The Hong Kong Polytechnic University

School of Nursing

# Caring for Stroke-impaired Elderly Family Members: A Study of Family Adaptation in a Chinese Context

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A thesis submitted in partial fulfilment of the

requirements of for the degree of Doctor of Philosophy

September, 2005

# CERTIFICATE OF ORGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written nor material which has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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# ABSTRACT

Although it is known that the role of the family is critical in stroke rehabilitation, little is known about the process of caring among Chinese family caregivers of stroke-impaired elderly relatives. Previous research on the process of family caring has focused on burdens and negative outcomes. To fill this gap, this study aims to explore and explain the experiences of 15 Chinese family caregivers using a grounded theory approach, which allows the formulation of hypotheses and the generation of theory from gathered data. Glaser (1978, 1992) and Strauss and Corbin's (1998) grounded theory method, which are based on symbolic interactionism (Blumer, 1937; 1969), were used to collect and analyse naturalistic data rich in human experience. Emphasis was placed on developing an analysis that illuminated the area under study and remained faithful to the constant comparative method described by Glaser (1978, 1992) and Strauss and Corbin (1998). This method allowed the more recent responses of the participants to be compared with those of earlier participants in order to identify similarities, consistencies, discrepancies and anomalies. In the course of the study, concepts emerged as the data were collected and analyzed concurrently.

A two-interview qualitative approach to data collection was adopted between January 2001 and September 2003. The first in-depth interviews consisted of 15 family caregivers held between January 2001 and June 2001. The second interviews were held two years later between May 2003 and September 2003 with

13 family caregivers drawn from the first round participants. The second interviews were conducted over a period of four months and compared participants’ caring and adaptive behaviours with those investigated two years earlier in the interviews. The findings of coping behaviours and caring patterns of a culturally distinctive kind were refined and confirmed in the second interviews.

Data were collected utilizing different forms of reflection as suggested by Glaser (1978, 1992) and Strauss and Corbin (1998). Data management was facilitated through the use of coding notes, memos, diagrams, and the software program QRS NUD*IST (Version 4.0). The researcher then identified a core category of “Regaining Self-perceived Control” emerging from study data which reflected the Chinese family caregivers’ process of striving to continue to fulfil the demands of their role during the transition. “Cognitive Reframing”, “Behavioural Reframing” and “Experiential Reframing” were identified as the conceptual indicators that linked all the other concepts relating to the core category of “Regaining Self-perceived Control”, and they appeared to be fundamental to family caregivers’ coping strategies. A theory of five stages in the adaptation process that family caregivers described as a means of regaining self-perceived control include: Uncertainty, Disruption, Accommodation, Balance, and Reconciliation. Although caring strategies were found to vary, all were influenced by Chinese family caregivers’ particular common Confucian ethical values and customs.

This study set out to contribute significantly to the understanding of cultural issues and caring values that are unique to Hong Kong Chinese family caregivers of stroke-impaired elderly relatives. It will provide a basis for devising adequate interventions and resources to assist caregivers. Nurses and other health care providers can use this information in assessments and in planning individualized interventions that include family caregivers as active participants in managing caregiving. Of prime importance in meeting the complex issues of caregiving management is a client-provider relationship that permits open communication.

# PUBLICATIONS

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# CHAPTER ONE

# INTRODUCTION TO THE STUDY

Stroke is and has been the third leading cause of death in most countries in the world for a very long time. Stroke is also the third common cause of death in Hong Kong and is the major cause of permanent disability (Hospital Authority, 2003). Strokes are a more important cause of prolonged disability than any other medical condition. Survivors of strokes are often unable to return to work or to assume their former effectiveness as spouses, employers and active participants in their communities.

Despite a drop in the mortality rate of cerebrovascular diseases from 62.7 per 100,000 in 1981 to 49.7 per 100,000 in 2003, the total stroke mortality rate remained high because of the aging population in Hong Kong (Department of Health, 2004). For example, in 2001, there were 3,130 deaths from stroke, accounting for 9.4% of all deaths in Hong Kong (Hospital Authority, 2002). In 2001, there were about 16,000 cases of stroke (Ko, 2002) and stroke was the third-leading cause of hospitalization in Hong Kong (Hospital Authority, 2002).

## 1.1 Background Information on the Incidence of Stroke in Hong Kong Chinese

Stroke usually affects Hong Kong Chinese people aged 65 years or over (Hong Kong Epidemiology Association, 2000; Phillips, 1995). The risk of suffering from a stroke increases with age. The ageing population in Hong Kong is well recognized as an area to which the government should pay attention. In Hong Kong, stroke accounted for 10.1% and 11.7% of the total number of deaths in 1998 and 1999 respectively (Hospital Authority, 2000). With the advancements in medical science and technology, the mortality rate of stroke has been decreasing. Seventy percent who survive after stroke live an average of another seven years and approximately 10% of them had some degree of physical impairment (Chan & Yeung, 1998; Ho, 2002; Kay, 1993).

Stroke is the fourth leading cause of hospital admission in Hong Kong (Hospital Authority, 2001). It is projected that by the year 2015, 14.3 per cent of the population will be aged 65 or above, with the actual number exceeding one million (Census and Statistics Department, 2004). It has been projected that the morbidity of stroke will increase due to the ageing population in Hong Kong. The first acute stroke unit was established in 1996 in Hong Kong and over 120 stroke patients are admitted to this unit every month (Queen

Elizabeth Hospital, Central Nursing Division, 1999). There are approximately 16,000 new cases of stroke each year in Hong Kong (Ho, 2002).

### 1.1.1 What is Stroke?

Stroke, or cerebral vascular accident (CVA), is a medical term referring to an injury to the brain produced by the blood flow that supplies the brain (American Heart Association, 2002). Strokes are caused by many different conditions. The two major causes of stroke are a lack of blood in a part of the brain and bleeding into the brain. That is, stroke may occur in two ways: ischemic and hemorrhagic with both producing similar symptoms in a stroke victim. Stroke is a heterogeneous condition which causes disability in terms of cognitive deficits and motor impairments affecting speech and swallowing difficulty and activity limitations. Stroke severity and disability can be assessed using the Glasgow Coma Scale (Teasdale & Jennett, 1974) and Barthel Index (Mahoney & Barthel, 1965) respectively. Barthel Index is a conventional clinical scale of functional status that is suited to measuring the severity of disability and it is used to evaluate a stroke survivor's ten basic daily activities. The Barthel Index is used mainly to measure motor impairment after stroke. The Chinese version of Cognistat (Chan, Lee, Fong, Lee, & Wong, 2002) provides profile scores which reflect the cognitive functioning of stroke patients in seven areas including orientation, attention, language, construction, memory, calculations, and reasoning. The Neurobehavioral Cognitive Status Examination (Cognistat) (Northern California Neurobehavioral Group, 2001) is designed to quantify strengths and weakness of patients' cognitive functioning in a graphical format.

In Hong Kong, there is a very long wait for both medical infirmary and care-and-attention homes, and it is a pity to note that some elderly do pass away during the long waiting period. It seems unfair that their rights and entitlements to long-term care services are not properly catered to. Study carried out by Ngan, Leung, Kwan, Yeung and Chong (1996) found that respondents who were waitlisted for the infirmary did suffer from a significantly higher prevalence of stroke (43.1%), dementia (24.8%) and Parkinson's disease (7.5%) as compared with other sample groups. This indicated that stroke and dementia are common diseases that require extensive patient care.

### 1.1.2 Stroke Morbidity

With a predominantly Chinese population and a cultural tradition of respecting the old, Hong Kong has long relied on the family to support its elderly members. Economic success has not, however, spared Hong Kong from encountering the same problems as other industrial societies, such as the loosening of its traditional values. Although the Hong Kong Government has adopted a "care in community" policy since the mid-1970s, evidence shows that the responsibility must now be shared between the government and the family (Lou & Chi, 2001; Kwan, 2002). It is a well documented fact that the inclusion of family members in the caregiving process of stroke rehabilitation improves recovery (Han & Haley, 1999; Mackenzie, Holroyd & Lui, 1998; Lee, 2004; Sim, Lum, Sze, Or & Woo, 1997; Stein Shafqat, Doherty, Frates & Furie, 2003). However, most family caregivers are elderly spouses who often have their own health problems to deal with (Barusch & Spaid, 1989; Biegel, Sales & Schulz, 1991; Stone, Cafferata & Sangl, 1987; Given & Given, 1991; Laizner, Yost, Barg & McCorkle, 1993; Lee, 2004; Monahan & Hooker, 1995; Robinson, 1986; Zarit & Zarit, 1982). In Hong Kong, over 60% of Chinese family caregivers are elderly spouses (Census & Statistics Department, 2001). A large number of studies have already indicated that caring for dependent relatives at home is burdensome (Abraham & Berry, 1992; Archbold, Stewart, Greenlick & Harvath, 1990; Lee, 2004; Lee, 2001; Ngan et al., 1996; Twigg, 1992; Wright, 1998; Zarit, 1989). Such stress in caregiving with daily activities may be extreme if the person being cared for is moderately to severely disabled. Thus, family caregivers of stroke-impaired elderly relatives need to have the appropriate resources to assist them in coping with the stress and strains arising from the multiple demands of long-term caregiving.

Although there has been a slight increase in the incidence of stroke in the younger population, an increased incidence of stroke is expected in coming years in the elderly population (Kay, 1993; Chu & Pei, 1997). Several factors are leading the rise in the incidence of stroke in Hong Kong: risk factors inherent in the lifestyles of Hong Kong Chinese such as increasing population of elderly due to increased life expectancy for men and women; early discharge programs in health care forcing family members to take over the caregiving task at home; and limited available support services provided for families with stroke-impaired elderly relatives (Lui & Mackenzie, 1999; Ko, 2002). Kwan, Cheung and Ng (2003), Lee (2004) and Lui and Mackenzie (1999) revealed that Chinese family caregivers expressed different levels of stress in caring for stroke-impaired elderly relatives in Hong Kong. Mackenzie and Holroyd (1996) and Lee (2001) also found that Chinese family caregivers of stroke-impaired elderly relatives in Hong Kong experience extraordinary difficulty in providing care, especially for those with long term care problems. It is therefore essential to investigate the experience of caregiving of Chinese family caregivers since there is limited information available on them. In the context of this thesis, the term “caring” encompasses both emotional and behavioural aspects of the caregiving role.

The researcher has chosen Chinese family caregivers of stroke impaired elderly relatives as the target group for the study because rehabilitative care of stroke patients will continue from the hospital to a home setting for months or even for years. Thus, in helping stroke survivors make a maximum recovery and successfully adapt through the process of a partial recovery, family caregivers have a significant role to play. About 30 per cent of stroke patients will die within the first three months following their stroke and a further 30 per cent will regain full independence. While some patients do have spontaneous recovery requiring no treatment, around 40 per cent require rehabilitation (Hospital Authority, 2000). More than two-thirds of those who have suffered a stroke are left with disability and are dependent on family members to care for them (Mackenzie et al., 1998; Chui & Dai, 1996; Ho, 2002). It is therefore important to provide on-going support for family caregivers of people who have suffered a stroke as the person often has limited ability.

### 1.1.3 Stroke Rehabilitation

Mortality and morbidity rates are high in elderly stroke patients. Early mobilization and prevention of stroke-related complications improve their ability to participate in a more intensive and comprehensive rehabilitation program. An appropriate approach to stroke rehabilitation restores functional loss, improves quality of life, and decreases long-term economic costs. Important parts of stroke rehabilitation include patient and family education, treatment of stroke-related complications, and prevention of recurrent stroke. A healthy and caring spouse and the mobility of stroke individual are the most positive predictors of stroke outcome (Reddy & Reddy, 1997).

Rehabilitation begins quickly in the process of recovery from a stroke. The main recovery following a stroke takes place within the initial two months, but improvement continues for six months to many years, as affected parts of the body are exercised and used. The primary goal of rehabilitation is for the person to live as independently and as productively as possible (Chan et al., 2002; Ko, 2002; Ng et al., 2004). To reach this goal the person must have the will and the ability to participate and actively cooperate in the rehabilitative process. Weakness, fatigue, and often depression are common during the rehabilitative process. For these reasons, stroke sufferers need a great deal of encouragement and support from family members and rehabilitation personnel in order to persevere.

The challenge is broad. Re-education is usually necessary to some degree, while rehabilitation of muscles is required to compensate for the damage to the brain the stroke has caused. Rehabilitation is also important for the prevention of additional muscle wasting and atrophy, contractures, and pain which comes with unused and atrophying muscles. Rehabilitation services are therefore crucial. For the first several weeks after a stroke it is difficult to predict how long the various symptoms will last and which will remain. Treatment should also include adequate psychological support and means for reducing the complication of immobility.

The hallmark of rehabilitation is a positive, reasonably demanding approach that understands and yet counteracts the person's despair with firm, kind and hopeful support. Rehabilitation centers provide all necessary rehabilitative equipment such as exercise mats on low platforms, weight machines, and other equipment for the retraining of muscles. In day centers all patients attend a rehabilitation program and return home to their family between sessions. When people begin active therapy, however, progress is slow. At that point family members and health care personnel must help patients sustain momentum. They should help individuals maintain the highest level of mobility the patient is capable of, and continue to offer emotional support.

## 1.2 Significance and Scope of the Study

The role of the family is critical to stroke rehabilitation, but relatively few studies have examined the process of family caring within the Chinese context and nursing care is still mostly limited to patients and largely ignores family caregivers. The purpose of this study, therefore, is to explore and explain the experiences of Chinese family caregivers of stroke-impaired elderly relatives from the time of incidence throughout the course of rehabilitation. Caregiving for stroke survivors can be especially stressful because of the various impairments including cognitive, motor, affective, sensory, and language problems. There are a large number of people with different degrees of stroke-induced disability in the community. Depending on their level of functional abilities, these people rely on the support of their families to cope with daily activities. Support for family members with stroke-impairment can range from minimal to extensive, and needs to be provided by close relatives (Lui & Mackenzie, 1999; Hu, Sheng, Chu, Lan & Chiang, 1992; Ngan & Wong, 1995).

It is well documented in the literature that family caregiving can be very challenging and family caregivers are at risk for negative health outcomes such as increased morbidity and mortality and psychosocial impairments including depression (Han & Haley, 1999; Low, Payne, & Roderick, 1999; Schulz & Beach, 1999).  Unlike family caregivers of persons with other chronic conditions such as dementia, caregivers of stroke survivors are forced unexpectedly and suddenly to provide care.  The need for stroke family caregivers to develop immediate caregiving skills is extremely demanding and often has a devastating effect on family caregivers in that they must adapt to significant changes in their lives.

Bakas and Burgener (2002) and Bakas, Austin, Jessup, Williams and Oberst (2004) found that the strongest predictor of emotional distress and negative health outcomes for stroke caregivers was the difficult tasks that they had to face. Although the literature is replete with studies centering on the physical and psychosocial care of a stroke survivor, less is known about the personal factors and variables individuals experience when becoming primary givers of care, especially in the Chinese context (Burton, Newsom, Schulz, & Hirsch, 1997; Grant, Bartolucci, Elliot, & Giger, 2000; Killeen, 1989; Tang & Chen, 2002). Burton and colleagues found that caregivers with a low level of caregiving self-efficacy had negative health behaviours compared with caregivers with a high level of caregiving self-efficacy. Killeen found that family caregivers' age, educational level and length of caregiving affected their lifestyle behaviours. Younger, more educated caregivers, who provided care for shorter periods of time, reported engaging in more health promotion behaviours. Additionally, Tang and Chen (2002) found that personal factors of the family caregivers such as income and health status influenced caregiving and its consequences. They found that family caregivers manifested increased negative reactions to caregiving when cared-for-persons had a low level of functional status, a large number of health problems, poor general health status, or required a longer duration of caregiving.

No study has yet examined the meaning and process of family caring in the experiences of Chinese family caregivers in the context of interaction with stroke-impaired cared-for-persons and other family members in Hong Kong. The majority of studies are cross-sectional, thereby limiting the understanding of the evolution of the caregiving role. Changes in the functional status of the stroke survivor and the caregiver’s responses to caregiving over time suggest that time is an important variable that must be considered in the design, analysis, and interpretation of the results of caregiving studies.

## 1.3 Purpose of Study

The purpose of this study is to describe and explain the ways in which caregivers make sense of, or derive understanding from, their role as caregivers for a stroke-impaired elderly relative. Data collection through participant interview is done over the course of two years. In the knowledge of the researcher, the experience of Chinese family caregivers of stroke-impaired elderly relatives in Hong Kong has never been systematically studied in this way. Since family caregivers have constant interaction with their stroke-impaired relatives to provide kinship support over time, longitudinal studies like the present one will increase understanding of how family caregivers adapt their responses to cared-for-person as illness symptoms change over time. The caregivers in this study were able to describe changes in the process of caring that occurred over time and with developing experience. It is hoped that knowledge of that experience will inform this study in terms of cultural factors related to process of caring, and help to identify points of effective intervention for families who struggle in the caregiving role.

## 1.4 Research Question

This research aims at answering a single broad question, “What is the experience of family caregivers of stroke-impaired elderly relatives in Hong Kong”?

## 1.5 Definition of Terms

For the purpose of this study, the following operational definitions will be used:

### 1.5.1 Chinese Family Caring

Wong and Pang's study (2000) found that Chinese family caregivers have a moral duty to provide a therapeutic environment in which healing can occur and that caring is grounded in the Confucian ethical system of role relationships. Moral duties are located primarily in kinship in this view and the concept of caring challenges the task-based model of care delivery in that the task-based model downplays the holistic view of caring in a being. In the context of this thesis, the term "caring" encompasses both emotional and behavioural aspects of the caregiving role.

### 1.5.2 Elderly

In Hong Kong, persons aged 65 and over have been taken generally as the target population in planning services for the elderly. However, selected services for the elderly are also provided for persons aged 60 and 64. For the purpose of this study, the term elderly persons refers to the resident population aged 65 and over for both sexes. In 2003, there were 795,000 persons aged 65 and above in Hong Kong, representing 11.7% of the whole population (Census and Statistics Department, 2004).

### 1.5.3 Family Caregiver

Family caregiver is identified as a lay person responsible for the daily tasks of caregiving in meeting the physical, emotional and social needs of their sick relatives at home (Chan & Chang, 1999). The term caregiver no longer describes only health care providers. Increasingly, individuals and families have assumed the caregiver role for family members or friends suffering from chronic illness or disability and, many of them are elderly. For the purpose of this study, the Chinese family caregiver is the family member identified by the stroke victim as the person who primarily meets the self-care deficits of the stroke victim at home, has done so for at least six months, and is not receiving remuneration for those services.

### 1.5.4 Stroke

According to the American Heart Association (2002), a stroke, or CVA, occurs when an artery or vein in the brain becomes occluded or bursts. As a result, the brain receives insufficient oxygen and nutrients. In a very short period of time, brain cells die. CVA may occur in two ways: ischemic and hemorrhagic with both producing similar symptoms in a stroke victim. Stroke is a heterogeneous condition which causes disability in terms of cognitive deficits and motor impairments affecting speech and swallowing difficulty and activity limitations. Ischemic stroke is the most common type and it accounts for about 70 to 80 percent of all strokes. It occurs when a blood clot forms and blocks blood flow in an artery bringing blood to part of the brain.

### 1.5.5 Family Adaptation

Family adaptation refers to “the family’s struggle to manage the situation created by illness, it is used to describe the outcome of family efforts to bring a new level of balance, harmony, coherence, and functioning to a family-crisis situation” (Danielson, Hamel-Bissell & Winstead-Fry, 1993, p.35). Family adaptation refers to the process of family caregivers’ coping and caring in this study.

## 1.6 Objectives of Study

The objectives of this study are:

1. To identify the different characteristics, care issues, coping strategies, coping resources, caring tasks and perceived burdens of Chinese family caregivers;

2. To identify the existing patterns of caregiving in the caring process among Chinese family caregivers and how the process is influenced by critical elements of their personal situation;
3. To develop a theoretical framework which describes how events and predisposing factors can be interpreted and their influences on caring outcomes can be appraised; and

4. To initiate the development of a substantive theory that describes how Chinese family caregivers experience the process of caring for their stroke-impaired elderly relatives.

## 1.7 Impact of Stroke

The transition period from hospital to home of the stroke-impaired elderly is very traumatic for family caregivers because most patients are discharged home usually with physical impairment. They still require extensive rehabilitation for a period of time. Many of the patients rely heavily on support from their families and the daily lives of those family members involved are severely impacted. The greatest step for post-stroke patients and their family members is not from the hospital to the rehabilitation centers but from the rehabilitation centers to home and then to the community. The caregiver adapts from an accepting, supportive, barrier-free, and ordered existence to all the contradictions and exigencies of family caregiving. Initially, the patient and their family are delighted about the prospect of homecoming, only to find that being home is physically harder and that the work toward reaching an optimal level of functioning continues. The suddenness of stroke leaves those who are affected and their families no time to prepare for the changes they have to make, especially during the transition period from hospital to home when hospital support ceases (Exall and Johnston, 1999; Coyne and Mares, 1995; National Health Science Executive, 1996).

## 1.8 Current Services for People with Stroke in Hong Kong

Most gerontologists agree that ageing is inevitably associated with a deteriorating health condition, illnesses and disabilities. With longer life expectancy and the prolongation of chronic illness such as stroke due to medical advancement, health and welfare services for the elderly need to be sustained for longer periods. Elderly people are at the highest risk in the population for suffering illnesses and are by far the group utilizing medical services most frequently (Ko, 2002; Kwan, 2002; Ngan et al., 1996). The increasing financial burden of these medical services on society and the decreasing number of economically active persons to shoulder the burden present major challenges for the Hong Kong Government.

In Hong Kong, over 70 per cent of the elderly still live with their families, either with their spouse or children (Census & Statistics Department, 2001). The Hong Kong Government started planning services for elderly people in 1972. Various kinds of services for elderly people have been developed. The services now include community centers, day care centers, care and attention homes, geriatric units and geriatric day hospitals. However, services and support for family caregivers of stroke-impaired relatives in the home setting have received little attention. With a predominantly Chinese population and a cultural tradition of respecting the elderly, Hong Kong has long relied on the family to support its older relatives (Chow, 1993; Kwan et al, 2003). Appropriate and relevant educational information and support to family caregivers are important in enabling the caregiving task. It is therefore necessary to understand the nature and demands of caregiving first before specific educational and support programmes can be planned. Leininger (cited in Rosenbaum, 1986) defined care as “supportive actions that assist, support, or help another person or group with evident or anticipated needs to improve a human condition or lifestyle” (p.414). All these factors are significant in achieving the objectives of this study and they will be discussed in the following chapters.

## 1.9 Assumptions of the Study

In qualitative research, the researcher is concerned with understanding how people attach meaning to and organize their lives, and how this in turn influences their actions in order to understand human behaviour from the participant's perspective. Qualitative researchers seek to uncover the thoughts, perceptions and feelings experienced by participants. The strength of the qualitative approach lies in its ability to generate rich data regarding a family's subjective caregiving experiences, thus increasing understanding of family motivations and behaviours as caregivers adjust to the caregiving situation. The present researcher adopted Glaser's (1978, 1992) and Strauss and Corbin's (1998) the basic philosophical and methodological principles that underlie grounded theory. In this study, the naturalistic paradigm and its ontological and epistemological axioms suggested by Guba and Lincoln (1994) were also adopted.

First of all, ontologically, the researcher holds the view that human beings are active agents who constantly confront and interpret the world. Secondly, in terms of investigating the patterns of adapting among Chinese family caregivers, the method should facilitate the exploration of all the concerns of caregivers as they form strategies to cope, and should allow them to interpret the aspects that are significant to the adaptation process. Third, the study method should facilitate an exploration of the rationales and conditions that affect the use of adjusting strategies and their effects on the outcomes of caring. This is one of the weaknesses in the existing research on Chinese caring. Finally, the method should allow the exploration of the cultural characteristics inherent in the adaptation process. With these considerations in mind, a grounded theory philosophically rooted in Symbolic Interactionism (Blumer 1937, 1969, 1998) was adopted.

Glaser's (1978, 1992) and Strauss and Corbin's (1998) basic philosophical and methodological principles that underlie grounded theory were adopted as the methodology for exploring the adaptation process experienced by Chinese families caring for stroke-impaired elderly relatives. The origins of grounded theory are derived from Symbolic Interactionism (Blumer 1937, 1969, 1998) and this gives grounded theory particularity as a method. Interactionists argue that people live in this world by a process of negotiation and re-negotiation and make reflexive use of symbols to construct and modify themselves as social entities in relation to the meaning attributed to the situation. Thus the perception of an individual's reality is fluid and constantly created according to the definitions and meanings attributed to the situation and according to the negotiated response of the self and others within the situation. This is the essence of change and process of constructed and negotiated perceptions of the social world as it occurs in a natural setting. The basic premises of

Symbolic Interactionism (Blumer 1937, 1969, 1998) in grounded theory constitute the foundation of assumptions in this study. Meaning is derived from intra-familial and extra-familial interaction with others. These assumptions are:

1. Caregiving is a family caregiver's appraisal of the demands of caring for their stroke-impaired elderly relatives.
2. Family caregving is a complex process that may change over time and in different situations.
3. The family is the basic unit of growth and provides caring in the general system. Many interactive activities are among family members in daily routine. Families have the strength to adjust to stressful situations.
4. A process-oriented approach addresses both the positive and negative appraisals and attributions to the meaning of caring for family caregivers and can facilitate adjustment.
5. The meaning of caring can be understood by analyzing the events and predisposing factors during family caregiving.
6. There could be positive gains from family caregiving in the system analysis.
7. Gains and losses may come together; effectively consolidating the meanings of the caring and fostering long-term commitments.

8. The process of caring provided by Chinese family caregivers of their stroke-impaired elderly relatives can be studied and interpreted by using a qualitative research method.
9. Realities are multiple, holistic and constructed in natural settings.

## 1.10 Summary of Chapter One

Epidemiological studies help us to gauge the extent of the problem of stroke-impairment in the population. To facilitate maximum recovery for stroke survivors and their successful encounters of any residual disability, both family caregivers and health care providers have significant roles to play. It is anticipated that the findings of this study will provide detailed information of the process of caring, patterns of caring strategies and the caring attributes of caregivers in Hong Kong Chinese society. This will hopefully also develop insights about how caregivers in Hong Kong determine their own needs and make decisions concerning various support services. These findings might also challenge health care providers practicing within the community. It is not just that individuals, like family caregivers, have different needs in different settings, but also that the priority of needs change according to available resources and the health status of family caregivers. It is hoped that the findings of this study will assist health care providers to appreciate and recognize the health practices of family caregivers and assist them to engage in meaningful and stress-reducing practices. This is an important partnership to be formed in caring for stroke-impaired elderly relatives within the community of Hong Kong.

## 1.11 Organization of the Thesis

The thesis is organized into six chapters. Chapter One has presented an introduction and an overview of the purposes and significance of the study. Chapter Two examines the conceptualization of family caring, the Chinese cultural context in family caring and how traditional cultural values such as Confucianism influence; how caring is expressed and patterned in a Chinese cultural context. Chapter Two also reviews the relevant literature on the historical development of family caring and caregiving in different contexts; the impact of stroke on family functioning; support networks in Western and Chinese contexts; the characteristics of family caregivers; and the distress related to family caregiving.  Chapter Three delineates the methodology of study.  The rationale for choosing the qualitative approach and grounded theory method is discussed. The entire research process is included: recruiting study participants from purposive to theoretical sampling, holding a two-interview approach over two years for data collection, coding data based on interview scripts, field notes, memos and diagrams, and using constant comparison analysis. The second interview was held to refine and confirm data collected in the first interview. A grounded theory approach was used with emphasis on understanding of how events and predisposing factors help to interpret and appraise the process of family caring.

Chapter Four presents the data analysis process and describes the findings, including the characteristics of the participants. The phenomenon of family caring in the Chinese context is then interpreted. It also discusses the development of an Adaptation Theory of Regaining Self-perceived Control that reveals the adaptation that family caregivers undergo following a loss of self-perceived control. This is shown to be a process of adaptation consisting of five stages. Chapter Five will provide a critical discussion of the literature relevant to the concepts and categories identified in the findings. It also highlights how the self-perceived control process influences adaptation to caregiving. An important section of Chapter Five is dedicated to discussion of the development of the Adaptation Theory of Regaining Self-perceived Control based on five stages emerging from the study findings. Finally, Chapter Six will present the conclusions of the study, the concerns of social policy in family caregiving, recommendations for future research and clinical implications in providing care and support to families of elderly stroke-impaired elder persons.

# CHAPTER TWO

# A REVIEW OF THE LITERATURE ON FAMILY CARING

This chapter presents a review of historical developments in the conceptualization of family caring. The review illustrates the gap that exists in the literature on Chinese conceptions of family caring of stroke-impaired relatives. This chapter is organized as follows: First, there is an overview of the historical development and the conceptualized definition of caring and caregiving in the family based on literature review. This is presented in order to clarify the context of caring in this study. The overview is followed by a review of family caring literature to set the discussion of the experiences of family caregivers in context. It is then followed by a comparison of the experience of family caring in western and Chinese cultures, emphasizing the conceptualization of caring as a process evaluated by outcome. Caregivers' characteristics and caregiving factors in the literature which appear to be particularly relevant to this study are also addressed. Finally, the implications of the study's findings for health services and nursing care practice for family caregivers in the Chinese context are examined.

## 2.1 Introduction

The main purpose of the study is to explore and explain the experiences of 15 Chinese family caregivers throughout the course of stroke care. The literature review is conducted with caution so as not to overly influence the theory which is expected to evolve from the data (Bartlett and Payne, 1997; Morse, 1998; Morse & Johnson, 1991; Pandit, 1996). Thus, the literature review has not simply taken place before the study, but is an ongoing process and continues during and after data collection, being directed by the concepts identified from the data in order to validate, at least in part, emerging theory. A critical discussion of the literature relevant to the concepts and categories identified in the findings of this study is therefore provided in Chapter Five. The present researcher hopes that the review of literature in this chapter related to family caring in general and to family caring of stroke-impaired elderly relatives in particular helps to strengthen the conceptual and methodological framework for this study.

Most of research on family caregiving has been conducted using quantitative methods where the experience of family caring and caregiving is predefined (Given & Given, 1991; Montgomery, 1989). The need to identify how Chinese people define and sustain family caring in their culture is important for both Chinese society and health care professionals in order to achieve a holistic focus by incorporating a cultural dimension into the concept of caring. Cross-cultural studies of self-reliance are limited and have targeted the comparisons and contrasts of individualism and collectivism of various cultures (Chin, 1990; Schwartz, 1990). In order to understand a caregiver's experience, the complex nature of the adaptation process must be accounted for and the constructs and factors that play a role in the caregiving must be carefully investigated. As our knowledge of human behaviour has grown, it has become clear to most scholars and clinicians that, in addition to biological and psychological factors, social and cultural factors have a significant impact on people. It is almost impossible to describe or understand the nature of human behaviour without focusing on the social and cultural dimensions behind such behaviour. Thus, an analysis of the historical development of the meaning of caring is essential to understanding the caring experiences of Hong Kong Chinese family caregivers presented in this study. Based on the following literature review, the conceptualized definition of Chinese family caring has been formulated.

## 2.2 A Critical Review of Concepts of Family Caring

Despite the current emphasis in nursing literature on caring as a central concept of nursing (Leininger, 1993; Roach, 1992; Watson, 1988), there is little nursing research in which the process of Chinese family caring is examined. According to Graham (1983), the concept of caring includes the dimensions of both labour and love. Graham refers caring as the emotions and feelings associated with care and caregiving refers to the tasks and activities that are associated with care. Pepin (1992) attempted to clarify the differences between caring and caregiving in a review of literature and concluded that “caregiving has been conceptualized mainly as an activity or set of tasks, while caring has been conceptualized mainly as commitment, respect and protection toward the cared for, as well as an activity” (p.130). In the context of this thesis, the term “caring” encompasses both emotional and behavioural aspects of the caregiving role.

As Graham (1983) suggested that caring refers to the emotions and feelings associated with care and caregiving refers to the tasks and activities that are associated with care. The present researcher argues that caregiving is not solely a task activity, but a process that interacts with multidimensional aspects of caring and coping adjustments made by family caregivers. These interactions are not always observable activities, but may have important consequences for the lives of the family caregivers. Therefore, a good understanding of the process of Chinese family caring must involve an appreciation of the cultural context within which events and actions take place, including the ‘frames of interpretation’ which the individuals involved use to adjust to the process of caring. Caring gives meaning to an individual's life and determines what matters to him or her (Heidegger, 1975). Caring is a dynamic relationship between the individual's attitudes and beliefs and family expectations. As Leininger (1991) and Greenleaf (1991) state that the individual's structural and social context has provided the necessary supports for caring. Those interrelationships between the social and structural factors are critical to understanding the human caring behaviours (Leininger, 1991).

Morse, Solberg, Neander, Bottorff and Johnson (1990) point out that some researchers have examined the concept of caring by simply exploring patient outcomes without focusing on the process of caring. Thus, the concept of caring has become vague and diffuse. Morse et al. argued that inadequate attention has been paid to both the structural components of caring and the relationship between caring and patient outcomes. Valentine (1991), Silver and Wellman (2002), and Woods, Wills, Higginson, Hobbins and Whitby (2003) find the process of caring is strongly related to the interactions and satisfaction of outcome measures of all the components parts in the caring process. The concept of caring challenges the traditional task-based medical model as it underestimates the therapeutic aspect of human relationships and human dignity (Wong & Pang, 2000).

Therefore, caring is an essential process through which society maintains the mental and physical health of its members. It is important that health care professionals adopt a family perspective in order to understand the experience of family caring in the cultural group. Relevant interventions and goals are those which support family caring. Kellett and Mannion (1999) suggested valuing the family member’s involvement in caring because it provides a great deal of underlying meaning and significance in their lives. Kellett and Mannion also emphasized the importance of identifying the family caregivers’ needs through a process of human interaction which fosters families’ meaningful involvement in caring at home. It is through engaged involvement that family caregivers are able to ascribe meaning to their everyday caring experience. Ultimately, it is such meaning which determines their ability to cope with the situation.

The term “caregiver” no longer describes only health care workers. Increasingly, individuals and the family as a unit have assumed the caregiver role for family members with chronic illness or disability, many of whom are elderly. Nuclear family refers to a family form composed of a husband, wife, and children. Family is defined by Beutler, Burr, Bahr and Herin (1989) as a unique social group involving “generational ties, permanence, a holistic concern for members, heightened emotionally, caregiving, qualitative goals, an altruistic orientation to members, and a primarily nurturing form of governance” (p.10). It is therefore important to assess the family system’s reaction to the illness. The present researcher believes that the significant advantages of using the family as an open system helps to analyze and understand the experience of family caregivers, and identify relevant health services reforms.

### 2.2.1 Conceptualizing Family Caring

As the population ages, the issues of the provision of help, assistance and care to the growing number of elderly people in need is directly, and sometimes painfully, confronting more and more families. Despite the substantial volume of research literature in the field of family caregiving, the meaning of caring that a Chinese family caregiver experiences in taking care of an elderly relative with stroke-impairment is not well understood. Indeed, most caregiving research, both national and international, has focused on negative aspects of the family caregiving experience, examining concepts such as caregiver burden in the 70s and 80s (Montgomery, Gonyea & Hooyman, 1985; Novak & Guest, 1989; Poulshock & Deimling, 1984; Robinson, 1990; Zarit, Reever & Bach-Pererson, 1980).

Most of these studies focused only on the stresses and burdens of the instrumental aspect of caregiving. Therefore, there is a need to undertake further studies taking a wider view of caregiver experiences in order to provide more accurate descriptions of what caregiving brings to a caregiver's life. In the late 80s and early 90s, number of researchers began to take a broader perspective by including positive aspects of caregiving including caregiver satisfaction in their investigations (Given et al., 1992; Kinney & Stephens, 1989; Lawton, Moss, Kleban, Glicksman & Rovine, 1991; Picot, Debanne, Namazi & Wykle, 1997; Pruchno, 1990; Strawbridge & Wallhagen, 1991). Other researchers also examined the uplifts of caregiving (Kinney, Stephens, Franks & Norris, 1995; Wallsten & Snyder, 1990) and finding meaning through caregiving (Ayres, 2000; Farran, Miller, Kaufman & Davis, 1997; Farran, Miller, Ksufman, Donner & Fogg, 1999). As Kramer (1997) states "A broader perspective on caregiving is needed in order to help clinicians and practitioners to work more effectively with the family caregivers (p.219)." This gap in information was also identified by Walker and Walker (1985).

Recent research on family caring and caregiving offers a more holistic perspective by focus on the caregivers' well-being related to burden and uses a qualitative; two interview approaches than previously using burden and appraisal instruments (Chappell & Reid, 2002; Hunt, 2003). As Crotty (1998) suggested that researchers should critically examine how meaning is constructed and their roles in the construction of meaning. This creates challenge for researchers who explore how participants give meaning to their experiences is to learn to listen and to critically reflect on all aspects of the research process from the construction of the research question right through to data analysis. Researchers on caregiving have begun to incorporate meaning in their investigations of caregivers' experiences (Farran, Keane-Hagerty, Salloway, Kupfere & Wilkin, 1991; Motenko, 1989; Nolan, Grant & Keady, 1990). Motenko found that wives who described caring as a duty experienced less satisfaction from the process than those wives who identified caregiving as reciprocal or nurturing. Nolan et al. suggested that caregivers' burden was more related to the meaning of particular tasks or events than to the objective features of those events or circumstances, and suggested that caregiving stress was "in the eye of the beholder" (p.544). Farran et al. found that many caregivers were able to find positive meaning in the caregiving experience and described this process as "Finding meaning through suffering" (p.483). Munford and Sanders (2000) and Folkman (1997) studied that caregivers were able to experience positive psychological aspect when they search for meaning.

Finding the meaning in the caregiving experience may be particular relevant in the spouse-caregiver situation because a strong and long-standing emotional bond can lead to a uniquely positive and gratifying reaction to caregiver strains in specific cultural groups such as the Chinese culture (Chen

& Rankin, 2002; Lee, 2004; Mackenzie & Holroyd, 1995; Shyu, 2002). This will provide relevant information to assist the health care providers in acknowledging the needs and satisfaction of caregiving role.

Although there has been research on caregiver's beliefs and definitions about caregiving, less is known about the general process by which caregivers make sense of their situations. As Cartwright, Archbold, Stewart and Limandri (1994) state "Knowledge [is] limited about the processes by which families create meaning…in caregiving…" (p.32).

### 2.2.1.1 A General System View of Family Caring

This study draws its conceptual framework from a general system view of the family with a constructivist orientation to study the nature of the caring experience within Chinese families. When used together these theoretical orientations draw attention to caregivers' patterns of adaptation. These orientations were chosen because they proved instrumental in directing the researcher through a careful investigation and analysis of the process of human interactions within which caring/coping strategies emerged.

A system perspective stresses that phenomena are linked together and are dynamic in nature. Actions are viewed as ongoing patterns of interactions that cannot easily be reduced to statements of cause-and-effect (Von Bertalanffy, 1968; Weiss, 1969). Weiss (1969) and Von Bertalanffy (1968) searched for a more holistic scientific model capable of expanding the limits of scientific inquiry and developed the general systems theory. Engel (1977) proposed the biopsychosocial model based on the works of Weiss (1969) and von Bertalanffy (1968). This model suggests that a person should be viewed in the context of the systems within which they exist. Engel's model (1977) found support in Doherty, Baird and Becker (1987), who stressed that a patient's health, behaviour during illness, and physical signs and symptoms need to be examined in the context of significant personal relationships, including the health professional-patient-family relationship.

Family systems can be closed or open, according to whether they interact with the environment (Friedman, 2003). Closed systems do not interact with the environment. Family systems are self-regulating, adapting according to environmental feedback. Thus, individuals and families are open systems and the goal of family assessment and intervention should be to promote optimum functioning, adjustment, maintenance, organization, adaptation and growth (Friedman 2003).

This means that no single event can be studied in isolation from others; rather, events must be viewed as being connected. In considering use of the general systems approach to study the nature of family caring and its relationship to stress in caregiving, Pearlin and Schooler (1978) suggested that coping should be viewed as ‘Behaviour that importantly mediates the impact that societies have on their members’ (p.1). It challenges us to recognize the fact that adaptation affects the usual organization and functioning of the entire family, not just the individual.  For example, family caring is viewed as a subsystem of the caregiver’s wider environment. Similarly, elderly relatives with stroke impairment are understood to be their own individual subsystems of the family system.

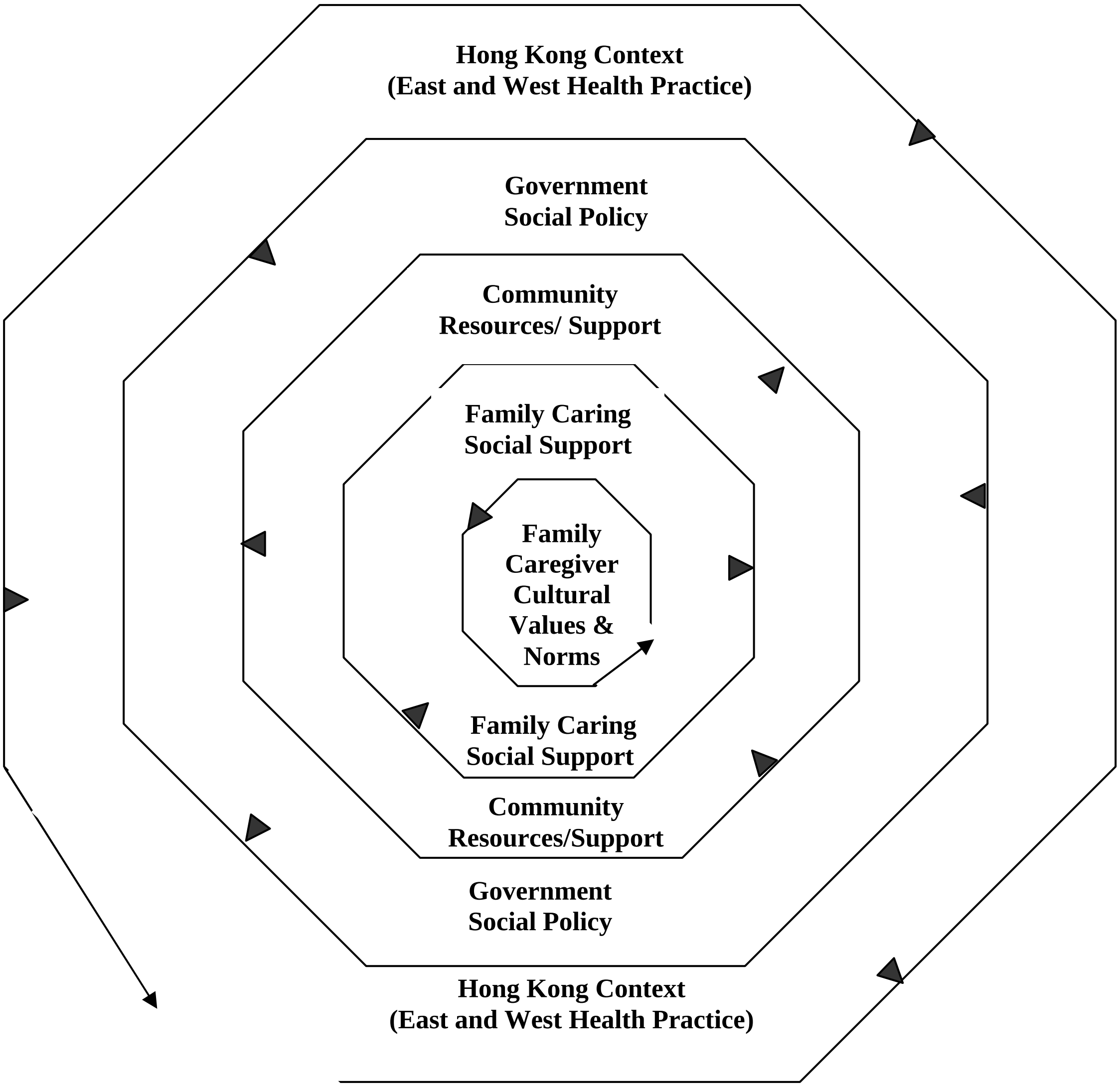
The family system in this study is assumed to be an open system that is influenced by inputs from external sources in the environment (See Figure 2.1 below). The helping agents who become involved with stroke families are also part of a larger system, the helping system. It is therefore important to understand the nature of the interactions that develop between members of the subsystem. It is insufficient to simply sum up the transactions between the members.  It is important to develop an understanding of the caring patterns and strategies adopted by family caregivers in the context of their interactions with those involved in their caregiving roles. Fisher, Kokes, Ransom, Phillips and Rudd (1985) identified the family system as a complex one that could only be analyzed in relation to its own socio-cultural factors and dynamics.

#### 2.2.1.2 <u>The Constructivist Orientation of Family Caring</u>

Group life has a universal impact on the way people formulate knowledge about their social world. One can not interact with others and, as such, is constantly engaged in a process of “meaning-making” (Bell, 1992; Bateson, 1979). Information must be selected, edited and interpreted in such a way that all members arrive at a common understanding about the nature of the world (Pollner & McDonald-Wickler, 1985).

This is particularly true of the coping involved in caregiving of stroke-impaired elderly relatives. It is a stressful process and it has few visible markers or symptoms for investigation. Instead, coping strategies must be inferred from the behavioural and interactional of patterns of family caregivers. Therefore, adopting a constructivist orientation means drawing attention to the ways how people interpret and give meaning to phenomena (Marshall, 1987; Strauss, 1987; Watzlawick, 1984). This is achieved by attending to the subjective features of family coping with stress, rather than the objective conditions under which care is provided. Of particular interest and concern in the caregiving decisions including coping patterns and strategies are the possibilities of creating a self-fulfilling prophecy, an issue that the researcher discusses further in the following section.

Adopting a constructivist orientation, in combination with a system perspective illustrates the necessity of attending to the perceptual as well as cognitive appraisal of family members. In particular, it demonstrates the significance of attending to the way in which boundaries are maintained in the family and the interaction with the outside world (Aldous, 1978; Boss, 1988; Buckley, 1967). Attending to the ways in which boundaries are reconstructed directs attention to the way families define who is part of and who is not part of the family (Boss, 1988; Wuest, 1998). External boundaries separate one system from another. They define the unique character of the family caring in relation to the outside world. Internal boundaries, on the other hand, help members to define themselves vis-à-vis one another (Rosen, 1990). Boundaries are differentially open or closed. In families where boundaries are open, individuals are free to express their thoughts and emotions. In families where boundaries are closed, attempts to express unacceptable ideas are discouraged. In situations involving cognitive appraisal, such as coping, families characterized as closed find the discussion of problems associated with coping very difficult, if not impossible. Conversely, open family systems find it easier to discuss these issues (Rosen, 1990).



Dark line = Evolving interaction
Arrows = Input and output System

**Figure 2.1 Open System with Input and Output**

#### 2.2.1.3 The Recurring Possibility of Self-fulfilling Prophecies in Perceived Control

Once a situation is socially constructed, the chances are high that the conditions or patterns have been laid for the reoccurrence of what is perceived as an expected event. For example, the identification of a stressful event might lead researchers to closely examine family caregivers' caring and coping strategies for further evidence of a pattern. The more the family caregiver is examined, the more that is "understood". All coping actions of the family caregiver may be constructed as evidence of cognitive appraisal. When this happens it "creates a reality which would not have arisen without it. This action, that is at first neither true nor false, produces a fact, and with it, its own "truth" (Watzlawick, 1984, p.96).

Once established, such a circle is beyond beginning and end, beyond cause and effect. In this vicious cycle, the effect feeds back on its own cause (Watzlawick, 1984). The outcome is a self-fulfilling prophecy which, when accepted as real, guides life accordingly (Rosenhan, 1973; Watzlawick, 1984; Von Forester, 1984). Lazarus and Folkman (1984) credited with introducing the idea of cognitive appraisal into discussions about stress and coping. This is a mental process in which people assess whether demands pose a threat to well-being and appraise their resources for meeting the demands. Hence, in Lazarus and Folkman’s (1984) term, coping is defined mainly in terms of the problem-solving efforts that people employ when a perceived demand is seen to levy their adaptive resources. Lazarus and Folkman further state that the appraisal of the level of stress in the coping process is largely subjective, a point which guides many of the understanding of caregivers’ cognitive interpretations reported in this study.  Bugental and Lewis’s study (1998) found that adults with low perceived power as caregivers are particularly vulnerable to threats to control, that is, they are more likely than others to react negatively that might be interpreted as a threat to their control.

In understanding the relationships that are characteristic of caregivers with high or low self-perceived control, Kofta, Weary and Sedek’s (1998) cognitive interpretation of the processing pattern model used to explain the ways of responding when triggered by interpersonal events including any event pose a threat or demanding relationship in the process of caring. According to Kofta and his colleagues, the presence of potential challenge or threat in life is a persistent process within human experience and such responses are motivated by the perceived need to prevent further erosion of control or to regain self-perceived control. However, the reactions to such experiences are varying as the ways in which how they are interpreted.

Variations in ways of thinking and responses to those challenges and threats reflect differences in the perceived control of interactants and are best understood as dyadic representations that include a role for self and others.

It has been found that those who are deprived of control will show increased withdrawal and reduced efforts to regain control (Pittman & Pittman, 1980; Wortman & Brehm, 1975), whereas only very high levels of lost control may lead to helplessness and effort withdrawal. Bugental (1992) found that individuals with low control over caregiving outcomes were described as having low perceived control.  Bugental found that individuals with low self-perceived control access thoughts about the cause of caregiving problems more quickly than others.

Variations in responses to social challenge reflect differences in the caregivers' perceived social power or control. The presence of stressors is significantly related to psychological and physiological adaptation. According to Kofta et al. (1998), individuals lack access to the opportunity for practicing self-control skills or control tactics would have difficulty to regain personal perceived control. Pollock's (1986) identified control as one of the three components of health-related hardiness concept by defining control as the sense of mastery or self-confidence needed to appropriately appraise and interpret health stressors. Thus, caregivers' sensitivity to loss of control, situational variations in threats to control, and situational opportunities for repair of lost control were important domains for interpretation during the process of caring.

To conclude the review of the conceptualized definition of family caring based on the above literature review using the perspectives of general system, constructivist orientation and self-fulfilling prophecies in perceived control. The present researcher is specifically interested in caregivers' cognitive interpretations and responses to loss of self-perceived control as they occur during the course of interpersonal interactions among caregivers of stroke-impaired elderly relatives. The term "caring" encompasses both emotional and behavioural aspects of the caregiving role in the context of this thesis.

## 2.3 Historical Development of Family Caregiving in the 60s, 70s, 80s, 90s

In recent years, there has been a significant shift of responsibility for care of chronic disease person from the formal care system to family caregivers in the community. Family members are taking on increasing caregiving responsibility in an era of uncertain economic, social, and familial resources (Reinhard, 1994). The impact of that responsibility on caregivers is affected by what the caregiving experience means to them (Reinhard, 1994). The present researcher made strenuous efforts to review both the local and international literatures in family caring and caregiving in different cultural contexts in order to examine the current understanding of the experience of family caring in both the west and the east. Family caregiving has been well documented since early 60s in the west. Grad and Sainsbury (1963) present the earliest literature of family caregiving related to mental illness. At that time, they referred to the "caregiving burden" as the stress and difficulties experienced by family caregivers as a result of the support and help they anticipated. Since then this concept had been widely used and documented in a variety of different ways in the literature and research in the 60s, 70s, 80s, 90s and 2000s. A historical review of the literature reveals the evolution of the experience of family caring and caregiving as presenting burdens, negative outcomes, poor quality of life and self-losses. It is hoped that this review will lay the foundations for the development of a theory of family caring in this study.

