demographic characteristics of stroke survivors and primary family caregivers is presented in Table 5.13.

Table 5.13. Spearman's correlation coefficients of characteristics of survivors and primary caregiver and survivors' ADLs at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

Characteristics of survivor and		ADLs			
primary caregiver	$T1^1$	T2	Т3	T4	
I-ADL		709**	774**	810**	

*P<.05, **P<.01, ***P<.001

¹I-ADL was not measured at one week (T1) after discharge.

As shown in Table 5.13, Spearman's correlation indicated that the progress of functional performance in ADLs was only negatively associated with social activities at

one (T2), three (T3) and six months (T4). This suggests that higher independence in

ADLs leads to more involvement in social activities living in the community.

The association between the emotional status of survivors (CES-D) and the socio-demographic characteristics of the stroke survivor and primary family caregivers is revealed in Table 5.14.

Table 5.14. Spearman's correlation coefficients between emotional status (CES-D) of survivors and characteristics of survivor and primary family caregiver at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

Characteristics of survivor and	CES-D							
primary family caregiver	$T1^1$	T2	T3	T4				
SEGH	530**	807**	706	791**				
ADLs	634**	484**	554*	561*				
I-ADL		.604**	.666**	.630**				

*P<.05, **P<.01, ***P<.001

¹I-ADL was not measured at one week (T1) after discharge.

As shown in Table 5.14, Spearman's correlation indicated that the emotional status of the survivors was negatively and significantly associated with the survivors' self-evaluation of general health at one week (r=-.530; p<.01), at one month (r=-.807; p<.01) and at six months (r--.791; p<.01); negatively and significantly associated with the survivors' and functional performance in activities of daily living at one week (r=.634; p<.01), at one month (r=-.484; p<.01), at three months (r=-.554; p<.01), and at six months (r=-.561; p<.01); and finally positively and significantly associated with survivors' social activities at one month (r=.604; p<.01), three months (r=.666; p<.01) and six months (r=630; p<.01).

5.6 Well-being of the primary family caregivers

Well-being of the primary family caregivers is described by their self-evaluation of

general health (SEGH) and emotional status (C-ESD).

The changes in well-being of the primary family caregivers by type of family well-being at the four point times are presented in Table 5.15.

Table 5.15. Self-evaluation of general health (SEGH) by the three types of family well-being at one week (T1), one (T2), three (T3) and six months (T4) after discharge home

Time	SEGH		Ту	pe of family well-	-being	_	
	(1—10)	Total	Optimal	Functional	Dysfunctional	KW	P-value
		(N=18)	(<i>n</i> =9)	(<i>n</i> =4)	(<i>n</i> =5)	(<i>df</i> =2)	
T1	Mean±SD	$4.4{\pm}1.1$	4.2 ± 1.0	3.8±1.0	5.3±1.0	4.08	.130
	Median	5.0	5.0	3.5	5.5		
	Range	2.5-6.0	2.5-5.0	3.0-5.0	4.0-6.0		
T2	Mean±SD	4.5 ± 1.1	4.3±1.0	4.0 ± 1.0	5.7±0.6	5.46	.065
	Median	5.0	5.0	4.0	6.0		
	Range	2.5-6.0	2.5-5.0	3.0-5.0	5.0-6.0		
T3	Mean±SD	4.5±0.6	4.6±0.7	4.3±0.6	4.3±0.4	1.26	.533
	Median	4.75	5.0	4.0	4.3		
	Range	3.0-5.0	3—5	4.0-5.0	4-4.5		
T4	Mean±SD	4.4 ± 0.9	4.7±1.0	4.0±1.0	4.0 ± 0.0	1.61	.446
	Median	4.0	5.0	4	4.0		
	Range	3.0-6.0	3—6	3.0-5.0	4.0-4.0		

KW: Kruskal-Wallis Test.

SEGH: Scores ranged from 1—10 (1 representing the worst and 10 the best).

The Kruskal-Wallis Test in SEGH for primary caregivers showed there was no significant difference by type of family well-being at one week (T1), one (T2), three (T3) and six (T4) months. However, it was also noted that the primary family caregivers in families with optimal well-being showed higher SEGH than those with functional and dysfunctional well-being.

Most primary family caregivers reported normal scores (zero), and statistical analysis could not be conducted, which indicated that less negative emotion was presented by primary family caregivers by the three types of family well-being at the four time points after discharge home.

5.7 Discussion

The findings with regard to the socio-demographic characteristics of the stroke survivor, primary family caregiver, family, the use of health care service, and the changes in standard measures in both survivor and primary family caregiver are discussed below in the light of the previous studies described in chapter three.