In the West, many of the early studies of the family caregiving in aging families show that caring for elderly was not a burden to their families nor did their families intend to place them in institutions. These beliefs and attitudes were prevalent in the 60s and 70s in spite of the development of social mobility in western communities (Jarrett, 1985). Many elderly no longer lived with their children as before. Instead they lived on their own interdependently from their families and their communities. Therefore, many researchers focused on confirming care receivers' feelings of either "being estranged" or "being close" at that time. Either intimacy at a distance or high levels of contact and mutual aid between two generations were found to exist (Adams, 1967; Brody, 1979; Cooper, 1971; Rosenmayer & Kockeis, 1963; Shanas et al., 1968). This led to the assumption that caregivers and care receivers were happy with this type of arrangement of family caring and it assumed that caregivers were happy to provide care to family members who needed it in the social context of the 60s and 70s.

It was not till the 70s that research on family stress focused on family properties relating to how well families were able to recover from crisis. Hansen's (1965) and Burr and colleagues' (1979) work on the concept of regenerative power was important here, as was Burr's (1982) noting of, "variations in the ability of the family to recover from a crisis" (p.28). These two concepts became the major focus points for researchers to explain why some families are better coping than the others.

Family caregiving is a coping process in which caregivers adapt to their transitional role. Adaptation is viewed as a continuous process since caregivers cope with demands on a daily basis. The continuous demands portray the flow of experiences and events as caregivers adapt to their day-to-day situation to reconcile their lives. Coping is a highly complex concept that involves the dynamic interplay between a host of both actual and potential stressors as appraised by individuals.

Lazarus and Folkman (1984) define coping as constantly changing cognitive and behavioural efforts to manage specific external and / or internal demands. It is a mental process in which people assess whether demands pose a threat to well-being and appraise their resources for meeting the demands. Although coping most often has been conceptualized at the individual level, coping in this study is identified as the day to day activities family caregivers encounter and deal with in order to fulfil their caregiving tasks. Indeed, a thorough search of the literature reveals that no study exists which uncover the full process of how caregivers adapt to their transitional roles.

Studies of family caring and caregiving done in the 80s and 90s generally reported that persons who provide care were at risk for health problems including strain (Bunting, 1989; Clark & Rakowski, 1983; Kwan, 1991; Ngan & Cheng, 1992), anxiety (Vachon, 1980; Akkerman & Ostwald, 2004; Sansoni, Vellone & Piras, 2004), nervousness and difficulty sleeping (Jensen & Given, 1991; Teel & Press, 1999) and depression (Tang et al., 2003; Beeson, 2003; Lee, Brennan & Daly, 2001). In fact, negative stress responses have been well documented in the 70s and 80s for family caregivers of persons with chronic illnesses. The development of an aging exchange model in the 70s and 80s reinforced the recognition of caregiving responsibility in the academic field in the West (Dowd, 1975). Though rarely made explicit in the literature, the assumption was that individuals did not expect to be reciprocated in the West in comparing that to the East.

This is reflected in some of the literature on family caregiving of spousal and parent caring (Brody, 1981; Archbold, 1982; Finch, 1989; Finch and Groves, 1983; Hawranik, 1985; Bowers, 1987; and Tonti, 1988). Brody (1985) also remarked that family members had a "primordial commitment" to care (p.26) and Berman (1987) made this assumption even more strongly "Children have an irredeemable obligation toward parents. Nothing they can do can ever make up for the initial parent gift" (p.25) when he referred to the caregiving responsibility of adult children. Given the responsibility to care, and the devotion which was viewed as inherent in this relationship, much of the early research in this tradition focused on describing the roles, needs, and burdens of family caregivers (Clark & Rakowski, 1983; Fengler & Goodrich, 1979; Golodetz, Evans, Heinritz & Gibson, 1969; Montgomery et al., 1985; Robinson & Thurnher, 1979; Zarit et al., 1980). These writings drew attention to the necessity of action and an advocacy-oriented policy to assist and restore these vital social relationships in the 80s and 90s (Abrams, 1977; Biegel & Blum, 1990; Froland, 1980; Twigg, Atkin & Perring, 1990).

As the evolution of family caring became part of the public policy agenda in society from the 80s and 90s, more refined conceptualizations of the issues began to emerge. These did not just simply address the needs of family caregivers providing care to their elderly relatives. Instead, it was found necessary to detail the different types of demands being placed on caregivers and their impact on families. Zarit et al. (1980) and Zarit (1989) focused only on the burden of family caregivers in their “Burden Interview”, Brody (1981) and Archbold (1982) identified the impact of caregiving on women while Robinson (1983) developed a Caregiver Strain Index to emphasize these points. These studies together marked a turning point in research on family caring because it produced the development of a research interest devoted to detailing and elaborating the nature of family caregiving.

The literature shows that research studies conducted in the earliest stage of family caregiving have identified some characteristics of caregivers and their commitments and their caregiving behaviours using mainly quantitative measures (Brody, 1981; Archbold, 1982; Finch & Groves, 1983; Hawranik, 1985; Bowers, 1987; Tonti, 1988). Following this, the distinction between subjective and objective components of the caregiving burden was outlined in research studies on the theory building of family caregiving. Intense interest exists in identifying the correlation between objective and subjective data of caregiving that lead to burdens.

Objective data on burdens are related to concrete events and activities resulting from caregiving (Abraham & Berry, 1992; Archbold et al., 1990; Burr, Klein & associates, 1994; Montgomery et al., 1985; Morgan & Laing, 1991). Indicators included the age of the caregivers and the care-receivers (Bowers, 1987; Cantor, 1983; Fengler & Goodrich, 1979; Robinson, 1986), gender of the caregiver (Archbold, 1982; Aronson, 1985; Finch & Groves, 1983; Horowitz, 1985; Litwak, 1985; Treas, 1979), relationship status (Fisher et al., 1985; Johnson & Catalano, 1981; Johnson, 1983; Qureshi & Walker 1989; Shanas, 1979, 1980; Tonti, 1988), labour force participation (Brody, 1985; Brody, Johnson, Fulcomer & Lang, 1983; Campbell & Brody, 1986) and the severity of the care receiver's illness (Poulshock & Deimling, 1984; Zarit et al., 1980).

During this second stage of theory building, attempts focused on better conceptualization and quantitative measures of the concept of burden. Various burden scales were developed and burden was correlated with a variety of caregiver and care recipient variables such as age, labour force participation, health and mental health outcomes (Montgomery et al., 1985; Shyu, Lee &

Chen, 1999; Zarit, 1989). More sophisticated longitudinal quantitative designs and multivariate data analysis techniques (van Exel et al., 2004) were carried out during this stage, but empirical data from qualitative studies was inadequate to interpret family caregivers' interaction in the process of caring.

To summarize this part of the literature review, research evidence offered in the pre-theoretical era consistently confirmed the central role of the family in providing care to relatives with stroke. However, caregiving activities may vary widely among families as patterns of care are related to the characteristics of the caregivers as well as those of the care recipients and those caregiving factors. The first phase of scientific study of family caregiving has furnished us with rich descriptive data but many important questions remained unanswered. A keen awareness of this knowledge gap became a motivating force in this study to pave the way for the next phase, which includes developing a culture- specific theory for Chinese caregivers in Hong Kong.

### 2.3.1 Who are Family Caregivers?

Although there is great diversity among family caregivers, there are characteristics common to most. One survey estimates the number of households providing caregiving at 22.4 million and a "typical caregiver" is a middle-aged, usually 45-55 years old, married women {National Alliance for Caregiving and the American Association for Retired Persons (NAC & AARP), 1997}. Earlier studies explored caregiving commitment and behaviour provided by families ranging from occasional errands to round-the-clock care. Hooyman and Lustbader (1986) and Stone, Cafferata, and Sangl (1987) found that over 80 percent of respondents had provided unpaid caregiving tasks seven days a week. These studies also found that all spousal caregivers assisted daily caregiving activities while children including daughters and sons devoted only 30 percent of daily caregiving activities.

Caregiving behaviours include emotional support (Chenoweth & Spencer, 1986; Cicirelli, 1983; Grant, Glandon, Elliot, Giger & Weaver, 2004); direct service provision (Horowitz, 1982a; Kaye, Turner, Butler, Downey & Cotton, 2003); mediation with formal organizations and providers (Rankin, 1990; Warren, Kerr, Smith & Schalm, 2003); and financial assistance (Horowitz, 1982b; Zhan, 2004). In addition, sharing a household was considered to be a special form of caregiving.

Caregivers form a heterogeneous group with respect to certain characteristics that may be systematically related to the potential for experiencing emotional distress. These characteristics include age, gender, personality, and the quality of relationship with the cared-for-person. Caregivers’ gender, age and personality stand out as critical factors in determining caregiving experience.

#### 2.3.1.1 Characteristics of Family Caregivers: Age

Braithwaite and McGown (1993) examined the effects of distress on the capacity of family caregivers of stroke patients to obtain information about stroke and caregiving. The emotional state of the caregivers, however, did not affect how much they learnt. Knowledge after the seminar was best predicted from pre-seminar knowledge and age. Older caregivers were less well-informed afterwards, although they did not differ significantly from younger caregivers in their scores initially. Clipp and George (1993) found illness duration and caregivers' employment status did not help to explain the difference between cancer and dementia, but caregivers’ age was a strong covariate. Specifically, younger spouse caregivers were significantly more compromised than older spouse providers. Evangelista et al. (2002) examined the relationship between emotional well-being of cared-for-person and their caregivers. Both gender and age were associated with cared-for-persons’ emotional well-being; male and younger caregivers had higher (better) scores than female and older cared-for-person. This study concluded that the emotional well-being of caregivers was associated with the emotional well-being of the cared-for-person.

### 2.3.1.2 Characteristics of Family Caregivers: Gender

It has been found that gender and quality of marital relationship were each significant individually in predicting caregiver appraisal. In selecting informal caregivers, the “principle of substitution” has long been noted in research reports (Johnson & Johnson, 1983; Shanas, 1979, 1980; Silverman & Huelsman, 1990; Stone, Cafferata & Sangl, 1987). This principle declares that selection is based on kinship priority and operates according to formal familial distance from the member concerned. How might the changing society affect the responsibility of the eldest sons in the traditional Chinese families and in circumstances where male offsprings are not available? For example, when a married husband with adult children is stricken by illness, chances are that the primary caregiver will be his elder wife. If the wife is unavailable, then children usually the middle-age daughters, whether married or unmarried become the primary family caregivers.

Research data confirm consistently that most caregivers are women (Miller & Cafassmo, 1992; Skaff & Pearlin, 1992; Zarit, Todd & Zarit, 1986). However, men can be found in the role of primary caregiver in some studies (Horowitz, 1981; Stoller, 1983). Once in the role, how do they differ from women in their behaviour and experiences? Horowitz (1981) and Stoller (1983) concluded that when male and female caregivers were compared, men offered lower levels of overall assistance. The differences were most pronounced in those tasks requiring “hand-on” assistance such as domestic and personal care tasks and less apparent in areas such as decision making and linkage functions. As for the experiences associated with caregiving, wives reported higher levels of stress though the amount of care provided and /or level of impairment was controlled (Cantor, 1983; Fitting, Rabins, Lucas & Eastham, 1986). Brody (1981) explained that the greater stress came from being the “the women in the middle”. Caregiving daughters are often the middle generation, usually middle-aged and subject to competing demands on their time. But Maeda (1981) cast serious doubt on the relevance of this assumption in his examination of the historical context of caregiving outside western culture.

In the West, Horowitz (1985) observed that there was almost universal consensus about the identity of the primary caregiver, with selection following a hierarchical pattern. These family caregivers were predominately female with wives and adult daughters comprising the majority of the caregivers. Caregiving frequently is framed as a family issue when, in practice, women bear the primary responsibility, especially in the Chinese culture (Holroyd, 2001). Houde (2001, 2002) reports male caregivers are important providers of care to older adults who are functionally impaired in the home setting. Some results from research studies suggest that the male caregiver may provide different types of care and have different responses to caregiving than female caregivers (Yoneda & Ishikawa, 2004). Gallicchio, Siddiqi, Langenberg and Baumgarten (2002) reported that female caregivers were found to have significantly higher levels of perceived burden and depressive symptoms than male caregivers. These results suggest that there are significant gender differences regarding the mode of caregiving and experience of caregiver distress. It is important that future research be focused on supplying appropriate social support for family caregivers, taking gender differences into account.

The majority of research studies in the 70s, 80s and 90s in the field of family caring and caregiving have focused on the women caregivers. There has been a failure to acknowledge that the male caregiving experience may be different from that of females. Although previous studies found that the experience of female and male caregivers following heart attack on their family members, these differences have not been fully explored. Therefore, a qualitative study should be conducted in order to gain an understanding of the role of gender in the experiences of caregivers of stroke-impaired relatives. The need for more research related to the needs of the male caregivers and the value of traditional interventions for this group should further be addressed. It is worth noting here that this study involved 15 individuals, five of whom were male family caregivers of stroke-impaired family relatives.

### 2.3.1.3 Characteristics of Family Caregivers: Personality

The personality and mental health of the caregivers correlated with their caregiving satisfactions. The caregivers with inverted personality, who are closed and isolated, are more likely to be dissatisfied with their caregiving and lead to increased mental problems (Stengard 2002). Stengard’s study described how different types of caregivers’ personality cope with the demands imposed by a family member's mental illness. Five distinct types of caregivers’ personality were identified according to the caregiving dimensions: supervising, anxious, coping, resigned, and activating. The results of this study show that health professionals should be aware of the caregiving consequences, personal meaning in caregiving, and coping strategies used in order to be able to offer appropriate interventions that optimally meet caregivers' needs.

### 2.3.1.4 Characteristics of Family Caregivers: Quality of Relationship with Cared-for-person

Suitor and Pillemer’s study (1994) examined the effects of caregiving on marital satisfaction over the first year of caring for elderly with dementia. They noted changes in women’s martial satisfaction associate with variations in their husbands’ emotional support and barrier of the caregiving effort.

Given the importance of husbands' emotional support in explaining marital quality, there was relatively low correlation between husbands' time-one and time-two emotional support. This pattern was consistent with the pattern of changes in emotional support in Suitor and Pillemer's another study (1996).

### 2.3.2 Family Caregiving Factors

Evidence suggests that there is considerable variation in how caregivers adapt to their caregiving demands. Many studies have sought to quantify the association among caregiving factors ranged from caregiving resources to quality of life of the caregivers.  Contextual factors such as socio-economic status, care recipient factors such as level of functional status and severity of disability, intra-psychic factors such as mastery and self-esteem, coping strategies and social supports have all been associated with the psychological and/or physical outcomes of primary caregivers. In reviewing these issues, the literature appears to be limited by the use of traditional analytic approaches which examine the relationship between a factor and an outcome. These include burden on task difficulty, emotional strain, negative symptom behaviours, self-losses, quality of life and caregiving resources and they would be discussed in the followings. It is clear, however, that changes to single factors, as represented in these studies, occur very rarely even in the experimental context. The literature has also been limited by lack of reliance on specific theoretical frameworks.

### 2.3.2.1 Family Caregiving Burden

A large number of studies have already indicated that caring for dependent relatives at home is burdensome and family caregivers described their roles in a hierarchy of helping behaviours: companionship, handling finances, shopping, transportation, doing laundry, assisting the cared-for-person with personal care such as: eating a meal, taking a bath, using the toilet and dressing. (Abraham & Berry, 1992; Archbold et al., 1990; Ngan et al., 1996; Nolan, Grant & Keady, 1996; Twigg, 1992; Wright, 1998; Zarit, 1989). The stress may be extreme if the person who is being cared has been a victim of stroke, it is because of those who survive 70% are left with disability and handicap (Kerr and Smith, 2001; Han & Haley, 1999; Lui, 1997; Moore, Maiocco, Schmidt & Guo, 2002; White, Mayo, Hanley & Wood-Dauphinee, 2003). Hence, family members will have to continue the stroke person's rehabilitation needs in their caregiving. Family members frequently describe the demands of caregiving in the home as overwhelming. Anderson, Linto and Stewart-Wynne (1995) and Thommessen, Wyller, Bautz-Holter and Laake (2001) describe stroke caregiving as a chronic stress situation. Stroke caregiving stress results from coping with the daily demands of caring for an individual with profound physical, cognitive, and emotional changes, as well as impaired communication and social skills (George & Gwyther, 1986; Decker & Young, 1991; Williams, 1994). Caregivers report personal depression, burden, stress, decreased life satisfaction, and family dysfunction. Tiredness and adverse health problems also are common concerns of caregivers (McLean, Roper-Hall, Mayer & Main, 1991). Families who find the demands of caregiving overwhelming may institutionalize the individual who has had a stroke (Friedland & McColl, 1987; Kelly-Hayes et al., 1988; Ngan & Wong, 1993; Ngan et al., 1996).

A large number of studies have already indicated that caring for dependent relatives at home is burdensome (Abraham & Berry, 1992; Archbold et al., 1990; Ngan et al., 1996; Nolan et al., 1996; Twigg, 1992; Wright, 1998; Zarit, 1989). Caregiver burden is the strain and load borne by people caring for an elderly family member and it is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with caregiving experience. Two major dimensions of burden revealed from cross-sectional studies are objective burden relates to the tasks or activities that the caregiver is involved (Montgomery, et al., 1985; Thompson & Doll, 1982) and subjective burden relates to attitudes or feelings caregivers have in response to their roles (Zarit, et al., 1980). Such stress may be extreme if the person who is being cared is a victim of stroke, since of those who survive, 70% are left with disability and handicap (Kerr and Smith, 2001; Lui, 1997; Moore et al., 2002; White et al., 2003). Hence, family caregivers will have to continue the stroke person’s rehabilitation needs.

#### 2.3.2.2 Family Caregiving Emotional Strain

Family caregivers suffer from psychological and physical morbidity associated with the care of the chronic illness (Gonzalez-Salvador, Arango, Lyketsos & Barba, 1999). Studies evidenced that caring for the elderly with chronic illnesses endangers the physical and mental health of caregivers. Subjective data of the caregiving burden include feelings, attitudes and emotional reactions to the situation influenced by a variety of caregiving factors (Goldstein et al., 1998; Goldstein, Adamson, Barby, Down & Leigh, 2000; Montgomery et al., 1985; Zarit, et al., 1980). Caregivers’ emotional status such as depression, anxiety, and optimism affect their stress response to the care situation (Given, Kozachik, Collins, Devoss & Given, 1993). Caregivers who are emotionally distressed, might exhibit a more negative stress response to providing care (Dennis, O’Rourke, Lewis, Sharpe & Warlow, 1998). Caregiver emotional health could also affect the caregiver’s long-term emotional reaction to providing care (Schulz and Williamson, 1991; Winslow, 1997). Most of the family caregivers were careful to avoid provoking a recurrence of stroke. Reinhard and Horwitz (1995) also reported that over half of the caregivers in their study were worried that they might make the illness worse. But the long-term impact on caregivers’ emotional status and how they overcome those emotions during the adjustment process is not documented in the literature.

### 2.3.2.3 Family Caregiving Negative Symptom Behaviours

The perceived severity of negative symptom behaviours is related to the objective caregiver burden, but severity of positive symptom behaviours is not (Provencher & Mueser, 1997). These findings suggest that negative symptoms may have a greater impact on role function than positive symptoms, leading to greater burden. However, contrary to expectations, reduced responsibility attribution for negative symptom behaviours was related to higher levels of objective caregiver burden. Caregivers who perceive patients as incapable of altering their negative symptom behaviours and meeting certain role obligations may assume extra responsibilities, leading to higher levels of objective burden. The results indicate that there may be disadvantages for caregivers associated with assuming that patients have no control over their negative symptom behaviours.

Pearlin, Lieberman, Menaghan and Mullan (1981) argued that persistent role strains that individuals endure are potential sources of stress that can result in a diminishment of self. In defining self-loss as a loss of identity resulting from the overwhelming caregiver role, Skaff and Pearlin (1992) extend this proposition to family members who must assume the caregiver role and restructure their lives to manage the daily demands of caring for someone with physical and cognitive deficits. They found that limited social contact and lack of social roles outside of caregiving resulted in a greater loss of self in family members who provided care for individuals with Alzheimer's disease. Rose and DelMaestro (1990) also propose that caregivers of chronically ill family members face a series of losses and struggle to regain autonomy and redefine their own identity.

Caring for a stroke survivor with functional and cognitive deficits can be a difficult task. Family members commonly reported a loss of independence, restricted social activities, and limited opportunities to travel because of their caregiving role (Friss, 1990; McLean et al., 1991). In examining perceived losses following a stroke, Mumma (1986) found that activities, abilities and characteristics, and independence were the three major categories of losses experienced by both stroke survivors and their families, other investigators report similar losses related to changes in interpersonal relationships and social mobility (Coughlan & Humphrey, 1982; Holbrook, 1982; Robinson-Smith & Mahoney, 1995; Silliman, Fletcher, Earp & Wagner, 1986).

These potential losses were substantiated further by Smith, Smith and Toseland (1991), who reported caregiving concerns of individuals who cared for family members with a variety of chronic illnesses, such as heart disorders, arthritis, and stroke. Family caregivers reported inadequate coping skills and desired improved time management skills that would enable them to spend more time with their family and to pursue personal interests without relinquishing caregiving responsibilities. Even though caregivers recognized the limitations of formal and informal support, they desired more caregiving assistance from siblings, children, other relatives, and the community that would allow them more independence and autonomy in their own lives. Feelings of guilt were evident in the caregiving process, especially in expressing feelings about wishing to live their own life.

#### 2.3.2.4 Family Caregiving Quality of Life

The trend toward community-based care, along with advances in medical technology, has resulted in increased numbers of individuals with complex healthcare needs being cared for at home by their families. This shift from hospital to community care places increased demands on family caregivers. Families are now providing long-term care for chronically ill people with a variety of conditions. Caregiver research has, for the most part, explored burden, stress, and depression as outcomes of caregiving. There is little research assessing the quality of life (QOL) of long-term caregivers. In the research on quality of life, the patient is most frequently the focus. With the increased demand on families as caregivers, quality of life needs to be included as a variable in studying family caregivers for chronically ill individuals.

Canam and Acorn (1999) discussed issues in studying quality of life in family caregivers of persons with chronic conditions. They included the conceptualization of quality of life, measurement of quality of life and the research on quality of life, with a focus on the quality of life of the family caregiver.

Bond et al.'s (2003) study found the effect on spouse dementia caregivers of relinquishing care by examining whether change in quality of life variables was associated with time since yielding to formal care and time since death of the spouse. Bond et al. defined caregivers' quality of life in terms of their health status, psychological well-being, and activity participation. All participants were interviewed in their own homes. Different patterns of quality of life changes were observed between groups, with both positives and negatives associated with disengagement from the caregiving role. Positive changes were particularly evident in psychological well-being and activity participation. These findings were discussed in terms of their relevance for a life transitions approach to the relinquishment of caregiving. Women, younger caregivers, caregivers in poor physical health, and caregivers of patients with severe changes are at risk of burn-out. Support programmes should focus on self-efficacy, social support, and the coping strategy confronting. In this study, no specific time frame could be identified at which support programmes should be offered.

#### 2.3.2.5 Family Caregiving Resources

Caring for elderly relatives with chronic illnesses involves considerable resources, but the demands for these resources are often increased when caring for elderly relative with a disability. These demands have implications for the psychological and physical health of the caregivers. The support for stroke-impaired family members has been described as a “Tower of Babel” (p.15) by Morse and Johnson (1991) because health professionals use a different model to assess the needs of family members who provide primary care for stroke victims. This situation is worse when the family member’s perceptions are different from those of health care professionals. Regarding the role of informal support in family caregivers’ coping responses, it has already been reported that the more social support networks to which the caregivers belong, the better they anticipate future coping demands (Goldstein et al., 1998; Goldstein et al., 2000). Primary amongst these studies was the development of theory to interpret family caregivers' coping styles (Lazarus, 1993; Lazarus and Folkman, 1984; Turnbull & Turnbull 1993) and the situational variables, such as the availability of social support and family relationship (Cicirelli, 1983; Gilhooly, 1984; Rakowski & Clark, 1985; Shyu, 2000a; Robinson & Thurnher, 1979; Thompson, Fellerman, Gallagher-Thompson, Rose & Lovett, 1993; Yuen-Tsang, 1997).

Grant and Nolan (1993) studied the sources and concomitants of satisfaction among informal caregivers. Other studies found that perceived acceptance of available support networks was strongly related to well-being and this reinforces the conceptual distinctiveness of the latter two concepts (Sit, Wong, Clinton, Li & Fong, 2004; Yuen-Tsang, 1997). This suggests that quality of life of caregivers could be improved even with burden in their lives and that the overwhelming focus in caregiving research on burden should be supplemented with an emphasis on quality of life.

#### 2.3.2.6 Other Family Caregiving Characteristics and Factors

Hawranik (1985) and Robinson (1986) found that many ill and disabled elderly people had been able to remain in the community because of services provided to them by their families. They also reported that the bulk of care provided to the ill and disabled was not distributed evenly among family members. Rather, most of the care was provided by an elderly spouse or the adult women in the family. According to Morse and Johnson (1991), many studies have focused on the needs of care receivers rather than the caregivers. Health professionals have often tended to focus on disease and treatment processes for the cared-for persons rather than understanding the family caregivers' caring experiences. Such a perspective treats the individual as a person by integrating mind and body in the social context (Kleinman, 1986). It was not until the late 80's that a small number of researchers incorporated significant others into their studies. The role of family caregivers should also be the focus of the needs of family caregiver research. This is because of the kinship relationships and intra-family support among family members who are intimately involved in and affected by the impact of illness experience in the process of caregiving. Many studies provide evidence that family caregivers of persons with chronic illnesses report high levels of stress as a result of the caregiving (Archbold, Steward, Greenlick & Harvath, 1992; Chan & Leung, 1995; Holroyd, 2003a, 2003b; Lee, 2004; Given & Given, 1991; Mackenzie & Holroyd, 1996; Mok, Chan, Chan & Yeung, 2003; Rosenberg, 1998; Shyu 2000b). Thus, one of the objectives of this study is to widen the conceptual horizons of the process of family caring in the Chinese context for stroke-impaired elderly relatives in Hong Kong.

Many studies (Morse, 1994; Marshall & Rossman, 1998; Miles & Huberman, 1994; Morse & Johnson, 1991) showed that theories and models of human experiences should be developed from the individual's perspective rather than from the perspective of health professionals. Only by eliciting thick descriptions of the individual's caring experiences can an understanding of the individual's needs be developed and anticipated. Thus the identification of behavioural commonalties and the contextual factors in the developed model can then be identified and incorporated. Although there is some evidence that there are commonalties in the care expressions, patterns and practices of the caring process in Chinese family caregiving of stroke-impaired elderly relatives, studies have not yet fully explicated the process in Hong Kong (Lee, 2004; Mackenzie et al., 1998).

In addition, many studies use quantitative methods to measure the caregiving needs and difficulties of Chinese family caregivers of relatives with chronic diseases such as dementia, renal problems, Alzheimer's disease and cancer of Hong Kong (Chan & Chang, 1999; Chung, 2001; Lai, Wong & Liu, 2001; Luk, 2002; Shyu et al., 1999). So far, however, only one study (Mackenzie et al., 1998) has used a small-scale, qualitative method to identify the experiences of family caregivers of relatives with stroke impairment in Hong Kong. Mackenzie et al. (1998) piloted a Carer's Assessment Scale (CAS) with community nurses to assess the needs of 14 Chinese family caregivers of people with stroke impairment and compared the results with the assessment of community nurses in Hong Kong using both quantitative and qualitative methods. This study concluded that it did not seem feasible to incorporate CAS into the overall assessment of the patient and his/her family and recommended that further studies to refine CAS were needed, especially those using qualitative methods. Mackenzie and her colleagues' study (1998) did not explore the needs of family caregivers in-depth enough using the process of family caring approach. The majority of the empirical studies on family caregivers have adopted quantitative research methodologies that emphasize the measurement of perceived stress in family caregiving during periods of transition. While these have definite merit for studying the process of caring among family caregivers, this researcher would argue that studies on the Chinese conception of caring deserve an alternative research paradigm. It had been evidenced that there are differences among Chinese family caregivers' interpretations and expectations of family caregiving (Holroyd, 2003b; Lee, 2004; Mackenzie & Holroyd, 1995; Mok et al., 2003; Pang, Arthur & Wong, 2000; Wong & Pang, 2000). Thus, in the present study the emphasis is on the generation of inquiry from the interpretation of data and a deep understanding of the impact of historical, social and cultural forces on the process of family caring.

There are no studies in which researchers identified ways in which meanings are formulated through the caregiving experience or how those meanings are modified and reformulated over time. In a related area of caregiving, for frail elderly relatives, Phillips and Rempusheski (1986) found that caregivers engaged in a process of reconciling the present and past identities of the elderly person. Caregiving behaviours were based on beliefs about role responsibilities and proscriptions of personal standards for behaviour. These findings are important, but do not describe fully the interactions between caregivers and other family members, or how caregivers' responses evolved and changed with experience. These researchers and others, who examined caring for elderly relatives (Archbold et al., 1990, 1992; Chappell, Penning & Sorensen, 1995) and caregivers with chronic illnesses and cancer (Archbold et al., 1990; Archbold et al., 1992; Mok et al., 2003; Schumacher, 1996), provide important insights into the dynamics of caregiving. Although similarities may exist between these areas of caregiving and caring for relatives of chronic illnesses, it is not clear how these findings apply to Chinese family caregivers of stroke-impaired elderly relatives, who have less certain outcomes and less predictable illness trajectories.

## 2.4 A Cultural Context of Family Caring and Caregiving

The purpose of this study is to present a more complete understanding of the experiences of family caring in the Chinese context. The present researcher believes that a caring paradigm, if interpreted in its cultural context, provides the most productive way of exploration. Despite the shift towards a focus on the processes and patterns of family caring, there is also a need to have an empirically generated set of theoretical concepts in order to help shape macro level policy. Studies should also be sensitive enough to inform interventions for the stroke-impaired elderly and their family caregivers. Nolan et al. (1996) called for a more positive, multidimensional, and holistic approach to the study of family caregiving. In the knowledge of the present researcher, there is no existing knowledge and theory to help health care professionals to understand the experience of Chinese family caregivers caring for stroke-impaired elderly relatives at home.

To discuss caring and caregiving in Chinese families, it is essential to define the terms "culture" and "family". La Fontaine's (1988) definition of family as being kin in general is adopted in this study. Approaching of family through the expectations of kinship provides some insights into the fundamental processes that contribute to Chinese families' meaning of caring. D'Andrade & Strauss's (1992) definition of culture refers to values shared by significant others in the social group, either from being acted out, physically possessed or internally thought.

In order to describe the concept of culture, the use of this concept in different disciplines is examined. Historically, culture has been oversimplified as a set of rules and norms. The major concepts applied to understanding cultural similarities and differences were mainly derived from anthropological and sociological theories. Anthropologists define ‘culture’ in various ways. Kroeber and Kluckhohn (1952) referred to culture as learned and accumulated experience including knowledge, beliefs, value systems, customs or habits that are shared and transmitted by the members of a particular society. According to Keesing (1981), culture exists at two levels. The first is the observable phenomena that make up the patterns of life within a community. The second is the organized system of knowledge and beliefs that allows a group to structure its experience and choose between alternatives. Wallace (1951) defined culture as the social expectations and roles followed by members of specific cultural groups. According to Blumer (1937, 1969) and Thompson (1990), the meaning of symbolic forms is the expression of subjects. That is, symbolic forms are produced, constructed, or employed by a subject who, in producing or employing such forms, is pursuing certain aims or purposes and is seeking to express himself or herself; that is, what he or she ‘means’ or ‘intends’ in and by the forms thus produced.

Sociologists and anthropologists have used ‘culture’ as a collective noun for the symbolic and learned aspects of human society. LeVine (1973) defined culture as a set of organized norms and rules commonly shared by members of the same cultural group. These norms and rules guide the ways in which they perceive themselves and others. The depth of the internalization of these responses depends on an individual’s prior and ongoing patterns of socialization, which inform the extent to which given goals, are seen as desirable, thereby explaining why some options are more compelling than others. These cultural rituals of obligation have directive force, in that they are needed to help caregiver organize responses to the day-to-day needs of their cared-for-person. This suggests a culturally meaningful framework, where hidden assumptions may underlie feelings of entitlement and reciprocity that constitute the motivation to give care (D’Andrade & Strauss, 1992, Holland & Quinn, 1987).

In Leininger’s theory (1991), social structure is another major and important dimension to knowing and understanding cultural context. Social structure includes kinship and gender roles, and defines and delimits caring behaviour in relation to cultural norms, beliefs, and values. In most cultures, social sanctions imposed by cultural norms exert pressures that define caring behaviour among individuals or groups. These sanctions influence what is considered acceptable or unacceptable in the culture and social support network in coping with family caregiving. As with the case of the coping response, social support has been positively associated with better caregiving outcomes (Cicirelli, 1983). Scott, Roberto and Hutton (1986) surveyed 23 primary caregivers whose relatives had been diagnosed with Alzheimer's disease. They examined the instrumental and socio-emotional support provided by families to the primary caregivers. Again and again, it was found that the more support the families provided, the less of a sense of burden the caregivers felt, and the more effectively they coped.

Spector (1996), a nurse, defined culture as a complex whole with every part related to the other and which is learned by everyone in his/her family and social community. Spector explained further that what people think, believe, and do is determined by their cultural background including their language, beliefs and values; and that it is by these that one ethnic group can be distinguished from other ethnic groups. A widely accepted stance for analyzing Chinese culture was proposed by another nurse, Pang in 2003, who drew upon the historical-cultural context of modern China to analyze responsibilities for care in ancient China. Pang defined Chinese culture as associated with the notion that Chinese people exist through their hierarchical relationships with others; namely, the five cardinal relationships rooted in the teachings of Confucius. She argued further that how one should behave depends on which role one is assuming at a particular moment. 'Context' is that situation within which events and behaviour fit together, and ‘culture’ is the way people express themselves in order to identify the “structures of significance” and “frames of interpretation” and to indicate the ways in which people behave intelligently. It is also the medium through which individuality and human social relationships are expressed. Pang expresses the view that culture relies on a virtue-based milieu including rules, principles, morals, and customs. This means that the culture of any group of people is dynamic and is influenced by human and social factors.  This definition of culture has been adopted in this study, as it is closely related to the purpose of the study to understand family caring relationships in the Chinese context.  This, in turn, has major implications for Chinese health care providers, especially for those involved in planning and educating populations of their own culture or from cultures different from their own.

Friedman (1990) found that the family was the primary institution in society that preserved and transmitted culture.  However, an individual’s values and beliefs are not easily explained and understood without observing their interactions and listening to their concerns.  As Leininger (1991) stated culture is learned, shared and transmitted in the individual’s daily life. Understanding an individual’s behaviours can provide useful information about these invisible schemes that guide behaviour (Hart, 1999; Jackson, 1993; Leininger, 1991). Behaviours related to different cultures may be understood by identifying ways of life, including communications, diet, lifestyle practice and beliefs about health and illness (Thompson, 1990). For instance, Chinese people accept a moral duty to take care of their sick relatives which is grounded in the Confucian ethical system of family structure, roles and relationships for many centuries.

The family system was important for survival and it was also traditionally both a social and economic unit among the Chinese (Bond, 1993). Family income and property were held by the male head of the family, whether the family property was a piece of land and buildings or a family shop or business. The male head was responsible for the family's income and for improving the family's economic and social position. His wife or his mother, if she was still alive, was responsible for running the household. In Chinese society, each family member was expected to contribute according to ability and each received according to need, with 'need' being interpreted in favour of senior males (Wee, 1987). Leininger (as cited in Rosenbaum, 1986) defined culture as "supportive actions that assist, support, or help another person or group with evident or anticipated needs to improve a human condition or lifestyle" (p.414).

Increasingly, individuals and families have assumed the caregiver role for family members or friends suffering from chronic illness or disability, many of whom are elderly. Many ill and disabled elderly people have been able to remain in the community because of services provided to them by their families (Hawranik, 1985). Without understanding the culture and belief systems of the family and the phenomenon of the relationship between the individual and the family, nursing cannot become a holistic science. The concept of the family as a unit of nursing care originated with Nightingale's concern for family members (Gilliss, 1983). Analysis of cultural context is critical to the understanding of the process of family caring in the Chinese context. Therefore, it is necessary to understand the Chinese belief system and family structures. These factors will be discussed later in this chapter.

## 2.5 The Chinese Context of Family Caring and Caregiving

Adopting a culturally sensitive approach is especially important when the researcher wants to study family caregiving in a Chinese context. Taking care of the sick has always been regarded as a role for family members and the decisions regarding a patient's care were also always considered a family affair in traditional Chinese society. It is a well documented fact that the Chinese, because of the strong impact of their cultural values and tradition, exhibit certain personality characteristics and value orientations which are unique (Bond, 1996; Chow, 2000; Kwan, 2002; Phillips, 2000). In many western societies, individualism is the dominant ideology and a family is often perceived to be a unit consisting of a collection of related individuals. Recent studies have found that there is a hierarchy of family caregiving in western countries based on a caregiver's kinship relationship to an elderly relative (Draughn, Tiller, McKellar & Dunaway, 1995; Nolan et al., 1996; Wright, 1998). By contrast, Chinese culture traditionally assumes that the family is the basic unit of society. Confucian and Buddhist value systems uphold the perspective that caring for older people is a family responsibility. Confucianism also emphasizes the value of filial piety, requiring children to honour and look after their parents. The mutual obligation that characterizes filial piety has provided a firm basis for the provision of continuing care for frail elderly parents (Bond, 1993, 1996). This influences how Chinese people think and feel about their families and the expectations they hold of their lives as they age.

However, norms appear to be rapidly changing in some Chinese communities such as Hong Kong. Globalization, modernization and other social forces have influenced long-standing Chinese traditions. Structural changes also appear to be affecting the idea that the responsibility for elderly people providing care should be assumed by family members (Phillips, 2000). It is easier to be filial when families are large and life expectancy short. It is a bigger challenge in a modernized Chinese society with nuclear families and fewer children when one’s parents require long-term care. Having health problems, obligations towards one’s own family and holding a job are becoming socially accepted excuses for not assuming a heavy family caretaking role. It is also quite acceptable to employ others to care for an ageing spouse or parents.

In Hong Kong, it has been recognized that the family system is the only institution that elderly people can rely upon for help and support. Stroke profoundly affects the physical and psychosocial aspects of both the patient and the family (Lee, 2004; Lui, 1997; Mackenzie et al., 1998). A number of factors are behind the increasing stress of family caregiving in Hong Kong. They include the rise in the number of elderly people due to increased life expectancies for men and women and early discharge programmes in health care settings, which force family members to take over the task of caregiving at home; and limited support services provided for families caring for elderly victims of stroke in the community. The researcher argues that caregiving is not solely a task activity, but an activity that includes plans and decisions made by caregivers. These are not observable tasks, and may have important consequences for the lives of the caregivers. Smith and Smith (1991) reported caregiving concerns of individuals who cared for family members with a variety of chronic illnesses, such as heart disorders, arthritis, and stroke. The increasing burden and potential losses on caregivers has been well documented recently. These potential losses were substantiated further by

Hung, Liu and Kuo (2002), Scholte op Reimmer et al. (1998), Stein et al. (2003) and Sim et al. (1997).

### 2.5.1 The Chinese Confucian-based Family System

Confucianism is defined as ‘the ethical teachings formulated by Confucius and introduced into Chinese religion, emphasizing devotion to parents, family, and friends, cultivation of the mind, self-control, and just social activity” (Neufeldt & Guralnik, 1988, p. 293). It is important to examine how Confucianism shaped Chinese culture in order to understand Chinese health practices in family caregiving. The ethical foundation of the Chinese pattern of social relationships is Confucian. Confucius endeavoured to establish ethical principles that would promote peace and harmony in social relationships (Pang, 2003). It emphasized good behaviour in the five Cardinal Relationships: the relations between i) ruler and subject; ii) husband and wife; iii) parent and child; iv) older siblings and younger siblings; and v) friends. The individual knows his place in all human situations and shows kindness, benevolence, or ‘human-heartedness’ to other persons in ways that are appropriate to each situation (Reid, 1984, p.63-70).

The Chinese family system is based on Confucian ideas. As Lin (1988) stated, ‘…the family system is the root of Chinese society, from which all

Chinese characteristics derive' (p. 67). There is hierarchy in the traditional structure of the Chinese family. According to Lin, the oldest male members of the family head the hierarchy. The hierarchy of elders is determined by their relationship with the head of the family. Lin further stated that within the structure, the lines of authority-obedience are sharply drawn. The lineal head is the final authority, although he might choose to share his authority with his wife and also with other elders in the family. In the same family tree, authority for community affairs and public behaviour was shared by elders from various families under one primary authority figure in the community or village. This model of family structure, roles and relationships was basic to all levels of life and this pattern of social organization of human relationships has been part of Chinese life for many centuries (Pang, 2003).

### 2.5.2 Impact of Daode and Lunli on Chinese Family Caring

The present researcher adopted Pang's work (2003) on Chinese sense of family caring with lunlidaoda (倫理道德). Chinese conceptions of morality should be further explored, in order to understand the set of moral rules followed by the Chinese that continue to guide family caring. According to Pang (2003), morality is a set of basic rules and virtues that guide what a person ought to do and ought to be. *daode* (道德) and *lunli* (倫理) can be used interchangeably to signify morality and virtue in modern Chinese society. MacIntyre (1981) defined the Chinese meaning of virtue as follows:

> Virtue is an acquired human quality the possession and exercise of which tends to enable us to achieve those goods which are internal to practice and the lack of which effectively prevents us from achieving any such goods' (p.2).

According to Pang (2003), the meaning of *daode* (道德) emphasizes a person's compliance with virtue and the acknowledged good if one is to be considered to be practicing the rules and principles of *lunli*. She further stated that *lunli* (倫理), in the Chinese sense, is the rules, principles, and moral norms that govern human relationships and form a well-ordered society. This can help the researcher of this study understand why and how kinship relationships affect Chinese family caregivers who are either seeking intra-familial support or refusing extra-familial support when encountering stress and pressure as a result of their caring motivation and attitudes which influenced by input and output in the open and closed response systems.

Pang further elaborates that when there is conflict arise between two parties in their daily life, *li* (禮) and *ren* (仁) in the Analects of Confucius (倫語) would be used as the norms to justify 'right' or 'wrong'. Doctrine of the Mean (中

傭) states that it is the universal obligation of a person to perform one’s role with virtue. In traditional Chinese culture, this notion of obligation is a universal rule that should be observed by everyone in all circumstances. She stated that how a family member caring for a sick relative would be an important indication of his or her fidelity. In the Chinese sense, this implies that respect and affection should be practiced within the kinship ties that embedded in the social relationship. Family members usually build a communal support network within their own family. It is expected that children will devote themselves to caring for their sick parents even to the extent of sacrificing their lives. Thus, in Chinese culture, filial piety is considered as the crucial virtue, and this notion has been passed down from generation to generation (Bond, 1993).

The expectations of the filial duty of a person are best described in the Twenty-four Stories of Filial Devotion (二十四孝). With regard to moral obligation, it is important to fulfil one’s filial duty by taking care of one’s parents. In traditional Chinese society, it is expected that children will care for their sick parents. Besides, as a traditional practice in Chinese society, family members have been involved with treatment decisions. Traditionally, in Chinese society, if family members obtain help from outsiders, this can cause them to feel a sense of moral failure. This has important implications in assessing the caring patterns of Chinese family caregivers. In recent times, because of social and economic changes, it is acceptable in many Chinese societies such as Hong Kong for the younger generation to seek extra-familial support to care for their parents, by hiring someone to do so.

### 2.5.3. Reciprocity in Relationship with Cared-for-Person in the Chinese Context

According to Pang (2003), in traditional Chinese culture the caring role was expected to be assumed by women, such as a wife looking after her husband or a sister looking after her younger brother. According to Confucian teaching, good women should stay at home. During the Zhou Dynasty, a good woman was required to conform to the Chinese code for the conduct of women; namely, the three obediences and four virtues (三從四德). Traditional Chinese women were taught to manage a household and maintain family relations. It was usually their role to care for sick, and women needed their families to lead a private life in which they were not exposed to strangers. Pang further explained that it was considered that a woman who pursued a career would suffer a bad fate; and women were discouraged from pursuing an education and career. With the establishment of the first girls' school in 1844 in China and the rise of an anti foot-binding movement with the establishment of the National Feet Society in 1875 in Shanghai, women began to be able to pursue formal education and careers. When a Communist government assumed power in China in 1949, they declared that women should enjoy equal rights with men and freed women to enter the workforce.

Indeed, Mao Zedong, a founding member of the Chinese Communist Party and the first head of the People's Republic of China, regarded the liberation of women as one of the missions of a communist revolution (1927). He emphasized the importance of women's participation in the anti-feudal struggles for rural transformation. The communists helped to dismantle many of the restrictions on women in China and helped many Chinese women join the workforce to build a Socialist China.

### 2.5.4 Taoism and Confucianism in the Chinese Context

Although by definition culture is characterized by tradition, it is not static, but dynamic, and changes in response to events and changes in the environment. Chinese culture is no exception. In order to understand the traditional philosophy and religions of China, one can begin by examining the fundamental characteristics of Taoism, the ideas of which are sometimes considered as being opposed to those of Confucianism.

As Welch (1957) observed, ‘the Chinese themselves sum up Taoism by dividing it into Tao chia and Tao chiao – the “Taoist school” and the “Taoist sect.” The first category they restrict to partisans of the philosophy of Lao Tzu and Chuang Tzu. In the second they include all those groups that have taken immortality as their goal- alchemists, hygienists, magicians, eclectics, and in particular, the members of the Taoist church. This identification of the definition of Taoism is the creation of modern historians. “Tao chia” became current from the Han dynasty on as a bibliographic rubric, and in that capacity eventually came to cover works on alchemy, hygiene, magic, and religious ritual. This applied to ordained priests of the “the Taoist church” at least through the Six Dynasties (AD 220-589), and is even occasionally so used today. As for “tao chiao,” before modern times it meant simply “the teachings of the Way.’’ It was first applied in section 39 of the Mo-tzu to Confucian beliefs. By the time of the Southern Dynasties it referred to Taoist teachings of every sort, not in contradistinction to the Lao-tzu, but to Buddhism and Confucianism (Welch, 1957).

### 2.5.5 Filial Duty in Modern Chinese Families

In traditional China, taking care of the elderly was a filial obligation, and most frail elderly people were cared for in their own home by their children or other family members. Filial piety is a noble notion. But it needs to be backed up by appropriate home support care programmes so that filial sons and daughters can be provided with help in caring for their frail and aged parents over a long period in their own residences. Studies have found that most family caregivers are elderly spouses who also have chronic illnesses. The Chinese family is now very different in size and structure from families in the past. The notion of family duty in caring for ageing parents should be realistically assessed in the light of these changes, and in the growing ‘care gap’ (Walker and Walker, 1985) between the demand for family care and the supply of unpaid female caregivers (Ngan & Wong, 1993). These changes ought to be fundamentally examined in a successful Long Term Care Policy for the Elderly.

### 2.5.6 Kinship Relationships and Intrafamilial Support Networks in the Chinese Context

In traditional Chinese society, the relationships between and among family members were defined primarily by their roles and functions within the family system (Yang, 1992). These roles and relationships were symbolized in kinship terms. Learning these terms and the appropriate roles and functions they symbolized was basic to appropriate behaviour within the family system. In the Chinese context, *Guanxi* refers to social ties or connections among people and it also includes instrumental resources, generally based upon self-interest, and interpersonal resources that are considered both natural and necessary for one's emotional life in related to the Confucianism (Yang, 1992).

Kwan et al. (2003) and Chi, Lubben and Chappell (2001) explain that kinship *guanxi* is the strongest kind of intra-familial relations for Chinese individuals, followed by extended families and extra-familial relations such as neighbours, friends, co-workers and customers. They further state that g*uanxi* regulates the behaviour expected of people belonging to a particular network. An individual's social interaction, level of self-disclosure, and willingness to seek or provide help are some of the factors that contribute to the strength of *guanxi*. *Guanxi* also provides individuals with a sense of belonging and security. Moreover, it provides a framework of reference that assists in an individual's construction of social identity through a process of social comparison and self-evaluation (Pang, 2003).

### 2.5.7 Erosion of Traditional Values and the Weakening of the Obligation to Provide Support in the Chinese Context

Traditional Chinese values placed a heavy emphasis on filial piety and mutual support among kinship groups. However, it has been argued that with the influx of western ideology following the introduction of the open-door policy, traditional Chinese values are diminishing in influence and that many young people are seen to be prioritizing self-development and self actualization over family obligations and responsibilities (Sheng, 1992). According to Sheng, The emphasis on individualism, utilitarianism, and materialism is seen to be instrumental in eroding traditional Chinese values and undermining the traditional conception of the Chinese family. Although the influence of western ideology in changing Chinese values seems to have been exaggerated, social values in Chinese culture with regard to filial duty have indeed been changing.

In Hong Kong, many family caregivers found that they were increasingly unable to cope with the technical and emotional complexities of caring for elderly dependents whose health has deteriorated over time (Mackenzie & Beck, 1996). Indeed, in cases of senile dementia and paralytic stroke, the advice of specialized health care professionals such as physicians, home care nurses, physiotherapists, and occupational therapists on how to care for such elderly people at home is required. However, handicapped by a lack of such support and technical information, more and more caregivers are finding that the level of care that they had been giving their elderly dependents is proving to be inadequate. These caregivers then begin to feel helpless and ‘all alone’, and experience escalating levels of anxiety (Kwan, 1991; Ngan & Cheng, 1992). This increasing sense of helplessness, if not properly dealt with, may lead them to seek institutional care for their elderly dependents, even as the caregivers know that this may be against the elderly patient's wishes (Ngan, 1993; Ngan & Wong, 1995).

In the face of the challenges of an ageing population and changing social values, more and more families are finding it difficult to care for frail elderly members at home. Chong and Kwan (2001) found that hiring a maid to care for fragile elderly relatives was acceptable practice for family members in Hong Kong. They also identified that poor health and the unavailability of family members to care for the elderly are the two main reasons leading to the institutionalization of the elderly.

Hong Kong's ageing population has resulted in a greater need for public funding to care and support the elderly. The failure of the government to introduce any compulsory retirement protection system until recently has led to a higher percentage of the elderly today finding themselves in poverty and requiring public financial support. The diminishing functions of the family system to provide care, as well as the weakening value of filial piety, are other factors that have given rise to a greater demand for support services from the public sector. However, it would be a big mistake to assume that the care of the elderly is no longer a responsibility of the family. It may only be the form and the extent of care provided for the elderly that are not the same as before.

It is important for the government in Hong Kong to provide support to the family so that it is able to continue to perform its traditional role.

### 2.5.8 Intergenerational Reciprocity and Relationships in the East

Studies have been done to explore the kinship structures of Chinese families and the relationships among their members but not on the caregiving experiences of the Chinese (Chao, 1983; Baker, 1979; Fei, 1939, 1947; Hsu, 1967; Kwan et al., 2003). Chinese place high importance on love and devotion between generations in a family. Study showed that wives had a particularly heavy caring burden and they were also least likely to accept support services. A few studies found the interrelationships among the various components addressed by the individual stress and coping perspective (Lazarus and Folkman, 1984; Nagatomo et al., 1999; Schwarz, 1998; Williamson and Schultz, 1993). Clark (1995) and Jutras and Lavoie (1995) suggested that the ‘value map’ held by older caregivers were more likely to be concerned with issues of ‘self-identity’ than physical and mental health, and that interventions must focus more closely on the meanings that people give to their lives rather than simply assuring survival and postponing institutionalization.

The elderly in India have traditionally been assigned a place of honour and this status is reinforced through religion, social values, norms and social and economic organizations of the society. However, the Indian family system, which has been considered as a chief source of support and sustenance for the elderly, is changing in structure and functions because of industrialization, urbanization, modernization and occupational mobility. In this new scenario, have arisen many forms of institutionalized support. In addition, commitment to the care of elderly in different social groups varies substantially, reflecting subcultural values (Cumming & Henry, 1979). However at the micro level, even the elderly sharing religion, caste, subculture, economic status and living in the same region receive differential care from the family while some are entrusted to institutions.

Both in Japan and Korea, until the 1940s, the family was entitled to inherit the entire parent's fortune (Sung, 1992). Though the legal stipulation was later abolished, the burden of cultural expectation regarding parental caregiving is still on the eldest son. In the event that the eldest son does not play his role, another son is expected to assume the caregiving responsibility. A married daughter is not expected to take care of her aged parents, since she is regarded as having become a member of her husband's family.

In the People's Republic of China, family support is well defined by legislation. Children have the duty to support and assist their parents. When adult children fail to perform the duty of supporting their parents, parents who have lost the ability to work or have difficulties in providing for themselves have the right to demand that their children pay for their support. Zhu and Xu (1992) reported that regulations have been passed in 23 provinces, cities and autonomous regions to protect the legitimate rights of the aged. As an example, in the city of Tianjin, it is clearly stipulated in the Provisions on the Protection of Legitimate Rights of the Elderly that grown-up sons and daughters are duty bound to ensure the living standards of their parents with an income not inferior to their own average. Adult children who fail to meet their obligations may be punished under the criminal code. The incentives for adult children to support their elderly parents, then, lie not only in the tangible benefits they received and continue to receive from the parents, but also in the avoidance of the legal consequences associated with neglect of care of the elderly.

To summarize this part of literature review is to explore perspectives on caring and caregiving in Chinese families in relation to the contribution made by historical and social processes. It has been found that caring and caregiving emerge as profoundly complicated and ambivalent in the Chinese context, drawing on notions of filial piety, morality, obligation, kinship relationship and gender responsibility.

## 2.6 The Western Context of Family Caring and Caregiving

In the West, although caregivers described in some studies were likely to be older, Caucasian, and female (Laizner, Yost, Barg & McCorkle, 1993) and this was consistent with the participants' demographic characteristics, other studies found more diversity of age, race, and gender (Harrington et al., 1996; Jones, Roth & Jones, 1995). Some caregiver literature also identified the family caregivers as either older spouses or daughters (Laizner et al., 1993; Biegel et al., 1991; Given & Given, 1991).

Most program planning and research into case management and service integration has been framed within the perspectives of professionals, programme providers or system managers. Approximately 25% of all households in the United States provide care to family members (NAC & AARP, 1997). Studies focused on the perspectives of family caregivers of survivors of chronic disability, a client group that typically has complex and long-term needs, placing them "at risk" for discontinuity in care planning and integration (Gaugler, Kane & Kane, 2002; Kwan et al., 2003; Wright, 1998). Although the caregivers in these studies were faced with overwhelming obstacles and irreversible changes in their own lives, they did not seek to relinquish their role as primary caregiver. However, it was apparent that these individuals urgently needed support to enable them to continue to bear the physical, social, and financial costs of their caregiving responsibilities.

### 2.6.1 Motivations for Assuming Family Caring in the West

A multitude of institutional, social and psychological factors come into play to determine the decision for assuming care (Finch, 1990; Globeman, 1996; Guberman, Maheu & Maille, 1992; Hirschfield, 1983; Walker, Pratt, Shin & Jones, 1990). In Guberman et al.'s (1992) in-depth qualitative interviews, 40 female francophone Quebecois family caregivers of frail elderly reported on their material, social and psychological conditions. These conditions included feelings of warmth and emotional affection and interconnectedness with family, gender-role conditioning and life situation. The availability of other family members and the inadequacy of community and institutional alternatives were other reasons given by the caregivers.

Horl, Wanner, Schollmeyer, Schaefer and Heidland's study (1989) based on 49 life history case studies/biographical research among caregivers in Vienna. They reported that caregivers were motivated more by variables such as gratitude from those cared for. Material compensation and mutuality in the relationships, a sense of obligation (based on reciprocity) and a distinct feeling of a lack of alternatives were secondary incentives for assuming care.

However, contrary findings were reported by Sung (1992). Sung investigated 130 Koreans who were awarded the Filial Piety Prize between 1970 and 1985 identified the following as significant motives: respect for parents, filial responsibility, maintenance of family harmony, repayment of debts and filial sacrifice (Sung, 1992).

By contrast, Finley, Roberts and Banahan, (1988) examined the attitudes of filial obligation by parent type (father, mother, mother-in-law, and father-in-law) and by gender of the adult child (son, daughter and daughter-in-law). They surveyed 1,760 subjects and found that caregiving obligation was affected by structural and demographic factors such as distance and role conflict. The varied associations with filial obligation by parental type could be explained by varying costs, rewards and levels of reciprocity.

Pioneer researchers have consistently identified that one family member occupies the role of primary caregiving (Cantor, 1983; Horowitz, 1982b; Johnson & Catalano, 1981; Noelker & Poulshock, 1982). Other family members or friends, if involved at all, play secondary roles and shared responsibility between two or more members of the informal support system is very much the exception to the rule. There is also almost universal consensus about the identity of the primary caregiver, with selection following a hierarchical pattern. Simply, the primary caregiver is a spouse, if one is available and capable, and an adult child, if there is no spouse. In the absence of spouse and children, other relatives such as siblings, nieces and nephews take on the responsibility of primary caregiver. Only for the minority of older people lacking any functional kin are friends and neighbours identified as the primary caregivers (Shanas, 1979, 1980; Stoller, 1983). Robinson (1986) indicated that the bulk of care provided to the ill and disabled was not distributed evenly among family members; rather, elderly spouses and adult women in the family provided most of the basic services. These findings draw attention to the complexity of caring and provide direction for health professionals in their work with individuals and families and in lobbying for necessary resources.

### 2.6.2 Intergenerational Reciprocity and Relationships in the West

Reciprocity emerged as a component of the complex of factors in the ongoing caregiving relationship. For example, Magdzik, Naruszewicz-Lesiuk and Czarkowski's study (2000) carried out in Poland; changes of the socio-political situation in Poland over the last ten years have had a strong impact on the economic and social situation of the elderly as well as on their family position and intergenerational relationships. The aim of the study was to analyze the family life situation of the elderly in contemporary Polish society. The analysis was based on the survey conducted in 2000 on the representative sample of 600 interviews of aged over 65 years old. The results of the study showed that elderly people are strongly involved in their family life. Over 75% of older people live with somebody. Almost 75% of the elderly are asked for advice concerning the important family questions. 87% of children have an appropriate respect for their old parents. 64% of the elderly take part in family meetings at least a few times a year. More than 94% of old parents estimate their relationship with their children as very good or quite good. If an old person was in need, he/she would turn for help mainly to family members. The role of reciprocity is quite common in the analyzed families. Apart from a decrease in the percentage of old people living together with their younger family members, and some changing customs among the younger generations, the family in Poland remains stable and is the most important group for meeting the psychological, social and caring needs of the elderly people.

Canada's steadily aging population is becoming top heavy with persons in their late 70s and 80s who are at increased risk of chronic health problems and physical and cognitive impairments that threaten their ability to maintain independent households. It is important to analyze reciprocity, which is a key element in preserving a sense of self-worth and integrity for the elderly. It is generally recognized that care provided to a frail relative constitutes a non-reciprocal relationship between caregiver and care recipient, particularly when the latter suffers from dementia. Little research has been done into the question of the subjective assessment of care of a frail relative. In Canada, Lavoie, Miller, Coneay and Fleet, (2001) found the meaning of caregiving means reciprocity and four types of reciprocity found in this study in providing care for a frail relative. There was a connection between the type of reciprocity and the type of disability (cognitive or physical) experienced by the relative, the type of reciprocity is primarily tied to social and family norms, the quality and the nature of the relationship between the caregiver and the cared-for-person. The ability to see care as a reciprocal relationship seems to enable caregivers to continue involvement in the care of their relative by compensating for some of the difficulties they may experience.

Relationship is often strained by the problems of sustaining the parent in some kind of normal existence in the community without support within the family or from outsiders. Simple tasks such as daily personal care activities could be a source of tension. Studies found that older spouses were more likely to personally provide care than adult children and paid community support staff was more likely to give personal care when adult children were caregivers (Orel, Ford & Brock, 2004; Dautzenberg, Diederiks, Philipsen, & Tan, 1999). Less was expected of adult children than was expected of spouses as caregivers in the families. Thus, nurses must advocate culturally competent programs to support caregivers of the elderly in order to bridge the gap.

MacLellan, Norris and Joffres's study (2001) focused on the caregiving relationships between aging parents and adult children with lifelong disabilities and concentrates on the care provided by the parents to the adult children in Canada. Results shown that the uni-directional depiction of caregiving seems plausible given the impact of disability, but it does confirm the general understanding that caregiving is usually not a one-way activity in aging families. Rather, caregiving can be reciprocal.

Differences are sources of conflict and misunderstanding in caregivers and cared-for-person relationships among different ethic group (Angel & Thiots, 1987; Blumhagen, 1982; Good, 1977; Kleinman, 1980). It is important to identify intergeneration relationships and issues in each culture. It is also the purpose of this study. Thus, health care providers must advocate culturally relevant programs to support caregivers of the elderly in order to bridge the gap in understanding.

### 2.6.3 The Effects of Family Caregiving on Quality of Life in the West

The important role of family caregivers in maintaining their disabled and elderly members in the community is becoming increasingly recognized. Caregiver research, for the most part, has explored burden and emotional distress as outcomes of the caregiving experience. Although there is a growing consensus among health-care researchers concerning the importance of quality of life as an outcome, there is little research examining quality of life of family caregivers.

Studies focusing on the relationships between stroke survivor and family caregiver factors and the caregiver's health-related quality of life found significant correlations using quantitative measures (White et al., 2003). Burton, Zdaniuk, Schulz, Jackson and Hirsch (2003) reported the trajectory of health outcomes associated with caregiving was generally downward. Those who transitioned to heavy caregiving manifested more symptoms of depression and poorer self-reported health and health behaviours. They suggested that the transitions into and within the caregiving role should be monitored for adverse health effects on the caregiver with interventions tailored to the individual's location on the caregiving trajectory. Further research is needed to investigate interactions between caregivers and cared-for-person to identify the negative health outcomes and its impact on the overall quality of the caring experience (Phillips et al., 1995).

To summarize this part of literature review, many studies done in the West focus on the ‘pathologizing’ aspects of care and fail to address the way in which how experiences, orientations and social relationships change over time in caregiving experiences (Bond, 1996; Nolan et al., 1996; Twigg and Atkin, 1994). The importance of the family caregiver’s perceptions of the intention and purpose of caregiving (caring) has not been acknowledged, especially in the Chinese context. Consequently, research findings in the field of family caring offer a fragmented understanding of the process of family caring experienced by Chinese family caregivers caring for stroke-impaired elderly relatives. Nolan et al. (1996) and Kramer (1997) called for a more positive, multidimensional, and holistic approach to the study of family caregiving.

In view of the fact that the majority of the existing studies on family caring have been written in the West and have largely relied on concepts and theories developed in the West. It argues whether these concepts and theories of family caring can be applied directly to the Chinese context.

## 2.7 The Impact of Stroke Rehabilitation on Families in Hong Kong

Several authors have investigated the responsibilities undertaken by Chinese family caregivers of stroke-impaired relatives, the difficulties they experience, and the impact of community support groups for them in Hong Kong (Lee, 2001; Lee, 2004; Lui, 1997; Lui & Mackenzie, 1999; Mackenzie et al., 1998; Woo, Yuen, Kay & Nicholls, 1992).  All these studies found that the impact of caring for stroke patients was traumatic and exhausting. It has been posited that education and support groups can enable these family members to better carry out their responsibilities. But patients and family caregivers have not been asked for their opinion on how services should be improved.

Mortality and morbidity are high in elderly stroke-impaired patients. Early mobilization and prevention of stroke-related complications improve their ability to participate in a more intensive and comprehensive rehabilitation programmes. An appropriate approach to stroke rehabilitation restores functional loss, improves quality of life, and decreases long-term economic costs. Important parts of stroke rehabilitation include patient and family education, treatment of stroke-related complications, and prevention of recurrent stroke. A caring and flexible family caregiver and the mobility of the stroke-impaired individual are the most positive predictors of stroke outcome (Sit et al., 2004; White et al., 2004). Rehabilitation is an important part of recovery and should begin as soon as possible after a stroke. Understanding the effects of stroke and tailoring learning to the individual client can make a big difference.

Rehabilitation begins quickly in the process of recovery from a stroke. The main recovery following a stroke takes place within the initial two months, but improvement continues for six months to many years, as affected parts of the body are exercised and used. The primary goal of rehabilitation is for the victim to live as independently and as productively as possible. To reach this goal the stroke-impaired person must have the will and the ability to participate and actively cooperate in the rehabilitative process. Weakness, fatigue, and often depression are common during the rehabilitative process. For these reasons, a stroke-impaired person needs a lot of encouragement and support from their family members and rehabilitation personnel in order to persevere.

### 2.7.1 Community Care in Hong Kong

With a predominantly Chinese population and a cultural tradition of respecting the old, Hong Kong has long relied on the family to support its elderly relatives. Most elderly Chinese would rather stay at home and they would rather be cared for by family members even if their health status is deteriorating. Ngan et al. (1996) found that family support is crucial in determining the need for long-term care in living in the community. Appropriate support and strategies should be developed to enhance the ability of Hong Kong families to look after elderly dependents with physical, functional, and mental disabilities (Leung and Lo, 1997). How effective are efforts to integrate the elderly in the community? Few services and little support have been extended to family caregivers in the home setting, however (Chow, 2000; Leung, 2000; Ngan et al., 1996; Kwan, 2002). While community integration has been a policy objective since 1977, the community-wide survey conducted by Ngan et al. in 2000 found that older handicapped adults showed moderate to fair levels of knowledge of their community, and demonstrated a modest level of social interaction. Adults with a moderate to severe level of intellectual disability showed significantly lower levels of assertiveness, knowledge about their community and social services, and availability of a companion.

Previous studies have revealed that home care was more relevant for stroke patients and their families than hospital care (Lui, 1997; Lui & Mackenzie, 1999; Woo et al., 1992). Therefore, the effective management of the health problems of the elderly depends greatly on their family members. These family caregivers supplement the care and services provided by formal agencies and help delay or even prevent institutionalization. Since the 1990s, the government's policy has been to promote community care, as a partial substitute for institutional care. This, along with changes in the traditional family structure that have led to a reduction in family ties and diminished social support, has increased the burden on family caregivers. Chow and Chi (1999), Leung (2000) and Kwan (2002) point out that it is important that the needs of family caregivers be met to prevent or at least delay the institutionalization of the elderly. They emphasize that the expense of maintaining them at home would be less than the expense of providing care in institutions, and argue that some of the cost of maintaining the elderly in their homes should be borne by health and social services.

Most of the newly industrialized societies in Asia are experiencing a rapid ageing of their population and reduced levels of family support in caring for elderly people. In order to help frail elderly to stay in the community, most of these societies are developing community care programmes for their senior citizens. Although the Western experiences in developing community care services are useful to Asian countries, differences in historical background, in political and economic development, and in culture can have very different concerns and patterns of community care in these societies.

In Hong Kong, the concept of ‘community care’ is central to Government’s approach to providing care and services to the elderly. The 1979 White Paper entitled ‘Social Welfare into the 1980s’, and the Report of the Working Group on Care for the Elderly’, published in August 1994 affirmed the policy of ‘community care’ (Hong Kong Government, 1979, 1994). ‘The concept of “ageing in place”, otherwise known as care in the community, is essential to the existing philosophy of providing services for the elderly persons’ (Hong Kong Government, 1994, p. viii). In a broad sense, this means that appropriate support services are to be provided for the elderly and their families to enable them to live in their familiar social environment. Such a concept is close to

Baylay's (1973) elaboration of 'care in the community' and 'care by the community'. This basic principle applies to the fields of health, welfare, and rehabilitation. With a range of formal and informal services from these fields to meet the various needs of elderly people, it is believed that such people should be helped to lead an independent and dignified life in the community instead of being institutionalized in hospitals or in homes for the elderly.

But in the 1980s, community support services were desperately insufficient. Several surveys revealed that the informal support systems of frail and disabled elderly patients were weak and poor (Chi & Chui, 1999; Ngan, 1990; Ngan & Kwok, 1990). Ngan and Kwan (1995) further stated that 'community care' became 'family care', since informal support networks mainly consisted of family members. Poor interpersonal relationships within the family, insufficient personal care paid to the elderly, and a lack of time to attend to the young generation are possible social costs of the practice of 'family care'. In view of this, both Ngan and Kwan (1993) and Kay (1993) advocated better support for both families and elderly people in the community, and also better coordination of formal and informal support systems (Ngan & Kwan, 1993; Kay, 1993). In the late 80s and early 90s, more community support services were developed in both the welfare and health sectors. Examples included the establishment of out-reach service teams to help elderly people living alone, elderly health centres, community-based geriatric assessment teams and psychogeriatric teams (Lo & Lau, 1988; Hong Kong Government, 1994).

However, the increase in these services did not seem to improve community care for the needy. The duplication of direct services to the same target groups and gaps in service still remain. For instance, a stroke patient demands a great deal of support from family members in terms of psychological acceptance and extra care after being discharged (Han & Haley, 1999; Low et al., 1999; Morrison, 1999). Family members must be educated by members of the rehabilitation team from different disciplines about possible profound emotional changes in the patient and appropriate home care (Brody, 1985). Without effective coordination between these formal and informal support systems, the patient may not receive proper care. Fragmented services would not provide holistic care for elderly people and will not enhance the concept of ‘community care’ (Chow, 1993).

### 2.7.2 The Challenges of an Ageing Population in Hong Kong

Over 95% of Hong Kong’s population is Chinese, who traditionally rely on themselves and their families for assistance in times of need. In line with such traditional Chinese values, an older person should be provided with help to live in and integrate with his/her own community with dignity. To this end, a spectrum of services and opportunities should be provided to facilitate the person’s continued participation in the community both socially and economically for as long as possible.

There are different views of the impact of ageing on the health and welfare systems of a society. Some demographers are optimistic that with healthier lifestyles, control of environmental health risks, and a greater proportion of people retiring with pensions, people will be healthier in their later years and the need for health support services will likely to be compressed into a person’s last years of life.

Most gerontologists, however, are less optimistic about this (Chou & Chi, 2003, 2004; Chow, 2000; Leung, 2000; Ngan & Kwan, 1995). They realize that ageing is inevitably associated with deteriorating health, illnesses, and disabilities. With longer life expectancies and the prolongation of chronic illnesses due to medical advancements, health and welfare services for the elderly will need to be extended for longer periods. The increasing financial burden of these services on society, and the decreasing number of economically active persons to shoulder the burden due to low birth rates and other factors such as unemployment, present major challenges for the Hong Kong government. As one response, the Government of Hong Kong has introduced a system of forced saving for retirement, the Mandatory Provident Fund Scheme.

Another major challenge faced by the Hong Kong government is the changing needs of the elderly. The next generation of elderly people in Hong Kong includes those who were born in the 1940s, after the Second World War. Unlike the present older generation, this group has generally enjoyed a better diet, nurturing, and education. They may also have higher expectations of what society should provide for them in their old age.

Increased labour mobility in recent years has also resulted in some less physically or economically mobile elderly persons being left behind in Hong Kong while their children have migrated to other countries. While nuclear families have proliferated, many elderly persons choose to live separately from their children. This had led to an increasing demand for housing for the aged and to problems associated with elderly people who are living alone.

Apart from material requirements, elderly persons need to have a sense of security and of belonging either to their families or to the community. They need to enjoy their later years of life in dignity through meaningful social and recreational activities within their physical and financial reach. This need is all the greater, as they can expect to enjoy a longer life after they retire than previous generations.

Since the 1980s, Hong Kong has become an ageing society. In 1999, 10.7% of Hong Kong’s total population, or 734,100 people, were aged 65 and above. The population of elderly is expected to increase greatly, especially those 80 years and older, who made up 12.6% of the population in 1996 and constitute 16.8% in 2016 (Census and Statistics Department, 2004). Hong Kong has adopted the community care policy since the 1970s and this policy is still upheld by the government. Community care will likely always be the cardinal principle in the provision of welfare services for older people in Hong Kong. After the handover of sovereignty over Hong Kong from Britain to China in 1997, there was a change in the rationale behind community care, which is now often taken as an actualization of filial piety.  This is an excuse to shift the responsibility of taking care of the older generation to the family, especially to the women in Chinese families in Hong Kong. With the increase in the old-old population (those over 80 years or more in age) and the recognition of the difficulties that families face in caring for increasingly frail or demented older people. The government should consider formulating a more explicit family support policy to maintain as far as possible the traditional roles of the family and community in supporting elderly people.

The government is now more ready to directly face the issue of an ageing population. The Elderly Commission, which is a high-level advisory body, was set up in 1997 to advise the government on the formation of policies and the monitoring of programmes. Several new initiatives have been launched to facilitate ageing in place, such as services to family caregivers and projects for the demented elderly. While this change in rationale is in the right direction, planning efforts are still rather piece-meal and reactive. Some initiatives have launched without careful prior consideration.

## 2.8 Summary of Chapter Two

A review of the literature shows that Chinese family caring of stroke-impaired elderly relatives as a process that occurs and changes over time has not been adequately addressed. It is also noted that the different family caring experiences and processes reviewed in the previous sections were based on the studies done overseas. The phenomenon of stroke-related family caring has not been studied extensively in Hong Kong. With the changing socio-economic situation of Hong Kong society, the findings of studies in understanding Chinese family caregivers' experience of stroke care have to be considered with caution. Target services based only on the findings from western studies may not be effective in a Chinese community, but it is important to build up real and accurate knowledge of the understanding of the family caring experience of Chinese family caregivers of stroke-impaired elderly relatives. Welfare policy should also be formulated to assist the family caregivers to continue to provide care in the community of Hong Kong.

Despite the large number of studies carried out in the field of stroke, the process of adjustment that the family caregivers needed to cope in order to provide care is not well understood, especially in the Chinese cultural context in Hong Kong. Many studies have documented specific aspects of rehabilitation with stroke victims such as post-stroke perceptions, the incidence of anxiety and depression and the frequency with which recovered individuals return to work. However, the importance of the experiences and perceptions of significant others as the primary caregivers of stroke-impaired elderly relatives in the Chinese cultural context in Hong Kong has not been well covered in the literature. Consequently, research findings in the field of stroke rehabilitation offer a fragmented understanding of the process of adjustment experienced by the significant others following stroke.

Previous studies have identified predictors of caregiving burden, depression, negative health outcomes, self-losses and poor quality of life but little has been done to identify positive predictors of caregivers at risk. It is the purpose of this study to identify both positive and negative predictors of caregiving with respect to the process of caring of different family caregivers. This study examines the experiences of Hong Kong Chinese family caregivers in terms of their level of importance and the perceived level of the family caregivers' satisfaction. By listening to the voices and concerns of the caregivers, this study aims to fill the gap in knowledge and sensitize the government so that they will address community care issues and design programmes to assist family caregivers. This will help health care providers to understand how traditional cultural values such as Confucianism influence the acceptance of intra-family and the rejection of extra-family support networks and shape the caring outcomes within a Chinese cultural context.

By the year 2015, people aged 65 and older will comprise 14.3% of the Hong Kong population (Census and Statistics Department, 2004). More important, people age 85 and older are the fastest growing group in this population. These demographics increase the need for clinical interventions with the old and very old. Kwan et al., (2003) identified the older female spouses as the primary caregivers in family caregiving. However, nursing interventions must be based on research. While there has been growth in gerontological nursing research over the past two decades, there is an inevitable need for clinical intervention studies that are theory-based, have reliable designs, and apply advanced research methods (Adams, 1986; Murphy & Freston, 1991; & Whall, 1989).

Therefore, the focus of the literature review is to identify and examine the existing body of knowledge of family caring within which patterns and strategies in family caring emerged from study data. By conducting a thorough review on the concept of family caring, it is hoped that a more sophisticated and holistic understanding will emerge that will add to theoretical and methodological debate, and indeed to policy and practice in family caring.

To conclude, the reasons promoting sustained caregiving involvement differ among different ethnic groups and thus socio-cultural context must be addressed prior to planning programs and making funding arrangements. Programmes could be redesigned to more fully acknowledge and respond to the perspectives and needs of family caregivers. By focusing on the caregivers' perspective, this study addresses a gap in the research literature. A gap that is especially wide in terms of Chinese family caregivers of stroke-impaired elderly relatives.

# CHAPTER THREE

# DESIGN OF THE STUDY AND ANALYSIS OF DATA

This chapter outlines the methodological considerations in the study and justifies the research strategies used to explore and explain the experience of caring as described by Hong Kong Chinese family caregivers of stroke-impaired elderly relatives. The following will be discussed in this chapter: a) the study approach, b) theoretical sampling, c) the procedures used in collecting data, d) ethical considerations, e) and the procedures used in analyzing the data.

## 3.1 Introduction

This study adopted a qualitative research design, since this allows a researcher to proceed inductively and to understand the Chinese conception of family caring through the use of the grounded theory approach. This will provide us with an understanding of how Chinese family caregivers make decisions to continue to provide care for their stroke-impaired elderly relatives. To facilitate the identification of the patterns and outcomes of family caring, a two-interview qualitative approach was adopted. The researcher initially planned to recruit 20 family caregivers to achieve a substantial collection of data. After interviewing 15 caregivers, no further new data categories were identified. This means that it was not necessary to recruit further participants, since data saturation was achieved. The second interviews were arranged two years after the first interviews as a means of refining and confirming the results of findings from the first interviews. Ultimately, the study was based on a two-interview approach which included two in-depth home interviews with 15 family caregivers meeting the criteria for inclusion in the study.

## 3.2 Research Design

The purpose of the study is to explore the meanings, patterns, variations and relationships among the components of the caring experience in Hong Kong Chinese families. Interpretive explanations of perceived needs and their variation among the 15 family caregivers were inductively generated from the data. It is hoped that the findings of this study will provide insights into and an understanding of the patterns and attributes of caring. The longitudinal nature of the research is likely to yield deeper insights into these phenomena than would be possible with a cross-sectional research design.

### 3.2.1 Theoretical Basis of Grounded Theory

This study employs an exploratory and descriptive design based on a grounded theory approach. Grounded theory (Glaser, 1978, 1992; Glaser & Strauss, 1967) is a method used to discover social process within social structure. Grounded theory, then, allows the present researcher for exploration of the caregiver's caring process within the changing health and social systems. This method was chosen to permit generation of a model or theory of a little known area based on statements made by family caregivers. This position values the distinctiveness of the Chinese caring experience and alerts us to the importance of culturally distinct practices. Sensitivity to cultural factors helps the underlying needs of caregivers in Chinese families to be identified accurately. Silverman (1993) argued that cultural sensitivity directs our attention to the unique experiences of individuals and reveals how such experiences are created by given forms of representation.

The majority of empirical studies of family caregivers have adopted quantitative research methodologies that emphasize the measurement of perceived stress in family caregiving during periods of transition (Abraham & Berry, 1992; Chan & Chang, 1999; Clark & Rakowski, 1983; Dennis et al., 1998; Lee, 2001; Pound, Gompertz & Ebrahim, 1993; Sim et al., 1997; Stewart, Archbold, Harvath & Nkongho, 1993; Wilkinson, Wolfe, Linto &

Warburton, 1997). While these approaches to studying the meanings, variations, and patterns of family caregiving have definite merits, the present researcher argues that the phenomenon of caring within Chinese families deserves an alternative research paradigm. Here, the emphasis should be on developing an explanatory model, which emerges from interpretation of the data, and on developing a deep understanding of the impact of historical, social and cultural forces on the process of caring in the Chinese context of Hong Kong.

A grounded theory approach was used in this study, in which the researcher developed a theory with at least four interrelated properties including fit, understandability, generalizability and control, as suggested by Strauss and Corbin (1990, 1998). Using the grounded theory approach allows the phenomenon of caring among Hong Kong Chinese family caregivers to be better understood by health care providers. Appropriate policies and services can then be implemented to support caregivers.

According to Morse and Johnson (1991), a model or theory of the experience of illness should emerge from the data without the need to impose another model or theory on the experiences. Such a model or theory must also fit into what is already known about the experience of illness. Such concerns can be overcome by using qualitative methods to develop a satisfactory inductive model, because the strength of the qualitative approach lies in its capacity to generate rich data on a family’s subjective experiences, thus increasing the understanding of family motivations and behaviour in stressful situations. The grounded theory approach is particularly appropriate for describing processes or patterns, as it allows for the adaptability that is required for understanding the course of experience of illness. A theory derived from data is more likely to resemble ‘reality’ than a theory derived by putting together a series of concepts based on experiences or solely on speculation.

Lofland and Lofland (1984) emphasized that a qualitative research method begins with a researcher’s personal concerns and involves determining what he/she cares about, independent of the social sciences. Knafl and Deatrick (1987), in a review of research on families with chronic illnesses, noted that quantitative studies aim to predict and control the impact of chronic illness on family life. This is because quantitative approaches such as caregiving burden scale measurement have limitations in that they do not need the family caregivers’ voice and concerns and so may not provide a suitable basis for the recommendation of appropriate services. Fisher et al. (1985) asserted that a major problem in quantitative measurement is ‘creating data that will reflect the family as a unit’ (p.213). A qualitative approach to researching the family is appropriate when the purpose of the research is to explore or to understand family processes, relationships, or characteristics. In a classic exploratory study of the poorly understood phenomenon of family violence, Gelles (1974) conducted qualitative, unstructured interviews of families with a history of domestic violence. Rose (1983), a nurse researcher, used in-depth interviews with seven families to explore the process by which family members develop an understanding of mental illness and its treatment following a family member's first psychiatric admission.

### 3.2.2 Grounded Theory: Symbolic Interactionism

In this study, the grounded theory approach, based on symbolic interactionism, is used as the guiding theoretical framework for the collection and analysis of data. This conceptual perspective is useful for studying how individuals make sense of their experiences throughout life, and how interaction with others helps give shape to the meaning in people's life. Grounded theory approach originates in the interpretive paradigm of symbolic interactionism (Annells, 1996). The basic tenet of the symbolic interactionist perspective emerged from Mead's (1962) study of social nature and the origin of self. Drawing on the work of Mead (1962) and Blumer (1937, 1969), three basic premises of symbolic interactionism are outlined as follows: (a) interaction with others is based on communication using symbols, which most often consist of words but also can be body language as well as attributes and artifacts; (b) adopting the perspective of symbolic interactionism enables researchers to gain an interpretative understanding of social interaction, so that an explanation is acquired social messages, the process of internalization of cultural models and the motivational force on which to sustain caregiving; (c) individuals will act towards things in terms of the meaning they have for these things. Meanings are central to the understanding of behaviours. Constant comparative analysis facilitates examination of caring phenomena in the context in which they occur. Indeed, its intention is to move beyond the merely descriptive, to reveal or explain patterns and variations in caregiving, and develop cultural models that provide direction. LaRossa & Reitzes (1993) and Reiss (1981) found that symbolic interactionism was particularly well suited to family studies. The influence of symbolic interactionism gives grounded theory its distinctiveness as a method in that the major assumptions underlying symbolic interactionism are that an individual's actions are based on the meaning that events have for him/her, and that the meaning of these events is derived from interaction with others (Annells, 1996).

Blumer (1969) condenses the essence of symbolic interactionism in the following words:

> Whatever the action in which he is engaged, the human individual proceeds by pointing out to himself the divergent things which have to be taken account in the course of his actions. He has to note what he wants to do and how he is to do it… he has to take account of the demands, the expectations, the prohibitions and the threats as they may

> arise in the situation in which he is acting. His action is built up step-be-step through a process of such self-indication. The human individual pieces together and guides his action by taking account of different things and interpreting their significance for his prospective action (Blumer, 1969, p.81).

This study approach is consistent with Rowles and Reinharz's (1988) definition of qualitative gerontology. The approach is: "Concerned with describing patterns of behaviour and processes of interaction, as well as revealing the meanings…that pervade elderly people's experiences and the experiences of others in relation to old age" (p.6). This type of approach was made possible through the use of a multiple-case design with theoretical sampling and constant comparison analysis for coding processes to generate a theory from study data. The decision to organize the data by "cases" was made for a number of reasons. Firstly, such an approach allowed the researcher to engage in an intensive analysis of a single case by comparing it other cases using the constant comparison analysis method (Strauss and Corbin, 1998). Secondly, this approach also helped the researcher to recruit study participants from purposeful sampling to theoretical sampling. As Jarrett (1992) states "First hand knowledge of real-life situations and processes in natural settings… and an understanding of the subjective meaning that actors give to the behaviours and events being observed and discussed" (p.176). Thirdly, a case-study analysis allows me to address the issues of process and transience because the emphasis is on developing a theory to account for the process of events as they evolve (Miller, 1986; Strauss, 1987; Strauss & Corbin, 1990; 1998).

### 3.2.3 Stance of the Researcher

Symbolic interactionism rooted in grounded theory is based on the concept that behaviour occurs within a social setting, influenced by socially derived concepts of self, others and group (Mullen, 1986). Therefore, grounded theory is the method of choice when examining a social problem within a dynamic process with the aim to discover the basic processes that people use to deal with these problems (Benoliel, 1996).

The study investigates caring experiences by interviewing family caregivers to obtain a description of their caring experiences. Employing grounded theory (Strauss and Corbin, 1990; 1998) allowed the researcher to enter the world of the participants and gain insight into the experiences of caregivers from the cultural perspective of Hong Kong Chinese. In a naturalistic inquiry, the following are usually expected: (a) phenomena are investigated as they occur naturally; and (b) research outcomes are derived inductively (Lincoln & Guba, 1985).

The basic philosophical and methodological issues that underlie the axioms of this naturalistic paradigm have been discussed by Lincoln & Guba (1985). According to Lincoln & Guba, paradigms are axiomatic systems characterized by their own differing sets of assumptions about the phenomena being studied. They are used to guide the study process in order to allow the researcher to understand family adaptation through caring in the Chinese context rather than to verify theories already developed in the West. This study argues against the ‘positivistic’, conventional paradigm of inquiry, and proposes an alternative paradigm that is ‘naturalistic’.  The six basic axioms of a naturalistic paradigm are described as follows (Lincoln & Guba, 1985):

1. Natural setting: Realities are whole and cannot be understood in isolation from their contexts, nor can they be fragmented for a separate study of the parts.
2. Human instrument: Uses himself or herself and other people as the primary data-gathering instrument.
3. Multiple-cases reality: Uses multiple cases as to compare among cases
4. The possibility of generalization in a specific cultural context,
5. The nature of the explanation (the viability of the concept of causality)
6. Utilization of tacit knowledge: Argues for the legitimization of tacit knowledge in addition to propositional knowledge.

In this study, in-depth interviews were used to gather specific and detailed data in the natural home setting of the participants. Non-directive and open-ended inquiry guides were used with the participants to stimulate potential areas of free thinking related to the phenomenon of inquiry. In-depth interviews were held to elicit detailed information related to the meanings and experiences of care within different life contexts. Interviews were conducted in the participant's home, the usual place of caregiving. According to Streubert and Carpenter (1995), truth, for the purpose of this discussion, is defined as reality. The four ontological positions regarding reality developed by Lincoln and Guba (1985) are: objective, perceived, constructed, and created. For the purpose of this study, the researcher adopted the ontological stance that truth or reality is socially constructed.

## 3.3 The Grounded Theory Process and its Application to the Present Study

The grounded theory process is influenced by the emerging theory and has been referred to either as cyclical and spiral (Glaser, 1978, 1992) or hierarchical and recursive. For the purpose of this study, four cyclical stages of grounded theory process are integrated as: research question identification, data collection, and constant comparison method and data analysis.

### 3.3.1 Study Setting

Fifteen participants were recruited from family members of patients of two stroke wards in two metropolitan hospitals and two community stroke support groups. Stroke rehabilitation programs are managed in the multi-disciplinary approach in the hospitals and community agencies in Hong Kong. To recruit participants in the social welfare agency, letters and study information sheet were sent via the person-in-charge in the social welfare agency to each family member, inviting him/her to join the study. The researcher then contacted those participants who replied directly to the person-in-charge. To recruit participants in the stroke support groups, the person-in-charge of each stroke support group introduced the researcher to the members in their monthly meetings. Family members who met the criteria for inclusion in the study were scheduled for interview appointments. The participants were reassured that their responses during the interview would in no way affect the health care given to their relatives at that time and in the future. The purpose of the study was stated and informed consent was obtained before an interview was conducted. Of course, it is possible that power differentials might have caused members to feel obliged to participate.

### 3.3.2 Initial Phase

Interviews consisted of exploratory questions dealing with experience of providing care for elderly relatives with stroke after discharge from two hospitals with stroke ward and out-patient clinic service (See Figure 3.1 below). The researcher approached family caregivers in the out-paitent clinic of two hospitals by introducing the purpose of study and obtained verbal permission to schedule home interviews. Question areas were grounded in exploring the family experience of caregivers caring for stroke-impaired elderly relatives. Four participants were selected based on the inclusion criteria of the study as the purposeful sampling in the initial phase because they were judged to have some knowledge of the domain being studied and, thereafter, because they are sources of information that may illuminate emerging hypotheses or theoretical questions. The researcher derived the cues for the open-ended questions in interview guide (Appendix VIII) from specific conceptual themes drawn from previous studies (Lee, 2001; Mackenzie & Holroyd, 1995; Mackenize et al., 1998). An analysis performed with the aid of a methodological expert showed that the questions were appropriate but would benefit for some minor alterations. The questions in the interview guide were then modified with the assistance of the supervisor in the light of the emerging data from in the first four interviews. The initial interviews were included in the data analysis of this study.

### 3.3.3 Concurrent Data Collection and Analysis

Data of this study were collected from 33 interviews (composed from both first and second interviews) of 15 family caregivers mainly in their home settings, used a two-interview approach with first and second interviews over the course of two years. These 15 participants were clients of stroke wards from two metro hospitals and members of a large, community-based agency providing supportive services for family members and patients with chronic illnesses in Hong Kong. Within these institution and agencies, there were specific services oriented towards providing practical seminars, health education and social gatherings to stroke clients and their families. The primary objectives of these services were to assist individuals and their families to adjust at “moments of critical change in their lives” which allows the continuation of “mutual caring and sharing” for one another (quotes from the agency’s manual of operating procedures). Health education and therapeutic counselling were specifically excluded, as these were not objectives of this study. At the time of study, the client group was primarily Chinese families with stroke-impaired family members. The researcher only approached those families with stroke elderly relatives were over 65 years of age as stated in the study inclusive criteria. Those families, with relatives younger than 65 of age or who had hired a maid as the primary caregiver or who placed relatives in home for the aged, were excluded from this study.

### 3.3.4 Theoretical Sampling

In the initial phase, purposive sampling was used to recruit the sample of Hong Kong Chinese family caregivers who met the five inclusion criteria of this study (See Figure 3.1). Only the first four family caregivers were recruited using the purposeful sampling method. The researcher then recruited another eight family caregivers as the theoretical sampling method after analyzing study data from the first four recruited participants in this initial phase. Another 3 family caregivers were recruited as the participants to provide information on the phenomena of caring. Theoretical sampling was particularly important in this study because the present researcher sought an explanatory theory that was reflective of diverse Chinese family caregivers' caring experiences (See Figure 3.1 below).

To be included in the sample, family caregivers have to be in possession of a formal diagnosis that their elderly relatives were indeed in need of post-stroke care in the family. Data from the completed medical records from both stroke wards in the hospitals and stroke support groups were sufficient to show that all study participants were family caregivers of stroke-impaired elderly relatives and met the inclusion criteria prior to their being contacted. This was in keeping with the emphasis of this study on the lived experience of the process of caring among family caregivers of stroke-impaired elderly relatives. The researcher used purposive sampling for the first four interviews in the initial phase of data collection to investigate the experiences of family members caring for their elderly relatives. Purposive sampling relies on a smaller number of informants deliberately chosen to inform the researcher in detail about personal meanings and perceptions (Streubert & Carpenter, 1995). The criteria for inclusion in this study were: (a) the family caregiver was the dependent person's relative; (b) the family caregiver was identified by the dependent person as the primary caregiver; (c) the family caregiver had been the primary caregiver for more than six months; (d) the family caregiver was taking care of the dependent person in a home setting; and (e) the dependent person had suffered a stroke.

Data collection and analysis were conducted in parallel after the first interview, allowing the transition from purposeful to theoretical sampling and facilitating the evolution of hypotheses (See Figure 3.1 below). Erlandson, Harris, Skipper and Allen (1993) stated that: 'Random or representative sampling is not preferred because the researcher's major concern is not to generalize the findings of the study but to maximize discovery of the problems that occur in the particular context under study' (p. 82). Sandelowski (2000)

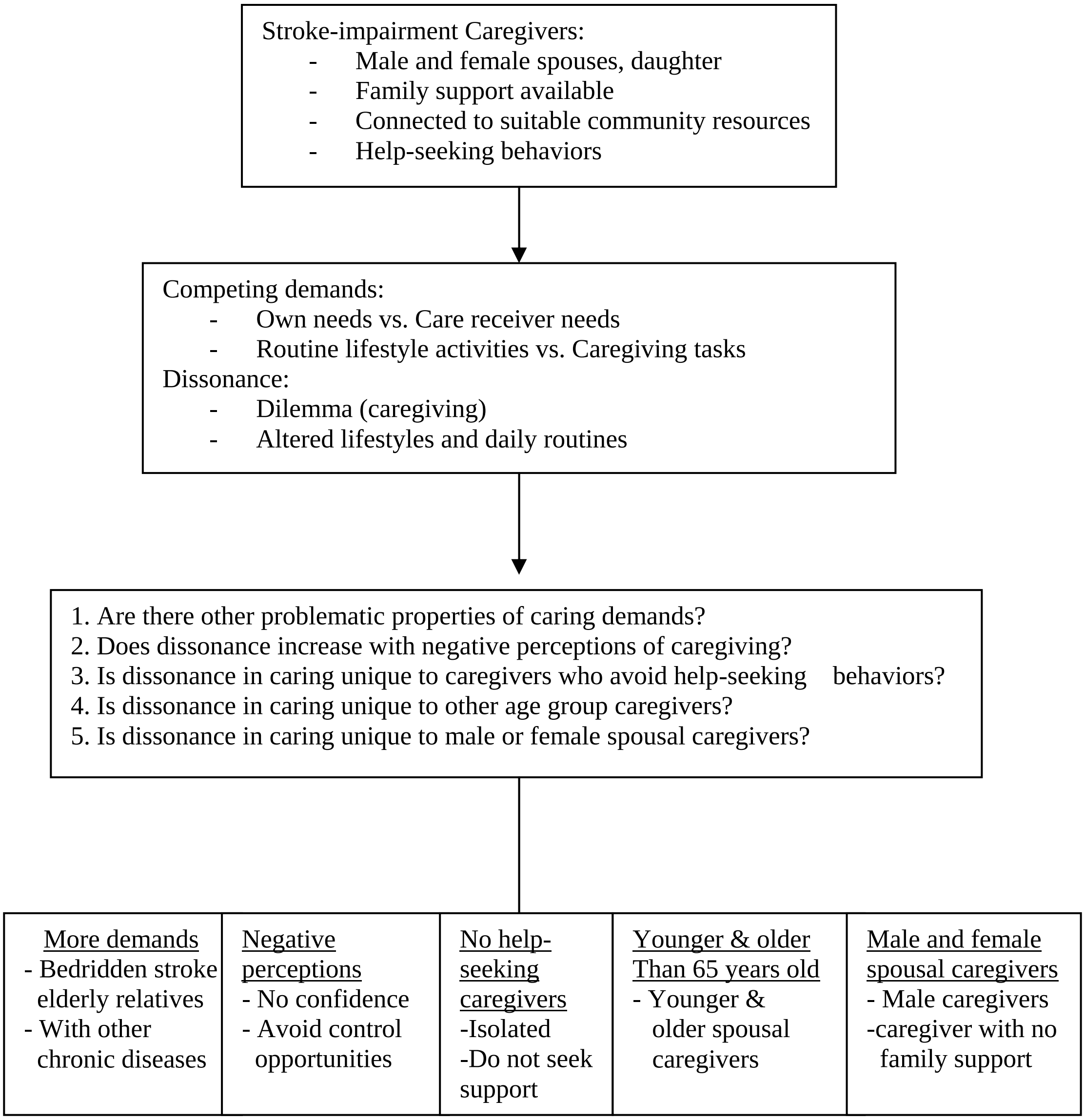


**Figure 3.1 The Emerging Design: Theoretical Sampling**

suggested that a sampling strategy is employed when researchers decide what events, settings and artifacts they want to collect as data as there is a very large pool of potentially information-rich cases. By using the grounded theory approach (Glaser, 1978, 1992; Strauss & Corbin, 1990; 1998), the researcher initially employed family members responsible for providing care as the purposeful samples. Theoretical sampling is driven by concepts derived from the evolving theory of the emerging data (Glaser, 1978, 1992; Strauss & Corbin, 1998).This means that the researcher controls the process of data collection to maximize the discovery of variations among concepts and categories in terms of properties and dimensions. In this study (See Figure 3.1 above), inclusive criteria for the selection of the study sample was imposed. Thus, a small number of participants were deliberately chosen in the initial phase of data collection so that it would be possible to convey in detail personal meanings and perceptions of the study phenomena. In the initial phase, four family caregivers were interviewed to refine the interview guides and study procedures, and to identify core conceptual categories and related categories as these emerged from the data. Based on the emerging concepts and themes in the initial phase, the researcher made a decision about where to sample next. In order to capture a range of incidents and variation of experiences of family caring, discriminate sampling became important and it was chosen for its potential to maximize differences among emerging concepts. Another eight family caregivers were then recruited from two community agencies and interviewed to further explore the features and process of caring. According to Glaser (1978, 1992), Glaser & Strauss (1967) and Strauss and Corbin (1990; 1998), such recruitment is important when exploring new or uncharted areas because it enables the researcher to choose those avenues of sampling that can generate the greatest theoretical return. To ensure theoretical saturation, three additional family caregivers were interviewed to ensure that each category was saturated. This means that data have been captured and categorized efficiently and the identified categories are well developed in terms of their properties and dimensions. The process of collecting data continued until no additional concepts and information emerged from the analysis of the data, at which point data saturation was considered to have occurred (See Figure 3.1 above).

## 3.4 Family Caregiver Characteristics

Sampling for all data collection was drawn from the outpatient clinics of two metropolitan hospitals and two stroke support groups in Hong Kong. The selection of participants ceased at the point of data saturation. Although there are no rules for sample size, previous studies suggest that 15 to 20 participants or more are commonly needed to achieve both data saturation and maximum variation in a qualitative study (Marshall & Rossman, 1989, 1995, 1998; McCraken, 1988; Patton, 1987).

### 3.4.1 First In-depth Interviews

The first round of in-depth interviews was conducted between January 2001 and June 2001 with 15 family caregivers. Each family caregiver was interviewed between 1 and 3 times. The interviews were conducted in living rooms where table and chairs were available. A total of thirteen of the cared-for-persons were present during the interviews with family caregivers, but only three of them became involved in the discussions during the interviews. The other ten sat quietly nearby the family caregivers. The final two cared-for-persons were bedridden. In the first round of the interviews, one daughter and a husband were interviewed at a quiet café as per their request for convenience. The researcher found the participants generally to be open after trusting relationship was established with them by addressing them by name and ensuring confidentiality.

In each interview, the researcher tried to elicit spontaneous and free-flowing responses from the participants with a minimum of framing within the domains of interest. Topics were raised at the highest level of generality, and further elaboration and development of the perceptions that emerged were then sought. All interviews were taped with the participants' permission. The length of each interview ranged from one and a half hours to two hours. Since most of the interviews wre conducted in the cared-for-persons' homes, the researcher could observe the home environment and sometimes interactions among family members and maids.

For five caregivers, a second interview was held in the first round of interviews (See Table 3.2 below). The purpose of the second interview of these five caregivers was to obtain a deeper understanding of their caregiving situations and perceptions. The researcher also revisited these five participants with relevant transciptions and validated the data with them. Minor changes were made to the two interview scripts after they were clarified by the two participants. For one of these caregivers, a third interview was conducted in the first round of interviews. This followed the new diagnosis of a benign breast tumour in the cared-for-person which created a lot of anxiety for the family caregiver in the second interview before the confirmation of the tumor as benign rather than malignant was known. The goal of the data collection was to generate a theory to explain and predict events, thereby providing guidelines for action. As Trost (1986) states it is common for qualitative studies to employ statistically non-representative opportunistic samples. The emphasis of this study was on examining the range of types of cases that represent the specific phenomenon of caring of stroke-impaired elderly relatives among Chinese family caregivers.

### 3.4.2 Second In-depth Interviews

The researcher found that the sample of 15 Chinese family caregivers recruited for the first interviews in 2001 reflected major family adaptation strategies and patterns in terms of support network use and overall caring outcomes. However, it was necessary to conduct second interviews in order to validate and confirm the findings arising from the analysis of data collected in the first interviews. The second interviews were held two years later between May 2003 and September 2003 with 13 family caregivers drawn from the body of first round participants. Two of the original 15 participants could not be contacted. The second interviews were conducted over a period of four months. During the second interview period in May 2003, the researcher's interest was focused on confirming and verifying the outcomes of the caring process, the variations in caring patterns, and caregivers' social networks. These three areas provided the main focal points in the first interviews.

Of the 13 interviews, 11 family caregivers were scheduled for second interviews successfully in their home settings and two female family caregivers refused home interviews, but were willing to be interviewed by the researcher over the phone. One cared-for-person of these two family caregivers had passed away and the other one was institutionalized in a private old people's home. One of the daughters of the cared-for-person had taken early retirement and the other full-time employed daughter had married one year after the first interview. Two more family caregivers had hired full-time Philippine domestic helpers and the other three family caregivers had also used the government subsidized part-time home care services over the course of two years of family caring. During the second interviews, three family caregivers were planning to place the stroke-impaired relative in an old people's home due to their own health problems following hardships over the past two years and/or the deterioration of the functional status of the cared-for-person.

Study findings analyzed in the first interviews needed to be confirmed by participants as member checks. Five study participants had done member checks in the first interviews. Another advantage of carrying out second interviews two years after the first is that the researcher was able to identify the coping strategies that family caregivers developed to cope with caring demands over the course of two years and verify the types of caregivers which identified in first interviews.