5.7.1 Characteristics of stroke survivor, primary family caregiver and family structure

Characteristics of stroke survivors

The findings concerning the characteristics of stroke survivors are consistent with previous studies in terms of age, gender, and marital status, working status, such as with advanced age, most married, lower level of education, and most retired (Haggstrom et. al. 1994, Bays 2001, Hilton 2002, Doolittle 1992, Folden 1994, Nilsson et al. 1997, Pilkington 1999, Burton 2000a, Muro et al. 2000).

The mean age of the stroke survivors among 18 survivors was 67 years (ranging from 44 to 82 years). The mean age of this group of survivors is similar to those in previous studies: 60-70 years (Gresham et al. 1979, Dejoing & Branch 1982, Kotila et al. 1984, Kelly-Hayes et al. 1989, Muro et al. 2000, Lincoln et al. 2000).

Most stroke survivors were male (61.1%) and this result is quite similar to that in previous ones, but it seems that the percentage was slightly higher in this study than in previous reported studies, which ranged from 51% to 55% (Dejoing & Branch 1982, Kotila et al. 1984, Muro et al. 2000).

Most were married (72.2%) and this also indicates that the rate of survivors living with their spouses in Wuhan is higher than those of previous studies, which ranged from 56% to 60% (Dejoing & Branch 1989, Muro et al. 2000) and 28% (Kelly-Hayes et al. 1989).

As for educational level, 50% had at least high school education, 10% lower than the findings of a previous report at 60% (Muro et al. 2000). Regarding their working status, most were retired (88.9%) and most had no religious beliefs (94.4%). There is little information in the present reviewed literature with which to compare this finding.

As shown in Table 5.10, the findings support that emotional status of stroke survivors is a significant indicator in determining the prognosis of stroke recovery and well-being of stroke survivors after discharge home over time.

Characteristics of primary family caregiver and family structure

Among the 18 families, 17 had primary family caregivers. Most were females (64.7%),

consistent with previous studies, which ranged from 63% to 89% (Brocklehurst et al. 1981, Stroker 1983, Silliman et al. 1987, Schulz et al. 1988, William 1993, Anderson et al. 1995, Bethoux et al. 1996, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999, Teel et al. 2001, King et al. 2001, Morimoto et al. 2003). The mean age of the primary caregivers was less than 60 (mean=56.5, ranging from 19-80). Meanwhile, the mean age of this study is younger than that of previous reports, with most primary family caregivers aged less than 65; however, the range of their ages was similar (16-89) (Brocklehurst et al. 1981, Stroker 1983, Silliman et al. 1987, Schulz et al. 1988, William 1993, Anderson et al. 1995, Bethoux et al. 1996, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999, Teel et al. 2001, King et al. 2001, Morimoto et al. 2003).

Most of those who provided primary care for survivors were spouses, children and grandchildren. Of these, most were spouses (70.6%), consistent with previous studies which indicated that 62% to 85% were spouses (Brocklehurst et al. 1981, Stroker 1983, Wade et al. 1986, Schulz et al. 1988, William 1993, 1994, Anderson et al. 1995, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999). There were more wives (52.9%) than husbands (17.7%) in the present study, which is consistent with other studies that found more wives (54%) than husbands (27%) to be primary family caregivers (Brocklehurst et al. 1981, Stroker 1983, Wade et al. 1986, Schulz et al. 1988, William 1993, 1994, Anderson et al. 1995, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999).

The remainder (29.5%) was children and grandchildren, which is also consistent with

previous reports in which 9% to 32% were children (Brocklehurst et al. 1981, Stroker 1983, Wade et al. 1986, Schulz et al. 1988, William 1993, 1994, Anderson et al. 1995, Dennis et al. 1998, Lee et al. 1998, Bugge et al. 1999).

As for their educational level, half (50%) had at least high school education. Most were retired (70.6%), and most had no religious belief (94.1%). These findings show some differences with the previous studies in two aspects: effect on working status and religious belief. Regarding working status, the previous studies indicate that most primary caregivers' working status was affected by stroke, 16% had stopped, and 2% had reduced their work (Wade et al. 1986), and 14% had given up their jobs during the first year due to the patient's stroke (Stroker 1983). In respect of beliefs, most had religious beliefs, such as Protestant, Catholic (Teel et al. 2001). However, only 6.9% had religious beliefs (e.g. Buddhist) in 17 primary caregivers in the present study.