### 3.4.3 Overview of the Characteristics of Family Caregivers

The majority of study participants were from a lower to middle-class background. The record of their income and other demographic data are presented in Table 3.1 below. It is important to realize this is a cohort of individuals who live, for the most part, either on modest pensions or social

## Table 3.1 Characteristics of the Family Caregivers (N=15) of the Study

| | N=15 | Frequency | Percent |
|---|---|---|---|
| Sex | Male | 5 | 33 |
| | Female | 10 | 67 |
| Age | | | |
| | 25-59 years old | 3 | 20 |
| | 60-64 years old | 3 | 20 |
| | 65-79 years old | 8 | 53 |
| | > 80 years old | 1 | 7 |
| Relationship with Stroke-impaired Elderly | | | |
| | Wife | 7 | 47 |
| | Husband | 5 | 33 |
| | Daughter | 3 | 20 |
| Education | | | |
| | Never | 5 | 33 |
| | Primary | 5 | 33 |
| | Secondary | 4 | 27 |
| | University | 1 | 7 |
| Marital Status | | | |
| | Married | 13 | 86 |
| | Single | 2 | 14 |
| | Divorced / Separated | 0 | 0 |
| Income Source | | | |
| | Social Assistant Allowance/ | 5 | 33 |
| | Disabled Allowance | 10 | 67 |
| | Retirement Pension | 1 | 7 |
| | Self- finance (No salary/income) | 7 | 46 |
| | Salary | 2 | 14 |
| Monthly Income | | | |
| | Less than $ 5,000 | 8 | 53 |
| | $ 5,001 - $ 10,000 | 5 | 33 |
| | $10,000 - $ 20,000 | 2 | 14 |
| Employment | | | |
| | Full-time employment | 2 | 14 |
| | Part-time employment | 0 | 0 |
| | Retired | 7 | 46 |
| | Housewife | 6 | 40 |
| Number of hours spent on caregiving /day | | | |
| | 1 to 4 hours | 0 | 0 |
| | 5 to 8 hours | 5 | 33 |
| | 9 to 16 hours | 3 | 20 |
| | 17 to 24 hours | 7 | 47 |

welfare security. All of them received a monthly disability subsidy from government. Four of them owned their own homes; one of them rented an apartment with elevators and the other ten rented subsided apartments. Twelve spousal caregivers provided 24 hour care for their relatives in their own homes and three of them hired a maid to assist in meeting the physical demands of care such as lifting, bathing, toileting, and feeding.

In keeping with the maximum variation sampling suggested by Strauss and Corbin (1998), the present researcher considered such characteristics as age, gender, relationship, prior family caring experiences, health condition, the functional status of the cared-for relative, and length of the daily caring role. Participants included both males and females and seven were wives, five were husbands and three were daughters presented in Table 3.2 below. Five male family caregivers participated in this study and they represented one third of the study sample. They ranged in age from 27 to 87 years, with a mean age of 65 at the time of the first interviews. About seventy-five per cent (12) of the interviewed family caregivers were elderly themselves. The oldest caregiver was 87 and the spouse of the dependent person. The youngest caregiver, who was a daughter of the dependent person, was 27. Three participants were the daughters of the cared-for-persons. Two daughters were working full-time and they were not married at the time of the first interview. Three of the fifteen families had no children in their lives. Relatively few family caregivers (two of the fifteen) were in full-time employment at the time of interview. The remainder was either retired or were housewives. The majority of caregivers came originally from Mainland China and had migrated to Hong Kong over past ten to fifty years. Twelve of them were Mainland China-born and they were spousal caregivers. Another three participants were Hong Kong-born and they were the children caregivers. All these three children were daughters who provided continuous care for their stroke-impaired elderly relatives in home setting. They all had more than six months' caregiving experience in the home setting. Length of time as a family caregiver ranged from six months to five years. Although the stroke-impaired elderly relatives were not involved in this study, they gave verbal approval for family members to be contacted. The family caregiver was the person who was the main source of support for the stroke-impaired elderly relative and who was the primary person involved in treatment decisions.

The health status and of the 15 stroke-impaired elderly relatives and their disabilities are presented in Table 3.3 below. Three elderly relatives in this study were bed-ridden and required total assistance in their daily activities. Four elderly relatives were ambulatory. Another eight elderly relatives were wheelchair-bound after discharging from hospital to home. All these eleven elderly relatives required total care in daily life from lifting to washing activities. Four of them had been diagnosed with dementia syndrome. All of

**Table 3.2 Characteristics of Family Caregivers (N=15) of the Study**

| Code No. | Gender | Age | Relationship with Cared-for Person |
|---|---|---|---|
| 1** | M | 74 | Husband |
| 2* | F | 72 | Wife |
| 3* | F (D) | 47 | Daughter |
| 4* | M | 70 | Husband |
| 5* | F | 60 | Wife |
| 6 | F | 68 | Wife |
| 7 | F | 60 | Wife |
| 8 | M | 68 | Husband |
| 9 | F | 74 | Wife |
| 10 | F (D) | 27 | Daughter |
| 11 | M | 87 | Husband |
| 12 | F(D) | 46 | Daughter |
| 13 | F | 63 | Wife |
| 14 | M | 68 | Husband |
| 5 | F | 75 | Wife |

***= Participants were interviewed twice in the First Interview**

****= Participant was interviewed three times in the First Interview**

them required services from community rehabilitation programmes after being discharged. The participants in this study are also considered with their cultural expectations with regard to selection of caregivers, and understand how Chinese individual's beliefs and values affect the caring process in the families.

### 3.4.4 Caregivers' and Cared-for-persons' Demographic Status

A table 3.3 below presents the characteristics of the 15 cared-for-persons of the study. The majority, 12 of the family caregivers (80%), was over 60 years old, and these older spousal caregivers also had physical health problems and experienced significant deterioration in their health after becoming primary caregivers (ee Table 3.4 below). All participants had heart disease problems ranging from diagnosis of hypertension to having a pacemaker. Three had a

**Table 3.3 Characteristics of Cared-for-Persons (C=15) of the Study**

| Code No. | Gender | Age | Medical Diagnosis | Functional Status |
|---|---|---|---|---|
| 1 | F | 65 | Stroke, Depression | Ambulatory with walking aid |
| 2 | M | 75 | Stroke Hypertension | Ambulatory with walking aid |
| 3 | F | 74 | Stroke, Dementia | Wheelchair-bound with total dependent care |
| 4 | F | 67 | Stroke Hypertension | Wheelchair-bound with walking aid |
| 5 | M | 78 | Stroke, Parkinson | Wheelchair-bound with total dependent care |
| 6 | M | 66 | Stroke Hypertension | Wheelchair-bound with walking aid |
| 7 | M | 65 | Stroke Hypertension | Bedridden with total dependent care |
| 8 | F | 69 | Stroke, Epilepsy, Leukaemia | Wheelchair-bound with total dependent care |
| 9 | M | 77 | Stroke, Dementia | Bedridden with total dependent care |
| 10 | F | 67 | Stroke Hypertension | Ambulatory with walking aid |
| 11 | F | 88 | Stroke Hypertension | Sel-ambulatory |
| 12 | F | 78 | Stroke Hypertension | Wheelchair-bound with total dependent care |
| 13 | M | 68 | Stroke Hypertension | Wheelchair-bound with walking aid |
| 14 | F | 65 | Stroke Hypertension | Wheelchair-bound with total dependent care |
| 15 | M | 81 | Stroke, Dementia | Bedridden with total dependent care |

**Table 3.4 Characteristics of Family Caregivers and Cared-for-Persons**

| Participant | Family Caregiver | Cared-for-Person |
|---|---|---|
| No. 1 | 74 years old Husband (caregiving for 4 years)<br>Retired / Retirement Pension<br>Lives with cared-for-person | Wife<br>diagnosis: stroke, depression, breast tumour<br>3 previous hospitalizations |
| No. 2 | 72 years old Wife (caregiving for 2 years)<br>Housewife/ Disability Pension<br>Lives with cared-for-person | Husband<br>diagnosis: stroke<br>No previous hospitalization |
| No. 3 | 47 years old Daughter (caregiving for 3 years)<br>Housewife/ self-finance<br>Lives close by cared-for-person | Mother<br>diagnosis: stroke, dementia<br>1 previous hospitalization |
| No. 4 | 70 years old Husband (caregiving for 4 years)<br>Retired / Social welfare security<br>Lives with cared-for-person | Wife (Wheelchair)<br>diagnosis: stroke, depression<br>2 previous hospitalizations |
| No. 5 | 60 years old Wife (caregiving for 8 years)<br>Housewife/ Self-finance<br>Lives with cared-for-person | Husband (Wheelchair)<br>diagnosis: stroke, prostate cancer, Parkinson<br>10 previous hospitalizations |
| No. 6 | 68 years old Wife (caregiving for 1 year)<br>Retired / Self-finance<br>Lives with cared-for-person | Husband (Wheelchair)<br>diagnosis: stroke, depression<br>No previous hospitalization |
| No. 7 | 60 years old Wife (caregiving for 2 year)<br>Housewife / Self-finance<br>Lives with cared-for-person | Husband (Bedridden)<br>diagnosis: stroke, dementia<br>1 previous hospitalization |
| No. 8 | 68 years old Husband (caregiving for 2 year)<br>Part-time / Self-finance<br>Lives with cared-for-person | Wife (Wheelchair)<br>diagnosis: stroke, epilepsy, leukemia<br>Numerous previous hospitalization |
| No. 9 | 74 years old Wife (caregiving for 3 year)<br>Retired / Social welfare security<br>Lives with cared-for-person | Husband (Bedridden)<br>diagnosis: stroke, dementia<br>4 previous hospitalization |
| No. 10 | 27 years old Daughter (caregiving for 2 years)<br>Daughter/ Self-finance<br>Lives close by cared-for-person | Mother & father<br>diagnosis: stroke<br>No previous hospitalization |
| No. 11 | 87 years old Husband (caregiving for 1 year)<br>Retired / Social welfare security<br>Lives with cared-for-person | Wife<br>diagnosis: stroke<br>1 previous hospitalization |
| No. 12 | 46 years old Daughter (caregiving for 3 years)<br>Blue collar / Self-finance<br>Lives close by cared-for-person | Mother (Wheelchair)<br>diagnosis: stroke<br>2 previous hospitalization |
| No. 13 | 63 years old Wife (caregiving for 2 years)<br>Housewife/ Self-finance<br>Lives with cared-for-person | Husband (Wheelchair)<br>diagnosis: stroke<br>No previous hospitalization |
| No. 14 | 68 years old Husband (caregiving for 3 year)<br>Retired / Social welfare security<br>Lives with cared-for-person | Wife (Wheelchair)<br>diagnosis: stroke<br>3 previous hospitalization |
| No. 15 | 75 years old Wife (caregiving for 2 year)<br>Retired / Self –finance<br>Lives with cared-for-person | Husband (Bedridden)<br>diagnosis: stroke, dementia<br>3 previous hospitalization |

history of stomach ulcers. Eight complained of different degrees of joint pain from arthritis. All expressed mild to severe emotional disturbances after becoming primary caregivers, especially at the beginning of the caring process. Two male spousal caregivers and two female spousal caregivers did think of committing suicide when the pressure increased during the caring process. The principal sources of caregiver strain were physical demands of care associated with stroke disability, dementia syndrome and incontinence. Strain was exacerbated for some of the caregivers by the lack of supportive response by local health services, and by lack of support networks in the community and, sometimes, criticism from other family members. Family conflict was commonly encountered by the caregivers participating in this study.

## 3.5 Multiple Sources of Data

### 3.5.1 Interview scripts

The two in-depth interviews with 33 interviews of the fifteen participants were tape-recorded and transcribed into Chinese. They were then translated into English. Back translations were also completed for three transcripts. In addition, field notes and memos were also written up immediately after each interview. The English version of the interview scripts were then put into QRS NUD*IST (Version, 4.0) (1997), a software programme for management of text-based data, for data organization and analysis in this study.

### 3.5.2 Agency files

The researcher was able to access all fifteen participants' demographic information by telephone from the staff of relevant institutions. The person in-charge at the institutions provided the researcher with a summary from their referral and intake sheets after obtaining permission from relevant institutions and participants. For the purposes of the study, the researcher attended the regular meetings of the stroke support groups and kept in contact with the presidents of the support groups. The researcher is a member of the community agency of the stroke support groups and she often receives the regular newsletter of the stroke support groups. This offered the opportunity to learn the system from the inside out as professionals work through their task of helping their client-families on a regular basis.

### 3.5.3 Field Notes

The researcher recorded the observations and feelings after each interview in the field notes (see Appendix VII) as the third type of data collected and analyzed for this study in both first and second sets of in-depth interviews. This offered the opportunity to track the progress of research cases on a regular basis. The researcher kept detailed notes of this experience. Following Lofland and Lofland's advice (1984), the field notes were made immediately after each interview. They included the impressions of the physical setting of the interview, reflections of feelings the researcher had approaching the interview, the observations of the interaction among family members, and the content of the interview.

### 3.5.4 Coding Memos

The researcher's record of thoughts and interpretations written in the memos were also included in the data analytic process. Memos were maintained throughout the process of analysis to document the ideas and insights generated. These memos were useful when the researcher returned to the 15 participants in the first and second interviews and attempted to identify the linkages among concepts and their relations to the study core category.

## 3.6 Data Management

The first interview script was tape-recorded, transcribed into Chinese and then translated into English during the initial phase. Data analysis and coding were carried out in parallel and began with the first interview held by the researcher and her supervisor in the initial phase prior to interviewing successive participants. As suggested by Glaser (1978, 1992) Glaser & Strauss (1967) and Strauss and Corbin (1990; 1998), sampling and analysis should be carried out sequentially with analysis guiding data collection in order to ensure that the categories are evenly developed. Following the initial phase, the remaining twelve Chinese family caregivers were interviewed, tape-recorded and the interview scripts transcribed into Chinese. Three transcriptions were back translated into Chinese and five transcriptions were taken back to the study participants for verification and clarification through member checking. Field notes with observations and researcher's thoughts were recorded after each interview. Observations on the caring activities were made spontaneously during the interviews, and observed caring acts or family events were recorded in the field notes immediately after the interview visits.

After each interview, a field note (see Appendix VII) was completed within the same day the data were collected. The purpose of the field note was to document observations of the behaviour of the interviewee and to summarize the main points and concerns raised during the interview. The note also contained a reflection of the researcher's feelings and ideas following the interaction with the caregiver and, if the interview had taken place in the home, a description of the home setting. Upon the completion of each interview session, the tape-recorded interviews were transcribed and typed in Chinese as soon as possible. The audiotapes were listened to again to ensure that the transcription of each interview was complete and accurate. Five typed Chinese transcription of the tape was returned to the participants for verification with their initials on each page as the member checks. Clarification was also sought by the researcher during verification. A code number was assigned to each study participant to protect the anonymity of research subjects. The typed interview transcript was set up as an individual text file. A case summary sheet was also documented after completed the opening coding of level I analysis in QRS NUD*IST (Version 4.0) (1997). The case summary sheet provided an overview of each case and a quick review for researcher.

In this study, all the individual responses given during the interviews made up the content universe, and the entire universe was analyzed by using QRS NUD*IST (Version 4.0) for data analysis. Several strategies were used to enhance the quality of data. The original transcripts in Chinese were first carefully and repeatedly examined line by line to identify key elements and similar patterns, including norms and exceptions, as codes. The original Chinese transcripts were then analyzed and the key elements and categories that had been identified. The original transcripts in Chinese were then put into QRS NUD*IST (Version 4.0) with codings. Words with similar meanings were aggregated to form a code and then a category. The final categories were then labelled so that they were semantically as close as possible to the original text, in order to minimize the distortion in the meanings. Propositional statements were explicitly stated to characterize the properties and definition of each category. These properties were combined into rules for the inclusion of text into each category.

This set of rules served as a categorical scheme that explicitly guided the selection and assignment of words or phrases into categories and justified their inclusion. The entire list of categories and the coding scheme were reviewed after the coding of the first transcript of each participant. Using the constant comparison method on the next set of transcripts, analytical ideas were developed and changed over time. The coding scheme was revised in order to accommodate the new categories and themes that had emerged in the new data from the next set of transcripts. As no further codes emerged from the data, the final theoretical scheme was formulated to validate and refine theory such as the four types of identified family caregivers in this study.

### 3.6.1 Special Issues in Interviewing Family Caregivers of Stroke-Impaired Elderly Relatives

The researcher was unable to standardize interview time due to lack of funding and more importantly because some of the older family caregivers of this study were busy caregiving and suffering fatigue. Interviews ranged in length from 45 minutes to two hours with the average being seventy-five minutes. Careful attention was devoted to assessing the impact of in-depth interviews on the participants in terms of diminishing interest and/or decreasing energies. It was apparent that the length of the interview was not a concern to the study participants. As McCraken (1988) states, there is "something in the process that proves to be so interesting and / or gratifying that it keeps the respondent going" (p.27). On many occasions, participants remarked that it was the only opportunity they had to share their experience and feelings about the caring process.

### 3.6.2 Bracketing

The researcher's presuppositions relating to nursing care for stroke patients were set aside or bracketed, to be revisited after the interview data were analyzed. To avoid pre-empting the findings, a comprehensive review of the literature was also delayed until after the analysis had begun. McCraken (1988) asserted that qualitative research following the long interview method can stop when the patterns become repetitive and the materials are thematically saturated. This can be justified because 'qualitative research does not survey the terrain, it mines it' (McCraken, 1988, p. 17). To elaborate further, McCraken upheld the views that while the emphasis in quantitative research are on generalizability, the focus in qualitative research is on access, which means access to the ‘complicated character, logic and organization of a particular group or culture’ (p. 17). According to Leininger (1985, 1991), participants are generally more knowledgeable about the domain of inquiry and are usually interviewed in-depth on several occasions; whereas general participants are less knowledgeable, reflect community views, and are interviewed fewer times but on opportunistic occasions. Participants in the Chinese community were deliberately chosen based on their knowledge of the domains of inquiry and their willingness to share ideas with the researcher.

### 3.6.3 Ethical Issues

After gaining approval to implement the study from the Human Ethics Committee of The Hong Kong Polytechnic University (see Appendix I) and from community agencies (see Appendix IX), proper procedures were followed according to instructions from staff of the institution before access was gained to the participants. Throughout the study, the rights of the participants were respected and safeguarded. First, the risk to participants from becoming involved in the study was minimal. There was no possibility of physical harm, although there was a small risk of the participants experiencing a minimal amount of psychological discomfort during the interviews. However, the potential benefits of contributing to a better understanding of the needs of caregivers and to the development of interventions specific to their needs outweighed the inconvenience and time required from the participants. Secondly, potential participants were informed that any involvement in the study was voluntary and their right to self-determination was respected. Participation was enhanced by the provision of truthful and complete information regarding the aims of the study and emphasizing that non-participation or withdrawal from participation would bring no penalty. The following information was provided to the participants in the cover letter of the questionnaire: the identity of the researcher, the purpose of the study, the time and procedures for involvement required of the participant, the manner in which the participant had been selected, the issue of confidentiality, the participant's right to refuse to answer any question or to withdraw from the interview at any time. Questions were encouraged and answered. Informed consent was obtained throughout the two stages of the collecting of the data.

### 3.6.4 Confidentiality

The confidentiality of the participants was safeguarded in several important ways. First, a code number was assigned to each participant and no names were recorded on any of the data collection forms, including the interviewing schedules, contact summary sheets, and interview transcripts. There was a need to record the names and contact phone numbers of the participants in this study because follow-up interviews were required with some of the participants. By doing so, any disturbance caused by approaching the family members of the participants again throughout the period of data collection could also be avoided. Details of the participants and their appointed identification numbers were recorded separately from all information sheets. Second, the participants' name list and audiotapes of the interview were kept in a secure, locked room and were stored separately from the forms containing their personal particulars and from the consent forms signed by the participants. Access to these files was restricted to the researcher. All audiotapes, contact summary sheets, and memos recording the names of participants were destroyed at the end of the study, except for the interview transcripts. All of the data collected were handled and accessed only by the researcher and her supervisors involved in this study. Finally, breaches of confidentiality were minimized during the writing up of the report since identification of the participants was removed in the report. This makes it impossible to identify the individuals involved in the study.

## 3.7 Data Collection

Figure 3.2 below shows the approach to data collection and the two-interview nature of the study. A Chinese version of information sheet (see Appendix V) stating the objectives of the study and the inclusion criteria for participants were distributed to the person in charge of each stroke support group and the person in charge of the social welfare agency. After approval had been obtained from the relevant ethics committees, the eligible participants were then identified by these organizations. A briefing session was held to introduce the study, explain the inclusion criteria for the participants, and clarify any issues raised by the person in charge of the stroke support group involved in each centre.

All the interviews took place at the homes of the family caregivers, with the exception of two, which took place in a quiet café and a park at the request of the participants. Family caregivers were asked whether or not they wanted to have the interview conducted in the presence of the care recipient. Ten family caregivers were interviewed in the presence of their recipient relatives. The Chinese version of informed consent (see Appendix VI) was obtained before the interviews were conducted. A set of interview questions (see Appendix VIII) were prepared and taken with the researcher during the interviews. A series of prompts was used to encourage the participants to continue

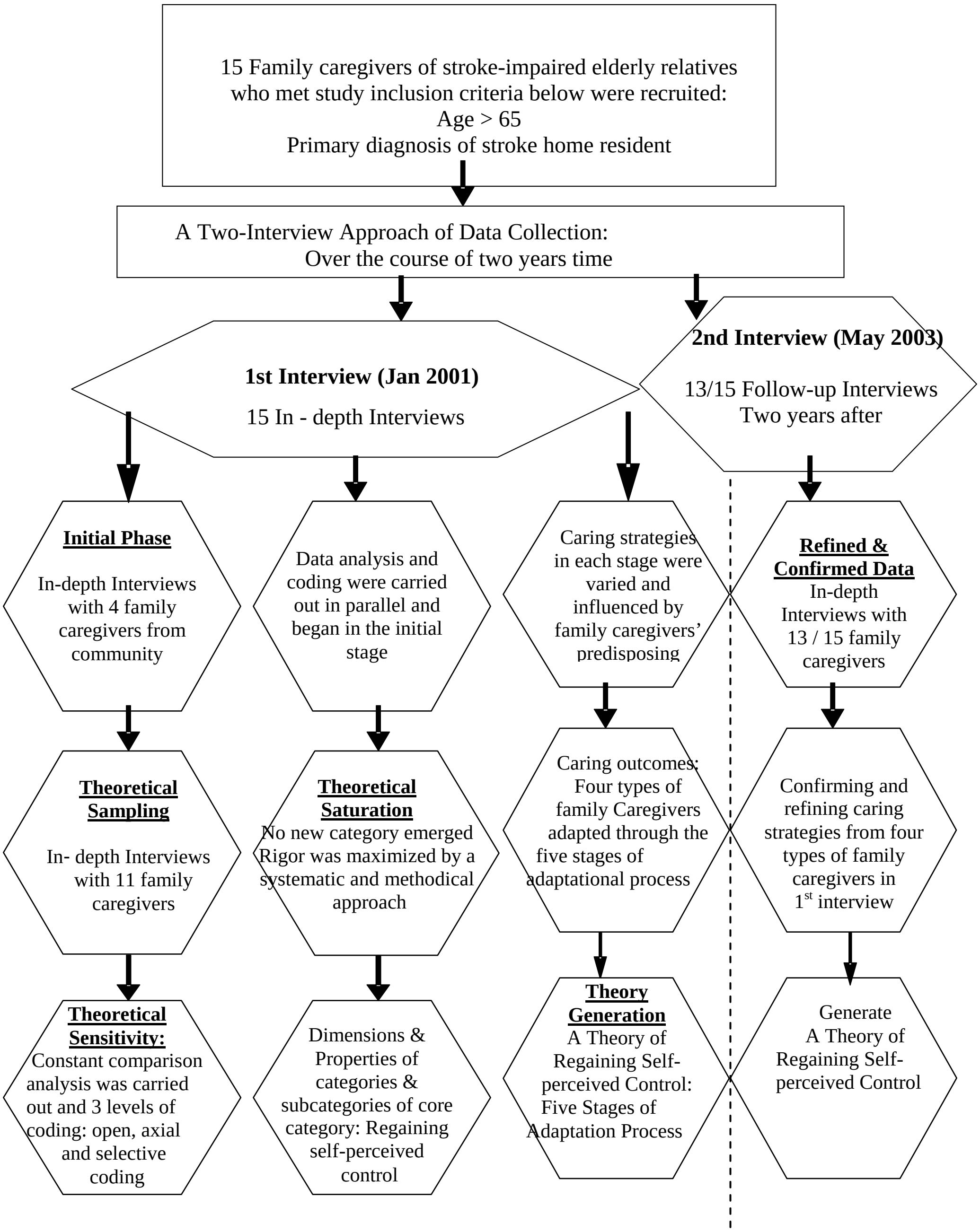


Figure 3.2 Flow Chart of the Two-Interview Approach

describing their experiences in as much detail as possible. The interviews were carried out in semi-structured mode and an open-ended format was followed to encourage the family caregivers to describe their experiences within their own frame of reference.

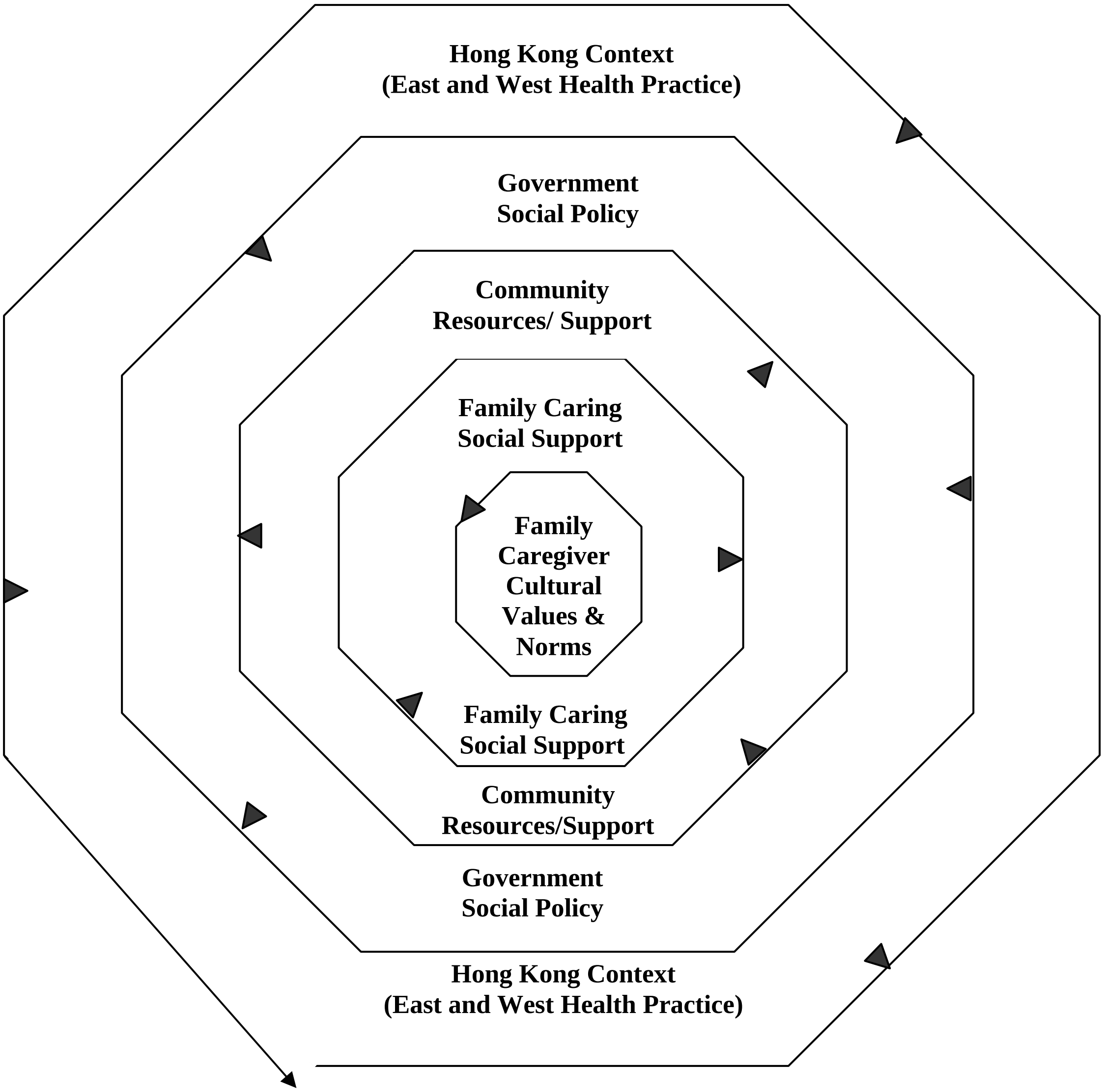
An important factor in the process of selection was the desire to include negative and positive experiences of family caring. Both typical and divergent data were sought to maximize the range of information obtained about the context of family adaptation through caring (Erlandson et al., 1993). The researcher was the most significant instrument for data collection and analysis in this study. As Erlandson et al. (1993) stated: “The realization that objectivity in research is an illusion frees the naturalistic researcher to do truly effective data collection and analysis” (p. 39). The researcher used self-as-instrument for collecting and analyzing the data in the interactive process in this study. This interactive process of collecting data is the main characteristic in the grounded theory approach. This methodology allows incidents and responses to be compared so that they may be integrated with other incidents. The approach of comparing and linking concepts along with rich, thick descriptions allows the readers to draw assumptions from the multiple perspectives of the participants. The present researcher used the grounded theory approach to develop and make the best use of her observational and analytical abilities by comparing samples and transcripts that provide feedback for participants to provide care. After recruiting twelve participants for this study, one more male and two more female family caregivers were also added to the list of recruited participants for the purpose of determining the nature of the role played by male family caregivers and to reach data saturation point in the study. This additional information from Chinese male family caregivers provided information and understanding of the impact of gender on the experience of caregivers.

Family caregivers were asked to reflect on their narratives using an inductive approach that would be discussed in the data analysis session. To avoid pre-empting the findings, a comprehensive review of the literature was also delayed until after the analysis was under way. The researcher managed to conduct in-depth interviews with 15 Chinese family caregivers in January 2001 through the process of gradually expanding and enriching the interviews with the participants using the theoretical sampling method of the grounded theory approach (Glaser, 1978, 1992; Strauss and Corbin, 1998).

### 3.7.1 The Conditional Structure Matrix

The diagram of the conditional structure matrix (see Figure 3.3 below) is important in understanding family stresses and is therefore an integral part of the family adaptation through caring model presented in the next chapter because it presents a broad picture of the dynamic evolving nature of the caring experience. The matrix consists of a series of concentric and interconnected circles with arrows going both toward and away from the centers. The arrows represent the intersection of conditions and the resulting chain of events. According to Strauss and Corbin (1998), the conditional matrix (see Figure 3.3 below) is a coding device or a conceptual guide that facilitates the researcher in data analysis using the constant comparison method of grounded theory approach. The matrix presents an explanation of its diagrammatic features and suggests how to map out the paths of inter-connectivity among conditions, interactions and consequences of family caring. The conditions or actions in the process of family caring do not stand alone in the matrix but rather always integrate into situational context and relate to conditions or actions as the process evolves and changes over time.

The present study focused on the process of family caring but this did not mean the other areas such as structure, properties, dimensions, and consequences of family caring were neglected. Rather, actions might be taken in response to multiple conditions and the relationship between conditions and consequences and subsequent actions / interactions do not follow a linear path. Although the concepts contained within the matrix are quite sophisticated, the researcher could capture some of the complexity and richness of related



Dark line = Evolving interaction
Spaces between = Sources of condition/consequences which makes up
structure and context
Arrows = Interaction structure with process

**Figure 3.3 The Conditional Structure Matrix (Represent constant interplay / action [**Process**] with conditions / consequences [**Structure**] and the dynamic evolving nature of caring experience**

concepts of family caring by keeping a picture of the matrix in mind while analyzing data.

### 3.8 Analysis of Data and Theory Generation

The qualitative data analysis in this study was examined as an ongoing iterative process that involved specification and re-specification of relevant aspects of the data. According to Glaser (1978, 1992) and Strauss and Corbin (1990; 1998), data analysis should emphasize systematically developing an analysis that remains. The strategy adopted for analyzing and interpreting the data primarily followed the constant comparative analysis method as suggested by Strauss and Corbin (1998); and Glaser's (1978) process of theoretical coding which consider categories in terms of theoretical codes such as degrees, dimensions, process, cutting points, and strategies, and the six C's to uncover properties, and linkages between them. The six C's of Glaser's Coding families are Cause, Consequence, Conditions, Covariances, Contingencies, and Context. The computer programme QRS NUD*IST (Version 4.0) (1997) was also used to aid data management.

The researcher approached the research setting with “a sensitizing perspective”, a general systems and constructivist orientation to investigate the experiences of caring from the perspective of the 15 Chinese family caregiver participants. Based on a preliminary interview guide, the researcher piloted the interview questions in the guide in the first two interviews to refine the interview guide and study procedures. The interview guide (see Appendix VIII) was conducted with four family caregivers and refined with the assistance of the researcher’s thesis supervisor, and these interviews were included in the analysis. Interviews were conducted face-to-face by using the interview guide with eight open-ended questions as follows:

1. Tell me how you became the family caregiver of your stroke-impaired elderly relative.
2. Please describe your present life in relation to caring for your elderly family member after hospital discharge.
3. Please tell me the routine of a day starting in the very early morning till you go to bed.
4. Are there any difficulties in providing care for your elderly family member after hospital discharge? What are they?
5. What are the things that have changed after the relative came home?

6. What are the things that were different from what you expected before the discharge?
7. Tell me about the community services that you have used during your caregiving.
8. What is the information that you think you need in providing care for the stroke-impaired elderly?

Observations of the caregiving activities and interactions were made spontaneously during the interviews, and observed caregiving or family events were recorded in the field notes immediately after each interview. The researcher did not intervene with any family caregiving conditions. Data collection and analysis were carried out in parallel and began with the first interview. Issues of potential importance and interest were identified in the preliminary data analysis and a core category and major categories were developed. In the first interviews, five family caregivers were interviewed twice and one family caregiver was interviewed three times for further exploration and clarification of interview data. Additional interviews were conducted with five family members as member checks. In addition, the sampling strategy changed and continually modified in relation to the emerging data as the research study progressed.

### 3.8.1 Analytical Steps

A multi-step approach to data analysis was adopted. The development of this multi-step data analysis technique was a synthesis based on the work of grounded theorists, Glaser (1978, 1992), Glaser and Strauss (1967), Strauss & Corbin (1998). The initial step in synthesizing was to draw diagrams to illustrate the analytical steps in order to help the researcher to map out the whole picture of the recursive process of data analysis prior to actually performing the grounded theory analysis for this study. Strauss and Corbin's work has been criticized for being procedural and unmanageable because of the number of steps they outline (Benoliel, 1996; Melia, 1996). In fact, Strauss and Corbin's work (see Figure 3.4 below) helped to determine the specific analytical steps of grounded theory analysis and how subsequent steps might be taken. It is more likely that mistakes will be made if there was no such adherence to detailed analytical steps (Becker, 1993; Wilson & Hutchinson, 1996). Strauss and Corbin's work is highly recommended for aiding novice researchers and doctoral students in performing data analysis in a grounded theory approach (Melia, 1996).

Drafting memos and drawing diagrams are important elements in the initial analysis and this continued throughout the research. The present researcher

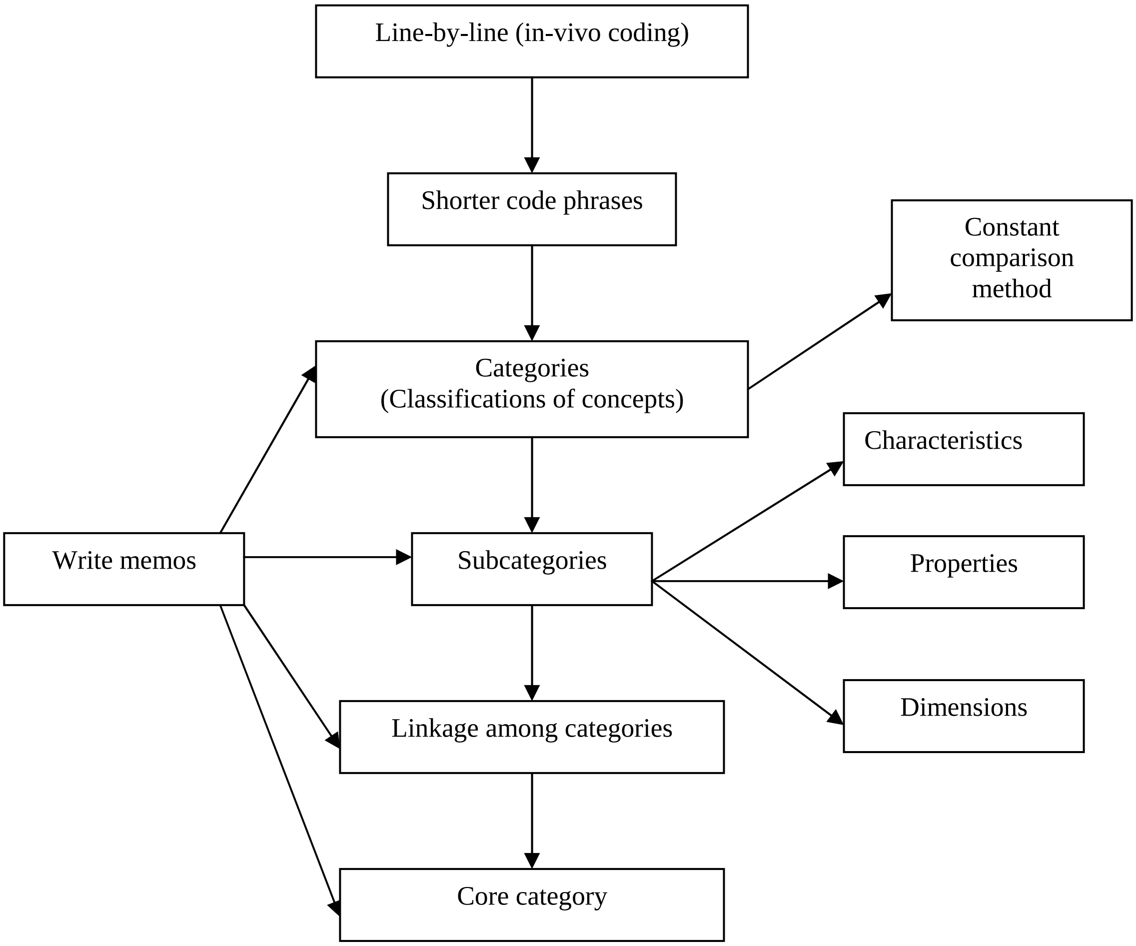


**Figure 3.4 Diagrammatic Representation of Multi-step Analysis Technique of Grounded Theory [Strauss & Corbin, 1998].**

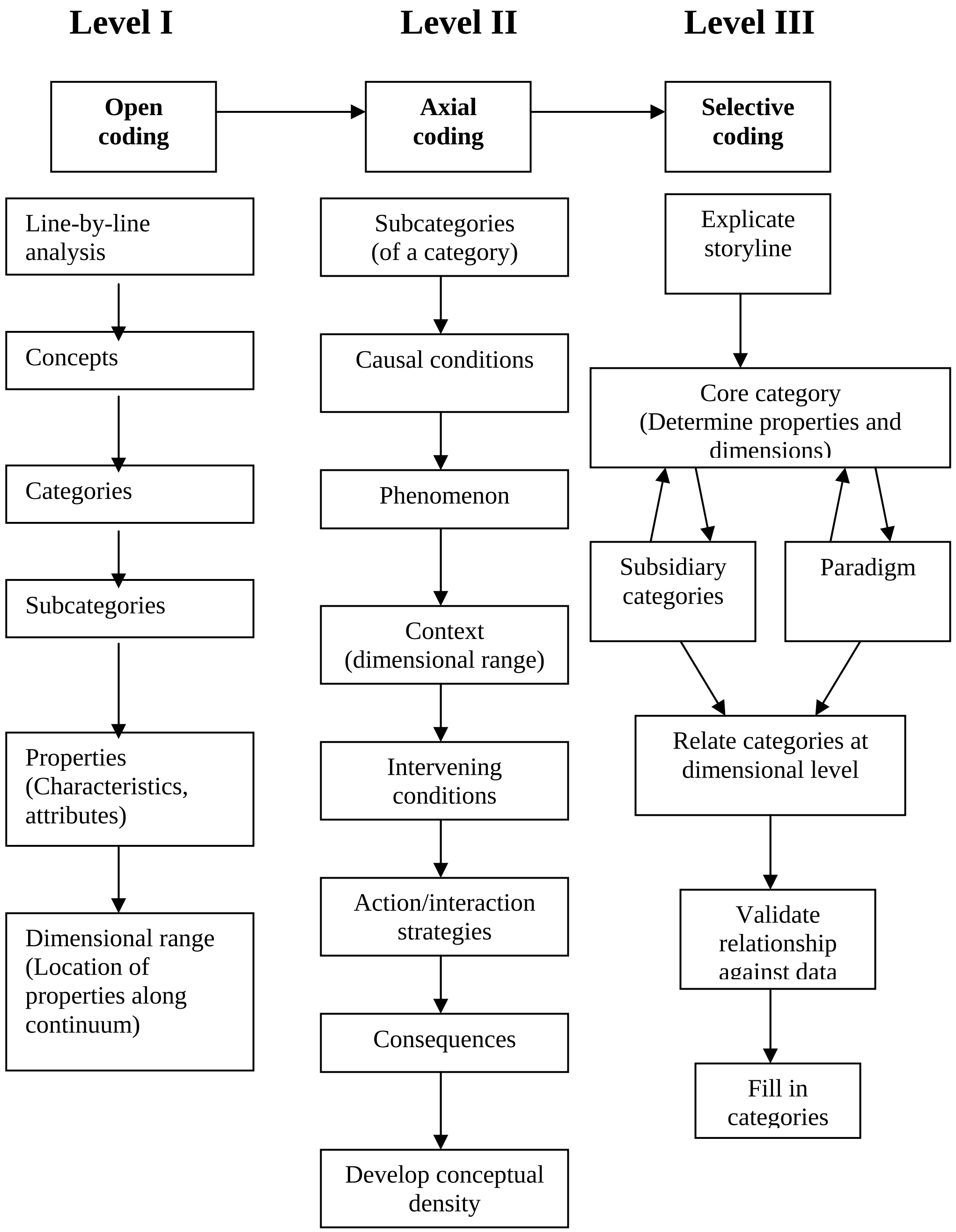


**Figure 3.5 Diagrammatic representation of Strauss and Corbin's (1998) Coding and Analysis of Grounded Theory Data.**

followed the three levels of theory building process and the steps illustrated in Figure 3.5 above, which is based on Strauss and Corbin's work (1998) and Strauss (1987). Constant comparison analysis of grounded theory approach (Strauss and Corbin, 1998) was also used to analyze the data. Analysis was carried at three levels: open, axial, and selective coding, which were more or less interwoven. Initially, open coding broke down, examined, compared, conceptualized and categorized the raw data line by line without preconceived notions. The most recent responses of the participants were compared with their previous responses to search for inconsistencies, discrepancies, anomalies, and negative cases. Memos and diagrams were set up at the beginning of analysis and the researcher used them as to reflect the analytic thought as the study progressed. Reviewing memos and diagrams also revealed which concepts needed further development and refinement. The concepts emerged as the data were collected and analyzed.

#### 3.8.1.1 Level I: Open Coding

Figure 3.4 above shows the three Levels of coding in grounded theory. Firstly, the Chinese transcript was chosen for line-by-line in-vivo coding by underlining key terms in the text, restating key phrases and developing shorter code phrases. This involved a line-by-line and paragraph-by-paragraph reading in order to develop sensitivity to the content of the data at the analytical level, to look at an abstract level, to see into the data and to turn everything upside down using the so-called flip-flop technique (Strauss & Corbin, 1998).  The purpose of open coding was to capture the substance of the data, and to break it up into smaller segments through identifying and joining together substantive codes or concepts in order to form abstract categories. Substantive codes were made up of statements such as:

“I was not used to it and I had a great deal of pressure” (No. 2),
“Even though I was away, I still worried about him” (No.12),
“I have lots of pressure look after him all the time” (No. 9).

A search was made to find ideas or codes that summarized the material. In this way, connections, courses of events and hidden messages were identified. Code phrases were reduced by grouping similar code phrases together and then creating clusters using QRS NUD*IST (Version 4.0). Clusters were then reduced and labelled. Each discrete incident, idea or event in the process of family caring was given a label.  Secondly, a listing was made of all codes and shorter code phrases were developed based on what the family caregivers said and illustrated in a tree diagram with the aid of QRS NUD*IST (Version 4.0). Codes, as identified by Strauss & Corbin (1998), are shorthand devices used to label, separate, compile and organize data. In this study for example, one of the family caregivers stated, “I am always worried about her disease and I am afraid that her illness will get worse” (No. 1), was given an open code “worry about illness condition”. This code simply labelled what event was happening and it was not based on any current conceptual framework. In this study, another family caregiver’s comment, “I would be so happy if someone like you, a health care professional, came to visit and check on me at that time” was coded as “needed in role negotiation-require assistance in connecting to continuing services”. In this study, all the family caregivers complained, “I felt much stressed shortly after discharge from hospital”. This was labelled with properties and dimensions at the margin as “being pressured at the beginning of role transition”. These labels then became concepts.

#### 3.8.1.2 Level II: Axial Coding

The next step of data analysis is the axial coding in Level II of the constant comparison method. The axial coding involved sorting the information and searching for patterns. Data were combined into a large whole, by means of associations between categories and their subcategories. Connections or patterns describing cause and effect emerged from the data. An example of axial coding was: “I am a full-time caregiver for my husband, but I need to have time for my own [circumstance]. He is very emotional and so am I. I need to go out to relax [phenomenon]. I ask my niece to come over and care for my husband [strategy]. So I am able to go out on my own [consequence]." (Participant No. 5). The core category of "Regaining Self-perceived Control" began to emerge from the concepts of open coding in Level I through the constant comparison method of comparing concepts in codes and developing categories for discrepancies, similarities and relationships that exist among codes and categories in various cases. Subcategories were then identified as characteristics and properties of categories along a continuum or dimensional range (Strauss & Corbin, 1998). Linkages were made among categories and this was done by asking questions about relationships in the data using the constant comparison method (see Figure 3.6 below). For example, by doing all these multiple steps of data analysis, the core category of "Regaining Self-perceived Control" emerged as particularly important for this study.

#### 3.8.1.3 Level III: Selective Coding

The attributes or characteristics of categories were constantly refined based on the properties and dimensions of the identified concepts as the interviews and analysis were carried out in parallel (Glaser, 1978, 1992; Strauss and Corbin, 1998). This was done by asking constant questions: What are those factors that influence the process of caring related to the core category of “Regaining family caregivers? How are meanings of Regaining Self-perceived Control defined among Chinese family caregivers? Why do Chinese engage as caring agents in the family? How do they do this? What do they expect? This allowed the researcher to identify missing pieces of information, construct new questions and refine thoughts as the data collection continued. This core category development led to discovery of a basic social process (BSP). The BSP was similar to a core category with at least two distinct stages to account

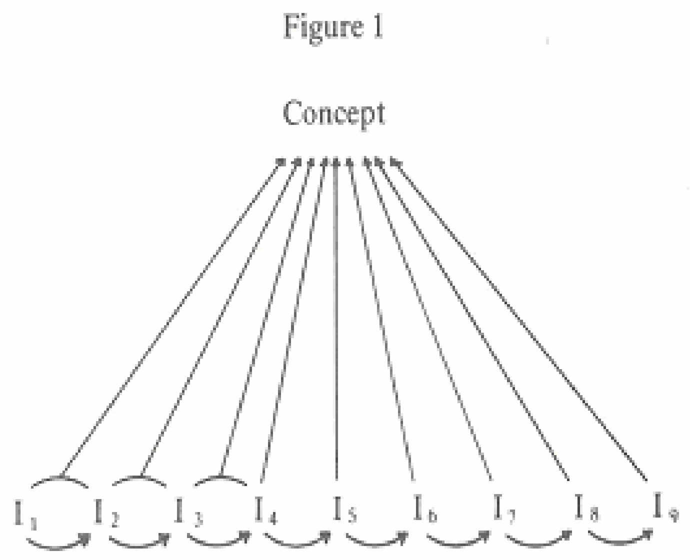


**Fig. 3.6 Multi-concept Indicator Model**

for process, change and movement over time (Glaser, 1978, 1992; Strauss & Corbin, 1998). Therefore, an explanatory framework of family adaptation process through caring was developed based on the goal of striving to regain a sense of self-perceived control.

To keep track of the emerging framework, the researcher revisited all the summaries 20 interview script from the first interviews and other materials including field notes, coding, and memos, diagrams that the researcher had generated over the multiple steps of data analysis with the purpose of identifying the key linkage or core category (see Figure 3.7 below). They are devices that describe the relationships among concepts. Concepts are the building blocks of theory. In Strauss and Corbin's (1998) words "Memos and diagrams help the analyst to gain analytical distance from materials. They force the analyst to move from working with data to conceptualizing. We believe that memos and diagrams are so important to the developing theory…" (p.218-9). The researcher returned once again to the first stage of 20 cases of the study data from the 15 family caregivers and began to arrange and rearrange them in relation to the core category of "Regaining Self-perceived Control". The entire research process was exploratory and developmental and the study direction was guided by the concepts and insights emerged from data collected in the three Levels of coding process

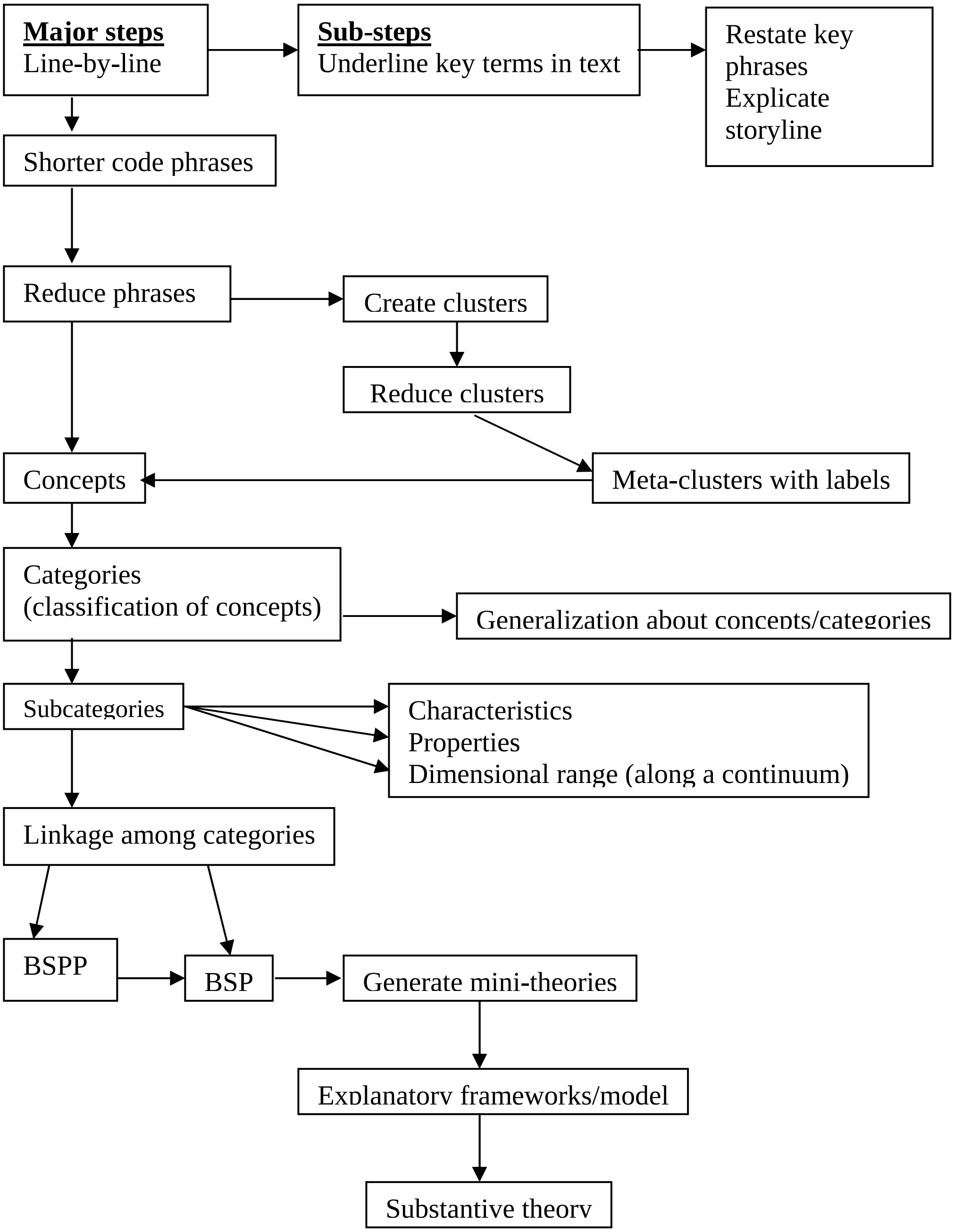


**Figure 3.7 Synthesis Approach to Grounded Theory analysis based on Strauss and Corbin (1998)**

as suggested by Glaser (1978, 1992) and Strauss and Corbin (1998) (see Figure 3.5). Through the processes of opening coding, axial coding, and selective coding, the researcher identified the adaptive modes of caring by which Chinese family caregivers regain personal control. The use of the coding paradigm and the constant comparative method were remarkably useful in permitting a systematic and rigorous analysis of the study data. Through this inductive method, the development of the theory gradually moved to a higher level of abstraction.