It was also observed that most primary caregivers had at least one chronic health problem (70.6%), such as coronary heart disease, kidney problem, anemia, muscular-skeletal problem, and others. While their health status and problems are compared with other studies, only negative effects and difficulties encountered are indicated, such as greater financial burden (Muro et al. 2000), complaints of deterioration in self-rated health, poor physical health, taking drugs, and housing problems (Carnwath & Johnson 1987, Lee et al. 1998). Emotional distress, such as anxiety, anger, hostility, and depression, is salient in previous studies (Macnamara et al. 1990, William 1993, 1994).

Investigation of the types of family structures showed that most were living with extended family. This supports the contention that most survivors are living with family members after discharge home and need support and assistance from their families during this period (Leung 1995), and that the traditional extended Chinese family is still expected to be a major form of care provision for members living with stroke residual disability in the home care setting.

Stroke has an impact not only on the individual, but also on the family as a whole. In this study, women and other members (e.g. grandchildren) of younger age, with a lower educational level were found to have to offer more care to the person with residual disability. However, they had limited knowledge about stroke conditions, chronic health problems, stroke survivors' physical and emotional status, and how to provide proper and skilled care at home. And the burden of care can not be overlooked while there is functional dependence in daily tasks (e.g. eating, walking, toileting, eliminating), emotional disturbance (e.g. anger, anxiety, depression), and family and social activities (e.g. simple housework, meal preparation, transportation).

5.7.2 The use of health care services

The use of health care services during hospital stay

In respect of the affected side of residual deficits, it was found that two survivors (11.1%) were hemiplegia, six (33.3%) hemiparesis, and ten (55.6%) weakness. This also reflects some differences with other reports (Gresham et al. 1979), which it makes it difficult to compare because it may contribute to the different criteria and examination measures used from country by country.

On the health status of survivors, 18 had at least one kind of chronic illness: of those 15 survivors (83.3%) had two or more chronic illnesses. The first three leading illnesses were hypertension (94.4%), coronary heart disease (27.8%) and diabetes (11.1%). In previous studies, 53% had hypertension, 40% heart disease, and 16-22% diabetes (Gresham et al. 1979, Kotila 1984). Based on this comparison, hypertension is 40% higher in the present participants than in other studies reported, and might be attributed to high incidence of stroke recurrence, which was found more recurrent stroke (55.6%) than first onset of stroke (44.4%), twice as high as in the previous studies, whose findings ranged from 14% to 24% (Gresham et al. 1979, Muro et al. 2000, Lincoln et al. 2000). Thus both hypertension and stroke recurrence should receive much attention from health care providers in planning and developing stroke prevention program in the home care setting.

Findings also showed that most families selected the use of Western medicine (94.4%) and nobody mentioned any rehabilitation medicine having been used during the hospital stay. This may reflect the lack of a planned and organized stroke care in the hospitals of Wuhan.

Most families (72%) had worry and some worry about their financial status. This figure indicates that it is three times higher than Muro et al. (2000) study (24%), particularly in the process of seeking medical care services, both in therapeutic and medication maintenance after discharge home. Comparing health care cost during acute management in the hospital (mean=7035.00 yuan) and after discharge at home for six months (mean=3042.7 yuan), medical expenditure during acute care occupied over half (64.1%) of family income for one year, and during care at home after discharge over a quarter (27.7%). This suggests that medical fees are expensive during hospitalization and most families can not afford them in comparison with Wuhanese annual income (from 1996 to 2001, mean annual total income 8631.00 yuan for each working person). Even though after discharge home, it was decreased to less than 30%, it was still costly in comparison with the level of family income among the 18 families (mean=850.00 yuan). The fees were still high perhaps because most families were seeking hospital-based health care service instead of community-based service. These medical help-seeking behaviors were also a recurrent theme, consistent with a previous Chinese study (Chu et al. 2000b).

As regards health care service utilization after discharge home, 15 families had used Western medicine and three had used the Traditional Chinese Medicine (TCM) to deal with their physical problems. Among the three types of family well-being, most families with optimal type of well-being selected self-prescribed therapeutic measures other than those prescribed by doctors. Further, both hospital-based and community-based health care services were utilized by most survivors after discharge home. These services included medical consultancy, access to government hospital in OPD (out-patient department), drug stores, self-exercise regime and active joint help with family caregivers after discharge home. The availability of this post-discharge health care service has also been reported in other studies (McLean et al. 1991, Rosenthal et al. 1993, Mant et al. 2000, Lincoln et al. 2000, Miller & Spilker 2003), which is divided into two major kinds of services: (a) hospital-based services including rehabilitation center services, physical therapy, occupational therapy and speech therapy, and (b) community-based rehabilitation services containing physiotherapy and exercises therapy, speech therapy and drug therapy, information about continuing care and resources in the community, and technical aids provided. Further information on these services will be provided in the final chapter (Chapter ten) discussing the implication of the study.