### 3.8.2 Data Analysis: QRS NUD*IST (Version 4.0)

Emphasis was placed on developing an analysis that remained faithful to and illuminated the area under study as suggested by Strauss and Corbin (1998). Data management was facilitated through the use of the computer-assisted program QRS NUD*IST (Version 4.0). The names of categories were generated from the tree of concepts already discovered in the data. This facilitated the data management by grouping the similar concepts together with “perceptions of own future”, “ways of providing care”, “attitudes towards seeking support” illustrating those as a tree diagram (see Figure 3.8 below). Such computer entries with the following identified concepts from the data included: “dealing with seeking help from others”, “dealing with own emotions/feelings", "attitudes towards sharing with others", "anticipating the future" and so on. The researcher put all these identified concepts that emerged from data in Level I of open coding into the computer program and facilitate the development of the concept trees. The central concept of "striving to regain a sense of self-perceived control" at the top level of the tree diagram represents the core category that emerged from the data.

The present researcher began the analytical process by following the multiple steps of Glaser (1978, 1992) and Strauss and Corbin's (1998) grounded theory

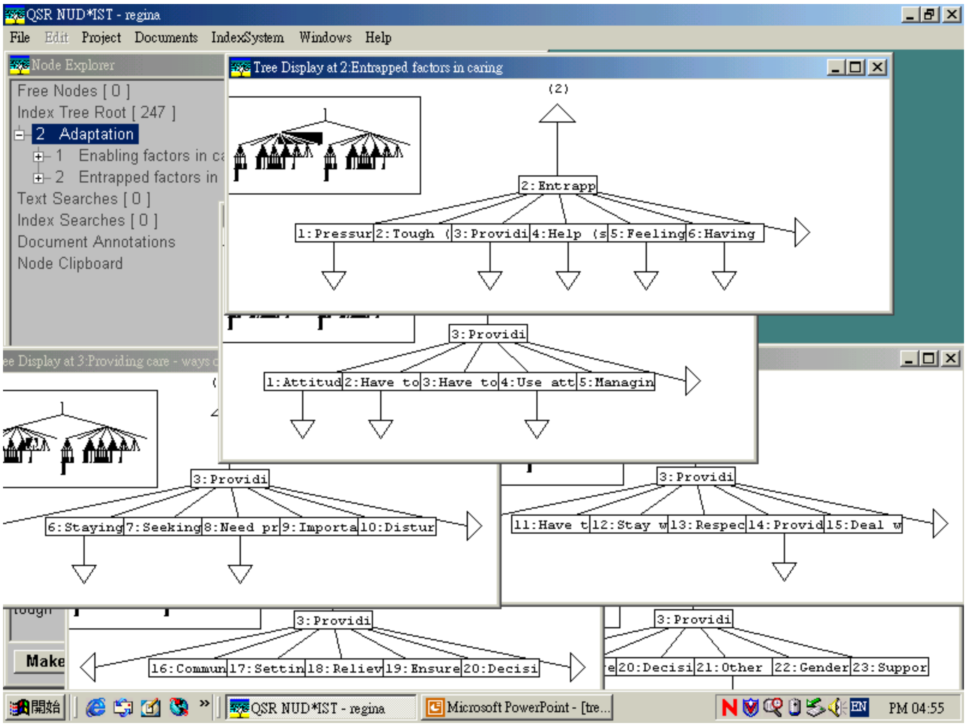


**Figure 3.8** QRS **NUD*IST (Version 4.0): Coding Scheme of Concepts**

approach with three Levels of coding procedures used in order to generate categories and subcategories of concept classes. The core category of “Regaining Self-perceived Control” was revealed through constant comparison analysis and theoretical sampling technique. Concepts pertaining to this identified core category of regaining self-perceived control had been further classified and specified in terms of their properties and dimensions as discovered using in vivo codes. Through delineation of properties and dimensions, the researcher was able to differentiate a category from other categories with precision. For example, with regard to the concepts of “avoidance of seeking” of support versus “persistent seeking” of support in the process of Regaining Self-perceived Control, the researcher wanted to know what attributes distinguish each and labelled them as either examples of “avoidance of seeking” or “persistent seeking” of support, depending on the properties brought out in each situation: frequency, amount, duration, and timing of use and / or type of support used. It is the properties of support seeking that enable the researcher to place incidents into a large, more abstract classification of categories.

After having gained an overview of the situation from some open coding of the study data, the researcher then started the process of axial coding. The researcher attempted an intense analysis focused on one category as the central category “Regaining Self-perceived Control” in the first phase of research process.  Categories generated during the stage of open coding such as receiving spousal/parental cooperation, closed family ties, kinship relationships, strategies, reciprocity, filial piety, and so forth were undertaken in axial coding. Axial coding is the process of linking categories systematically, and the paradigm is an analytical device for organizing data and integrating structures with processes (Glaser, 1978, 1992; Strauss & Corbin, 1990, 1998). In the process of axial coding, the researcher gradually found that the data yielded an initial conceptualization of the Chinese view of acceptance or non-acceptance of supportive relationships in striving to regain a sense of self-perceived control. The researcher also found that there were certain core categories such as self-care, self-efficacy, problem-solving self-efficacy and perceived coping efficacy that were central to the emerging social adapatational process of striving to regain a sense of self-perceived control.

Selective coding Level III is the process of integrating and refining the theory (Strauss & Corbin, 1998). In the process of selective coding, the researcher identified coding around categories, which were only related to the core codes of the emerging theory of the Chinese conception of caring. Therefore, the researcher focused on codes in categories that were central to a “Theory of

Regaining Self-perceived Control" revealing the process of regaining a sense of self-perceived control". Such categories included the nature of relationships, availability of social support, strategies for seeking help, filial piety in Chinese culture, and consequences of caring central to the adaptational social process. The coding of the core category was then integrated into the process of developing a grounded theory. This helped to make the theory dense and ultimately saturated.

According to Glaser (1978, 1992) and Strauss and Corbin (1998), subcategories specify a category further by denoting information such as why, where, when and how a phenomenon is likely to occur. Subcategories also have properties and dimensions. For example, one subcategory of "support seeking" might be "frequency of support seeking", which explains the "how" of support seeking. Frequency of support seeking might be classified according to the specific properties demonstrated such as attitude towards seeking and identification of support provider.

Using constant comparative analysis within and across all 20 interview scripts of the 15 family caregivers in the first round of interviews, many different concepts were formulated and similar concepts were grouped together to develop categories that were more abstract in explanatory terms. These initial codes in Level I open coding became the conceptual labels of this study. This was made possible because interviews broadly followed the study purpose by examining “the experience of Chinese family caring” and so the codes which emerged were reflective of this type of structuring. Herein lays one of the biases of this study and one of the ways this study deviates from a strict grounded theory analysis. The core category of “Regaining Self-perceived Control” emerged in the axial coding in Level II, while properties and dimensions related to the core category were determined in Level III selective coding. The core category of “Regaining Self-perceived Control” was the central theme or story line of the data around which all the other major categories of “Cognitive Reframing”, “Behavioural Reframing”, “Experiential Reframing" were identified (See Figure 4.2 below).

These three major categories are the cultural domains of the core categories of “Regaining Self-perceived Control”. Data analysis reveals the development of coping behaviours of a culturally distinctive kind in terms of caregivers’ perceptions of their own future, making knowledgeable decision, perceptions of responses to life outcomes, sense of independence, attitude towards support seeking, social interaction, relationship with others and perceived confidence and competency in caring. These coping behaviours are subcategories quantify the major categories and core category of “Regaining Self-perceived

Control" by specifying its particular properties and dimensions. In the context of health promotion and chronic illness, "Cognitive Reframing" refers to the belief that one can assume personal control over health problems by learning key aspects of care. Higher levels of self-perceived control are expected to lead to health-promotion behaviours and improved measures of physical and mental health. "Being reformative" measures have been correlated with performing self-care behaviours (Bandura, 1991; Holman & Lorig, 1992; Horan, Kim, Gendler, Froman & Patel, 1998; Lorig, Maxonson & Ho, 1993).

As Strauss and Corbin (1998) have indicated axial coding begins when the researcher relates the categories to their subcategories according to their properties and dimensions. In this study, the major categories of "Cognitive Reframing" and "Behavioural Reframing" varied and changed over time among the 15 family caregivers. To illustrate the subcategory of the categories of "Cognitive Reframing", "Behavioural Reframing" and "Experiential Reframing", for example, data showed the level of "perceived pressure and stress" varied among interviewed caregivers. The level of "perceived pressure and stress" was lower among high level of self-perceived control family caregivers, who were able to make better judgment and predict outcomes positively. They perceive pressure and stress from caregiving as a challenge and it was only temporary. They were willing to seek or accept support from other family members and outsiders. By contrast, the level of "pressure and stress” increased and lasted longer among those low self-perceived control family caregivers. They perceive pressure and stress from caregiving as a threat and their thoughts are more likely to include a negative appraisal of caregiving consequence.  Caregivers did not seek or accept support from their family members and outsiders.  As Strauss and Corbin (1998) state “Patterns are formed when groups of properties align themselves along various dimensions” (p.117); and “…when an analyst groups data into patterns according to certain defined characteristics, it should be understood that not every object, event, happening, or person fits a pattern completely” (p.118).

The proposed Theory is similar to psychological model developed by Kofta et al.’s (1998) Model of Processing Pattern Response System which is used to determine the ways in which caregivers with high or low perceived self-control respond to the demands associated with interaction. The Model allows assessing the causal inference in the observed relationship in order to understand caregivers’ cognitive interpretations and responses to social challenge or threat. Use this Model, the present researcher assumes that the caring outcomes of the process of caring are strongly influenced by the perceptions and management of caregivers’ self-perceived control. The Model will be discussed in details in the next chapter.

With a proposed Theory of Regaining Self-perceived Control in mind, the study data were revisited one last time with the purpose of establishing the specific conditions under which the conceptual indicators identified during the axial coding (family interactions, caring strategies and behaviours and coping styles) vary or conform across the four types of family caregivers. This proved crucial in confirming the identified typing of the interviews. Assessing each family caregiver’s caring strategies and consequences and defining them accordingly were crucial to determining what category of family caregiver each participant fell into. Not all the family caregivers in this study fell neatly and easily into the dimensions of the core category “Regaining Self-perceived Control”. Indeed, the researcher had considerable difficulty coding two family caregivers for this study. The researcher went back and forth over which dimension of the core category they belonged in and was only able to solve this problem after refining and confirming two participants’ data in the second interviews, and considering the general adaptation process of family caregiver’s experiences.

## 3.9 Rigor of Data

This study used specific techniques to establish rigor. The researcher attempted to address the following aspects of rigor or trustworthiness throughout the study: fit, work, credibility, modifiability and multiple data sources. These were the criteria for evaluation identified by Glaser (1978, 1992) in the examining the structures of validity of a qualitative study such as this one employs grounded theory approach.

Rigor in the interpretation of qualitative data reviews the criteria and discusses how they may be used to evaluate qualitative research presented in this study. This multiple steps of the data analysis of grounded theory method guides the development of concepts (memos, diagrams, coding, field notes, case summaries, category and theme) related to qualitative content analysis; illustrates the use of concepts related to the research procedure; and proposes measures to achieve rigor (fit, work, be modifiable, be credible and be based on multiple data sources) throughout the steps of the research procedure. Interpretation in qualitative content analysis is discussed in light of criteria suggested by Glaser's (1978, 1992) validating research measures means making cases for their "rigor". According to Glaser, grounded theory has "grab" means a theory must have fit and relevance and be readily modifiable, and it must work and it should be based on five criteria: fit, work, be modifiable, be credible and be based on multiple data sources. The following sections discuss these concepts and the strategies used to investigate these issues.

### 3.9.1 “Fit”

According to Glaser (1978, 1992), by fit means the categories of the theory must fit the data. Data should not be forced or selected to fit pre-conceived or pre-existent categories or discarded in favour of keeping an extant theory in negotiation. Since all the categories of the Theory of Regaining Self-perceived Control in this study are generated directly from the data using constant comparison method and theoretical sampling strategy, the criteria of fit is automatically met and does not constitute an unsatisfactory struggle of half fits. The present researcher had modified them to constantly refit and fit with new demands in order to ground the fit of categories as close as possible.

Congruent with the term applicability are the concepts of transferability and fittingness (Byrne, 2001; Sandelowski, 1986). Specific strategies used to achieve transferability include making detailed descriptions and conducting purposive sampling. It is impossible to form generalizations that will hold for all times and places. The generalizability of this study refers to the theoretical applicability of the developed model to other family members caring for stroke-impaired elderly relatives. In order to make possible the transferability of the findings, a database containing detailed descriptions was obtained by the present researcher for purposive sampling. Detailed descriptions of the data provided enough information for the researcher and the participants to judge the key elements, clusters, categories, and themes of the analysis. This may allow future researchers to apply the findings of this study to other settings.

The diverse caregiving experiences of the process of caring of the 15 Chinese family caregivers in this study were similar, despite the patients' different prognoses and treatment. It was these patterns of care that were associated with the role of being family caregivers that were drawn together to develop a Theory of Regaining Self-perceived Control for Chinese family caregivers caring for their stroke-impaired elderly relatives.

### 3.9.2 "Work"

For the theory to work, its categories must be fit and relevant to the core category of what is going on by systematically collecting and generating from data. According to Glaser (1978, 1992), a theory should be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive or formal inquiry. The development of the “Theory of Regaining Self-perceived Control” is an adaptation process explains a considerable portion on the interactive action of caregiving and relates to most categories of lesser weight used in or making the theory work. Thus this adaptation process integrates the three major categories identified in the theory in this study: “Cognitive reframing”, “Behavioural reframing” and “Experiential reframing”.

The confirmability or dependability of the research process is another criterion used to judge a qualitative study. Confirmability is achieved through the researcher’s audit trail (Byrne, 2001). In this study, the audit trail specified the process by which the data were collected and analyzed; changes made to the questions included in the interview guide; and the process by which the audiotapes, the complete Chinese and English transcriptions of the interviews, field notes, case summary sheets, and memos were made. Establishing such an audit trail helps an independent examiner evaluate the process of inquiry and ascertain the credibility of the findings. Following the audit trail ensures that the researcher’s interpretation was logically driven by the emerging data and, hence, that explanations offered for the phenomena under study are plausible.

### 3.9.3 Credibility

Establishing the credibility of a research method and of subsequent findings can be achieved through numerous strategies built into the processes of collecting and analyzing data, including during the making of observations, the conducting of interviews and the analysis of documents. In this study, credibility was enhanced by looking for non-verbal cues, employing effective communication techniques to establish relationships of trust, and through prolonged engagement with the participant. To achieve prolonged engagement, the researcher first spoke with the families during the regular meetings of the stroke support group and established a relationship of trust through telephone contact. The researcher ensured the appropriateness of the study sample and the adequacy of the data collected by using a purposeful sample, selecting the sample according to the theoretical needs of the study. The researcher also conducted pre- and post-face interview and telephone conversations to enhance the credibility of the findings. The initial exposure and the follow-up contact provided the researcher with the opportunity to establish a trusting relationship with the participants and gain insight into the multiple facets of their lives and into the contextual social factors.

The second strategy used to enhance the credibility of the findings was to pursue referential adequacy. To enhance the referential adequacy of this study, the interviews were audio-taped and transcribed into Chinese and English by the researcher. The data could be easily retrieved for the purpose of identifying common patterns and testing emerging hypotheses. This was necessary for later examination, comparison, and audit. The adequacy of the study data was determined not by the number of participants involved, but by the amount of data obtained for saturation when all aspects of family adaptation through caring were richly described. Adequacy is achieved when theory is considered valid and complete.

The third strategy for checking the credibility of research involved returning to study participants in the first interviews. The purpose of arranging second interviews was to further confirm the analyzed data by means of a member check. Thirteen family caregivers from the first interviews were contacted successfully. This was achieved by integrating the participants into the data analysis phase of the study (Byrne, 2001). For member checking, the researcher returned to the 13 study participants to determine whether the findings accurately represented their experience and helped them explain their own experiences. This was also done by asking the participants for their opinions and comments on the existing data in subsequent interviews. Clearly, the researcher's reconstruction of the realities should be recognizable to the participants if such a reconstruction adequately represents their own experiences. Extensive readings from nursing, psychology and sociology literature and discussions with nurse researchers and researcher's two supervisors were used to increase the researcher's theoretical sensitivity (Strauss & Corbin, 1998).

### 3.9.4 Modifiability

Various grounded theories generate over the years. According Glaser (1978, 1992), although the basic social processes remain unchanged, their variation and relevance are ever changing in the world. To keep up with all changes and new data, a hypothesis could have been outdated and required verificational effort for updating. The process of theoretical coding in grounded theory allows for quick and ready modification to help explain new variations and the ever changing in the adaptation process of family caregiving in this study. It is through this quick approach that the tractability of grounded theory over social life is maintained for its relevance.

### 3.9.5 Multiple Sources of Data: Techniques for Rigor

The techniques used to ensure rigorous of this study including persistent observation and field notes, coding memos, prolonged engagement, and member checks.

### 3.9.5.1 Persistent Observation and Field Notes

The researcher recorded the observations and feelings after each interview in the field notes as the third type of data collected and analyzed for this study in both first and second sets of in-depth interviews. This offered the opportunity to track the progress of research cases on a regular basis. The researcher kept detailed notes of this experience. Following Lofland and Lofland's advice (1984), the field notes were made immediately after each interview. They included the impressions of the physical setting of the interview, reflections of feelings the researcher had approaching the interview, the observations of the interaction among family members, and the content of the interview.

### 3.9.5.2 Coding Memos

The researcher's record of thoughts and interpretations written in the memos were also included in the data analytic process.  Memos were maintained throughout the process of analysis to document the ideas and insights generated. These memos were useful when the researcher returned to the 15 participants in the first and second interviews and attempted to identify the linkages among concepts and their relations to the study core category.

#### 3.9.5.3 Establishing Rapport

The objective of this study was to understand the Chinese family caregivers' process of caring for their elder relatives who had suffered stroke. It was believed that valuable substantive findings could be obtained by establishing a stable relationship with the caregivers. Maintaining a good rapport with the participants and letting the participants define a role for the researcher reduces the distance between the researcher and the participants. As suggested by Guba & Lincoln (1981), the researcher attempted to practice reflexivity by consciously revealing the underlying assumptions that led to the formulation of the questions and to the presentation of the findings in a specified way.

#### 3.9.5.4 Prolonged Engagement

There were two periods during which face-to-face interviews were conducted: January 2001 and June 2003. Joining the monthly gatherings of the stroke support groups and establishing trusting relationships with some of the participants permitted the researcher to demonstrate engagement and concern. Telephone contact with the participants before and after each interview also provided opportunities for the researcher to gain a general understanding of the characteristics and needs of Chinese family caregivers and their caring patterns.

#### 3.9.5.5 Member Checks

Member checks were another method used by the researcher to ensure the credibility of the findings in this study. Member checking involves allowing the participants to give responses to the interpretations of the data. According to Lincoln and Guba (1985), member checking refers to the process by which the researcher's data, categories, interpretations, and conclusions are validated by the members from whom the data were originally collected. The present researcher transcribed the data and went back to 5 participants and discussed her observations and interpretations. The researcher also conducted second interviews of data collection two years after the first interviews with the 13 study participants in order to refine and confirm the data which collected in the first interview.

Thirteen family caregivers were recruited successfully in the second interviews of data collections and there were 11 home visits and two telephone interviews. After the second interviews of data collection, the present researcher also discussed with the chairperson of each of the four stroke support groups her major observations and interpretations of the Chinese family caregivers' caring experiences. Also after the second interviews, the researcher telephoned three study participants to discuss their interpretations of the Chinese conception of family caring. Their positive response affirmed the credibility of the interpretations of the findings of the study.

Initially, the researcher attempted to examine the range and variations in the experience of adaptation through caregiving. When data was lacking in particular areas, additional participants were purposely recruited to collect further information on that area. This was necessary to collect data in areas such as the intensity, critical period, and gender issues in the adaptation process. In order to describe the process of caring in the caregiving experience as accurately and clearly as possible, the researcher returned to the five participants to validate the interpretations and collect additional information from the first interviews. There was close interaction among data collection, data analysis, and the research approach. As the descriptions and explanations were determined by analyzing the data in grounded theory approach, further requirements for the collecting of data were guided by referring to the previous interview transcripts and assessing for data saturation. The point of saturation was analyzed carefully, in order to construct theoretical coding from the study data, an explanatory scheme that would systematically integrate various concepts through statements of relationship. The theorizing was then completed. The following four criteria proposed by Glaser (1978, 1992) were used to decide when to end the process of collecting data: (a) exhaustion of sources, (b) saturation of categories, (c) emergence of regularities, and (d) overextension.

### 3.10 Summary of Chapter Three

In this chapter, the researcher has justified the use of a grounded theory approach in achieving understanding of the experience of caregivers of stroke-impaired elderly relatives. The characteristics of grounded theory, the application of this methodology and the rigor in the present study were also addressed in terms of sampling, data collection and analysis. The researcher also discussed the multiple steps in designing of the research to fit and work for the process of forming a grounded theory including theoretical sampling, data saturation, theoretical relevance, coding memos, three coding Levels and the rigorous of the study's findings. The techniques used to ensure rigorous include persistent observation, coding memos, neutrality, prolonged engagement, peer debriefing, and member checks. The rigorous use of multiple sources of data collection methods helped to ensure the credibility of the study's findings. The research process and study findings may, therefore, be considered rigor and trustworthy.  The next chapter will discuss the findings and the resulting categories and their linkages that form the theoretical framework accounting for the processes involved when newly caregivers adapt through their transitional role in caring for stroke-impaired elderly relatives.

# CHAPTER FOUR

# REPORT OF FINDINGS

This chapter describes the processes through which Chinese caregivers adapt through their transitional roles. The core and major categories and the different stages that emerged as caregivers provided continued care are explained. The strategies that they adopted through different stages of the adaptation process are also examined. Four types of family caregivers are identified to reflect how each type of caregiver via caring behaviours strives to regain a sense of personal perceived control in each stage of the adaptation process. The experiences of those caregivers who were able and unable to regain self-perceived control smoothly are explained via the cognitive interpretations. Finally, the development of a Theory of Regaining Self-perceived Control is also described.

## 4.1 Introduction

In spite of extensive research on stroke and the family, little is known about the process of taking on the caregiving role when a family member is diagnosed with stroke. In this study, the initial analysis revealed that caregiving can not be understood in isolation from the experience of caring and that a reconceptualization of the target phenomenon was needed. Accordingly, the family caring as a process was set to encompass both caregivers' self-perceived control and ways of coping with caring demands. Caring patterns and the dynamic of interactions fluctuated over time, a phenomenon labelled shifting patterns of self-perceived control and caregiving. Shifting patterns of self-perceived control and caregiving are so characteristic of stroke care during rehabilitation that they became the core concept of the grounded theory in this study. This conceptualization emphasizes the dynamic and interactive nature of caring during rehabilitation.

The core category of Regaining Self-perceived Control facilitated the adaptational social process and helped caregivers to overcome the day-to-day vicissitudes of life. Findings revealed the basic social psychological problem of loss of personal control as, a core category and eight subcategories (variables) as the enabling and entrapping factors. These factors were identified from four types of caregivers in adapting to regain self-perceived control: ability to anticipate future, ability to act on decisions, ability to make choices, perceptions of responses on life outcomes, attitudes of seeking support, extent of social networks, relationships with others, perceived confidence and competence.  Five stages of the adaptational social process were identified: uncertainty, disruption; accommodation; balance; and reconciliation. Caring strategies and caring patterns emerged from the 15 family caregivers' detailed responses to the challenges of stroke family caregiving and elaborated the day-to-day experiences.

Regaining a sense of self-perceived control as a critical social challenge has been identified by the 15 Chinese family caregivers of stroke-impaired elderly relatives in this study. The study findings show that the process of caring has been associated with stressful events around which caregivers’ strategies of coping related to a range of seeking support behaviours from avoiding to persistent seeking of support to cope with the demands of caregiving. The family-based structure in Chinese society forms the structural approach of the kinship support network which correlates with all the dynamics and interactions in the caring process. In this study it was found that the changing nature of social ties evolves in the process of family caring and correlates with the caregiving situations including the caregiving characteristics and caregiving factors. The cultural dimension of kinship support network and their impact on caring relationships and behaviours in the process of family caring were then understood.

## 4.2 The Core Category: Regaining Self-perceived Control

Following discharge from hospital to home, there is a basic social process of family adaptation that may last from eight months to two years (Ko, 2002; White et al., 2003). “Regaining Self-perceived Control” is the core category that explains the activities and social processes involved as the 15 Chinese family caregivers in this study adapted to their transitional role. The social process is influenced by dynamics of interactions and it changes over time (see Figure 4.1 below). Clearly, this complex social process involves sequences of evolving interaction prior to adapting through the caregiving process. Family members who assume the caregiver role must restructure their lives to manage the daily demands of caring for stroke-impaired elderly relatives with physical and cognitive deficits because of the limited social contact and lack of social roles outside of caregiving resulted in a greater loss of self in family members who provided care for individuals. Seven family caregivers (Nos. 2, 6, 9, 12, 13, 14, and 15) experienced the loss of self-perceived control as a result of the caregiving is often overwhelming.

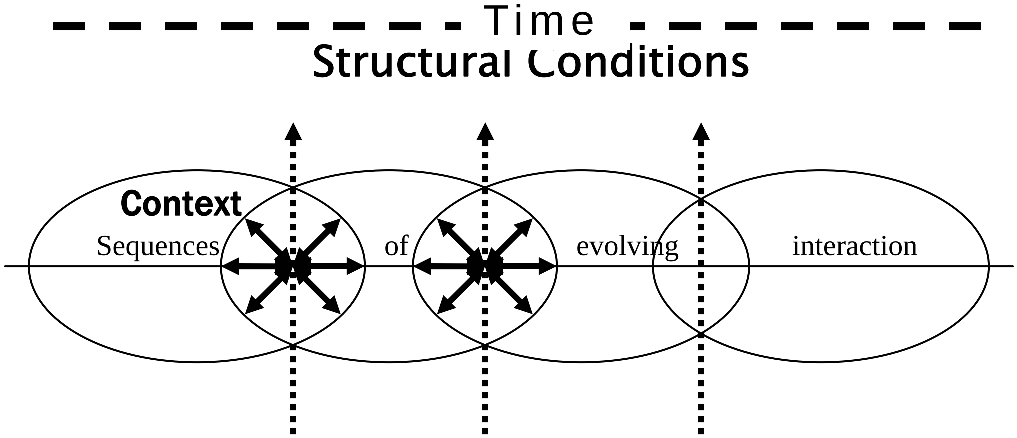
A 74 years old female caregiver (wife) in this study states:

> I do not request to have a home helper because I could do housework when he is sleeping. I used to do housework on my own. I am getting old and I should not have too much request. Some time ago I was asked to hire a domestic helper once a week to help me out, but I did

> not. I did everything on my own instead. So I did not need any assistance from others. I often do not sleep well at night, but he always sleeps well. So I have time to do the housework. (No. 9)

A 75-year-old wife caring for her husband with bedridden stated:

> “I am seventy-five.…I have difficulty in taking care of him… very troublesome to care him…can’t stand when going to toilet, totally can’t stand…trouble me when go to toilet…his hand totally can’t move and dress him. (No. 15)



Straight lines = evolving inter/action
Circles = context for inter/action
Overlaps in circles = intersection of conditions and consequences leading to change of variation in context and adaptations made in interaction to keep it flowing

**Figure 4.1 Structural Conditions of the Family Caring Process Adopted from Strauss & Corbin (1998)**

Major theme constituting the experience of caregiving centered on caregiver concerns about ways and behaviours of striving to regain a sense of personal control. Caring for a stroke-impaired survivor with functional and cognitive deficits can be a difficult task. In this study, all 15 family caregivers commonly reported poor health outcomes, a loss of independence, restricted social activities, and limited opportunities to travel because of their caregiving role.

Through successfully regaining a sense of personal control, eight caregivers (Nos. 1, 3, 4, 5, 7, 8, 10, and 11) were able to maintain a sense of predictability in face of the uncertain physical demands in providing care.

A 60-year-old wife with the desire for independence featured strongly:

> I am a full-time caregiver for my husband, but I need to have time for my own. He is very emotional and so am I. I need to go out to relax. I ask my niece to come over and care for my husband [Strategy]. So I am able to go out on my own. (No.5)

A 70-year-old husband caring for his severe disability wife stated:

> It is related to something that the society should realize that there was nobody available to teach me as carer on those caring knowledge of how to care for her, why it is so tough? Why she is crying all the time ? I don't know why and so I cry with her. This is very foolish and I cry so much that I want to end my life. I don't know why. I open up myself and talk about it now. Everything is okay. (No.4)

Not surprisingly sleep deprivation exhausted some family caregivers, especially if their stroke-impaired relatives were afflicted with Alzheimer's disease and incontinence. Here a 68-year-old committed male caregiver gives voice to his problems:

> I woke up in the middle of night because I heard her calling me, then I realized that she was unable to talk. Every night I have to check her nappy and I have to change her if the nappy was dirty in the middle of night. I always felt tired in the day time. I hope she does not have to go to the toilet in the middle of the night. I need to assist her on the commode every time. If she needs to go a few times, I usually feel very tired the next day. (No.8)

Some of the family caregivers experienced problems with stroke-impaired relatives being doubly incontinent, but they never gave it as a reason for caregiving at home coming to an end. This 60-year-old woman looking after her husband (negative case) expresses typical positive resignation:

"One time there were six bed sheet hang all over the house because his prostate has a health problem and he is incontinent. I don't mind doing all these washing". (No.5)

Four family caregivers, a daughter (No.12) and three wives (Nos.7, 9, and 15) in the second interviews reported that because of the continuing need to provide physical demands in caring, they came to believe that they were ‘giving up’ or ‘suspending’ their own futures. They were waiting to send their relatives to Government’s Care and Attention Home when their care had generally been a period of increasing dependency and they could no longer cope with unexpected and chronic conditions such as seizure and dementia. For example, a 74-year-old woman looking after her husband said:

> I didn’t want to send him to the care home, it is so far away. But my health is getting worse and I could not cope physically with care tasks. I am worried who is going to care for him if I become sick in the house. I will only send him to the care home ran by Government because there are nurses there. The social worker told me that it would take a few years to be admitted to the care home. (No. 9)

A caregiver’s own health problems could make it difficult to continue providing care at home. Two older female spouses and one male spouse in the second interviews, their stroke-impaired relatives needed physical help in getting into a bath or getting out of bed or with dressing, reported being unable to continue because of serious back problems. For example, a 75-year-old woman looking after her husband stated:

> My health is not good and I have arthritic problems for my age. I have a bad back. So I cannot move him by myself. I do not sleep well at night time and I have found that it is very difficult caring for him in the day time since I am always so tired. My health is not well and I am very worry that something might happen suddenly and I won’t know what to do with him. (No. 15)

The older spouse family caregivers in this study were more likely than the daughters to report serious health problems. High blood pressure and angina were mentioned by all elderly family caregivers. One of the husbands, for example, felt unable to continue looking after his wife following heart bypass surgery. He then hired a helper to do household tasks. The importance of needs is identified by the family caregivers' as the perception of the significance of requirements for care and help from others. Satisfaction of needs is the subjective judgment made by the family member about the degree of satisfaction with the perceived needs. It was also found that when stroke – impaired relatives became less dependent on family caregivers and the better quality of life increased greatly. The opposite was, of course, the case when the cared-for-person became increasingly dependent due to deteriorating health. A concern in family caring is that the health statuses of both caregivers and cared-for-persons continually change. When the functional status of the stroke elderly relatives deteriorates, caregivers may no longer be able to continue to meet the increased caring demands.

Regaining Self-perceived Control" was the central theme that linked all other concepts, and it appeared to be fundamental to caregivers' caring strategies. All family caregivers in this study were willing to take responsibility for the caregiving tasks of their stroke-impaired elderly relatives. But not all the caregivers in this study were able to regain a sense of personal perceived control smoothly and satisfactory and they had to come to terms with physical suffering, poor health outcomes and emotional strain. “Regaining Self-perceived Control” emerged as the core category and reflected the Chinese family caregivers’ process of striving to fulfil the caregiving demands of their transitional role.

## 4.3 Three Major Categories of Core Category of “Regaining Self-perceived Control

The cultural domain of self-perceived control that emerged from the data is a composite of three major categories or conceptual indicators that give cultural meaning to the domain of Chinese self-perceived control. The major categories are the three ways that caregivers strive to gain a sense of controland they include: “Cognitive Reframing”, “Behavioural Reframing”, and “Experiential Reframing”. It was found that the core category “Regaining Self-perceived Control” is a complex social process which relates to the interaction and the relationships between the three major categories (domains), eight subcategories (variables) and five stages (see Figure 4.2 below). Regaining a sense of self-perceived control has been suggested as an important construct in understanding individuals' reactions to caring-related stressors. Within the stages of Theory described, three major categories of caring strategies of Chinese family caregivers were identified.

### 4.3.1 Cognitive Reframing

The first strategy, which was most commonly adopted by the caregiver participants of this study, was the 'cognitive reframing strategy' refers to the belief that caregiver can assume personal control over problems by learning key aspects of care. Higher levels of self-perceived control are expected to lead to health-promotion behaviours and improved measures of physical and mental health.

A 47-year-old daughter caring for her mother with Dementia stated:

> "Of course it would be better to get help from others". (No.3)

### 4.3.2 Behavioural Reframing

The second strategy was the 'behavioural reframing strategy' refers to caregivers' willing to change and make adjustment by changing the current interfere behaviours and replace it with a new and well defined behaviour.

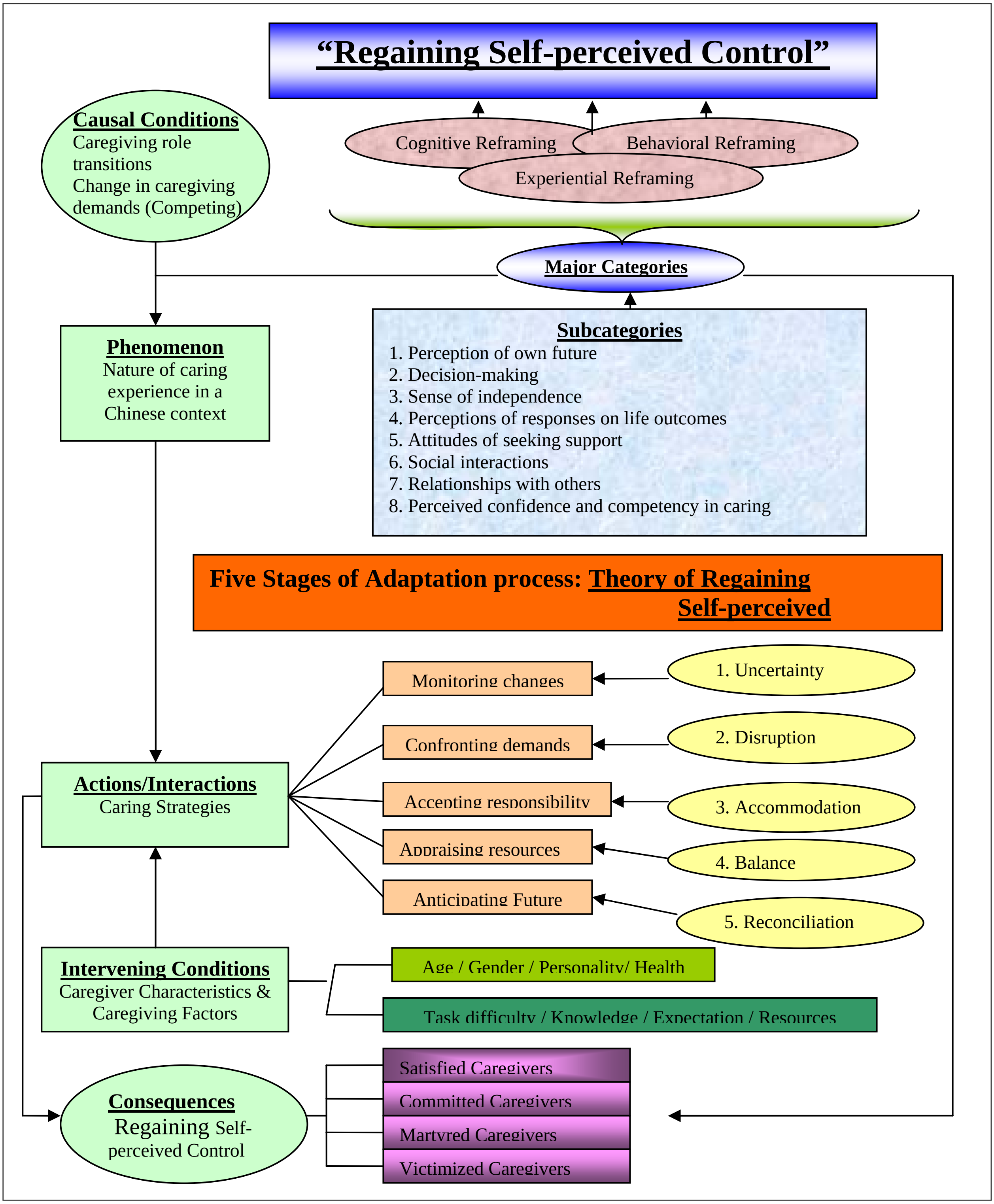


**Fig. 4.2 Flow Chart Depicting the Process of Merging Categories to Form Core Category: Regaining Self-perceived Control**

A 75-year-old man looking after his wife with moderate disability stated:

> “I really need someone to help me to care for my wife. It was impossible to care for her without assistance from others”. (No.1)

### 4.3.3 Experiential Reframing

The third strategy, the ’experiential reframing strategy’, refers to caregivers’ caring acts were ritualistic. Caregivers achieve a stage of behaviour and thought being automized. This was adopted by those caregivers who had significant opportunities practice self-control skills and so became linked to multiple sources of support networks.

A 70-year-old husband caring for his severe disability wife stated:

> “So I called the social worker and complained the inconvenience with broken wheelchair for my wife, then the broken wheelchair got fixed sooner than we expected. I was very happy and so was my wife”. (No.4)

## 4.4 Adaptation process: Theory of Regaining Self-perceived Control

In this study, caregivers’ went through an adaptational social process which is comprised of five stages (see Figure 4.2 above) of a Theory of Regaining Self-

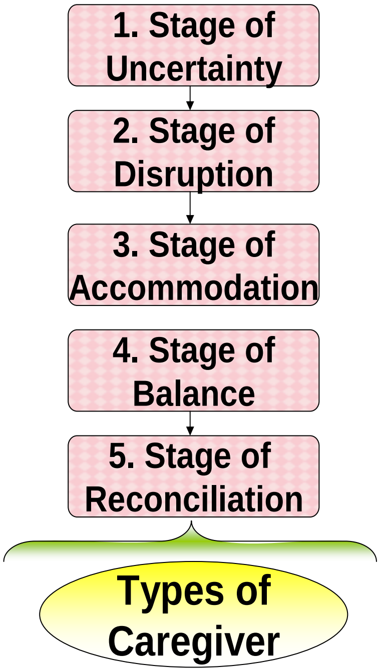


**Figure 4.3: Theory of Regaining Self-perceived Control: Five Stages of the Adaptation process**

perceived Control of the adaptation process: (a) Uncertainty, a sense of impending doom (uneasiness) a struggle with a perceived loss of control; the ability to act on decisions is disrupted by limitations and this involves those caring strategies to monitor changes; a struggle with a perceived loss of personal control; (b) Disruption, a desire to regain control and preserve self by alleviating the signs of distress and reducing the adverse effect of excessive state control motivation; (c) Accommodation, a sense of adapting strengthens self-determination and this involves an individual's sense of perceived control; the individual is no longer to trust his or her abilities and therefore must rely on others for support; the individual begins the struggle to re-establish a sense of control over his or her life; (d) Balance, a sense of equilibrium restore realistic perception of event by accepting support and result in resolution of problem; and (e) Reconciliation, a sense of independence by making it through and anticipating future and Regaining Self-perceived Control successfully. Family caregivers may go through this adaptation process and make sense of the experience of caring before they are able to adapt by regaining a sense of self-perceived control. The different stages of adaptation and their relationships to the core category would be discussed in the following with the caregivers' own words to illustrate their experience of taking on the caring role after discharging from hospital. However, the verbatim data presented below have been translated directly from the original Chinese interview scripts and may therefore appear grammatically incorrect in some places.

### 4.4.1 Stage One: The Stage of Uncertainty

Three of the caregivers (Nos. 5, 10 and 14) had previous experience in providing care for stroke-impaired elderly relatives. Although all of the caregivers had accepted the sudden imposition of caregiver roles, they felt uncertain about the increased demands on them and the unpredictability of their futures. This stage began from the date of discharging from hospital and lasted for two weeks to one month. Caregivers' folk beliefs and traditional values in respect of role responsibilities were being challenged with all the unpredictability of their future and this leads to the possibility of threats. The caring strategies are used by caregivers in the first stage of this adaptation process are suspecting and monitoring.

#### 4.4.1.1 Suspecting Threat

The caring experience commenced as the caregivers suspecting that something was wrong. They sensed that things were not quite right as before. They seemed more stressed, a feeling of 'uncertainty' overtook them. They suffered insomnia, poor appetite and general negative health outcomes. The following remark is illustrative:

A 74-year-old woman looking after her husband with severe stroke disability and dementia reported:

> I need to clean him after each bowel motion when he was discharged home, but he is uncooperative and this made me feel very annoying. He sat on the bowels although he could not sit up properly. I wonder why? After all these, I could not eat well during the day and I could not go back to sleep in the middle of night. I thought, "I wonder why". I gradually lost weigh and I always have stomach ache, I thought, "How long this will be lasted? (No. 9)

Thus, caregivers were attempted to make sense of these negative health symptoms by determining their meanings. Uncertainties began to crawl into their minds as they identified those threats that seriously affected them in reality. During the interviews, caregivers used a lot of words such as “why”, “wonder”, “thought”, and “feel”. This process of suspecting was a closed response strategy for practicing the self-perceived control techniques. Through suspecting all the negative health symptoms, caregivers began to rehearse a mental picture of what went on at home. In suspecting negative health symptoms, they developed an easily accessible explanatory system that permitted sensitivity to the possibility of threat. When caring situation demands were consistent with threat, there was a match between their explanatory system and the stimulus posed by the caring situations. Actual and potential opportunities of threat against Regaining Self-perceived Control were assessed and identified. Therefore, caregivers have greater than normal access to “threat” and lose self-perceived control at this stage.

#### 4.4.1.2 Monitoring Symptoms

Through suspecting closely the negative health symptoms, a mental picture was established which helped caregivers to observe the interactions of family caring using their own experiences to evaluate the present symptoms and, when the uncertainty continues, by comparing their own symptoms with their friends' experiences with family caring. They are in the process of monitoring and they did not seek information from others because they preferred to remain in self-perceived control and to regard those negative health outcomes as minor. Stomach ache was considered such a minor illness that these caregivers would rather avoid the embarrassment of "troubling others" than have their worries and concerns alleviated. This process, however, was more evident in the older female caregivers than the male and younger caregivers. Three older female caregivers (Nos. 2, 9 and 13) said that their monitor skills were very thorough and they did not seek any help. One of the older female caregivers, a 68-year-old woman looking after her husband with severe stroke disability had this to say:

> This is my own business that I have to deal with myself. I slightly have some idea what is happening. This is just my own body reaction from stress after all these. I don't want to make troubles to others unless it is really necessary. This is my philosophy. (No. 6)

In order to accurately determine the causes of the negative health symptoms, caregivers began to identify situations that worsen or alleviate those symptoms. This occurred quite commonly and over a period of time before the older female caregivers accepted the fact that those negative health outcomes from stresses were unhealthy and that they should seek support from others. This process of monitoring symptoms was not limited to physical symptoms, it also allows caregivers to evaluate emotional states and interpersonal relationship with stroke-impaired relatives in order to determine what was happening to them. Thus caregivers with high perceived self-perceived control were able to monitor and prevent further erosion of self-perceived control including things happening around care providing.

A 74-year-old man looking after his wife stated:

> I always check her blood pressure and prepare low fat and salt diet. I make sure she has adequate exercise… I also check on her at night time to make sure her hands are not cold… I understand why she had bad temper due to the loss of functional level after stroke episode. I need to be patient and show love and sympathy for her. I should get mad on her, rather I should protect her. (No. 1)

The caregiving role is a complex one that requires individuals to respond flexibly to a wide range of needs as they arise. Caregiving often involves a good deal of responsibility, as well as cognitive, emotional, and sometimes tangible resources, caregivers must be motivated to accept that responsibility and expend the time and effort required to provide effective support. Results revealed that there were a number of distinct motivations for providing and for not providing care to their stroke elderly relatives. The motivations were associated with various personal features of the caregiver and the cared-for-person. The caregiver's perceptions of the relationship influence his or her caregiving motives and different motivations for caregiving predict different patterns of caregiving behaviour.

Quality of interpersonal relationships was also evaluated at this stage as this appeared to be a very common motive found in caregiving involving.  The quality of caregiving that occurs in the relationship and the characteristics of personal relationship might influence caregiving motivations.

A 74-year-old husband looking after his wife with severe disability said:

“I take up the caregiving role because she had been very good at bringing up the four children and babysitting to support the family financially when I stayed the dormitory at work”. (No. 1)

It was found that four caregivers were engaged in the processes of suspecting and monitoring longer. It might be that these four caregivers had lack of self determination and predictability and they were more likely than others to react negatively to threats to their control.  Although they noted things were different from before, none of them initiated to follow up to this observation. A lack of understanding and decisional control about what was happening meant they were unable to make autonomous decisions.

Two female older caregivers looking after their husbands with moderate disability reported:

> “It was very tough in the first two months. My mind always was blank and I didn’t know what to do”. (No. 7)
>
> ”I was very confused and frustrated and I did not know anything about stroke at that time”. (No. 15)

### 4.4.2 Stage Two: Stage of Disruption

All the caregivers (15) began to express their emotional reactions resulting from providing care in this study. As caregivers monitored all the happenings in the family, they established a reality of helplessness and become overwhelmed by worries and concerns, particularly if they detected that the stroke-impaired relative was worried. These reactions ranged from feeling very stressed to feeling tense and under pressure. The stage of disruption began when the family caregivers realized that caring responsibilities increased in caring demands as time went by. Initially, all family caregivers were willing to accept caring responsibility even though they might have a sense of being unable to take control in the new situations. Caring demands cause stressful situations for family caregivers. They were being overwhelmed by those negative emotions when confronting demands of tasks which had given them much pressure. The symptoms develop to a point where the family caregiver becomes overwhelmed by worries and concerns. Apprehension begins to grow when they realize the disability and increased dependency of the stroke-impaired person in daily activities with the process of perceptions of low self-perceived control.

#### 4.4.2.1 Relinquishing Self-perceived Control Techniques

Apart from caregivers' (Nos. 2, 6, 9, 12, 13, 14, and 15) mental state control motivation was stronger than task control motivation in the self-perceived control process, which is based on the open and closed response systems to human interactions. With the information gained from monitoring and observations made and from the process of perceptions of self-perceived control, the caregivers began to make sense of demands of providing care. By now, they had a thorough understanding of the demands and interactions of the process of caring, especially of those situations that pose a potential social challenge which caregivers considered to be like the "self-perceived control disadvantaged". This sense of lack of self-perceived control illustrated by one of the caregivers as:

A 68-year-old man looking after his wife with moderate disability said:

> I have to provide total care for her since she is unable to move on her own. This gave me lot of pressure and I don’t even have time for my own. I did think of ending my life at the beginning, but who is going to look after her… then I stop thinking of it. Sometimes, I feel very helplessness. The lady worked in the Social Welfare Department was not helpful to me at all… The government did not provide adequate services to help us as the caregivers instead they cut out resources for supporting us. (No. 14)

The other eight caregivers (Nos.1, 3, 4, 5, 7, 8, 10, and 11) accepted the control opportunities and were able to keep the self-perceived control process on course, which shows that the task control motivation was stronger than the state control motivation. It is worth noting that first seven caregivers did not regain of self-perceived control as those caregivers avoided confronting the situation because they were afraid of being overwhelmed by negative emotions when doing so.

#### 4.4.2.2 Accepting Caring Responsibility

The stage of disruption ends as the family caregivers begin to engage more actively in caring process and seek support from available resources. A lack of understanding about what was happening to one's life undermined caregivers’ sense of control, and the caregiver must make sense of caring by accepting caring responsibility before they were able to regain sense of control. The family caregivers feel that they must ‘keep it together’, not giving in to their own feelings of being out of control because they feel a sense of responsibility to act for their family members.

A 74-year-old man looking after his wife explained that:

> The most important thing is to do things for her as much as I could. I have to be careful not to hurt her. I prepare meals, shop grocery and do laundry. I also help her to do exercise. I will do whatever I could for her. No matter what happen, I will be there for her because she is my wife. (No. 1)

The eight caregivers who sought available support were able to regain self-perceived control by reducing the adverse effects of excessive mental state control motivation and opened to their present experience through the use of experiential self-perceived control skills. They were able to have their own time for themselves, they moved into the stage of striving to regain a sense of self-perceived control.

### 4.4.3 Stage Three: The Stage of Accommodation (Regaining Self-perceived Control)

When family caregivers have once more gained a sense of self, they enter into the rehabilitative stage of accommodation to Regaining Self-perceived Control and promoting physical wellness. The major task of this stage are regaining former relationships by reducing adverse effects of excessive mental state control motivation and once more asserting control over their own lives, learning to trust their cognitive perceptions, and attaining mastery over the situation.

#### 4.4.3.1 Adjusting Self

The relationship with the dependent stroke-impaired relative returns to former patterns without the imbalance caused by the dependency that accompanies relationships when one of the family members is ill. Frequently, the initiation of these changes comes from the rehabilitating person who is anxious to once again take charge. Seeing the ill individual return to activities such as walking, toileting and washing reinforces the perception that the individual is once again able to care for him/herself. In this stage, the family caregivers gradually learn to trust their abilities and work toward attaining mastery. They learn what their limitations are and how to extend their previous limits until they consider themselves well. As small goals are accomplished and progress becomes evident, the overwhelming idea of rehabilitation becomes more manageable. Constant comparisons are made with others or with one’s previous state in order to determine if one is progressing and if symptoms should be a source of concern.

A 68-year-old man looking after his wife with severe disability with epilepsy said:

> I have lots of worries. For example, my students were not very cooperative and I did have some teaching problems. I tried to put aside these worries since my wife's illness is always on my mind. I was panicking about the recurrence of her seizure. The most important thing is that I must have good health. I ought to be very careful about my life. I trust we can't resist fate ... What I can do is to try to relax whenever possible and not give myself too much pressure. (No. 8)

The process of attaining mastery can continue for a prolonged period of time. A sense of control and confidence are gained, and the family caregivers focus on other aspects of life. A sense that they have regained wellness occurs gradually and becomes evident only when they realize that they are no longer spending long periods of time being consumed by worry and concerns. Although they rejoice in the victories of making it through, they continue to be concerned about the future, are unwilling to be convinced that the end of illness is in sight and remain concerned about the reoccurrence of the illness. In this final stage, family caregivers engage in seeking closure. They cannot 'get on with their lives' until they have satisfactorily resolved what has happened to them. Some family caregivers may be unable to return to a state of wellness following the trajectory experience. Failure to resolve the experience, the continuation of symptoms, and disability may all contribute to an inability to successfully put closure to the experience. Finally, it should be noted the caring experience is not a simple linear process. Family caregivers experience ‘highs’ and ‘lows’ in this caring process.

### 4.4.4 Stage Four: The Stage of Balance (Harmonized feelings)

The stage of striving to regain self-perceived control begins when family caregivers seek information and support from others. They ask why they are in the situation, blame themselves, and take responsibility for caring. They provide support and give praise and encouragement by making lifestyle changes. The immediate needs of family caregivers are to regain control and preserve self. The paradoxical nature of buffering is to protect the sick person and also allow time for family caregivers to recuperate. They renegotiate roles and responsibilities.

#### 4.4.4.1 Appraising Support

A 60-year-old woman looking after her husband with severe disability and Parkinson’s disease said this:

> I would go by myself. I needed to have my own space. Although I cared for my husband, I told my niece that I needed to have some time for myself. I needed to go out and relax because he was emotional and so was I, when I was so tired at one point. I told them that I needed to go to

> the Cultural Centre. I asked them to come and take care of him for me. When I felt unhappy, I would have a buffet. I would go out for afternoon tea and I did not stay home. I would wheel my husband to the centre or to go to the M resturant for fast food for a change. I would feel better after. If I was unable to go out, I would sing with my Walkman in the house. I dealt with this problem okay. (No. 5)

Regaining Self-perceived Control is not a linear process but rather depends on the resources available at particular point of time. Throughout the stage of striving to regain self-perceived control, a sense of uncertainty prevails and the individual is forced to constantly seek reassurance from health care professionals. The suffering forces the family caregivers to re-examine their lives, appreciating the things they had often taken for granted. They confront their mortality and re-examine their values. For some this is a positive experience encouraging them to redirect their life goals; for example by making their relationships with their families a new priority. The family caregivers are beginning to look to the future and are committing to the struggle that remains ahead.

### 4.4.5 Stage Five: The Stage of Reconciliation (Resolving feelings)

The fifth stage, the Stage of Reconciliation is the final stage of the social family caregivers gradually learn to trust their abilities, and they work toward attaining mastery by learning what their limitations are and how to extend these limits. As small goals are achieved and progress becomes evident, the overwhelming idea of rehabilitation becomes more manageable. Constant comparisons are made with others or with one's previous state in order to determine if one is progressing and if symptoms should be a source of concern. The process of attaining mastery can continue for a prolonged period of time. A sense of control and confidence are gained and the family caregivers able to focus on other aspects of life.

### 4.4.5.1 Anticipating Future

A sense that they have regained balance occurs gradually and becomes evident only when they realize that they are no longer spending long periods of time being consumed by worry and concerns. Although they rejoice in the victories of making it through, they continue to be concerned about the future such as concerning the reoccurrence of illness, and are unwilling to be convinced that the end of caring is in sight. In this final stage, a major task that the family caregivers engage in is that of seeking closure. They cannot 'get on with their lives' until they have satisfactorily resolved what has happened to them.

A 74-year-old man looking after his wife with moderate disability voiced a view:

> I’ll tell you one of my happiest times was the summer after she was able to walk with the crane and we went out for dinner after the heart attack… I almost forgot about her stroke while walking along the road to the shopping mall. We were talking and it was very relaxing. (No. 1)

Eight family caregivers (Nos. 1, 3, 4, 5, 7, 8, 10, and 11) may be unable to return to a state of wellness and balance following the trajectory experience. Failure to resolve the experience, the continuation of symptoms, and disability may all contribute to an inability to successfully put closure to the experience. Finally, it should be noted the family caring experience is not a simple linear process because family caregivers do experience ‘highs’ and ‘lows’ in processing the caring relationships.

## 4.5 Caring Strategies of Adaptation process

Caregivers plan and implement ways to buffer the adaptation process. Those adopted by Chinese family caregivers are considered as adaptive modes or caring strategies (see Figure 4.4 below). Family caregivers reported adopting different coping strategies and desired improved time management skills that would enable them to spend more time with their family and allow them to pursue personal interests without relinquishing caregiving responsibilities. In this study, caregivers' perceptions to seek formal and informal support were varied and they were influenced by individual beliefs and values. Caregivers adopted a variety of strategies to cope with the situations and they also desired more caregiving assistance from children, other relatives, and the community that would allow them more independence and autonomy in their own lives. The related eight subcategories surrounding the core category of "Regaining Self-perceived Control" in the paradigm for this study includes: perception of own future, decision-making, perceptions of response to life outcomes, sense of independence, attitude towards support seeking, social interaction, relationship with others, perceived confidence and competence in caring (see Figure 4.4 below). They appear to be fundamental caring strategies and were adopted by the caregivers in this study.

The major theme constituting the experience of caregiving centered on caregiver concerns about ways and behaviours of striving to regain a sense of personal control. "Regaining Self-perceived Control" was the central theme that linked all other concepts, and it appeared to be fundamental to caregivers' caring strategies. All family caregivers in this study were willing to take responsibility for the caregiving of their stroke-impaired elderly relatives. The researcher found that caregivers developed caring strategies and behaviours based on their cognitive interpretations of the response system and their personal values and beliefs in the adaptation process of Regaining Self-perceived Control. It was found that only eight family caregivers (Nos. 1, 3, 4, 5, 7, 8, 10, and 11) in this study reported a high level of adaptability in response to the process of striving to regain a sense of self-perceived control. In doing this, the idea of "types of family caregiver" as the caring outcomes emerged. Those caregivers who had difficulty in regaining a sense of personal control had to come to terms with physical suffering, poor health outcomes and emotional strain. The significance of the sociocultural influences in the adaptation process has been discovered. The findings reveal that the development of coping behaviours of a culturally distinctive kind in term of caregivers' perceptions of their own future, decision-making, perceptions of responses to life outcomes, sense of independence, attitude towards help-seeking, social interaction, relationship with others and perceived confidence and competency in caring (see Figure 4.4 below). Analysis of the data showed that the patterns of caring of caregivers were influenced by traditional Chinese values in this study. Eight caregivers interviewed relied heavily on their close family members such as children and other relatives for practical and emotional support to foster a sense of solidarity in different caring situations. The kin relationship among family members forms the basic support system in Hong Kong society and constitutes the principle source of support for family caregivers. However, the data show that the caregiver participants of this study hold different values and beliefs in seeking help either from intra and extra-familial sources and this is strongly influenced by their own conception of the roles and responsibilities of others in family caring, including spouses, children and children-in-law and outsiders such as friends and health workers.

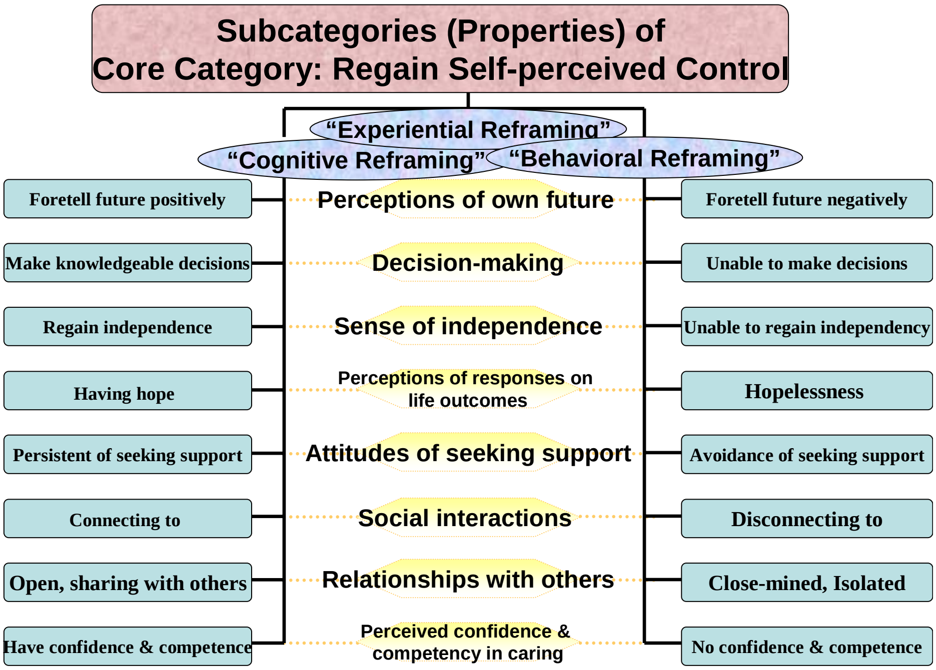


**Figure 4.4: Caring Strategies of Adaptation process**

The researcher was able to identify the family caring process varied in patterns and outcomes. The present researcher summed up the patterns of behaviours to bring out process and change using two key properties of adaptation process in the open and closed systems: (a) self-efficacy, which emphasizes the caregivers’ motivation to seek support and (b) self-perception, which focuses on the caregivers’ attitude towards connecting to support networks.

## 4.6 Types of Caregivers

In this study, it can be seen that the level of perceived stress and pressure varied among interviewed caregivers and this related to caregivers’ cognitive interpretation and appraisal. The level of perceived stress and pressure was appraised low among satisfied and committed caregivers (Nos. 1, 3, 4, 5, 7, 8, 10, and 11) who had high levels of self-perceived control. By contrast, the level of perceived stress and pressure was appraised high among martyred and victimized caregivers (Nos. 2, 6, 9, 12, 13, 14, and 15) who had low levels of self-perceived control. These could be explained with individual cognitive interpretation in the three major categories. The interrelatedness of the three categories in the domain of self-perceived control reflects the Chinese worldview of holism in which all entities and all phenomena are interconnected to form a whole (Wong & Pang, 2000). Figure 4.5 depicts a satisfied typology based on two key separate properties external to the concept of regaining self-perceived control. In trying to discover why some caregivers felt satisfied and other caregivers felt victimized. The present researcher identified two criteria: (a) self-efficacy: motivation to seek support for caregiving and (b) self-perception: attitude towards open and closed response systems. These two key properties were summarized from the eight subcategories (variables) surrounding the core category of “regaining self-perceived control” in the paradigm for this study includes: perception of own future, decision-making, perceptions of response to life outcomes, sense of independence, attitude of support seeking, social interaction, relationship with others, and perceived confidence and competence in caring (see Figure 4.4 above). According to participants, the success of regaining self- perceived control was influenced by these eight variables. Cutting across all eight subcategories (variables) of the behaviours of cognitive interpretation to stimuli of regaining self-perceived control are motivation to seek support and recognition of support network. The satisfied caregivers were usually motivated to seek help and highly recognized the availability of support network by getting connected to them.

As predicted, confidence in one’s ability to calmly respond was associated with caregivers’ cognitive interpretation to stimuli. That means caregivers’ confidence in ability to control over negative emotions such as stress and the coping on the demands of care. Therefore, it is the individual's open response system and cognitive closures from the ever-changing experiences characterize caregivers' adjustment and adaptation in the process of family caring.

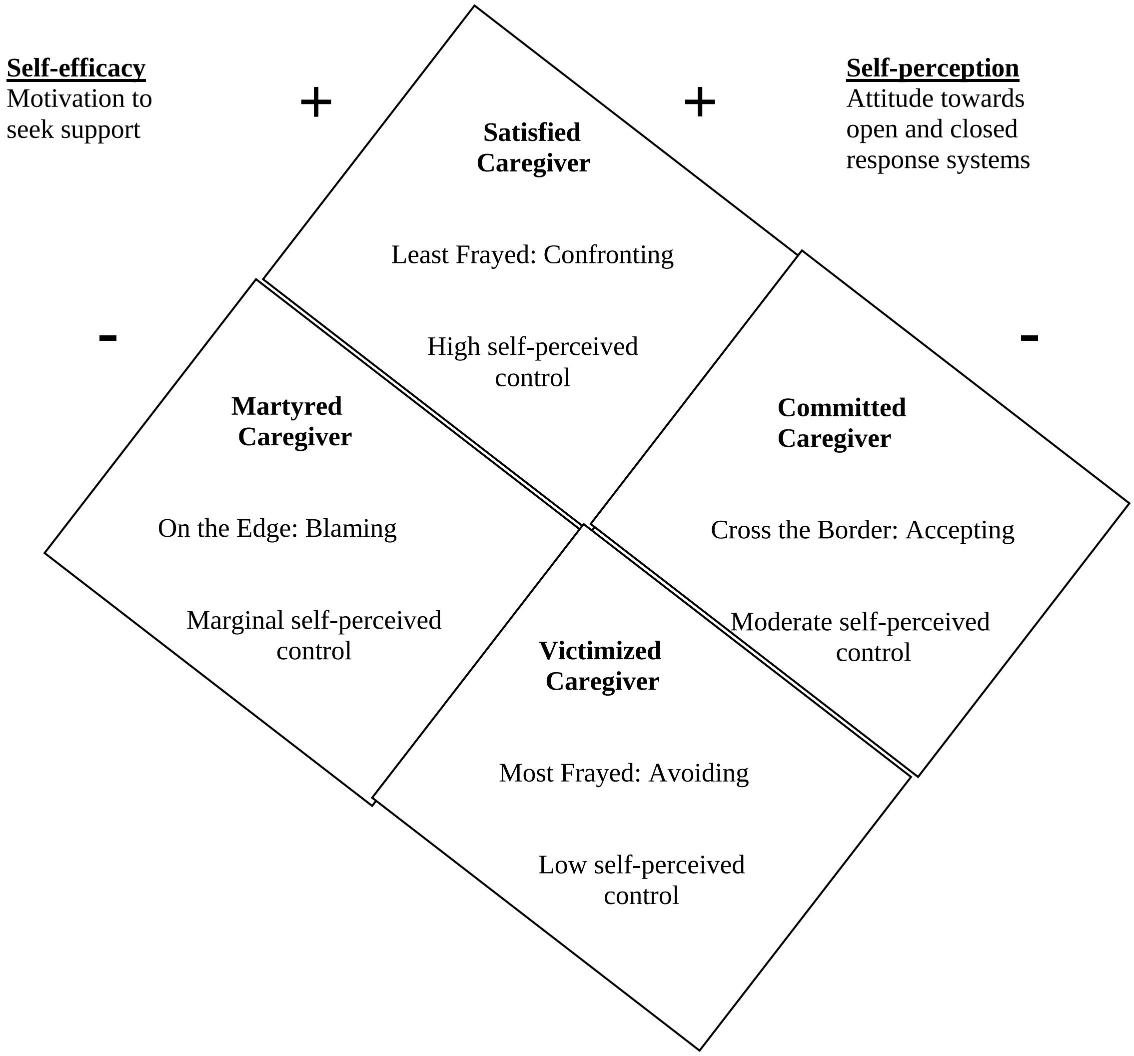


**Figure 4.5 Typology of Properties: Regaining Self-perceived Control**

Caregivers' acceptance of life changes and can enhance the development of new behaviours. It is the intricate interplay between openness procedures and the unexpected situation that gave them little control over the task; they made the interpretation by perceiving that they did report higher levels of chronic stress. For example, they often reported that they had psychological discomfort and complained of abdominal pain and headache manifested by the martyred caregivers and (Nos. 1, 3, 4, 5, 6, 7, 10, and 11) were more likely to provide care in a consistent and persistent manner when they felt able to control distressing thoughts. This is particularly relevant because one of the important aspects of health behaviour change involves gaining self-perceived control over disturbing and intrusive thoughts. This finding is also consistent with Bandura's (1997) that efficacy beliefs were involved not only in the exercise of self-perceived control over action, but also with the self-regulation of cognitions and affective states manifested by the satisfied and committed caregivers (Nos. 1, 3, 4, 5, 6, 7, 10, and 11) in this study.

As suggested by Bandura (1997), it is very important to understand how the beliefs of regaining a sense of self-perceived control for specific aspects of caregiving influence individual caregivers. By doing so, health care professionals may identify areas of vulnerability in handling the difficult demands of the caregiving situation. Such information could guide health care professionals to plan appropriate programmes in order to assist family caregivers to regain the personal sense of control. Psychoeducational interventions targeting personal mastery of relevant skills could be effective ways to promote caregiver personal control and well-being.

In this study, the present researcher mainly focuses on the prediction of response pattern. That is the concern with the alternate response patterns expected to be shown by caregivers with low self-perceived control as a function of control opportunities. The present researcher has made the assumptions that low self-perceived control caregivers demonstrate exceptionally high levels of assertion when the interaction setting facilitates control, but exceptionally low levels of assertion when the interactions setting limits control. It has been found that the caring outcomes of the caregiving process are strongly influenced by the perceptions and management of caregivers' self-perceived control in this study. Caregivers who believe they lack of control easily perceive threats to their sense of control and respond in ways that "defend" against such threats. If their environment allows them direct control over caring situations, this is the option they will take. If their environment precludes the possibility of control, they will seek more passive means of defense such as avoiding and blaming strategies.

### 4.6.1 Variations in Caregiving Patterns

In order to capture a range of variation of experiences, theoretical sampling was based on comparisons of coping styles such as attitudes towards support seeking in the process of regaining of personal control. Ways to regain personal perceived control and two key properties emerged as the motivation to seek support and the recognition of available support network as a result of positive and negative attitude towards utilizing the available support networks and relationship with others to receive the intra-familial and extra-familial support. Four types of caregivers' responses and patterns are identified and determined by their cognitive interpretations which provide control opportunities for them to regain a sense of personal perceived control. "Regaining Self-perceived Control" is the core category that explains the activities and processes involved as caregivers adapt to caregiving.

The constant comparative method was used to generate the theoretical explanation for the process of regaining personal control (Chenitz & Swanson, 1986; Glaser, 1978, 1992; Strauss & Corbin, 1990, 1998). The researcher identified a core category of "Regaining Self-perceived Control" emerging from study data and "Cognitive Reframing", "Behavioural Reframing" and "Experiential Reframing" was identified as conceptual indicators of categories that linked all the other concepts to the core category. These indicators appeared to be fundamental to family caregivers' coping strategies. Based on these eight subcategories, three major categories were also formulated through specification and dimensionalization. Patterns of seeking support were also discovered as the researcher examined how the categories vary dimensionally along the properties. The results reveal caregivers' characteristics and their values and beliefs.

Four types of Chinese family caregivers emerged from this study data and they are: (a) satisfied caregivers; (b) committed caregivers; (c) martyred caregivers; and (d) victimized caregivers. This study found that satisfied and committed caregivers exhibited higher levels of self-perceived control regarding their own abilities to handle the challenges of caring effectively would be likely to assume the role of primary caregiver following a family member's stroke diagnosis. In contrast, martyred and victimized caregivers with lower levels of self-perceived control. It has been also found that satisfied and committed family caregivers showed much more persistence than martyred and victimized caregivers in providing care as the cared-for-person's condition worsened and caregiving tasks become increasingly difficult. The satisfied and committed caregivers sought institutional support; handled the caring role with relatively little emotional distress and depression;

required relatively little support to maintain their own physical and mental health. By contrast, martyred and victimized caregivers showed less task persistence, reduced motivation to initiate an activity, and negative affective states including depression, anxiety, and anger. These findings have important implications for nursing practice in that nurses should identify family caregivers' strengths and needs from the personal control perspective.

### 4.6.2 Identification of Four Types of Family Caregivers

The researcher returned to the 33 interviews (first and second interviews) back and forth after identifying the key linkages of the core category "Regaining Self-perceived Control" and began to arrange and rearrange them in relation to this core category. In doing so, it became apparent that significant differences exist across cases. Specifically, caregivers varied in terms of perceptions of their own future, decision making, perceptions of responses to life outcomes, sense of independence, attitude towards seeking support, social interaction, relationship with others, perceived confidence and competency in caring. After considerable comparison across cases, the 15 family caregivers in this study were grouped into four conceptual categories: satisfied (Nos. 1, 3, 4, and 5), committed (Nos. 7, 8, 10, and 11), martyred (Nos. 6, 12, 14, and 15) and victimized (Nos. 2, 9, and 13) caregivers. These four distinct types of caregivers were identified according to caregivers' actions and patterns to strive for regaining a sense of personal control from being cognitive as "Cognitive Reframing", being behavioural as "Behavioural Reframing", and automized adaptive mode as "Experiential Reframing". These three conceptual indicators related to core category of Regaining Self-perceived Control. Thus, family caregivers' attributional beliefs may influence their caring consequences which indirectly affecting their health outcomes and quality of life. Family caregivers' coping styles and illness perceptions had been confirmed two years later as the cared-for-person's condition changes over time. This has assisted the present researcher to confirm the caring consequences based on the patterns of caring with three interviewed caregivers (Nos. 6, 12, and 15) in the second interviews.

All the caregivers in this study attempted to regain self-perceived control in their transitional role by interpreting their perceptions of self-perceived control and by demonstrating their help-seeking behaviours. The caring strategies caregivers used to interpret their self-perceived control included suspecting threat, monitoring illness symptoms, accepting caring responsibility, adjusting self, appraising resources and anticipating the future through the adaptational social process. A great deal of evidence reveals that there is considerable variation in how caregivers adapt to their caregiving demands. It has been evidenced that the caregiving situations are influenced by caregiving characteristics and caregiving factors. The findings of this study are consistent with this evidence.  For example, one of the properties of the subcategory (variable influence the process of Regaining Self-perceived Control) “attitudes of seeking support” that differentiates “self-limited seeking” of support from “persistent seeking” of support relates to the “frequency” (number of times per week) the caregiver is “self-limiting” or “persistent”. “Regaining Self-perceived Control” is therefore the core category that explains the activities and processes involved as caregivers adapt to transition. The same support was available to caregivers who could be persistent seeking or avoidance seeking. It depends on the congruence between caregivers’ attitudes and belief of the suitability and availability of support. The caregiver’s frequency of “support seeking” explains the activities and processes of the situation and yields the pattern of support seeking.  It was found that persistent seeking did not fit identified patterns, and so the present researcher developed a third pattern of “avoidance of seeking” support and a fourth pattern of “partial seeking” support. This quantified the core category of “Regaining Self-perceived Control” by specifying its particular properties and dimensions. This is important because the researcher was then able to identify patterns along with their variations.

In doing this, it became apparent that significant differences exist across these 20 cases among the 15 family caregivers in the first interviews. Specifically, different types of family caregivers used different caring strategies and patterns of managing transactions based on their beliefs about the role responsibilities and prescriptions of personal standards for behaviour. The "Typology of family caregiver" emerged from the consequences of the process of caring. After considerable comparison across cases these 15 family caregivers were grouped into four conceptual categories – satisfied, committed, martyred and victimized (see Table 4.1 below). The caring patterns manifested by the caregivers were found to be sustained through automatized adaptive factors towards support seeking including the availability and closeness of support networks and family relationships, own health status, coping strategies, and the demands of the caring tasks.

The largest variation in the adaptation process was found from second to third stage, family caregivers' cognitive interpretation of responses from perceptions of caring outcomes and their motivation to seek intra and extra-familial support in order to secure self in the stage of accommodation by accepting self, and to meet own needs and caregiving demands in the stage of balance. The rewards involved better health outcome and increased self-esteem, opportunities for personal growth, and opportunities for family growth. These two stages were found to be highly interrelated. Although some family caregivers were able to progress smoothly through the adaptation process from stage to stage, others remained these two stages for an extended period of time in a cycle of making sense of the event and learning to live.

**Table 4.1 Characteristics and Types of the Family Caregivers**

| Code No. | Gender | Age | Relationship with Cared-for-Person | Typology of Caregivers in First Interviews | Typology of Caregivers in Second Interviews |
|---|---|---|---|---|---|
| 1 | M | 74 | Husband | Satisfied | Satisfied |
| 2 | F | 72 | Wife | Victims | Victims |
| 3 | F (D) | 47 | Daughter | Satisfied | Satisfied |
| 4 | M | 70 | Husband | Satisfied | Satisfied |
| 5 | F | 60 | Wife | Satisfied | Satisfied |
| 6 | F | 68 | Wife | Martyrs | Martyrs |
| 7 | F | 60 | Wife | Committed | Committed |
| 8 | M | 68 | Husband | Committed | X |
| 9 | F | 74 | Wife | Martyrs | *Victims |
| 10 | F (D) | 27 | Daughter | Committed | Committed |
| 11 | M | 87 | Husband | Committed | Committed |
| 12 | F (D) | 46 | Daughter | Martyrs | Martyrs |
| 13 | F | 63 | Wife | Victims | X |
| 14 | M | 68 | Husband | Martyrs | Martyrs |
| 15 | F | 75 | Wife | Committed | *Martyrs |

The process is represented diagrammatically in Figure 5.1 below. The satisfied and committed family caregivers motivated to seek support and recognize the suitability of the support network. As a result, they moved smoothly from second to third stage through the adaptation process. The martyred and victimized family caregivers, on the other hand, had difficulty to recognize the suitability of the support network and refused to be connected to support networks. Thus they regressed between stages two and three quite a few times before moving on to the fourth stage of balance and final stage of reconciliation in the Adaptation Theory of Regaining Self-perceived Control.

The satisfied and committed caregivers were grouped as their smooth progress through the five stages of the adjustment process with the dimensions of control including the abilities to perceive and predict life outcomes, the abilities to make decisional control and the abilities to act on control. The four patterns of behaviour demonstrated by the caregivers were dependent on two factors: Motivation to seek support and the recognition of support network. The martyred and victimized caregivers were grouped as the low level of perceived control, thus they moved through the five stages of Theory of Regaining Self-perceived Control with difficulty in the adaptation process because they moved back and forth between stages two and three many times as the situation changed. It was found that the majority of the older family caregivers were the martyred and victimized caregivers in this study. Loneliness, disconnected and isolation were reported by martyred and victimized caregivers at both first and second interviews when compared with caregivers of satisfied and committed caregivers. Caregivers of martyred and victimized also reported the highest levels of distress and depression, and this confirmed in the second interviews which conducted two years later. Baker and Burgener (2002) has also found the similar result that elderly caregivers had difficulty in taking on the caregiving role and in making demands that emphasize their need to preserve dignity. Thus, it is important to understand how caregivers perceive the purpose of the caregiving including their cognitive interpretations and responses in the process of caring. It should also include those factors or variables influencing the processing and response patterns.

It has been found the satisfied and committed caregivers in this study needed to seek support as they adapted to the process of caregiving. With the availability of practical help controlled reactions better than martyred and victimized caregivers without any availability of support network to deal with caring responsibility. This leads to the question: What happened to stressed and isolated caregivers who did not have any available support network or did not perceive the need to seek help from outsiders? Here, the researcher was comparing along the dimensions of the core category of "Regaining Self-perceived Control" including the ability to exercise control over action, levels of stress, presence or absence of support network, age and attitude towards support seeking. The researcher dimensionalizes the property frequency by saying that with “self-limited seeking” of support, the martyrs and victims seek support only occasionally. To quantify or explain the term “self-limited seeking” even further, the researcher could say that the martyrs and victims seek support only when at a crisis point where support is readily available, whereas the satisfied and committed caregivers very often seek support when necessary either alone or with the help of outsiders. They tend to seek out support on their own initiative rather than waiting for outsiders to help out. The researcher then recruited family caregivers who did not seek available support systems as the theoretical sample (see Figure 3.1). It is important to note that the research did not sample family caregivers per se but rather sampled along the dimensions of the different properties of the core category of “Regaining Self-perceived Control”. The researcher wanted to explore how self-perceived control is regained when the conditions under which this occurs vary.

#### 4.6.2.1 Satisfied Caregivers: The Struggle as Motivated Beings

The key characteristic of satisfied caregivers is the acceptance of support, and thus satisfied caregivers are able to regain control smoothly and progress through the five stages in the adaptation process quickly. They are able to perceive and predict caring outcomes optimistically. Their ability to make informed decisions is very high. They are open-minded and fully connect to the available intra and extra-family support networks. They also have a positive attitude and connect well with other family and community members. They are prepared to ask for help when they need it. They are also content and satisfied in the role of caregiving. They are happy to be caregivers. Satisfied caregivers have a positive prior relationship with their cared-for-persons. They value reciprocity in relationships, but can waive reciprocity. They go through the five stages of adjustment process smoothly using different caring strategies to regain a sense of self-perceived control (see Figure 4.6 below).

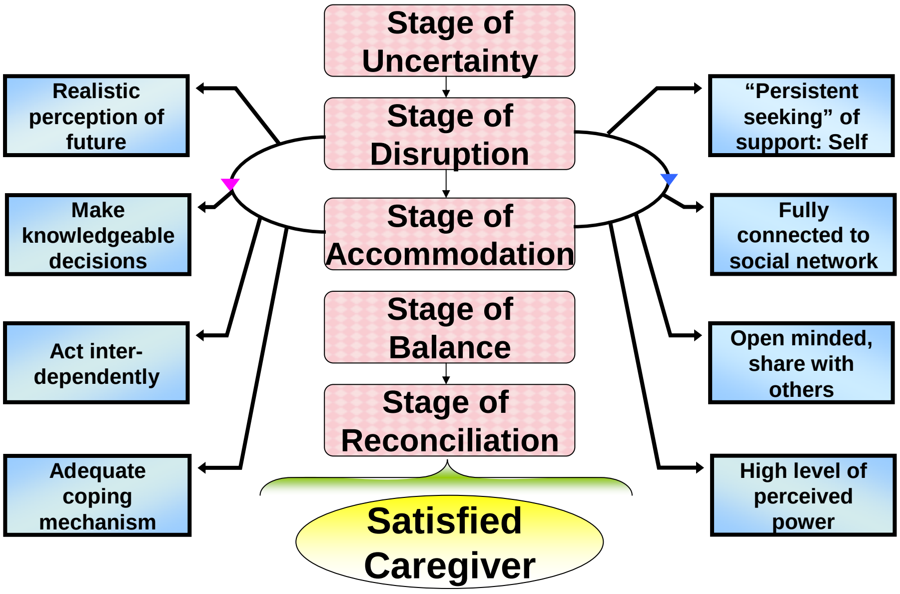


**Figure 4.6 Regaining Self-perceived Control: Satisfied Caregiver**

### 4.6.2.2 Committed Caregivers: The Struggle as an Obligated Role

The main characteristic of committed caregivers is the acceptance of support, and thus they are able to regain control smoothly and progress through the five stages in the adaptation process as quickly as the satisfied caregivers. They are able to predict caring outcomes, but are not as optimistic as satisfied caregivers.Their ability to make informed decisions is only moderate.

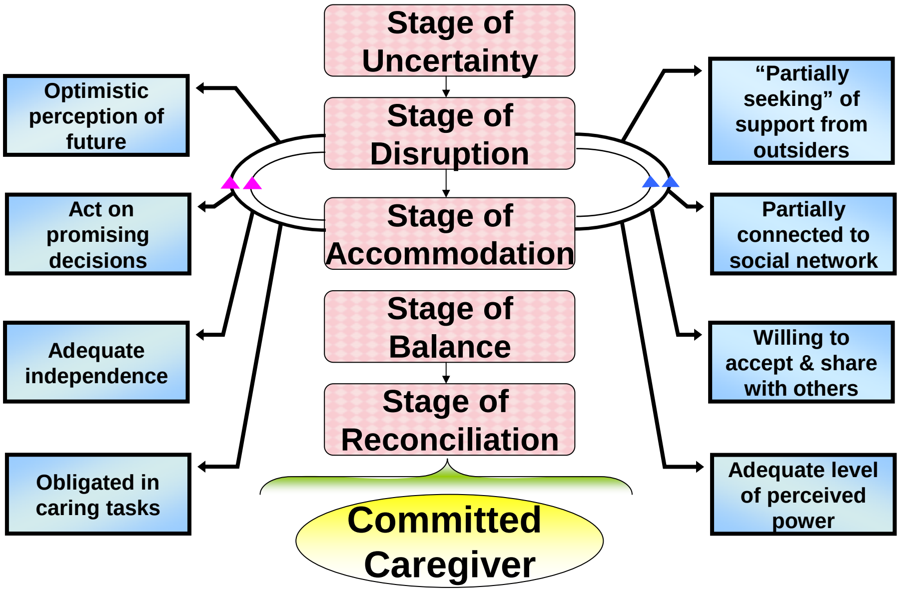


**Figure 4.7 Regaining Self-perceived Control: Committed Caregiver**

They are partially connected to the available intra and extra-familial support network. They have a positive attitude and are connected with other family members, but not with community members. They are prepared to ask for help when they need it, but they have some difficulty as they are only partially connected to available support networks. They feel obliged in the role of caregiving. Committed caregivers tend to have an obligated prior relationship with their cared-for-persons. They show loyalty to family caregivers. They value reciprocity in relationships, but can waive reciprocity (see Figure 4.7 above).

#### 4.6.2.3 Martyred Caregivers: The Struggle as an Endless War

The marked characteristic of martyred caregivers is that they do not accept support and thus have difficulty in regaining control and progress slowly through the five stages in the adaptation process because they tend to regress always between stages two and three. Their ability to predict caring outcomes is poor and is not as optimistic as that of satisfied and committed caregivers. Their ability to make informed decisions is very moderate. They are not connected to available intra and extra-familial support networks. They also have a mixed attitude towards caregiving and therefore are not very well connected with either family or community members. They are very adapting at manipulation in dealing with others in caregiving tasks. They are not prepared to ask for help when they need it. They do not complain because they often hide their unhappiness, but they make others feel sorry and have sympathy for them. They feel obligated in the role of caregiving, and guilty. They do not want to do it, but they feel pressure from others. They blame the cared-for-persons for any inconvenience suffered. They value reciprocity in relationships and therefore expect a return from others and from society for their caregiving. They do not anticipate caring outcomes because they do not have the ability to make decision and anticipate the future. Thus, they have many problems in progressing through the five stages of adjustment process in order to achieve a sense of self-perceived control (see Figure 4.8 below).

### 4.6.2.4 Victimized Caregivers: The Struggle as a Lonely Journey

The chief characteristic of martyred caregivers is their non-acceptance of their role. Thus they have great difficulty in regaining self-perceived control and progress very slowly through the five stages in the adaptational process because they tend to regress always between stages two and three and they are unable to regain a sense of self-perceived control. The majority of them are older female caregivers. There is evidence in this study that less-educated and isolated caregivers are at high risk of developing stress symptoms. By contrast, educated caregivers fully connected to support systems were likely to have more life skills including communication skills, stress management techniques, and health promotion and screening practices. Financially stable and educated caregivers had better ways to cope such as hiring a helper and

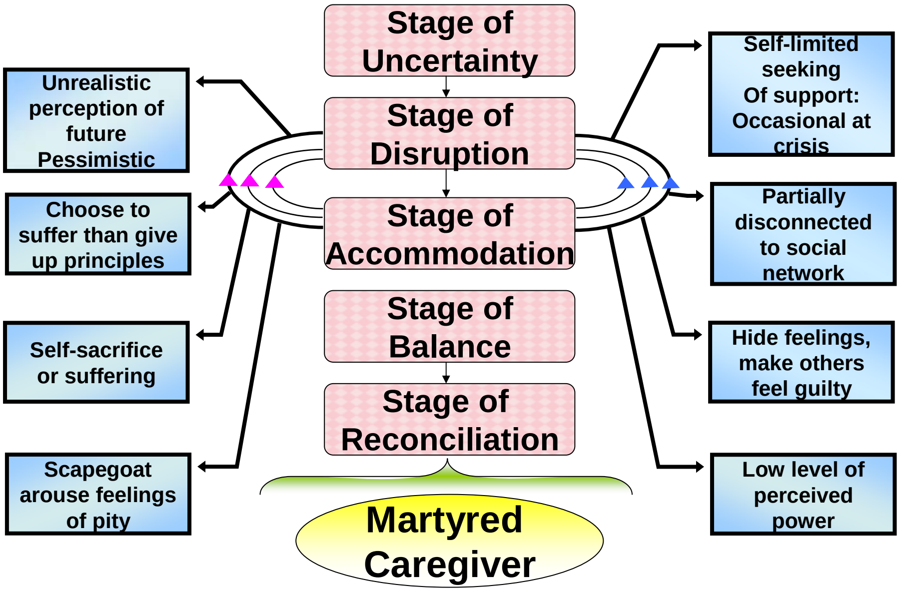


**Figure 4.8 Regaining Self-perceived Control: Martyred Caregiver**

taking a vacation to prevent the onset of stress symptoms (see Figure 4.9 below). This study delineated a new typology of family caregivers: satisfied caregivers, committed caregivers, martyred caregivers and victimized caregivers. When family caregivers are categorized by meaning of caring provided, the potential value of their efforts is more evident. The new family caregiver typology cuts across the dimensions of the dichotomy, providing an alternative theoretical framework for further research.

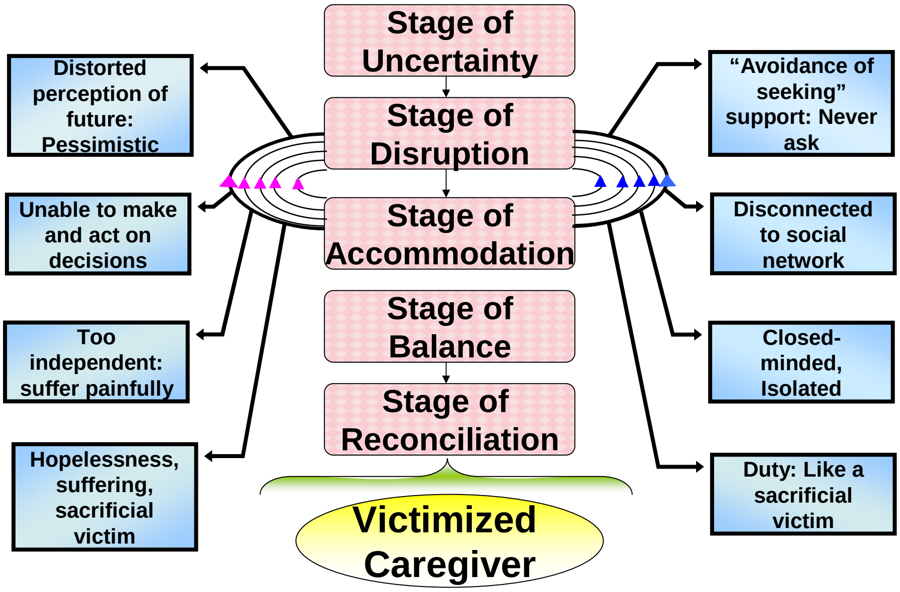


**Figure 4.9 Regaining Self-perceived Control: Victimized Caregiver**

## 4.7 The Overview of the Adaptation Theory of Regaining Self-perceived Control

The Adaptation Theory of Regaining Self-perceived Control emerged from data of 15 Chinese family caregivers in this study with the goal of striving to regain a sense of personal perceived control. The Theory consists of the structural conditions, caregiving characteristics, caregiving factors, the five stages, the caring strategies, patterns and the caring outcomes.

### 4.7.1 Regaining Self-perceived Control in a Chinese context

Eight of the Chinese family caregivers interviewed relied heavily on their close family members such as spouses, daughters, brothers and sisters for practical and emotional support in order to foster a sense of solidarity in different caring situations. The family-based structure forms the basic kinship support network in Hong Kong society. Kinship support constitutes the principal source of social support network for Chinese family caregivers. The study data also showed that the 15 Chinese family caregivers' cognitive interpretation of the response system is influenced by Chinese traditional values and beliefs as revealed in their connections to the kinship support network. There were similarities and differences between the valuing of traditional virtues hold by different caregivers and the valuing of modern virtues in kinship support among Chinese family caregivers in this study as shown by the four types of caregivers which emerged from the study data. The forms of social support provided by kinship support were incredibly rich and the impact of these support relationships was extremely powerful and wide-ranging.

Chinese culture promotes independence and endurance, management of one's own problems and minimization of social disturbance. In describing the results of this study, the caring experiences of Chinese family caregivers was categorized under the central concept of "Regaining self-perceived control" that is defined as the adaptation process in caring for stroke-impaired family members. Each family caregiver in this study took on a transitional role as a family caregiver accompanied by changes within the family unit and also affected by changes in social and economic situations. This transition role is a normative and predictive life event and it may happen to most individuals in a specific cultural group. The core variable that underlies the entire adjustment process of family caring is the acceptance of support for family caregivers to regain personal perceived control. The social adjustment process of regaining a sense of self-perceived control consists of a variety of strategies directed at supporting the physical demands of caring process, and the social distress extending from changed roles and responsibilities, and the uncertainty of the new role. Caring was conceived to be a comprehensive concept incorporating the experience of role relationship, caregiving satisfaction, the strain of trying to endure, the alienation of forced exclusion from everyday life, the plan of institutionalization, and the uncertainty of anticipating the details of the illness.

Previous studies have investigated perceived control within the individual's unique personal, social and environment context. However, Wallhagen (1992) stated that perceived control had been implicated in the adaptation coping and well-being of older adults and is especially relevant to older caregivers. He indicated that perceived control is defined as the perception that valued aspects of one's life are manageable and mediate the objective and subjective aspects of caregiving and caregiver adaptation. Wallhagen (1992) and Kofta et al. (1998) also found that perceived control had a direct relationship with life satisfaction and depression, and an indirect relationship with subjective symptoms of stress. This is consistent with the present findings which show that perceived control and adaptation are interrelated. Rose and DelMaestro (1990) also found that caregivers of chronically ill family members faced a series of losses and struggled to regain autonomy and redefine their own identity. Based on the finding of this study, it was found that regaining a sense of self-perceived control in the adaptation process was influenced by how family caregivers defined and recognized their individual self within the context of the caring and adaptation and its consequences on their lives. *Li* (禮)emphasized rules and Confucius emphasized *ren* as the moral obligations in the practice of virtue to determine the right way in dealing with people. In the Chinese cultural tradition, *Lunli* means principles and moral standards that govern different kinds of human relationships and bring a harmonious and well-ordered society (Brindly, 1989/90; Pang, 2003).

### 4.7.2 Gender and Age Issues in Family Caring

It has been found in this study that older and poorly educated female caregivers managed caregiving tasks with no intention of seeking help from others including their own children. Older female caregivers were the least likely to receive any available support including kinship support and appeared to be the most likely to turn down any support offered. For example, one of the elderly wives, who had found it increasingly difficult to cope with her husband daily activities and hygiene care incontinence of bladder and bowel, admitted that she had rejected offers of help.

A 74-year-old women looking after her husband with severe disability and dementia said:

> The social worker kept on asking, ‘Would you like any help?’ But what’s the point? I mean he was going (to the toilet) three or four times a day, but I didn’t know when and it could be in the middle of the night. How could I expect anybody in to help with that? So I just said, ‘No’. (No. 9)

This cry of frustration reflects the kind of problems typically faced by caregivers of chronically ill person. According to McCubbin, Cauble and Patterson (1982), a family experiencing illness-induced stress via a stroke-impaired relative, also experiences more of the general difficulties families face.

In this study, all 15 Chinese family members became caregivers immediately after stroke patients were discharged to home. All of them were equally likely to report feeling under pressure to care for their stroke-impaired elderly relatives after discharge from hospital to home. Most of them experienced “being under pressure” and “being in distress”. These were related to difficult activities in the caring process. Chinese family caregivers in this study described those hardships as stress, pressure, difficult, tough, hard, demanding, tiring, and laborious. A daughter was distressed by her mother’s situation and stayed around the clock to care for her.

A 47-year-old daughter looking after her mother with moderate disability had this to say:

> Yes, there was pressure. She was unable to eat, talk and walk. You need to be there around the clock to care for her. She needed changing or if she needed to go to the loo that has to be done promptly. (No. 3)

Discomfort in providing intimate care was not limited to male caregivers since they were at least spousal caregivers. A daughter caregiver taking care of her father expressed uneasiness over bathing him. Yet because her mother was not participating in care, she had no choice but to bathe him herself. A 27-year-old daughter caregiver noted:

> “I feel embarrassed to wash my father’s private areas and my mother would not let me wash them either, she feels embarrassed to have her daughter to wash them for her”. (No. 10)

## 4.8 Emerging Concepts in Chinese Family Caring

In describing the results of this study, the experience of Chinese family caregivers were categorized under the various unmet needs of caregiving as subcategories after identifying the core category of “Regaining Self-perceived Control". Family caregivers with unmet needs are those who are in greatest need of support, but who do not receive it from their children or from other sources. An analysis of the study data revealed that in providing care to their family members, Chinese in Hong Kong are very much influenced by the traditional Chinese values discussed earlier. In addition, one outcome of this analysis is the identification of 38 key elements of caregiving experiences pertinent to the experiences of family members caring for elderly relatives who had experienced strokes including both who were able and unable to regain self-perceived control in the process of family caring. The concepts formulated from these key elements were clustered into three major categories. The three major categories emerged as the participants explained their experiences of family caregiving: Cognitive Reframing, Behavioural Reframing and Experiential Reframing. Issues of culture, tradition, and religion dominated these situations. Therefore, the findings of this study contribute significantly to a new understanding and appreciation of those cultural issues and caring values that are unique to Hong Kong Chinese family caregivers of relatives with stroke-impairment. Caregivers' voices illustrate their experience in caring for their stroke-impaired elderly relatives. However, the verbatim data presented below have been translated directly from the original Chinese interview scripts and may therefore appear grammatically incorrect in some places.

## 4.9 Discussion

Research to date has focused on the negative impact of physical caregiving on the caregiver's physical and emotional well-being. Limited information exists about other dimensions of the experience which may serve to buffer or prevent negative caring outcomes. Findings of this study reveal that caregiver's cognitive interpretation and caregiving characteristics and caregiving factors are correlated in the process of regaining personal control.
The findings are discussed in relation to the concept of caring and the experience of family caregivers coping with challenging behaviours. The analysis shows that the notion of "Regaining Self-perceived Control" holds various meanings in Chinese family caregivers' narratives: "Cognitive Reframing" for cognitive reframing, "Behavioural Reframing" for behavioural reframing and "Experiential Reframing" for automized adaptive modes. According to the study caregivers, the process of Regaining Self-perceived Control was influenced by caring strategies in the adaptation process included acceptance of available support systems, taking practical action, and arranging 'time for self'.

The most significant variation of the adaptation process was found in the third and fourth stages, accommodating to caring responsibilities and balancing own needs in order to regain self-perceived control. These two stages were found to be highly interrelated and the interventions worked to restructure the caregivers' cognitive interpretations by accepting the control opportunities. The focal stimulus of perceived stress, the contextual stimulus of conflicts in the exchange of social support, and one component of the coping mechanisms (the passive/avoidance coping strategies) were positively linked directly or indirectly with psychological distress, which is an indicator of adaptation in the self-perceived control mode. Given their importance, these elements should be considered in the development of a middle-range theory of personal control in action derived from Kofta et al.'s (1998) Model of Processing Pattern Response System.

Although the satisfied and committed family caregivers in this study were able to progress smoothly from stage one to stage five through the adaptation process, the martyred and victimized family caregivers remained for an extended period of time in a cycle of adapting to the event and attaining a balancing point. The martyred and victimized types were low level of perceived control with no motivation to seek support and no recognition of support network. The typology of the satisfied caregiver is diagrammatically represented (see Figure 4.2 above). In this study, those family caregivers who were able to predict and maintain a positive perception and attitude progressed faster than those who had difficulty in establishing and maintaining a positive attitude. In fact they returned many times to the stage of accommodating to the caring responsibilities.

In doing this, it became apparent that significant differences exist across cases. Specifically, different types of family caregivers were identified based on their beliefs about the role responsibilities and proscriptions of personal standards for behaviour. Interfering factors were related to caregiver experience and intra and extra-familial support systems. From the more distant cognitive perspectives of predictability, self-determination and independence reflections on Regaining Self-perceived Control, the caregivers provided insights into how their family caring was grounded with their experience. The researcher found that caregivers developed caring strategies and behaviours based on their cognitive interpretations and their personal values and beliefs on how to strive towards “regaining a sense of self-perceived control”. It was found that only eight family caregivers in this study reported a high level of adaptability in response to the process of striving to regain a sense of self- perceived control. From this finding, the idea of “types of family caregiver” emerged.

The caregivers must restructure their cognitive interpretation in order to adapt through the caregiving process of “Cognitive Reframing”, “Behavioural Reframing” and “Experiential Reframing” before they are able to regain a sense of self-perceived control. These were the conceptual indicators and the three major categories related to the core category “Regaining Self-perceived Control”. “Cognitive Reframing” is the caregiver’s positive and negative attitudes towards the self as a totality; self-determination is an individual’s ability to control their reactions to cared-for-person’s; illness and independence is the caregiver’s ability to trust his/her own ability and act on decisions. The sense of the Regaining Self-perceived Control is defined by Seibert, Crant and Kraimer (1999) as “Self-perceived control consists of any proactive behaviour - either over or covert – that we do at one time to control our later behaviours and increase our chances of success in those later behaviours” (p.360). The adaptation process of regaining self-perceived control was smoother for satisfied and committed caregivers who had high level of mastery and struggled to decrease their negative stress response and to increase their perception of ability to meet care demands. These caregivers coped better with the caring situations and anticipated the future optimistically. The sense of personal perceived control that was associated with mastery has also been linked to good preventive health behaviours which could decrease the caregiver’s stress response by improving their overall health status. On the other hand, the martyred and victimized caregivers, who had a lower level of mastery of self-perceived control, took longer to accommodate to and balance the caring responsibilities in the adaptation process of Regaining Self-perceived Control. This was because they had difficulty in predicting life outcomes and perceiving responses. Caregivers (Nos. 2, 6, 9, 12, 13, 14 and 15) struggled to adapt and they proceeded to the stage of balance with much difficulty, emotional strain and negative health outcomes. For caregivers (Nos. 8 and 14), although they both struggled through this process alone because they had no children in the families, caregiver No.8 was a satisfied caregiver and No.14 was a martyred type because he complained and was unsatisfied with most of the support services in the community. For caregivers (Nos. 2, 6, 9, 13, and 15), although they had families who telephoned them regularly and came to visit them about once a month, they preferred not to share feelings of stress and helplessness. They had ambivalent feelings towards their family members, who put all the caregiving responsibilities on them. These caregivers perceived low self-perceived control and negative outcomes of the caregiving process by avoiding or by self-limiting seeking of support.

A 60-year old wife looking after her husband expressed her view resentfully:

> I am so sick now (complaints abdominal pain and poor eye vision) because of him. I had to put all my energy to care for him. I couldn’t sleep and couldn’t eat. I am so overwhelmed with all the care provided to him. ( No.7)

Despite the various way in which caregivers respond to these five stages, the goal of the adaptation process is to regain a sense of personal control as much as possible by proceeding to the different stages of the process more smoothly and with greater satisfaction. Although more than half (eight) of the caregivers in this study were committed to and satisfied with their caring experience, they revealed that they would have given up at times when they became very stressed and overwhelmed. In fact, two male caregivers thought of committing suicide with all the invisible stress and being pressured by tasks ranging from simple household ones to those related to caring for their stroke-impaired relatives. However, they practice the control opportunity by seeking support and they finally able to proceed to the different stages of the adaptation process. The restructuring of the cognitive interpretation had assisted them to continue to strive to regain a sense of personal control and such restructuring of the cognitive interpretation was not a feature of the other seven caregivers, who gave up the control opportunity.