Most families complained that the health care services that they received were far less

satisfactory because of cost, professional's attitude, and less trusty relationship, consistent with previous reports (McLean et al. 1991, Lui & Mackenzie 1999, Lawler et al. 1999, Eaves 2002, Zhang & Cui 2003, O'Connell & Baker 2004). Other issues were related to inconvenience such as the lack of accompanying family members, inability to walk independently (e.g. elevator not available), difficulties in transportation (e.g. far from home, fear of falling), and the lack of proper information. This also suggests that there is a lack of organized and planned community-based stroke care service.

5.7.3 Changes in well-being of both stroke survivor and primary family caregiver

From the observation of physical performance of activities of daily living in survivors over time, it was also shown that six survivors (33%) among the 18 survivors had achieved independent living in activities of daily (ADLs), but the remaining 12 (67%) still retained a certain degree of residual disability and were dependent upon other family members in self-care activities in the home care setting at six months after discharge home. In addition, the performance of functional status was remarkably improved, but social activities were less improved over time among 18 survivors.

Further, there were significant differences in emotional status in terms of CES-D for stroke survivors by the three types of family well-being for six months after discharge home, but little progress in I-ADL among 18 survivors. It also showed that the increasing progress in performing activities of daily living for stroke survivors does not necessarily yield corresponding improvement in emotional status and self-evaluation of general health over time. Emotional status and a sense of general well-being were significantly different by the three types of family well-being among the 18 families over time, which indicated that the survivors in families with optimal well-being had more positive affects and higher sense of general well-being than those in families with functional and dysfunctional types of family well-being. This finding has been also consistent with the previous studies (Ahlsio et al. 1984). Ahlsio (1984) on quality of life after stroke, which included the patient's "psychological situation". It was found that the ability to perform independent activities of daily living did not improve psychological health.

Stroke has an effect not only on the survivor's physical, psychosocial well-being, but also on the primary family caregiver's well-being. Changes in primary family caregivers' well-being were not indicated by the depression scale. Well-being seemed not to change dramatically over time under the present study. This was not consistent with previous studies (Wade et al. 1986, King et al. 2001). However, the literature reported high rates of depression in stroke caregivers compared with control groups among family caregivers (usually spouses). These estimates were about 34% as measured by the Center for Epidemiological Studies Depression Scale (CES-D) (Han & Haley 1999) for those living in the community. This is argued that this variance mostly depends on the population studied and the diagnostic tools used.

However, the present investigation showed that no depression was found among the 17

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primary caregivers. This can be explained in the current investigation by the following three reasons: (a) Chinese family caregivers do not frequently express for their own emotions in front of the care-receivers and an outsider: perhaps they might have a sense of guilt if their emotions were exposed in front of other family members or a stranger, or they might have focused all their attention and concern on the survivors, and prefer to discuss other issues, such as difficult situation encountered in daily care tasks, survivors' physical problems, and behavioral alternations which mattered to them. Even though there was less individual expression, their feelings of anxiety were somehow related to the severity of stroke-related disability, stroke recurrence, and financial constraints and medication issues, (b) among the 18 stroke survivors, only those survivors with limitation of functional status were included in this investigation, but others with severe medical conditions, and neurological impairments and deficits was excluded, such as communication problems (i.e., aphasia, dysphasia), cognitive impairments (e.g. dementia, memory loss). Thus the burden of care may be decreased and emotional status of the family caregivers may be less interfered, and (c) the length of caregiving may be another important factor to predict the burden of care and emotional disturbance for family caregivers. Only six months was studied after discharge home under the present investigation, thus a longer period of study is needed to further examine changes in emotional status of the family caregivers over time.

5.8 Summary

The findings indicate the high incidence of hypertension, stroke recurrence, stroke-related residual disability and stroke survivors' emotional status. And this issue warrants special attention to community nursing while planning stroke rehabilitation program to enable both stroke survivors and their families to cope with their problems in the local community of Wuhan. It is imperative that much attention be paid to how (a) to assess the severity of stroke related residual disability and emotional status, and identity the need of assistance for the family living with stroke after discharge home in a long run, and (b) to develop a low cost, available and accessible community-based health care service to meet the needs of the individual living with stroke after discharge home.

However, little information could be obtained from the above quantitative evidence about "*how*" survivors and family caregivers experienced life after discharge home, and "*why*" families with the three different types by family well-being performed differently over time based on the prior development of the study proposition. Corroborating the analysis of the qualitative interview verbatim transcripts and field observation notes, these questions are examined in the subsequent chapters.