### 4.10 Summary of Chapter Four

The loss of control experienced by family caregivers in this study was often devastating and the struggle to regain a sense of personal control was frustrating. The participants in this study described the family caring process as a threat to their lives. They felt fragmented after becoming family caregivers and they experienced a total lack of self-perceived control.
A 60-year-old woman looking after her husband stated:

> "It was so miserable that I could not even think of anything. My mind was blank". (No.7)

The process of adaptation was not completed until the family caregivers were able to regain a sense of self-perceived control, which may occur in the third stage of the adaptation process. In describing the results of this study, the caring experiences of Chinese family caregivers was categorized under the central concept of regaining self-perceived control that defined as the adaptation process in caring for their stroke-impaired family members. The present researcher differentiated caregiver types on the basis of the meaning of the caring, and explored variations in compensation arrangements.

Each family caregiver in this study took on a transitional role as a family caregiver accompanied by changes within the family unit and also affected by changes in socio-economical status. This transition role is a normative and predictive life event and it may happen to most individuals in a specific cultural group. The core variable that underlies the entire adaptation process of family caring is the enhancement of caregivers’ seeking of support by restructuring their cognitive interpretation and thereby regaining a sense of personal control. The adaptation process of regaining control consists of a variety of strategies directed at supporting the physical demands of the caring process, and the social distress deriving from changed roles and responsibilities, and the uncertainty of the new role. Caring was conceived to be a comprehensive concept incorporating the experience of both coping and sustaining, the strain of trying to endure, the alienation of forced exclusion from everyday life, planning for institutionalization, and the uncertainty of anticipating the future course of the illness.

This study shows that family caring is a process of five successive but overlapping stages (See Figure 4.10 below). These stages trigger stresses and affect caring responsibilities in the adaptation process of family the caregivers concerned, if necessary support is not received. Interactive parts of the adaptation process provide the foundation for assessing and analyzing transactions to facilitate understanding and the development of a culturally

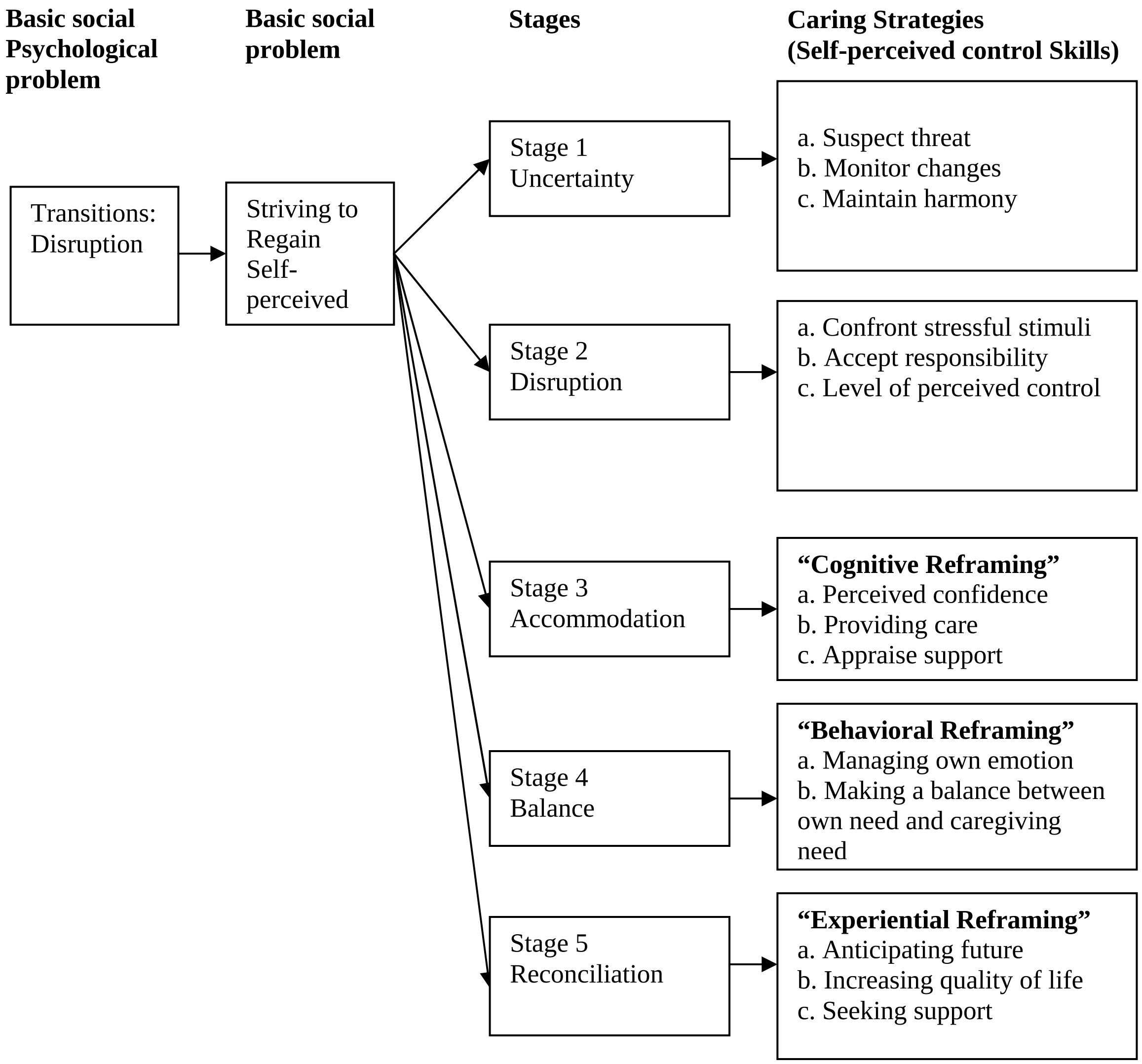


**Figure 4.10 The Social Adaptation Process of Theory of Regaining Self-perceived Control**

based family adaptation model. Adaptive modes of suspecting and monitoring, relinquishing and accepting, adjusting, appraising, balancing and anticipating are integrated within the model as a five stage process: (a) stage of uncertainty, (b) stage of disruption, (c) stage of accommodation, (d) stage of balance, and (e) stage of reconciliation. These adaptation stages are useful for assessing some families. However, the diversity of family life today precludes establishing these stages and accompanying tasks as norms that every family must follow. Nevertheless, this Adaptational Framework has explanatory power in terms of understanding the process of family adaptation through caring. The different stages of adaptation process and their relationships to the core category will be discussed in the next chapter.

# CHAPTER FIVE

# DISCUSSIONS

The adaptation process of how Chinese family caregivers regain a sense of self-perceived control through family caring has been described in Chapter Four. The purpose of this chapter is to discuss the issues associated with this process and highlight how the role of open and closed strategies influences the adaptation process in the Chinese context. An Adaptation Theory of Regaining Self-perceived Control and the implications of its five stages will also be examined. Finally, interventions that assist caregivers to adapt through acquiring self-control skills will also be addressed.

## 5.1 Introduction

The present researcher attempts in this chapter to discuss the caring experience of the Chinese family caregivers, using the four types of caregivers and the five stages as a theory emerged from study data. This is consistent with the principles of grounded theory approach; there is no intention to use existing theories in the literature as data.

## 5.2 Family Caring: An Adaptation Theory of Regaining Self-perceived Control

In the following discussion, the present researcher will argue for the need to employ a culturally-sensitive approach to examine the process of family caring in the Chinese context in order to address the deep understanding of cultural values and dynamics and their impact on the adaptation process of family caring. A theory emerged inductively from the data to describe the five stages as the Adaptation Theory of Regaining Self-perceived Control.

It has been found that the adaptation of family caregivers is affected by both caregiving characteristics and caregiving factors. Caregiving characteristics include both the care receiver’s functional level and quality of the relationship between caregiver and care receiver. Caregiving factors include caregiving task difficulty, the caregiver’s knowledge of the care receiver, and self-expectations of the caregiver and caregiving resources.

In this study, slightly more than half of caregivers (eight) interviewed relied heavily on their close family members such as children and other relatives for practical and emotional support to foster a sense of solidarity in different caring situations. The intergenerational relationship among family members forms the basic support system in Hong Kong society and constitutes the principal source of support for family caregivers. However, the data show that the caregiver subjects of this study hold different values and beliefs in seeking help either from intra or extra-familial sources and this is strongly influenced by their own conception of the roles and responsibilities of others in family caring, including spouses, children and children-in-law and outsiders such as friends and health workers. These hierarchical relationships are based in the teachings of Confucius, which valued the five cardinal relationships.

In this study, analysis of the data showed that the intergenerational relationships of Chinese in Hong Kong were very much influenced by traditional Chinese values. The teachings of Confucism act as those driving force to help to sustain the role of Chinese family caregiving. Their ways and patterns of seeking support identified as four types of Chinese family caregivers and also as the dimensions of regaining self-control emerged from this study: satisfied, committed, martyred, and victimized. The findings verify and confirm the development of coping behaviors of a culturally distinctive kind in terms of caregivers' perceptions of their own future, decision-making, sense of independence, attitude towards seeking support, social interaction, and perceived confidence and competency in caring. These findings contrast with those from western studies which show that western family caregivers adopt a more instrumental approach; in particular, mutual affection emerged as a key component of that responsibility for the provision of care for their elderly relatives.

According to Danielson, Hamel-Bissell and Winstead-Fry (1993), family adaptation is the outcome of family efforts to bring a new level of balance, harmony, and coherence, as well as a satisfactory level of functioning, to a family crisis situation. It involves coping strategies such as synergizing, interfacing, and compromising. Families struggle to achieve a balance between individual and family levels of functioning. A balance between meeting the needs of individual members of the family and the well-being of the family as a whole is sought at the first level of interaction in the social process of family adaptation. That is the caregiver’s cognitive interpretation and appraisal of functioning require coping with the change in family routines and the demand for continuous and predictable involvement of other family members. Danielson et al. further state family adaptation is enhanced when a mutually supportive relationship develops between the family and the health-care providers.

The sense of self-perceived control that was associated with cognitive interpretation of mastery has also been linked to good preventive health behaviours on the part of caregivers, which could decrease the caregiver's stress response by improving their health status. This finding is consistent with the findings of studies done in the West (Burton, Newsom, Schulz, Hirsch & German, 1997; Grant & Nolan., 1993; Nolan & Lundh, 1999). To have high level of self-perceived control means to perceive the self as a source of causation (Kofta et al., 1998). Therefore, the personal perceived control process has an essential role in the development of human action. It is recognized that caregivers avoid specific stimuli because they are afraid of being overwhelmed. Health care providers should understand caregiver's cognitive interpretation and response system in order to assist them to develop appropriate strategies to overcome the obstructive effects of undesirable experiential reactions to caregiving. This would prevent caregivers suffering from mental health problems and negative health outcomes. Family caregivers suffer from negative health outcomes including psychological and physical morbidity associated with the care of stroke-impaired relatives.

### 5.2.1 The Psychological Threat, Intellectual Helplessness and Affective States

An interactive relation links between intellectual helplessness and psychological threat in predicting negative affective states. When intellectual helplessness is severe by prolonging exposure to cognitive uncontrollability, psychological threat should evoke a more intense depressive emotional response than when intellectual helplessness is relatively benign. When the situation is beyond control, negative emotional responses such as depression, anxiety and emotion-focused coping responses are more likely to appear. On the other hand, when the stress situation is perceived to be controllable, the more likely responses are solution-focused coping and, once a successful solution has been found, considerable goal-directed effort aimed at managing the threatening situation.

The present study approach indicates that the state of stroke-impaired family caregivers' intellectual helplessness during role transition is the result of prolonged cognitive uncontrollability in caregiving.  This approach has been supported by the classic studies of Lazarus and Folkman (Folkman, 1984; Lazarus & Folkman, 1984). Lazarus and Folkman identified various processes of adaptation to stressful situations which emphasized the dimension of event controllability/uncontrollability, which is viewed as a significant determinant of the type of coping response applied in a given situation (Terry, 1994; Valentiner, Holahan & Moos, 1994).

Stroke is one of the most common disabling diseases. When a family member is affected by an illness perceived as life threatening or potentially disabling, this is often experienced as a critical event in life. The meaning and coherence of life are broken and the situation can be perceived as chaotic. It is well known from stress research, however, that the same type of event may evoke a marked variation in the amount of perceived stress among different persons. The appraisal of the event and the coping capacity of the individual are important factors behind the variations in family caregivers' individual responses. The dimensions of regaining self-perceived control were characterized as either "persistently seeking of support to maintain control" or "avoidance of seeking support to uphold control" of their environment. They will be discussed in the light of recent research

Bem's (1972) self-perception theory posits that people infer, think, and feel hierarchy of meanings and create a self-schema. This self-schema is an internal, yet hierarchical set of beliefs about us. It guides the ongoing process of self-relevant information and action. This link between self-schemas and external social influences is additionally strengthened with the propositions underlying self-discrepancy theory (Higgins, 1987). According to Higgins, a discrepancy exists between the individual's perception and the ideal view which then may lead to feelings of dissatisfaction and frustration. In response to discrepancy, individuals tend to display negative feelings and behaviours.

Gaining self-control skills are coping responses that help to organize one's own behaviour and to manage cognitive and emotional responses that disrupt ongoing, adaptive behaviour. The concept of regaining self-perceived control is applied to the chronically stressful caregiving experience in this study. It has been shown that there may be disadvantages for those caregivers who have no control over their negative symptom behaviours because self-control skills affect cognitive interpretations and responses in the caring situations. Regaining personal self-perceived control is therefore the basic social psychological process as described by Glaser (1978, 1992) (See Figure 5.1 below) through which new caregivers adapt through their transition role. It is also the “story line” which explains the processes and activities involved when they attempt to regain personal control over former routines and relationships within the demands of stroke care. Throughout this social process, caregivers deliberately identify actual and potential threats to practice self-control skills and implement coping strategies designed to regain a sense of personal self-perceived control in respect to reconcile their own lives. The experience of practicing self-control skills was related to how caregivers managed or coped with their caregiving situations. In this study, caregivers found that the most difficult time was to maintain control and balance between family caregiver and care receiver and meeting own needs and those caregivers received the least help from others in performing these tasks. Hartke and King (2002) identify caregiving characteristics and caregiving factors that influence the caring process as well as caring outcomes. Caregiving factors that include caregiving task difficulty, caregivers' expectations, and caregiving resources. Caregiving characteristics include age and gender, beliefs and values, health status of caregivers and cared-for-persons, and the caregivers' quality of relationship with others. In this study, caregivers who were elderly, close-minded, and avoided seeking support had fewer caregiving resources and unrealistic expectations for themselves and reported more difficulty in practicing self-control skills. They experienced negative caregiving consequences such as greater caregiving stress and gave poor quality of care due to own health problems. By contrast, caregivers who were male, younger, open-minded and optimistic about the future, and who were persistent in seeking support appropriately reported less difficulty in practicing self-control skills. They experienced positive caregiving consequences such as realistic expectations, better quality of life and satisfaction with caring.

Similar findings have been reported from earlier studies concerned with the experiences of caregivers of stroke, cancer and dementia (Kuuppelomaki, 1996; Kuuppelomaki, Sasaki, Yamada, Asakawa & Shimanouchi, 2004; Nolan & Lundh, 1999; Nolan, Grant, Caldock & Keady, 1994). Kuuppelomaki’s (1996) and Nolan et al. (1994) earlier studies found caregiving brought the family members closer and that was important for the well-being of caregivers. Kuuppelomaki et al (2004) suggest that caregivers derived most satisfaction from being able to provide care to their elderly relatives. This study focuses on sources of satisfaction among family caregivers of elderly relatives and related factors in Finland. Factors related to interpersonal dynamics, caregivers felt that this is one way in which they can show their love for the person they cared for. The family caregiver's as well as the care-for-person's gender, the family caregiver's age, caring burden and general life satisfaction were associated with sources of satisfaction. Nolan and Lundh (1999) identified that Swedish family caregivers derived more satisfaction than British caregivers’ experience. This also has a positive impact of caregiving on them.

### 5.2.2 Caregiving Characteristics: Age and Gender Differences in Caring

In this study, wives of four older caregivers in the Chinese community who cared for their stroke-impaired elderly relatives were far less likely to seek help than the five male and other six younger female caregivers. Wives (four older caregivers) had a particularly heavy burden of care and yet were the least likely to ask for support services. This relates to the closed self-control strategies of these caregivers.  Caregivers must let go of mental control and be genuinely open to their present experience through the use of experiential self-control skills.  Some of the family caregivers in this study had reached the point of being unable to cope either physically or emotionally with the relative's need for continual support. It was during this period that the caregiver's health was most vulnerable. One of the most stressful events is generally acknowledged to be the time when the patient is discharged from hospital to go home, without any support being given by health care providers. Such a move is likely to be traumatic for both the caregiver and the patient. As caregivers are not knowledgeable about caregiving, one cause of the traumatic is a fear of the unknown. Therefore, it is particularly important to develop effective and appropriate hospital discharge programmes to provide support and follow up from health authorities and community health services.

The study findings showed that older Chinese female caregivers were varying and their behaviour ranged from avoidance to self-limiting of seeking support. This behaviour contrasts with that of western female caregivers. This may be explained in terms of the mental state control motivation of the cognitive interpretation. Chinese female participants did not mentally let go negative emotions by reducing the adverse effects of mental state control motivation. This qualitative, grounded theory study set out to explain the cognitive interpretation complex process of family caring by caregivers within the current context of health and social reform. Wuest's study (2000) has found that female caregivers used a process of repatterning to reorganize caring activities and to reduce or overcome the negative effects of caring demands. These findings make visible both the losses and gains of female caregivers as they learn and employ expert strategies of anticipating, setting ground rules, juggling time, and relinquishing and replenishing. These findings are consistent with reports from other studies that identifying the experience of caregivers after taking on the caregiving role.

Family caregivers express anxiety about dealing with demands that pile up over time. Thus, factors contributing to the building up of 'pressure' are critical factors that should be taken into account as part of the clinical assessment process. This is particularly important to do in the case of sudden onset of diseases such as stroke when assessing a family caregiver caring for an elderly relative with physical disability or a chronic illness. Demands or needs of individuals, families and communities change over time. In this study, the family caregivers needed to stabilize the family environment at the initial phases of anxiety and disruption as a result of piling up of demands in the home.

Certain signs and symptoms were identified by family caregivers as consequences of caregiving. Such effects of caregiving are likely to represent adjusting behaviours stimulated by the appraisal of threat or burden. The health concerns described by family caregivers included chronic pain, sleeplessness, fatigue, dizziness, exhaustion and many other somatic symptoms together with worry, anxiety and nervousness. Physical complaints gave warning of health hazards associated with perceptions of threat that are associated with feelings of depression and fear. These complaints are occasioned by the demands of caregiving such as lack of time for oneself and existing health problems.

It was found that the older female caregivers in this study exhibited high level of tolerance and endurance. They isolated themselves to provide their own caregiving and refused to be connected to the available support networks. They had no intention of seeking help from others. They treat caregiving as family business with themselves as the responsible persons. Their ability to perceive and predict life outcomes is very poor and their ability to make decisions is very minimal because they isolate themselves and they do not have sufficient knowledge to make sound decisions. They are not good at manipulation, as are the martyred caregivers, when negotiating with others because they do not want to bother other family members and outsiders. They are not prepared to ask for help even they need it, but they do complain about their problems. They also make others feel sorry and have sympathy for them like the martyred caregivers. They react to the role of caregiving with guilt and blame, although they perceive it is their responsibility. Feelings of guilt are evident in the caregiving process, especially in expressing feelings about wishing to live their own life. They blame the cared-for-persons for any inconvenience they have brought to them. They value reciprocity in relationships very much although they seem do not expect any return from others. They are not happy because in their minds there is nobody in this world who can make them feel so. They do not anticipate any consequences because they do not have the ability to make decisions and anticipate the future. Thus, they have great difficulty in making it through the five stages of the adaptation process. They need to go back and forth to stages three and four a number of times prior to regaining a sense of self-control. This affects their health status negatively since they suffer and endure difficulties in the adaptation process of regaining of self-control.

The Adaptation Theory of Regaining Self-perceived Control described below is a useful theory for partially explaining why caregivers delay or refuse to seek support. There are, however, complex interactions between the cognitive-closing and the opening response system as described by Kofta et al. (1998). Caregivers' perceptions of negative feelings in the state control motivation are greater than task control motivation and appear to override the effects of an individual's emotional response to the acute event. Interventions should teach patients the skills associated with active-cognitive and problem-focused coping and take account of gender differences in their design.

The development of the Adaptation Theory is also useful in identifying the vulnerable group of caregivers whose self-control skills, social environment, and mental status could be improved through appropriate patient education strategies. The experience of Chinese family caregiving analyzed in this study expands our understanding of the factors which both interfere with and promote family caregiving. The key to successful caregiving appears to be Regaining Self-perceived Control. This is similar to the findings of western studies as defined by Seibert et al. (1999) as “Self-control consists of any proactive behaviour – either overt or covert – that we do at one time to control our later behaviours and increase our chances of success in those later behaviours” (p.360).

The adaptation process to rehabilitation care comprises the five stages of uncertainty, disruption, accommodation, balance, and reconciliation. These stages should not be taken as exact points in time through which all caregivers must pass. They are merely a convenient way to explain certain cognitive-emotional and behavioural patterns that are progressed through. As new problems arise and existing problems remain unresolved, caregivers may return to previously completed stages several times, behaviour exhibited by martyred and victimized caregivers. This means that their passage through the process may not be smooth and may involve cycling back and forth between stages, or even remaining in one phase from a period of time. What does seem clear is that caregiver will only be able to move to the subsequent stage when the tasks involved the previous stage has been successfully completed.

## 5.3 Implications of the Adaptation Theory of Regaining Self-perceived Control

A more comprehensive view of adjustment process of family caring, entitled a Theory of Regaining Self-perceived Control, has been developed by the researcher based on the identified central category of "Regaining Self-perceived Control" discussed in Chapter 4. This theory explains that the variations in responses to caregiving reflect differences in the perceived control of family caregivers' cognitive interpretation. In this view, the consequences of the family caregiver's caring relationships cause profound changes in family interactions associated with both motivation to seek support and recognition of support networks. These changes result in the caregiver experiencing loss of control. The task of regaining control, by regaining former roles and relationships with others, is a legitimate task that must be resolved before the family caregiver can regain a high level of wellness.

The study's development of the Adaptation Theory of Regaining Self-perceived Control is similar to the work on personal control in action by Kofta et al. (1998). The Adaptation Theory of Regaining Self-perceived Control was developed because it extends the general model of processing pattern model of Kofta and his associates, and thus its use can promote the integration of this study's findings into existing bodies of research. The newly developed Theory has five stages as the components of the responses to the cognitive interpretation process.

The five stages are the components of the Adaptation Theory that interact with one another to shape the process of Regaining Self-perceived Control in family caring. Its development was based on the findings discussed in

Chapter Four. The relative importance of these components in the framework is the stages of uncertainty, disruption, accommodation, balance and reconciliation. The dimensions of the conceptual indicator “Regaining Self-perceived Control” were ability to predict outcomes, ability to make informed decisions and ability to act on decisions. Caring strategies identified in this study may suggest a clinical plan for assessment and intervention incorporating this knowledge of family adaptation process. Despite the variation in strategies and responses that characterize each stage of the adaptation process, all are directed toward regaining a sense of personal perceived control.

In the knowledge of the researcher, no previous studies have been carried out in which investigators examined ways in which meanings are formulated for caregiving experience or how those meanings are adjusted and reformulated over time. This study examined the 15 family caregivers’ adaptation process over the course of two years. The process of adjustment for family caregivers usually began following the stroke relative being discharged from hospital.

This study’s systematic inquiry into family caring has given rise to a five-stage successive but overlapping process. These stages trigger stresses that affect caring responsibilities in the adaptation process of family caregivers if necessary support is not expected. Interactive parts of the adaptation process provide the foundation for assessing and analyzing transactions to facilitate understanding and direction towards developing a culturally based family caring model. The adaptation stages are useful for assessing and identifying the caregivers' problems in the adaptation process. However, the diversity of family life today precludes establishing these stages and accompanying tasks as norms that families may follow. Nevertheless, the explanatory nature of the caring is important in understanding family individual caregiver's cognitive interpretation and is therefore integral to the development of a theory for family caring in the Chinese context.

The purpose of this study is to examine the symbolic nature and characteristics of caring interactions in the process of family care. Adaptative caring, which deals with overcoming stressors and Regaining Self-perceived Control to the caregiver, has been identified as a basic social interactional process that fundamental to the optimization of caregivers' wellbeing during their transitional role. An understanding of the caregivers' process of Regaining Self-perceived Control in stroke care is crucial if subsequent educative output is to be positively influenced by individual's cognitive interpretation and responses.

The Adaptation Theory’s five stages were found to define the fundamental structure of these caregivers’ experience. According to the participants, caregivers’ adaptation process was influenced by these caregivers’ characteristics and caregiving factors. Few caregivers in this study cited deteriorating cared-for-person conditions and own health problems as the main causes of unsatisfied or discontinued caregiving. Martyred and victimized caregivers who were still providing home care over the course of two years were functioning less well than satisfied and committed caregivers who sought and connected to support network in caregiving. Similar findings also found in other studies (Robinson and Steele, 1995; Coen, 2002; Rawlings and Spencer, 2002) that caregiver burden is greater if they received less or no help from others.

Older female caregivers appear to have some disadvantages over male and younger ones, but this finding is not universally found in the results of studies. In comparison to men, the conflicted social networks of women were larger and comprised of more family members. Knowledge of the gender differences in network size and composition that have been identified in this study will contribute to nurses' ability to identify caregivers who may be at risk for inadequate social support. In conjunction with the findings from related studies these results have implications for nursing assessment and intervention in home care and long-term care settings. Caregivers attempt to regain self-perceived control in different ways based on their perception of their role. Such perceptions appear to inhibit older women from drawing upon a range of resources to help clarify the nature of the problem and how best to respond to it. Traditional Chinese beliefs about the females' role in caring have been complemented by the new concept of "self-perceived control" by which older women are said to be influenced when under stress.

These differing responses may differ in regaining personal perceived control lead to a range of behaviours based on caregivers' perception of their responses to personal perceived control to stressful events which inhibit women to draw upon a range of resources to help clarify the nature of the problem and how best to respond. The belief used for years in Chinese and it has been complemented by the new concept of "self-perceived control" in which older female caregivers with low perceived control when under stress. As older female caregivers were particularly vulnerable to threats to control, that is they were more likely than others to react negatively that might be interpreted as a threat to their control. Such caregivers may be thought of as ever defensive to the control implication of their response to stressful events.

The caregivers’ family caring experience may be interpreted by addressing the two key caring strategies: motivation to seek support and recognition of support network which has been identified in the theory of coping. In Lazarus’s (1993) framework, coping and support seeking are vital mediating variables. Coping has been defined as the “constantly changing cognitive and behavioural efforts used to mange specific external and internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1993, p.19).

A number of recurring patterns point the way to identifying caregivers who may be at increased risk for poor adjustment during their transitional roles. It is apparent that men and women adapt to their transitions somewhat differently. Whether men or women are at greater risk for poor adjustment, however, remains to be determined. There is some empirical evidence to suggest that lower socioeconomic status and linguistic barriers interfere with adjustment during transitions. There is a dearth of culturally relevant services to help stroke-care patients and their family members make the required adaptations. The literature makes apparent the need for open awareness of the impending stress and for careful and thoughtful planning for how the stress was interpreted by each individual (Kofta et al., 1998; Lazarus & Folkman, 1984). The regular and frequent presence of professional caregivers contributes to family caregivers' satisfaction with care. Discrepant findings point to the need to explore the issues that underline them. Older female caregivers appear to have some disadvantages compared to male and younger ones, but this finding is not universally reported in the results of studies. Methodological problems include small sample sizes and large variations in the particular caregiving outcomes studied.

Within the stages of Adaptation Theory described, three major categories of caring strategies of Chinese family caregivers were identified. The first strategy, which was most commonly adopted by the caregiver participants of this study, was the ‘cognitive reframing strategy’ refers to the belief that caregiver can assume personal control over problems by learning key aspects of care. Higher levels of self-perceived control are expected to lead to health-promotion behaviours and improved measures of physical and mental health. The second strategy was the ‘behavioural reframing strategy’ refers to caregivers’ willing to change and make adjustment by changing the current interfere behaviours and replace it with a new and well defined behaviour. The third strategy was the ’experiential reframing strategy’ refers to caregivers’ caring acts become ritualistic. Caregivers achieve a stage of behaviour and thought being automized. This was adopted by those caregivers who had significant opportunities practice self-control skills and so became linked to multiple sources of support networks.

Identified support networks include spousal support, intergenerational support, kinship support and non-kinship support. The present researcher will describe the types of support rendered through the different caring strategies and will also analyze the reasons that contributed to the adaptation of the social process of Regaining Self-perceived Control. Its focus is to make sense of the Hong Kong Chinese family experience in caring for their elderly relatives following stroke within the context of the identified stages of family caregiver's needs. This is supported by Holroyd's (2001, 2003b) study findings that concepts of Confucian antecedents, reciprocity and personhood and other modern ideas of filial duty influences the Chinese culture on family caregiving.

The variation initially described by the family caregivers creates a confusing picture because the family caregivers adopted four different types of patterns of caring strategies over the course of time. It was the identification of the researcher to determine the nature of this considerable variation. It was found that all the responses and strategies that the family caregivers discussed were directed toward regaining a sense of self-perceived control. Four types of family caregivers made sense of their situations in order to regain control and it was this understanding that guided their subsequent responses and selection of strategies. The researcher identified predisposing factors influencing the styles of coping such as acceptance of intra and extra-familial support networks. Certainly, family caregivers develop different styles of adaptation in the process of regaining a sense of personal perceived control. All the family caregivers in this study adopted different styles of caring. Many of the family caregivers emphasized the importance of evolving psychological “harmony” in the stage of reconciliation.

The Adaptation Theory of Regaining Self-perceived control developed in this study (See Figure 5.1) is a compensatory model and reveals family caregivers strive to regain personal perceived control during the adaptation process. After identifying the central category of “Regaining Self-perceived Control”, strategies required to sustain family caring through interactions with other family members were also addressed. Interactions involved ability to take decisional control and seek tangible or non-tangible supports from kin or non-kin sources. The researcher also examined closely the cultural aspects that might influence the adaptation process of Chinese family caregivers and the adaptive coping strategies. The development of the framework was based on the study data which emerged from the 33 interview scripts from the first and second interviews. The developed framework provides a “map” for health care providers who work with family caregivers tin that it helps professionals

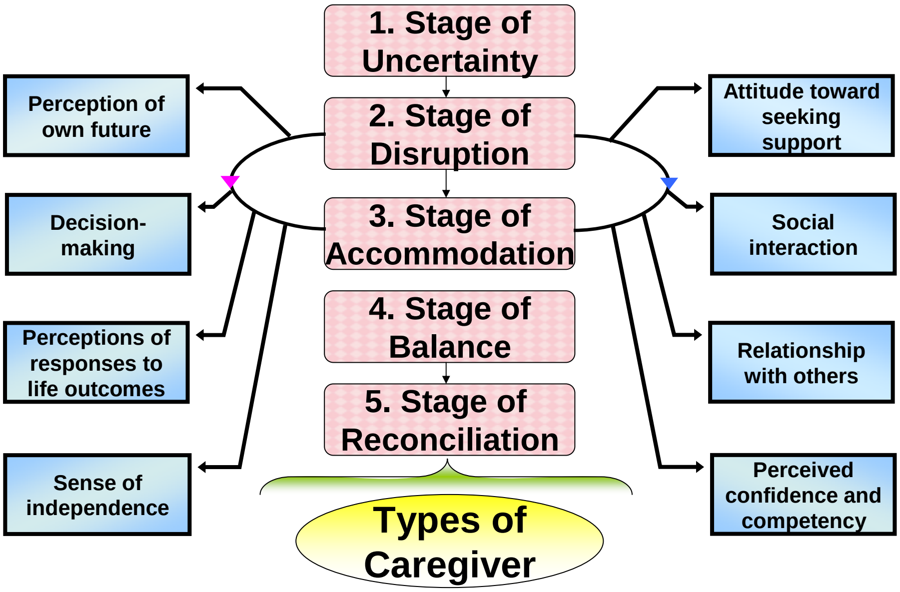


**Figure 5.1 Five Stages of the Adaptation Theory of Regaining Self-perceived Control**

to identify the patterns of caring behaviours and coping strategies that Chinese family caregivers adopt to regain self-perceived control and sustain caring. It is assumed that family caregivers employ a range of strategies and negotiate with other family members involved in the caring process to minimize suffering. The goal of individuals involved in family care is to minimize the suffering of the family caregivers or to share the suffering, thereby increasing the well-beings of all parties. The Theory also reveals the changing nature of caring relationships in Chinese society and the factors that influence the decisional control of family caregivers. Each stage involves facing change and accomplishing tasks as prerequisites for the successful transition from one stage to another.

## 5.4 Caring Strategies for Regaining Self-perceived Control

The 15 Chinese family caregivers in this study manifested over the course of two years more than just a set of different coping behaviours and caring outcomes throughout the five stages of the adaptation process. It was obvious that caring involved dynamic interactions and caring strategies. It integrated the styles of coping with the motivation and recognition of the suitability and availability support networks. In this study, the Adaptation Theory of Regaining Self-perceived Control was analyzed inductively using the grounded theory approach. The analysis showed that the caring responsibilities were influenced by the dynamic interplay of caring strategies provided by recognition of available kinship support (guanxi) and motivation to seek support. The family is the core of the kinship support network and this provides a frame of reference that assists the Chinese family caregiver in reconstructing the mode of seeking support through an adapation process of Regaining Self-perceived Control based on the Confucian ethical system of role relationships. The motivation and recognition of seeking support networks were remarkably varied. The impact of caring strategies was extremely powerful and influenced the caring outcomes of family caregivers.

## 5.5 Family Caring in a Chinese Context

Kinship guanxi (social ties or connections among people that result in mutual benefit) is the strongest form of guanxi for Chinese individuals, followed by extended family members and extra-familial relations, neighbours, friends, co-workers and customers. Caregiving in the family context was related to the Chinese family caregiver's self-identity in the caring relationships.

### 5.5.1 Intra-Familial Support Networks

In the Chinese context, a support relationship is usually described as guanxi. Guanxi is also includes instrumental resources, generally based upon self-interest, and interpersonal resources that are considered both natural and necessary for one's emotional life (Yang, 1992). Guanxi regulates expected behaviours of people belonging to a particular network.

Chances of social interaction, level of self-disclosure, motivation to seek support and recognition of support network are some of the factors that contribute to the strength of guanxi. Guanxi also provides individuals with a sense of belonging and security. Moreover, it provides a framework of reference that assists in an individual's construction of social identity through a process of social comparison and self-evaluation.

Therefore as O'Neill and Sorenson (1991) argue, there is a need to consider caring from a family perspective that recognizes both the role older people play as providers of care and the contribution that older cared-for-person can make to the family. Within this context caregiving is best viewed as a social process rather than primarily as an individual experience (Aranda & Knight, 1997; Brody, 1985). As Young and Kahana (1995) state this signals the need to develop dynamic and relational models of caregiving.

It is common in Chinese society that particular customs signify specific cultural meanings in the family caring process. The researcher discovered that the Chinese family caregivers were insistent on preserving their values and beliefs in obtaining support within own families and did not want to receive external support till they were no longer able to carry out caring responsibilities. This is the result of a sense of ‘place’ or ‘face’ in the family and that is a person’s sense of worth or self-esteem.

### 5.5.2 Seeking support

Family caregivers in this study were asked if they thought that any extra types of support or services might have made any difference to the caring task at home. Most of them agreed that an extra hand could have really made some difference during the first week when the stroke relatives were discharged home. Both elderly and daughter family caregivers in particular described themselves as overwhelmed by problems such as sleep deprivation or difficult behaviour, or being unable to cope physically with lifting and incontinence–problems that were difficult for community support services to address. Although some of the family caregivers had used a helper, they were also likely to feel either that the amount of support was inadequate or that it was available at inappropriate times.

Satisfied and committed caregivers with a high level of social skills were able to mobilize social support in their environments more effectively due to their ability to restructure the cognitive interpretations resulted in a decrease in the degree of perceived stress in the adaptation process and thus they progressed through the five stages of the Theory of Regaining Self-perceived Control smoothly and quickly.  By contrast, those martyred and victimized caregivers with a low level of self-control skills were unable to mobilize social support in their environments effectively due to their inability restructure the cognitive interpretations resulted in an increase in the degree of perceived stress and this they progressed through the five stages with great difficulty. This finding is also supported by other studies (Robinson and Steele, 1995; Coen, 2002; Rawlings and Spencer, 2002) that caregiving burden was greater if the family caregivers received less or no support from their social network including family, friends and community and if  quality of relationships with cared-for-person are poor (Yamamoto-Mitani et al., 2003).

Lazarus and Folkman (1984) indicate that cognitive coping processes merge into ‘reappraisal’, that is, the continuing reinterpretation of the two-way processes of threat, coping, outcome, and perception of outcome. Therefore, caregiving lies within the appraisal and reappraisal process.  The outcome response or the coping behaviour element is conceptually problematic in that as overt (obvious) behaviours, health responses, affective-psychological responses, and caregiving beliefs as possible categories of such responses to appraised threat.  The most significant contribution that the individual stress and coping perspective have been made to the scientific inquiry of family care concerns. The conceptualization of the consequences of caregiving is documented in the literature and show that several domains of an individual's life are potentially affected by being a caregiver. Four types of Chinese family caregivers include satisfied caregiver, committed caregiver, martyred caregiver and victimed caregiver were identified in the study according the conceptual indicators of the core category regaining of self-control.

The Chinese family caregivers with unmet needs in this study are those that were in highest need of support but received support from neither children nor other sources. This could disrupt their 'self-identity' due to their poor kinship support with other family members during the adaptation process. As Pang (2003) stated Chinese people's existence is defined by their hierarchical relationships with others and how one behaves depends on which role one is assuming at a particular moment in life. As pointed out in Chapter Two, according to the Four Books (1890), these hierarchical relationships are based in the teachings of Confucius, which valued the five cardinal relationships. Kinship is maintained in good order when each party fulfils their own role requirement within each of these five relationships. For example, the affection that exists between mother and daughter and the differentiation that exists between husband and wife are valued. In the Doctrine of the Mean, how a person acts on one's role is further explained as the universal obligation.

There is only affection for relatives and there should be no resentment of them. The expectation of filial duty is best described in Twenty-four Stories of Filial Devotion where children are driven by devotion to their parents and act against their own interest. According to The Analects of Confucius, *li* (禮) refers for the importance of rules and *ren* (仁) refers to two persons relating to each other in harmony. This puts us in mind of the kinship support between husband and wife and mother and daughter described this study.

Seven of the Chinese family caregivers interviewed did not expect any instrumental help or emotional support from their children because they admitted that the children were busy working or caring their own families. Instead they expect financial assistance from their children and social visits when they are free and available. The children of the three families in this study provided both instrumental and emotional support for their parents by relating to the teachings of Confucius which emphasizing devotion to parents.

### 5.5.3 Extra-Familial Support Networks

A wide range of different types of support from either social services or the community health services were identified by the Chinese family caregivers in this study. Family caregivers coped better after joining the Stroke Support

Group because it enabled individuals to acquire information, share common concerns, and receive respite and emotional support. These included home-maker services with the home-maker coming into the home to assist with personal and household tasks such as bathing, cleaning and washing. A few family caregivers reported support being purchased through Social Welfare Department. Husband and daughter caregivers in this study reported that they had used a package of one type of home support from the statutory services. One of the husband spousal caregivers (satisfied caregiver) stated “Now we hire a homemaker through Social Welfare Services to help us to clean the house once per week. I pay her a hundred dollars every time. She does a great job and I don’t have to climb up stairs to clean windows” (No. 4-95). Another wife as spousal caregiver (committed caregiver) explained “Hiring a homemaker can help me a lot in caring for him. She gives him a bath and she also goes to the market. But she leaves at 5 o’clock everyday and she won’t come in during holidays. That is very troublesome” (No. 7-23). Only a few family caregivers reported that the cared-for-person had attended a day centre one day of the week at the early stage of recovery after discharge from hospital.

Older female spousal caregivers (N=4), aged 68 or above in this study were least likely to seek support from the statutory services such as day care centers for elderly in the community. One of the older female spousal caregivers (Martyred caregiver) stated “Nobody will be available in helping me to care for him, except myself” (No. 6-295). Another older female caregiver (victimized caregiver) said “I’ve never thought about getting someone to help me!” (No. 2-43). Another older female caregiver (victimized caregiver) said “It is no good to ask others for help. I don’t ask others to help me even it is needed” (No. 9-33). This may be based on the teachings of Confucius, those ethical values and customs related to their guilt feelings or to their commitment in fulfilling role responsibilities. It was also less likely for older female caregivers than male and daughter caregivers to have the cared-for-persons attend a day centers. This might be related to their commitment in fulfilling their spousal responsibilities and therefore they refused any intra and extra-familial support. They were then unable to be connected to the available support network. One of the older female spousal caregives stated “The social worker told me that she could ask a homemaker to come to help me, but I refused as it did not fit my schedule and I did not know when I need her as I did not know when my husband would have a bowel movement” (No. 9-16).

### 5.5.4 Model of Processing Pattern Response System of Human Functioning

As the core category of “Regaining Self-perceived Control” emerged from the study data, this finding was found to be consistent and supported by Kofta et al.’s (1998) Model of Processing Pattern Response System (See Figure 4.6 below) and explained the ways in which caregivers cognitively construe their self-perceived control in coping with the demanding tasks and it serves to organize their responses to the process of caring. Kofta et al. further state those individuals who perceive and appraise themselves as lacking self-perceived control was found to be highly reactive to the possibility of lost self-perceived control.

The Model of Processing Pattern Response System (Kofta et al., 1998) is a processing and response pattern which reveals the ways in which an individual responds when triggered by interpersonal events or any event that poses a threat or demanding relationship. The presence of potential social challenge or threat is a chronic feature of human experience. The Model uses number strategies to determine the ways in which individuals with high or low perceived control respond to the demands associated with interaction. However, the reactions to experiences are as variable as the ways in which they are interpreted. Kofta et al. emphasize that variations in response to social challenge reflect differences in the perceived social control of interactants. Kofta et al. further state that individuals with low self-perceived control have an easily accessible representation of making a decision as to relative status does not require reflection. In contrast, individuals with high self-perceived control took longer to make such judgments under concurrent load circumstances than in the absence of concurrent load. This suggests that status judgments are not “precomputed” for them. According to Kofta et al. (1998), when exposed to situations that pose a potential social challenge, those who see themselves as having less control than others, are more likely to engage in defensive activity at both intra and interpersonal levels. Such responses are motivated by the perceived need to prevent further erosion of control or to regain control. Bugental, Brown & Reiss (1996) and Bugental et al. (1995) reported that perceptions of low self-perceived control easily lead to reductions in cognitive capacity. Thus, the Model allows health care professionals to assess the generality of observed processes while still affording the possibility of causal inference in the observed relationship in order to understand the caregivers’ cognitive interpretations and responses in the process of regaining personal control.

Loss of self-perceived control has very different consequences based upon the opportunities available for regaining a sense of self-perceived control. That is loss of self-perceived control may lead to either withdrawal of effort (consistent with the learned helplessness literature, Abramson, Seligman & Teasdale, 1978) or intensification of effort (consistent with the findings of

Pittman & Pittman, 1980). Kofta et al. (1998) found that individuals with low self-perceived control show an inconsistent pattern of response that may be thought of as reflecting the ambivalence between their motives and the situational opportunities such as attitude towards social support as they are lacked access to the control opportunity. They are also more likely than others to display a combination of strong evaluative comments voiced in a very unassertive fashion. Not surprisingly, such individuals display an overall pattern of social and cognitive disengagement (Bugental & Shennum, 1984). Disengagement may take many different forms. They show increasing indications of distress along with deficits in performance in cognitively demanding tasks. The demanding tasks may in turn be misinterpreted by these individuals as sources of “stress”, “tension”, and “pressure”. As caring interaction continues in the adaptational social process, caring strategies might easily come to be seen as “inadequate”.

## 5.6 Types of Family Caregivers

The study data show that the experience of personal control related to how family caregivers managed or coped with their caring situations in the adaptation process. The family caregivers must regain senses of predictability, self-determination and independence before they are able to regain a sense of self-control (Morse & Johnson, 1991). It was found that the 15 family caregivers to regain a sense of self-control was influenced by three caregiving characteristics (a) the individual’s beliefs about the meaning of caring in the Chinese cultural context; (b) their personality type and perceptions of life outcomes; and (c) their motives and recognition of seeking available support. Their beliefs, personalities and interface transactions were central to their motivation to continue to sustain caring in the family. The family caregivers used a number of strategies in the adaptation process to regain a sense of self-control. These included learning to trust their abilities to predict life outcomes, learning to trust their abilities to make informed decisions, learning to trust their abilities to act on decisions, and learning to trust their abilities to manage care and cope with stress. All these caring strategies influenced family caregivers in anticipating an increase in family involvement greater, family integration and increased participation in decision-making. These caring strategies show commonalties and differences among the four types of family caregivers.

It was also found in this study that external resources assisted satisfied and committed caregivers, who accepted available help, had better coping skills and regained self-control quickly and smoothly. The use of support service allowed them to vent frustration over care demands, to deal with difficult behaviours, and to manage changes in roles and relationships occurring as a result of providing care over time.

### 5.6.1 Meaning of Self-perceived Control relating to Caring Strategies in the Chinese context: Typology of Properties

The dynamic conditions and factors influencing the adaptation in the process of Regaining Self-perceived Control can be investigated by identifying variations in the support patterns of Chinese family caregivers. The present researcher was able to identify such variations in the process of ‘Regaining Self-perceived Control. The researcher was also aware of the different caring strategies adopted by these 15 Chinese family caregivers, as well as those personalities and cultural factors that influence the evolution of these support patterns over time.

Several factors that affect the caregivers' ability to implement modification strategies were identified in the analysis. These factors included attributes of the individual, attributes of modification, quality of the caregiver and elderly relationship, caregivers' skills, personal resources of the caregiver, and the informal and formal support available. These were identified as the primary and secondary controls suggested by Lazarus and Folkman (1984). Of these factors, the most important were the skills that caregivers need to implement environmental modifications (primary control). These findings point to the importance of caregivers receiving skills training in this important dimension. Intervention should be based on a collaborative approach that ensures the caregiver and care receiver's needs and preferences are respected.

### 5.6.2 The Chinese Meaning of Caring Principles

Based on the data analysis, caring was identified as a complex phenomenon involving more than a set of caring acts. Rather, it is a process of regaining personal control that relates to moral, cognitive and emotional components, which are culturally derived. Chinese culture promotes independence and endurance, self-management of problems and minimizes social disturbance. Analysis of study data found that the family caregiving of Chinese in Hong Kong is very much influenced by a moral duty to take care of sick relatives, grounded in traditional Chinese values. The experience of Chinese family caregiving analyzed in this study expands our understanding that particular beliefs and perceptions promote coping, use of adaptive resources, and stress management self-efficacy. Similar patterns of adaptative behaviours were identified in the process of analyzing data. No longitudinal research has previously been conducted to understand the adaptive patterns Chinese family caregivers adopted in caring for stroke-impaired elderly relatives in Hong Kong.

This qualitative study has worked towards a Chinese conception of family caring. Thirty-eight categories, generated from study data using open coding in a grounded theory approach, were found to be pertinent to the family caregivers' experiences. A central category of caring relationships and 8 subcategories associated with motivation to seek support and recognition of support network in order to regain a sense of personal perceived control were generated. The focus of this study was to understand the meanings Chinese family caregivers derived from providing care for stroke-impaired relatives in Hong Kong. Caring was identified as the sum of dynamic relationships within family ties and between kinship support and non-kinship support.

The study data show that the Chinese family caregivers held moral obligations such as filial responsibility and reciprocity to take care of their sick relatives. These were identified by the caregivers as the motives to continue providing care. In this chapter, the data from the 15 family caregivers is analyzed and an attempt is made to develop a theory of family caring. In this study, the 'value map' held by all the Chinese family caregivers consisted of cultural issues of kinship relationship that grounded in the adaptation process of Regaining Self-perceived Control in order to sustain caregiving responsibility. Study data showed that filial responsibility was conceptualized as a Chinese notion of family caring active in the process of cognitive interpretation of regaining of self-perceived control.

Filial responsibility and the family caregiver’s attitude towards seeking support were important factors in shaping family caring. The present researcher argues that family caring is not solely a task activity, but rather an activity which includes filial responsibility grounded in traditional Chinese moral obligations and family ties.

The majority of the Chinese family caregivers in this study were generally rather traditional in their orientation and the majority of them tended to subscribe to the value of respect the old and care for the sick family members. All the family caregivers decided to care for their relatives and endured the effects of being put under pressure. All spousal family caregivers stayed to care because they considered this was fair. They knew that the sick spouses did not expect to become disabled and dependent and they felt sorry for impaired spouses who were alone.

In the study, all the daughter family caregivers felt that these were their responsibilities and that they would be despised as unfilial should they failed to take up caring duties. They stated in the interview sincerely that their determination to take on the caring role related to the previous loving relationship with their mothers. This showed that the erosion of traditional values was not yet very evident among daughter participants. Although the daughter family caregivers in this study insisted on providing care at home, all their sibling brothers and sisters were against their decisions and suggested sending their elderly parents into private homes for the aged, especially when care became more demanding over the course of two years. The children felt that such arrangements were not indications of their lack of filial piety, but was a practical alternative to caring for the elderly while allowing themselves to continue with their personal careers and their own family responsibilities. There were some indications that the traditional values regarding filial piety and reciprocity are gradually being eroded in the fast changing society of Hong Kong.

The daughter family caregivers all expressed their gratitude and confirmed that reciprocation was involved in caring for their mothers. Even the youngest participant, who was treated badly by her father previously, was determined to take up the responsibility of taking caring of her stroke-impaired father. They also expressed the view that they would continue to care for the relatives if they needed care and attention in the future. Most of the older female family caregivers in this study strongly advocated customs and values than affection and love such as roles for families and responsibilities to husbands.

The researcher found that victimized family caregivers, the elderly caregivers, were insistent on preserving their values and beliefs in caring and they did not want to receive external support even though they were no longer able to carry out caring responsibilities due to their own health concerns or the deterioration in the cared-for-person's health status. They expressed the view that spousal and daughter kinship in the five cardinal relationships were the driving force that made them continue to provide care. This is the experience of the sense of 'place' or 'face' in the family and reflects the person's sense of worth or self-esteem.

## 5.7 Role Transition

Many role transitions involve loss of income, lower self-esteem, and for many loss of power attached to their former roles. Chinese family caregivers' behaviour is strongly associated with their cognitive interpretations and role relationships and how they obtain either intra-familial or extra-familial support in order to continue their caring responsibilities. Effective role transition calls for negotiation with health care professionals and social agencies.

The regaining a sense of self-perceived control was the central concept in understanding the family caregiver's struggle to adapt to caring for their relatives. According to Danielson et al. (1993), family adaptation is the outcome of family efforts to bring a new level of balance, harmony, and coherence, as well as a satisfactory level of functioning, to a family crisis situation. It involves coping strategies such as synergizing, interfacing, and compromising. A family struggles to achieve a balance between the individual and family levels of functioning. In this study, achieving a balance between meeting the needs of individual members of the family and the well-being of the family as a whole was found to be in the final stage in the five stages of the adaptation process. The long-term care needs of a chronically ill relative require a collaborative arrangement between the family and the health-care community. The family caregiver's success in caring for an elderly relative with stroke-impairment also depends on available support networks. According to Danielson et al. (1993), family adaptation is enhanced when a mutually supportive relationship develops between the family and the professional health-care team.

The Chinese families investigated were not static social units and they went through predictable transitions as the result of the changes in the extended family system such as conflicts, financial concerns and illnesses. Three major caring strategies adopted by the caregivers in this study were the “Cognitive Reframing” which involves establishing greater physical and psychological distance between the relative and the caregiver; “Behavioural Reframing”, involving intensification of relationship between the relative and the caregiver, usually spouse, to the exclusion of other relationships.  The automized adaptive mode as “Experiential Reframing” refers to caregivers’ caring acts become ritualistic. Caregivers achieve a stage of behaviour and thought being automized.  This was adopted by those caregivers who had significant opportunities practice self-control skills and so became linked to multiple sources of support networks.

This results in social regression (weakening) for spouse and role entrenchment (rooted) for adult children. An investigation specifically addressing the correlation between coping strategies and the subjective sense of burden was conducted by Pratt and colleagues (Pratt, Schmall, Wright & Cleland, 1985). They found that the three internal coping strategies adopted by caregivers were maintenance of confidence in problem-solving; reframing of the problem; and upholding of a positive outlook, was related to lower burden scores. The family caregivers in the present study employed these three common caring strategies to cope with daily demands of caring. It was found that among the four types of family caregivers in this study, the ability to anticipate outcomes of caring demands was a consequence of family efforts to cope. It is surprising to discover families struggling with what they perceive to be good coping efforts or strategies, only to discover that the short-run benefits might lead to greater long-term difficulties.

## 5.8 Spousal and Daughter Family Caregivers

There were five male family caregivers in this study and they accepted the obligation to undertake caring responsibility and derived a sense of identity and reward from their care. Their stroke-impaired relatives were all wheelchair-bound and they required total care for the first six to ten months after they were discharged from hospital. The Chinese male spousal caregivers in this study used extra-familial help, but not intra-familial help. For the two male family caregivers that did not have any children, coping strategies involved mainly extra-familial support. For the other two male family caregivers with children, coping strategies did involve extra-familial support. The other male caregiver was a step-father of three children and there was great conflict between step-father and step-children. Thus, his coping strategies involved only extra-familial support. The five male spousal family caregivers in this study showed their willingness to seek and accept extra-familial support compared to the four older female spousal caregivers, aged over 68 years.

### 5.8.1 Male Spousal Family Caregivers

Experiences of male caregivers have been underrepresented in the caring and caregiving literature. The five men who participated in this study were primarily spouses and similarities were noted within and between male and female spousal caregivers. One husband with no children or who lacked intra-familial support was found to have higher stress and pressure and expressed the least sense of control over the situation in compared that to the other male caregiver also with no children due to his cognitive interpretations. Four out of five of them classified as satisfied and committed caregivers and only one was classified as martyred caregiver. Their experience suggests that male caregiving is a critical area for future study.

Gender was another significant factor in how caregivers perceived self-control by accepting caregiver responsibilities. Most caregivers perceived the caring role as belonging to women. According to Ngan and Wong (1995), family caregiving of the Chinese elderly in Hong Kong evolved as a "caring trap" for female caregivers, especially unmarried daughters. Despite this, as Hong Kong is still a patriarchal Chinese society, most of the major decisions affecting the destiny of frail elders are made by sons or other male members of the family. Ngan and Wong also identified caregiving issues including unequal gender roles, obligations, and division of caregiving responsibilities within the Chinese family and their effects on the caring relationship in Hong Kong.

In this study, male family caregivers appeared to find it easier to separate themselves from the caring situation, to set limits on their involvement and to see themselves as primary caregivers with a legitimate need for support. As all five male caregivers in this study stated, “The only thing is that I am a man; if I were a woman, there would not be so much of a problem. You see, a man cannot care like a woman. You see, we usually leave caregiving to women, but as we are doing this, we do it the female way” (Nos. 1, 4, 8, 11 & 14). By contrast, older female family caregivers were likely to submit their own interests and devote all their energy to the stroke-impaired relative, to be less detached, and to regard the acceptance of help as a sign of failure. Study data showed that of caring across a variety of relationships, cross-gender caring appears to be more problematic when provided by males for females (Twigg

& Atkin, 1994, p.32). For example, all four male caregivers in this study expressed difficulty in adjusting to new role responsibilities such as cooking, bathing, and toileting.

### 5.8.2 Female Spousal and Daughter Family Caregivers

There were three daughters caregivers in the study. Kinship relationship between the daughter and mother was the driving forces and motive for the three daughters to become committed to continuing care provision. They tended to seek extra resources to sustain their filial responsibilities in some kind of normal existence in the community with support both within the family and from outside. Although they perceived simple tasks such as daily personal care activities as a source of tension, they showed a willingness to accept available support when they needed it. In the other hand, the present researcher found that older spousal family caregivers were less likely to seek extra-familial support in the caregiving responsibility than the children, daughter caregivers in this study. Paid home care services were more likely to be employed when children were caregivers. Less was expected of older female spousal family caregivers than was expected of children and male family caregivers.

Some key factors which family caregivers consider if their stroke elderly relatives continued to live at home include the role responsibility and kinship relationships between the family caregivers and their kin, whether the health status of the relative was improving or deteriorating, and the amount of support needed at home. Family caregivers in the study were asked whether their elderly relatives with stroke had needed help with personal care (such as bathing, dressing, using the toilet, or eating a meal) or with ordinary household tasks (such as cleaning, cooking or shopping) in their caring role. If help had been needed, information was obtained about who provided it and whether it had to be paid for. It was found that the amount of care provided by family caregivers gradually decreased as recovery occurred during rehabilitation. Most of the cared-for-persons in this study required from total to partial care when discharged from hospital. The difficulty of personal care encountered by most of caregivers were giving a bath, using the toilet, and cleaning after incontinence of bladder or bowel. When help was needed with any aspect of personal care or with any household task, older females and daughters were more likely than other family members to give personal assistance.

## 5.9 Importance of the Study Findings

The importance of the study findings includes the identification of the process of family adaptation which caregivers strive to regain self-control, increased understanding of cognitive interpretation of self-control process, explanation of the five stages of the Adaptation Theory of Regaining Self-perceived Control, construction of the typology of regaining self-perceived control with four types of caregivers, and identification of the variations of caregivers' characteristics and caregiving factors.

### 5.9.1 Family Caring Process: An Adaptation Theory of Regaining Self-perceived Control

Regaining a sense of personal control is the central concept in understanding the family caregiver's adaptation to manage those situations in caring for their stroke-impaired elderly relatives in this study. This study has described the evolution of Chinese family caregivers' experience in the caring process over a period of two years using a grounded theory approach. Results of this study can help health care providers intervene more effectively and directly to enhance experiential self-control with family caregivers by recognizing how caregivers interpret the caring situations and whether they need assistance to regain self-perceived control in order to continue to provide care through the adaptation process.  It was found that negative emotions affect family caregivers’ cognitive interpretation of Regaining Self-perceived Control and this indirectly affected care for the stroke-impaired elderly relatives. Caregiving coping skills, including restructuring the cognitive process, clearly need to be taught using cognitive response system as a strategy to overcome the obstructive effects of undesirable experiential reactions such as anxiety and guilt feelings. Caregivers should be taught how to cognitively restructure their experience in a more functional way and develop new and more adaptive personal theories. This is especially important with the older female family caregivers, who were found to have more difficulty than other types of caregivers in coping with the caregiving role, particularly in seeking support from others.

However, it was apparent that these caregivers urgently needed support to enable them to regain self-control in order to continue to bear the physical, social, and financial costs of their caregiving responsibilities. By focusing on the caregiver’s perspective, this study addresses a gap in the research literature. If replicated with other groups who are "at risk" for discontinuity of care, this research approach can be used to identify areas in which professional roles, programs and funding arrangements could be redesigned to more fully acknowledge and respond to the perspectives and needs of family caregivers. Health care professionals should raise questions in their practice regarding the involvement of caregivers in planning care in order to assess the appropriateness of patterns of responding.

### 5.9.2 Understanding of the process of Cognitive Interpretation of Self-perceived Control

Analysis of study data showed that ways of seeking support among Chinese family caregivers in Hong Kong are very much influenced by the caregiving situation, the cognitive interpretation of the self-control process and Confucian-based traditional Chinese values. The experience of Chinese family caring analyzed in this study expands understanding of caregiving characteristics, beliefs, and perceptions which both interfere with and develop caregiving that promotes coping skills, self-control techniques and the use of adaptive resources.

Although the women were moderately acculturated, indications of being in transition were evident. Analysis of interview data led to development of a substantive theory of caregiving reflecting the paradox of living and caregiving by a set of standards and worldviews. The primary strategies used to manage the caregiving challenges are influenced by individual’s cognitive interpretation and his own cultural values. Through personal growth and finding meaning, the caregivers integrated the caregiver role into their lives and became more connected with their families and with their communities.

### 5.9.3 Five Stages of the AdaptationTheory of Regaining Self-perceived Control

The theory presented in this study provides a model of the interface of the physical, psychological and social functioning of family caregivers. It is through the joint effort of a multidisciplinary team that the framework is able to explain and analyze the rehabilitation progress from the perspectives of individual specialisms.

The development of an Adaptation Theory is a starting point for further research on control and coping; it also provides direction for practice. The process of caregivers' ability to exercise control can be understood by examining five critical sequential stages that family caregivers described as a means of regaining self-perceived control: uncertainty, disruption, accommodation, balance and reconciliation. In the first stage, the caregivers strive to maintain control over their lives. In the second stage, they struggle with a perceived loss of self-control. In the third stage, they begin the struggle to re-establish a sense of self-control over their lives. In the fourth, they take increasing control over their lives. In the fifth and final stage, they are able to meet new challenges and anticipate future demands. An Adaptation Theory of Regaining Self-perceived Control emerged inductively from the data in Level III of selective coding to describe the structure, context, interactions and process in these five stages. Although caring strategies were found to vary, all were influenced by Chinese family caregivers' common Confucian ethical values and customs. The present researcher believes that the theory developed in this study will provide initial understanding of the Chinese conception of caring through family adaptation and guide further development of family caring aspects in nursing practice.

Most program planning and research on case management and service integration has been framed within the perspectives of professionals, program providers or system managers. This qualitative study focused on the perspectives of family caregivers of stroke-impaired elderly relatives, a client group that typically has complex and long-term needs, placing them "at risk" for discontinuity of care at home. According to the participants, the caregiver's process of Regaining Self-perceived Control is influenced by these five variables. Although faced with overwhelming obstacles and irreversible changes in their own lives, no caregiver in this study sought to relinquish their role as primary caregiver.

Given the findings of this study, it is important to realize that available services in the community are not necessarily appropriate and acceptable for meeting family caregivers’ needs. The terms acceptable and appropriate infer that a particular service or assistance is offered in a manner that is congruent with the ethocultural values of a target population, from the perspective of the population receiving the service or assistance. Culturally acceptable resources and options of assisting family caregivers should be brought to the attention of policy makers. Policies formulated from identified needs must be acceptable within the cultural framework such as the Adaptation Framework developed in this study.

### 5.9.4 Typology of Properties of Regaining Self-perceived Control

It was found that the 15 family caregivers in this study strive to regain a sense of self-control which was influenced by two key properties (a) the individual’s motivation to seek support in the Chinese cultural context, and (b) recognition of support networks. Their beliefs, personalities and interface transactions were central to their motivation to seek support to continue to sustain caring in the family. The family caregivers used a number of strategies in the adaptation process to regain a sense of self-perceived control. These included learning to trust their abilities to predict life outcomes, learning to trust their abilities to make informed decisions, learning to trust their abilities to act on decisions, and learning to trust their abilities to manage care and cope with stress. All these caring strategies influenced family caregivers whether to anticipate their increased in family involvement, family integration and participation in decision-making. It was found that family caregivers adopted different strategies as their caring outcomes to regain a sense of personal perceived control. These caring strategies manifested commonalties and differences among four types of family caregivers with reference to the typology of properties. The four types of family caregivers were the satisfied, committed, martyred and victimized types. Satisfied and committed caregivers progress smoothly through the five stages of adjustment in the process of Regaining Self-perceived Control. The opposite is the case for martyred and victimized caregivers, particularly those who are older and female.

### 5.9.5 Family Caring in a Chinese Context

Cultural beliefs give meaning to the experiences of health and illness by providing the individual with culturally acceptable causes for illness, rules for symptoms expression, interactional norms, help-seeking strategies, and determining desired outcomes. The goal of culturally sensitive care can only be achieved through conscious effort to gain knowledge of the family caregivers' processing and response patterns as they struggle to regain self-control. Understanding their problems in this respect is relevant to both the open and closed response systems since it intervenes in specific self-control techniques. The Chinese ethos of caring and sharing still penetrates many aspects of the lives of the people in Hong Kong and must be upheld. What clearly stand out in this study are the different types of self-control processes among Chinese caregivers and how they influence caregivers' caring strategies. These strategies in turn affect caregivers' quality of life.

Hong Kong's ageing population has resulted in a greater need for public funding to care and support the elderly. The failure of the government to introduce any compulsory retirement protection system in the past has led to a higher percentage of the elderly today finding themselves in poverty and requiring public financial support. The diminishing function of the family in providing care, as well as the weakening of the value of filial piety, are other factors that have given rise to a greater demand for support services from the public sector. However, it would be a big mistake to assume that the care of the elderly is no longer the responsibility of the family. It may simply be that the form and extent of care provided for the elderly are not the same as before. It is important for the government in Hong Kong to provide support to the family so that it is able to continue to perform its traditional role.

### 5.9.6 Gender and Age Differences of Family Caring

The findings show that the older female family caregivers of this study experienced more health damage as a result of the caregiving role. They are less skilled in seeking support than younger family caregivers due to their folk beliefs and traditional values in respect of role responsibilities. Male and younger caregivers in this study demonstrated better knowledge of what was happening both initially and over time. By contrast, older female caregivers did not correctly understand treatment intent, and avoided or refused to seek support, resulting in damage to their own health. Male and younger female caregivers also adapted and regained self-control more effectively and manifested fewer negative emotional symptoms than the older female caregivers in this study. Older female spouses participating in caregiving in the home need interventions directed at enhancing experiential self-control in order to enable them to be open and accepting of their emotional reactions.

The findings emphasize the relevance of gender and age to caring. Recent research on stress responses has also introduced gender as an important factor in generating differing responses. The 5 men who participated in this study were primarily spouses and differences were found between male and female spouses in the caregiving role. The experience of Chinese male caregivers has been underrepresented in the caring and caregiving literature. This study involved more female than male caregivers and this may reflect the fact that in the elderly population of Hong Kong, there are more females are more than males as life expectancy is greater for females. Along with spousal caregivers, this study involved adult daughters caring for aged parents. Adult sons did not undertake a primary caring role in the main, but did provide secondary support within the extended family network. The results of the study may be applied to nursing interventions for spouse caregivers with possible differing approaches, for female and male caregivers and also for older and younger caregivers. Recognition and support for family caregivers who are heavily involved in caring activities from the outset should be a priority.

There should be increased flexibility in health care providers' responses to participants' needs. Firstly, both the patients and their caregivers should be included as service recipients. For example, pre-discharge educational courses could be organized for caregivers to prepare them for the caregiving role. It is the government's responsibility to facilitate proper community care in a realistic way. More formal community service is required to improve the informal care network function. Resource constraints are a concern but it would be worth trying to supplement the existing community care service since it is under great demand.

Clarifying and understanding differences in perceptions of self-control process and preferred options between family caregivers and health care professionals on caregiving decision-making would not only improve communication and interaction between both groups, but also allow both groups to become full participants in current policy and practice debates on providing support for care in the community.

## 5.10 End of caring at home: Potential for institutionalization

Four older female family caregivers and one of the daughters in this study were considering seeking information about old age homes because of their own health problems resulting from providing care. The elderly spousal caregivers in this study were more likely than the daughters to report serious health problems. High blood pressure, ulcer, insomnia, and angina were the common illnesses mentioned by all the interviewed family caregivers. One of the husbands, for example, felt unable to continue looking after his wife following heart bypass operation and as a result had to use the home care service in assisting household tasks.

The majority of the family caregivers in this study were over 65 years old. Age by implication also becomes a significant factor in the provision of care. Elderly family caregivers aged over 65 years represent a considerable resource for providing care, and more than 75 per cent of the care in this study was provided by elderly spouses. These caregivers are typical of the way many elderly Chinese people strive to assert their endurance and independence for as long as possible. Three female spousal caregivers in their seventies either refused or avoided seeking support from their children when they encountered difficulties and felt themselves to be under pressure at the beginning of their caring responsibilities. Unlike the younger female daughter caregivers, older female caregivers did not dwell on the way caring had impacted on their social lives. They appeared to view many of the restrictions they faced as unexceptional and little different from other limitations of old age. They had learned to accept the disabilities and illnesses of their relatives and the resultant changes to their lives in a different way from other younger female and older male caregivers. Older female caregivers in this study reported inadequate coping capacity and desired improved time management skills that would enable them to spend more time with their family and to pursue personal interests without relinquishing caregiving responsibilities.

Three key factors appear to determine whether care-for-persons continue to live at home or not. These are: the stroke relative's stage of the recovery, the availability of a family caregiver at home, the availability of support needed at home and the services provided by the community. After years of providing caring at home, the martyred and victimized family caregivers in this study were so stressed that they found it difficult to comprehend what was being explained either about home support care services or other options. Being frail and in their seventies, they were particularly likely to be overwhelmed by the long, never ending caring. At this point, caregivers were found to consider institutionalizing their stroke-impaired relatives in a home for the aged.

There were discussions within the family about the stroke-impaired relative remaining at home or entering a care and attention home when either the caregivers or the cared-for-person's health was deteriorating. Data analysis showed that there are four key factors which family caregivers consider in deciding if their relatives should continue living at home or not. These are: the relative's stage of recovery, the availability of a family caregiver at home, the amount of support needed at home and the support services provided by community.

## 5.11 The Impact of Caregiving on Psychological Health

The affective and emotional attitudes that influence the continuation of family caring were found significant in this study. The emotional and psychological aspects of ethical dilemmas included difficulty in performing increased demands of caregiving tasks and the stress related to decision-making especially in moral aspects. Moral distress or compromise occurred when family caregivers knew that it was the right thing to seek extra-familial help, but other alternatives such as institutional care, or other constraints such as cost, made it difficult to pursue a desired course of action. The findings of this study show that the perceived available support network was strongly related to the well-being of caregivers in the process of regaining a sense of personal control.

In this study, it has also been found that all the 15 family caregivers exhibited negative emotions including emotional crisis, physical discomfort, guilty feelings, anxiety, social isolation, depression, hopelessness, and financial hardship correlated with the patterns of support seeking. This has been interpreted that those negative emotions could be alleviated by reducing the adverse effects of excessive mental state control motivation in eight of caregivers' (Nos. 1, 3, 4, 5, 7, 8, 10, and 11) in this study. They used the cognitive closed reactions as a defence mechanism to redress negative or adverse stimuli such as guilt and power disadvantage. Caregiving activities, caregiving characteristics and caregiving factors accounted for experiences of family caregivers. The caregiving experiences varied according to the different stages of the adaptation process.

The responses from those negative experiences including avoidance of and self-limited of seeking support inhibit the caregivers’ to accept the self-control opportunity. The notion of unresolved loss involves the failure to integrate representations of self of the caregivers following a loss of personal control. The features of unresolved loss can be understood as emerging as a result of the activation of unintegrated representations of the loss experience and cognitive and behavioural avoidance processes. One of the objectives of this study is to identify the existing patterns of caregiving in the caring process and how the process is influenced by critical elements in personal situations. It is hoped that this will provide a new perspective for understanding the meaning of family caring. One concept from evolutionary theory, regaining of self-control, provides a broad framework for understanding patterns of behaviours in family caregiving. The experience of regaining of self-control is related to how caregivers managed or coped with their caregiving situations. The dimensions of control were characterized as either "maintaining control" or as "lacking control" with each dimension relating to caregivers' beliefs about caregiving. Interactions that occurred to regain self-control included monitoring changes, accepting responsibility, negotiating tasks, appraising support, responding to family relationship issues, struggling with the health care system and anticipating future.

This study found that the community support services for Chinese family caregivers of stroke-impaired relatives are desperately insufficient. Consequently, either the elderly patient or the family caregivers may become victims. Wives (older caregivers) in the Chinese community who cared for patients were far less likely to seek help than daughters. Wives had a particularly heavy burden of care and yet were the least likely to receive support services. Family caregivers of martyred and victimized in this study had reached the point of being unable to cope either physically or emotionally with the stroke-impaired relative’s need for continual support. One of the most stressful events is generally acknowledged to be the time when the patient is discharged from hospital to home, without any support being given by health care providers. Such a move is likely to be traumatic for both the caregiver and the patient. As the caregiver lacks knowledge about caregiving, one cause of the trauma is a fear of the unknown. These findings are supported by Fiske, Morling and Stevens (1996). Therefore, it is particularly important to develop effective and appropriate hospital discharge programmes to provide support and follow up between health authorities and community health services. It is problematic to arrange for appropriate care when people need intensive personal attention. Care assistants were found to come either very late in the morning or very early in the evening to assist the patient in getting up or going to bed. The findings make it clear that when this kind of support was not available at appropriate times, this was itself another source of stress. Many of the family caregivers concerned felt that they had been pressured into moving their relative out of the hospital too early. The experience of Chinese family caregiving in this study also included the caregiver's perceptions of the relationships with the patient and health care providers. The inadequate education of health care professionals is also confirmed as an issue in family caregiving.

Considerations that affected decisions about obligation in caregiving include comorbid conditions, hesitancy about seeking extra help, and reluctance to share problems with others. Nurses and other health care providers can use this information in assessments and in planning individualized interventions that include family caregivers as active participants in managing caregiving. To offer better support for family caregivers, nurses must appropriately assess their needs in caregiving. This knowledge will enable nurses to assist family caregivers provide more effective care and conserve their own resources.

## 5.12 Intra and Extra-Familial Support for Family Caregivers

Some of the family caregivers in this study had reached the point of being unable to cope either physically or emotionally with the cared-for-person's need for continual support. It was during this period that the caregiver's health was most vulnerable. One of the most stressful events is generally acknowledged to be the time when the patient is discharged from hospital to go home, without any support being given by health care providers. Such a move is likely to be traumatic for both the caregiver and the patient. As caregivers tend not to be knowledgeable about caregiving, one cause of the trauma was a fear of the unknown. Therefore, it is particularly important to develop effective and appropriate hospital discharge programmes to provide support and follow-up from health authorities and community health services.

Hong Kong's ageing population calls for increases in public funding to care for and support the elderly. The failure of the government to introduce any compulsory retirement protection system until recently has led to a higher percentage of the elderly today finding themselves in poverty and requiring public financial support. The diminishing capacity of the family to provide care and the weakening of the value of filial piety are other factors that have given rise to a greater demand for support services from the public sector.

However, it would be a big mistake to assume that the care of the elderly is no longer the responsibility of the family. It may be only that the form and extent family of care provided for the elderly are not the same as before. It is important for the government in Hong Kong to provide support for the family so that it is able to continue to perform its traditional role.

The results suggest that family caregivers need more factual information relevant to the patient's condition and that communication of information is critical if he or she is to be satisfied. The health care professionals should therefore not only try to identify informational needs, but should also be qualified to meet them in the best possible way. In addition, the rates of anxiety and depression observed highlight the need for a more thorough evaluation and management of caregivers' psychological morbidity in the home setting.

The results of this study also show that nurses should be aware of the consequences, personal meanings, and strategies involved in caregiving in order to be able to offer appropriate interventions that optimally meet caregivers’ needs. Understanding more about styles of coping will help to identify profiles of family caregivers who are in need of education and in matching individually tailored interventions to family caregivers with specific learning needs.  The study findings show that experienced, satisfied and committed caregivers also needed legal and financial information, as well as support, and not just the martyred and victimized ones. It is also the case that female caregivers rated caregiving needs related to support as significantly more important than male caregivers. Nurses should realize that caregivers may have different information and support needs and that these needs may change throughout the caregiving experience. Health care professionals should assist families in determining for themselves the difficulties and hardships they face as a direct result of the providing care and whether they confront challenges in a manner that fosters positive long-term outcomes. The findings of this study suggest that a positive outlook in the caring role is positively associated with perceived caring outcomes and health status. This suggests the need for nursing interventions to assist caregivers to cope with their transitional roles in the caring process.

The study data reveals that in providing care for their family members, Hong Kong Chinese subjects are very much influenced by traditional Chinese values, which discussed earlier. In addition, one outcome of this analysis is the identification of 38 categories of caregiving experiences that were pertinent to the experiences of family members caring for stroke-impaired elderly relatives. The meanings formulated from one central concept of

Regaining Self-perceived Control with 8 subcategories of key elements clustered into two key properties of motivation of seeking support and recognition of available support network. It was found that issues of culture, tradition, and religion influenced these situations. It may be claimed that the findings of this study contribute significantly to a new understanding and appreciation of the cultural issues and caring values that are unique to Hong Kong Chinese family caregivers of stroke-impaired elderly relatives.

## 5.13 Study Approach

The study adopted a two-interview qualitative research design using grounded theory approach to discover and explore the meanings and processes undergone by family caregivers in a Chinese context (Lee, 2004). The strength of qualitative approaches lies in their capacity to generate rich data regarding the family’s subjective experience, increasing understanding of family motivations and behaviours within stressful situations. Constant comparison method (Glaser, 1978, 1992; Strauss & Corbin, 1998) was used to collect and analyze the data concurrently. The meaning of caring grounded in the Chinese context emerged from the study data rather than being preconceived by the researcher. The researcher of this study investigated the caring experiences by interviewing family caregivers and obtaining a description of their caring experiences in the first phase of this study. The grounded theory approach is particularly appropriate for describing processes or patterns, as it allows for the adaptability that is required for understanding the course of experience of illness. A theory derived from data is more likely to resemble ‘reality’ than a theory derived by putting together a series of concepts based on experience or solely on speculation about caregivers’ regaining of self-perceived control from the initial phase of this study.

## 5.14 Discussion

Physicians and other health care professionals should be aware of the important relationship between the health statuses of caregiver and cared-for-person. Family-centered policies and services that explicitly consider caregiver health are likely to benefit the well-being of both caregivers and their families. Future work should address the extent to which the family-centeredness of services, as experienced by caregivers, is associated with better health outcomes for parents and their families.

Informal caregivers, particularly women, are under considerable stress to provide a large volume of care with little support from formal caregivers. Program planners, policy makers, and formal care providers must act together to provide accessible, affordable, and innovative support services and programs that reduce family caregiving strain.

van den Heuvel, de Witte, Schure, Sanderman and Meyboom-de Jong (2001) found that caregivers with high perceived self-efficacy, satisfied with social support, and who made frequent use of coping strategies, experience less strain, greater mental well-being and greater physical vitality. Duration of the caregiving role appears not to influence caregivers' strain, mental well-being or vitality. Women, younger caregivers, caregivers in poor physical health, and caregivers of patients with severe changes are at risk of burn-out. Support programmes should focus on self-efficacy, social support, and the coping strategy confronting. No specific moment could be identified at which support programmes should be offered.

For those successful coping situations, families reported that they became empowered after the onset of their members' brain injury. They expressed possible factors leading to better adjustment, which included setting clear personal expectations, the flexibility to adjust life goals, a desire to master the situation, strong motivation, awareness of their own powerless state and willingness to ask for help from different sources. The results indicated that families cope with a brain-injured member differently, depending on the family's structure, and this should be explored further for the development of intervention guidelines.

As previously mentioned, many research studies have identified skill attainment needs and difficulties associated with the tasks required by family caregivers in Western rather than Asian societies. This lack of a culture specific measure motivated to address the unique needs of  Chinese family caregivers as a critical focus for research, as well as an a critical factor for policy makers. Identifying major priority areas to be addressed and determining which caregiving tasks are perceived as most difficult and time-consuming, and which of these predict negative outcomes, provides a starting point from which interventions in the practice setting can begin.

The Adaptation Theory of Regaining Self-perceived Control predicts caregivers' perceptions and responses to changes related to social functioning, subjective well-being, and physical health as a result of providing care. These results are guided by goal of regaining self-perceived control identified by (Lee,2004), which explains emotional distress,  stroke-specific outcomes, and in general health perceptions. In this study, the development of self-perceived control was the predictor of negative outcomes.

## 5.15 Implications for Practice

Various types of response tendencies may exist in different cultural groups. A number of systematic patterns are discernible in the responses to questionnaires made by members of various cultural or linguistic groups (Hayes & Baker, 1998). Chinese, in general, manifest strong social desirability traits in responding to questionnaires and tend to endorse milder to more subtle forms of expression than the stronger forms of expression used by Westerners (Cheung & Bagley, 1998; Devins, Beiser, Dion, Pelletier & Edwards, 1997, Iwata et al., 1998). Traditionally Chinese believe that it is inappropriate to express feelings in public (Howard & Berbiglia, 1997).

The traditional Chinese conception of caregiving and support strategies adopted by Chinese family caregivers presented in this chapter have given the impression that the Chinese, by and large, are relatively self-sufficient in terms of social support. Even those with weak support networks can still rely on latent kinship support networks for assistance during emergencies. Indeed, kinship support networks have provided a reliable and resourceful safety net for the Chinese and have enabled them to feel secure and contented even during times of adversity and life crises. It can be asserted that that the Chinese have been able to proceed smoothly through their respective life courses with confidence and courage largely because of the strong support provided by their mutual support networks.

## 5.16 Summary of Chapter Five

Findings from this study indicate that personal control, fortitude, and social support empower caregivers and impact on their preference for home care, whereas demand for informal user fees and perceived low quality of care influenced caregivers to avoid institutional care.

In conclusion, findings from this study suggest that perceived self-control, rather than pressure and depression, may be a particularly potent variable in monitoring family caregivers of relatives with stroke-impairment. In addition, the availability of practical help and gender-related needs of family caregivers may deserve special attention when considering the factors that may improve the caregiver’s ability to cope.

Finally, the stress response that results from striving to balance caring demands and caregiver needs is illustrated. Developing a theory for this caregiving population is the first step in assisting nurses to identify factors that place caregivers of stroke elderly relatives at risk for negative consequences, and to design interventions to improve caregiver health.

It has shown that there is a correlation between self-perceived control and self-control skills. However, the solution found in the Chinese participants was similar to the hypothesized five-dimensional structure presented by Lee (2004) and Lee, Mok and Wong (2004). This study provides further evidence of the cultural influences on participant responses. The findings of this study suggest that self-control skills among Chinese participants involve a multi-dimensional aspect.

Family caregivers of stroke survivors are at risk for negative health outcomes such as depression, psychosocial impairments, and even mortality as a result of providing care. Shortened hospital stays have contributed to the urgent need for caregivers to manage difficult and time-consuming tasks required for the care of stroke survivors in the home setting.

Developing an Adaptation Theory of Regaining Self-perceived Control may help to target individual support interventions for caregivers. Suggested interventions include referring caregivers to resources for tasks that fall outside the scope of nursing practice, supporting caregivers with tasks such as providing emotional support or managing behavioural problems, and encouraging caregivers to seek support for their own physical, emotional, or social needs. This study set out to contribute significantly to the understanding of cultural issues and caring values that are unique to Hong Kong Chinese family caregivers of stroke-impaired elderly relatives. It will provide a basis for devising adequate interventions and resources to assist caregivers. Nurses and other health care providers can use this information in assessments and in planning individualized interventions that include family caregivers as active participants in managing caregiving. Of prime importance in meeting the complex issues of caregiving management is a client-provider relationship that permits open communication.

# CHAPTER SIX

# RECOMMENDATIONS AND CONCLUSION

This chapter will summarize the findings presented in the preceding chapters by answering the broad research question posed in Chapter one and discussing the extent to which objectives have been achieved. Limitations of the study will discussed as well as recommendations for practice and for further research.

## 6.1 Introduction

A broad research question was explored in the course of the study. The research question is, "What is the experience of caregivers of stroke-impaired elderly relatives in Hong Kong"? In addition, four objectives were set and addressed. These are: (a) to identify the different characteristics, care issues, coping strategies, coping resources, caring tasks and perceived burdens of Chinese family caregivers; (b) to identify the existing patterns of caregiving in the caring process among Chinese family caregivers and how the process is influenced by critical elements of their personal situation; (c) to develop a theory which describes how events and predisposing factors can be interpreted and their influences on caring outcomes can be appraised; and (d) to initiate the development of a substantive theory that describes how Chinese family caregivers experience caring for their stroke-impaired elderly relatives.

## 6.2 Limitations of the Study

This study is limited in several respects. Some limitations relate to sampling bias, while others are related to the collection and analysis of data. There are many challenges in conducting longitudinal studies, including attrition and difficulty obtaining interviews at scheduled times. The multiple roles involved in caregiving as well as other roles of spouse, parent, and employee may contribute to this problem. Caregivers were often too busy in their caregiving role to be interviewed, and interviews were frequently rescheduled several times, leading to variability in the interview times.

The first limitation relates to the stage framework. The five stages should not be taken as real points in time through which all newly caregivers must pass. These stages should also not be seen as a simple, rigid and linear process. While adaptation to rehabilitation care is a process that occurs over time, caregiver responses can be varied and therefore it is not advisable to assign fixed periods of time to complete this process.

The second limitation relates to sampling. The theoretical sampling process is a combination of researcher choices, but also self-selection in relation to who is available for interview, who has the time, and who is willing to invest energy in the process. The resulting sample may reflect participants who are similar in terms of interests and ethics, or who have a stake in this field of practice. The sample then will not reflect the general population. Those individuals who chose not to participate because of scheduling problems may have had a different perspective to offer that is not represented in the findings. Thus, the findings of this study are limited to the characteristics of interviewed family caregivers. Over eighty percent of the study participants were over 60 years old and were spousal caregivers. Most interviews were held at the stroke-impaired relative's house to facilitate caregivers carrying out their work.  Sometimes, the stroke-impaired elderly relatives or other family members were there or arrived when the interview was in progress. Some caregivers stopped expressing complaints at this point to avoid offending their relatives. This might interfere with the reliability of the participants' reports although member checks were carried out to establish trustworthiness of the data.

Major research themes and categories were well-defined and saturated before the end of the data collection process. Determining saturation of the categories, when nothing new seems to appear, is not easy. Morse’s (1994) suggestion that data collection should end when there is enough data to build a convincing theory has the merit of rigor. However, as Strauss and Corbin (1990; 1998) note, total saturation is not possible, nor is it necessary.

All the data collection and analysis is the work of the present researcher although peer debriefing was aided by experts and her supervisor’s input is included in the data analysis. Interpretation of the data, the labelling of categories and the process of analysis were all done through personal perceptual filter of the researcher. Therefore, the interpretation is based on one individual’s interpretation of the “experience” of the respondents. All parts of the data collection process and the subsequent analysis could therefore be subject to a degree of subjective interpretation because of this limitation.

Despite these limitations, this study makes important contributions in exploring the experience of family caring of stroke-impaired elderly relatives in a Chinese context.

## 6.3 Implications for Practice in the Chinese Context

By fostering emotional support and helping family caregivers re-integrate into the community by maintaining their social contacts, the advantages of a family orientation in rehabilitation have been established. Findings from this research reveal that family caregivers dedicate an enormous portion of their lives to caring for their stroke-impaired family members. They experience their own form of suffering and negative health outcomes. In this study, wives (older caregivers) in the Chinese community who cared for stroke-impaired elderly relatives were far less likely to seek help than daughter caregivers. Wives (older caregivers) had a particularly heavy burden of care and yet were the least likely to ask for support services. This relates to the closed self-control strategies of the cognitive response system of these caregivers. Caregivers must let go of mental control and be genuinely open to their present experience through the use of experiential self-control skills. Some of the family caregivers in this study had reached the point of being unable to cope either physically or emotionally with the relative's need for continual support. It was during this period that the caregiver's health was most vulnerable.

One of the clear implications emerging from the study's findings is the need for a partnership between health care professionals and the families providing care. Results of this study can help nurses intervene more effectively with family caregivers by recognizing how caregivers manage and whether they need assistance to continue to provide care. The proposed Theory is a starting point for further research on control and caring; it also provides direction for practice. This finding in detail of analysis has provided direction for clinical application in counselling the spouses of stroke-impairment relatives or to manage the stress of their new life role.

Understanding Chinese culture and its association with health care practices helps nurses to establish culturally sensitive nursing interventions, develop appropriate discharge plans, reduce family stress, reduce future medical hospitalization costs, increase positive coping, and family function, and improve health outcomes of the stroke victim and the family caregiver. The development of culturally sensitive care also helps to avoid misunderstanding and frustration between professionals and family caregivers. There is a clear need for more education, advice and support for families affected by stroke. Community services in developing countries should consider training existing domiciliary outreach services, community-based multi-purpose health workers, to identify and support family caregivers.

These findings suggest the need for nurses to educate caregivers to use effective self-control techniques and to assess for variables that may influence caring strategies and caring outcomes. Nurses have a major role to play in preparing caregivers, but currently lack a systematic approach to assessment and intervention. Further empirical work is required to establish more clearly the needs of new caregivers and to develop and evaluate appropriate intervention strategies to address their needs. The present research summarizes culturally specific ways in which health professionals working with Chinese families involved in long-term care can target assessment and interventions before the onset of physical and emotional deterioration.

This study has considered the nurse's role in assisting family care when this is demanded suddenly following an acute health crisis. Family caregivers of stroke-impaired elderly relatives are used in this study as a 'paradigm' case to highlight the challenges faced by family members at the time of hospital discharge. The needs of family members who suddenly adopt a caring role are poorly understood, but greater awareness is needed as family caregivers have statutory rights to an assessment of their needs.  Evidence suggests that new family caregivers are currently poorly prepared to take on their role, and lack the information and skills needed to provide effective care. Further empirical work is required to establish more clearly the needs of new caregivers and to develop and evaluate appropriate intervention strategies to address their needs.

Many studies have shown that health practitioners and policy makers in many developed nations have adopted highly technical medical approaches for ageing societies and have ignored non-technical interventions such as those related to interaction and maintaining quality of life. Highly technical medical approaches do not respond fully to the needs of ageing populations. All ageing societies will need to consider medical approaches when necessary, but social policies for the elderly will need to be safeguarded. Thus, a more balanced approach is preferred. The results of this study clarify the various types of coping responses and self-control behaviours of Chinese family caregivers of chronic illness and illustrate the important influence that culture has upon such activities. This exploration of the self-control behaviours can be used to inform and enable nurses to adjust their practices to relate more appropriately to the perspectives of Chinese patients and their family members.

It is important that health professionals adopt a family perspective. Nurses are particularly suited to assist the spouses who are usually elderly during the stroke-impaired relative's initial recovery period. Acknowledging the overwhelming stress placed upon the caregivers, directing the caregivers to support programs and identifying the special needs of the caregivers should all be included in the initial discharge care plan. This study also recognizes the integration between cognitive and behavioural reactions in the open and closed response systems of the caregivers' self-control processes. Whether caregivers' are open to experience or closed to it, this integration constitutes an essential part of human functioning.  Open and closed response systems are the result of complicated adjustments and adaptations to the process of family caring.

Considerations that affected decisions about obligation in caregiving include comorbid conditions, hesitancy about seeking extra help, and reluctance to share problems with others.  Nurses and other health care providers can use this information in assessments and in planning individualized interventions that include family caregivers as active participants in managing caregiving. To offer better support for family caregivers, nurses must appropriately assess their needs in caring, especially their self-control behaviours. This knowledge will enable nurses to assist family caregivers to provide more effective care and conserve their own resources.

## 6.4 Recommendations for Further Research

This study can serve as the basis for further research in several directions. Firstly, the research recognizes the effect of the stages of the illness trajectory on the variation in perceived caregivers' needs for identifying the needs of caregivers of stroke-impaired elderly relatives. Examples of some major theoretical statements that arose from the Theory of Regaining Self-perceived Control and warrant further investigation are:

1. Caring experience and responses are influenced by caregivers' self-perceived control processes including the self-efficacy and open and closed response systems which represent the dialectic nature of human beings' interaction with their social and physical environment.

2. The ultimate goal of the stages in the Regaining Self-perceived Control is to regain self-control by overcoming self-generated impediments. This involves those caring strategies of the adaptation process.

3. Caregivers' characteristics (age, gender, personality) and other caregiving factors (variables) (task difficulty and functional level of cared-for-person),

particularly caregivers’ cognitive and behavioural reframing, affect the social process of Regaining Self-perceived Control.

4. In caregivers who have negative cognitive interpretation by avoiding specific negative emotional stimuli because they are afraid of being overwhelmed by negative emotions when confronting these stimuli, the mental state control motivation is usually stronger than the task state control motivation and their abilities to reduce adverse effects in the goal of Regaining Self-perceived Control are consequently impaired.

5. In caregivers whose prime motivation is to seek support is likely to have control motivation and their abilities to reduce adverse effects in the adaptation process of regaining self-perceived control are consequently enhanced.

6. If caregivers reduce the adverse effects of regaining self-perceived control, they must let go of mental control and be genuinely open to their present experience through the use of experiential self-control skills.  In this way, the process of Regaining Self-perceived Control is promoted.

Secondly, this study has attempted to address the gap in the literature by developing a substantive theory about the adaptation process through caring Chinese family caregivers using self-control techniques. The similarities and differences with respect to how Chinese and Western family caregivers cope with the various aspects of stroke care have been identified. Building on the evidence from this study, further research that takes into consideration the recognition of caregivers' cognitive interpretations and responses to the process of regaining a sense of personal control in different ethnic groups should be conducted. Indeed, this study has opened a promising avenue for further comparative studies of caregivers' cognitive interpretations and responses in the experience of family caring.

Thirdly, future research should build on linking the self-control process with the caregivers' cognitive and motivational mechanisms in order to develop a comprehensive understanding of the family caring phenomenon. By doing this, the effectiveness of any intervention in promoting self-perceived control can be evaluated appropriately by health professionals. Another important aspect to note is that the adaptation process revealed in this study is described by the caregivers as a "family journey". The perceptions of the stroke-impaired relatives and their influence on the adaptation process have not been identified in the Chinese context. Family-related research, including the long-term effects of such experiences on younger caregivers and their families is recommended. These are all relevant areas for future investigation.

Lastly, the Adaptation Theory of Regaining Self-perceived Control developed in this study has possible relevance for studying caregivers of other chronic illnesses of the elderly such as Alzheimer’s and Parkinson’s diseases. It could also be used in other areas where caregivers have to adapt to a new transitional role such as new parenthood and this will result in the wider application of a general formal theory of adaptation.

## 6.5 Conclusion

It is hoped that the findings of this study will advance current nursing care, including the devising of specific patterns of care by professional nurses to accommodate the cultural preferences of Chinese families in Hong Kong. This study has built upon existing knowledge on providing culture-specific care. Relatively little is known about the ways by which home care workers are incorporated into family households and how families and home care workers view the caring process in the Chinese context.  Close collaboration with family caregivers is considered an important indicator of high-quality nursing care.  Nurses should seek the family caregiver’s view of the possibilities of their participating in planning and decision-making, and find the most effective ways of participating in nursing care. Modes of family-centered nursing care are to be implemented and staff trained to allow more family involvement. A deeper understanding of the implications of different cultural contexts and different welfare regimes were identified as essential elements in intergenerational family solidarity, conflict, and ambivalence. This has implications for nursing practice in Hong Kong, which is influenced by western practice. It is recommended that the professional nursing role in Hong Kong be expanded to include postdischarge care, respite, and home-care services in order to allow families to keep their elderly at home as long as possible. It is also essential to provide culturally sensitive care to families that might be traumatized by having to violate ethnic Chinese cultural norms by institutionalizing elderly family members.

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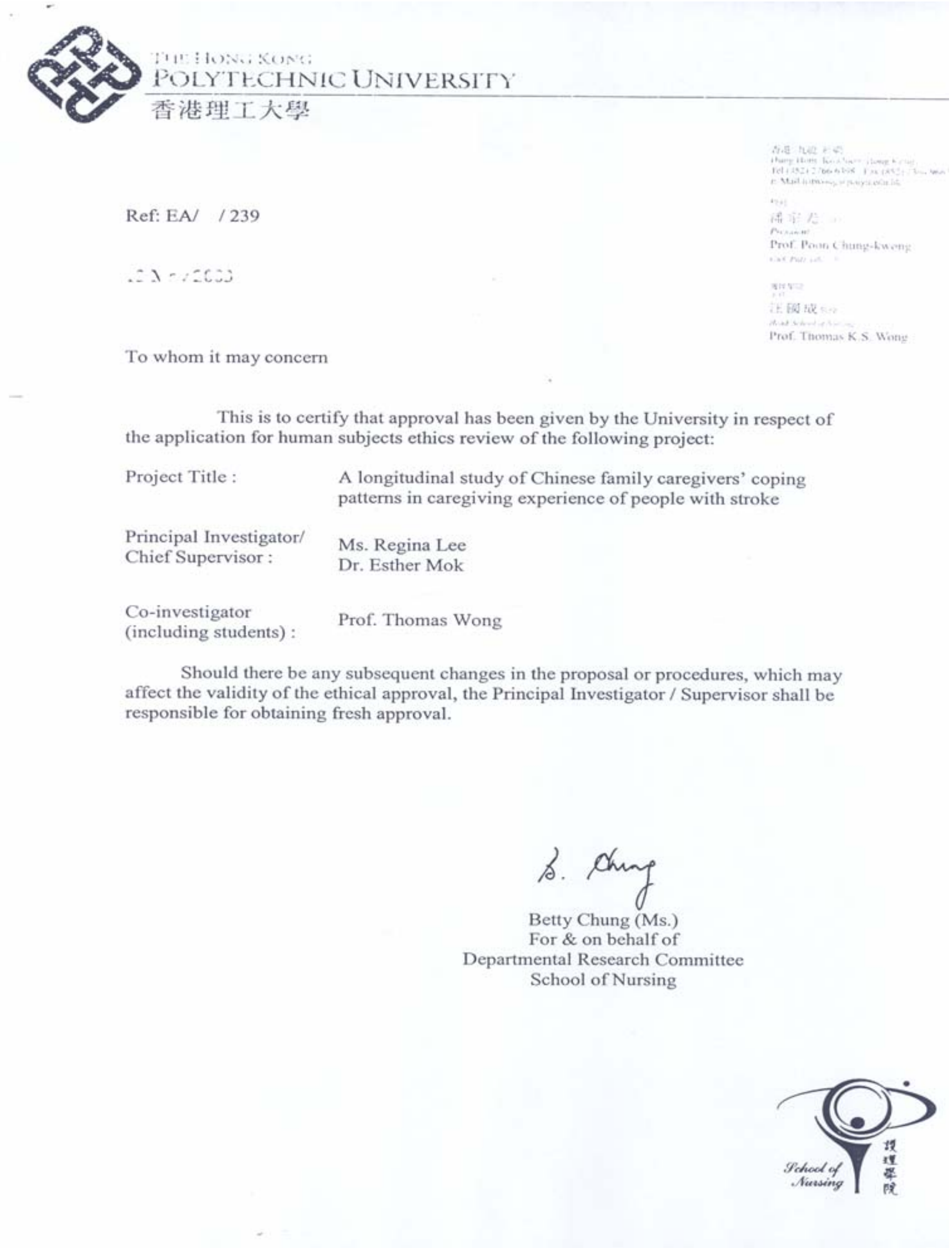
# Appendix I- Ethics Approval Letter



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

潘宗光
President
Prof. Poon Chung-kwong

汪國成
Head School of Nursing
Prof. Thomas K.S. Wong

Ref: EA/ / 239

12 Nov 2003

To whom it may concern

This is to certify that approval has been given by the University in respect of the application for human subjects ethics review of the following project:

| | |
|---|---|
| Project Title : | A longitudinal study of Chinese family caregivers' coping patterns in caregiving experience of people with stroke |
| Principal Investigator/<br>Chief Supervisor : | Ms. Regina Lee<br>Dr. Esther Mok |
| Co-investigator (including students) : | Prof. Thomas Wong |

Should there be any subsequent changes in the proposal or procedures, which may affect the validity of the ethical approval, the Principal Investigator / Supervisor shall be responsible for obtaining fresh approval.

B. Chung

Betty Chung (Ms.)
For & on behalf of
Departmental Research Committee
School of Nursing

School of Nursing
護理學院

# Appendix II- Coding Memo Sheet

| Direct Quote (extract) | Key elements | Subcategories | Category | Interpretation (Essence/theme) |
|---|---|---|---|---|
| | | | | |

# Appendix III- Information Sheet (English)

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

School of Nursing
護理學院

## INFORMATION SHEET

### **“A study of Chinese family caregivers’ caring experiences of stroke-impaired family members”**

You are invited to participate on a study conducted by Ms. Regina Lee, who is a post-graduate student of the School of Nursing in The Hong Kong Polytechnic University.

The aim of this study is understand better the caregiving experience of Chinese family caregivers of people with stroke. The study will involve an interview, which will take you about an hour. It is hoped that this information will help to understand the coping activities and strategies of stroke caregivers in order to provide relevant services and assist them in family caregiving.

The interview should not result in any undue discomfort. All information related to you will remain confidential, and will be identifiable by codes only known to the researcher.

You have every right to withdrawn from the study before or during the measurement without penalty of any kind.  The whole investigation will take about an hour.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Mr. Eric Chan, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Human Resources Office in Room M1303 of the University).

If you would like more information about this study, please contact Ms. Regina Lee on tel. no. 2766 6388 or Dr. Esther Mok on tel. no. 2766 6410.

Thank you for your interest in participating in this study.

Ms. Regina Lee
Principal Investigator

# Appendix IV- Consent Form (English)

## CONSENT TO PARTICIPATE IN RESEARCH

## "A study of Chinese family caregivers' caring experiences of stroke-impaired family members"

I ________________________ hereby consent to participate in the captioned research conducted by Ms. Regina Lee.

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

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

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

Name of participant ________________________

Signature of participant ________________________

Name of Parent or Guardian (if applicable) ________________________

Signature of Parent or Guardian (if applicable) ________________________

**Name of researcher** ________________________

Signature of researcher ________________________

Date ________________________

# Appendix V- Information Sheet (Chinese)

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

School of Nursing
護理學院

## 有關資料

### 一項對本港華人家屬在照顧中風病者時應變之研究

誠邀 閣下參加由李麗棠負責執行的研究計劃。她是香港理工大學護理學院研究生。

這項研究的目的是一項探討華人家庭成員在照顧家中中風長者之應變的研究。研究中所涉及到的談話需要花費 閣下大約一小時。希望這些資料能有助於理解關顧中風者家人的需要, 從而採用更好的應變方法。

這項研究只涉及訪問。凡有關 閣下的資料均會保密, 一切資料的編碼只有研究人員知道。

閣下享有充分的權利在研究開始之前或之後決定退出這項研究, 而不會受到任何對閣下的責任追究。全部過程將需要大約一小時。

如果 閣下有任何對這項研究的不滿, 請隨時與香港理工大學人事倫理委員會秘書親自或寫信聯絡 (地址 : 香港理工大學人力資源辦公室 M1303 室轉交)。

如果 閣下想獲得更多有關這項研究的資料, 請與李麗棠, 電 話 2766 6388 或 莫孫淑冰博士 (研究指導老師) 電 話 2766 6410 聯繫。

# Appendix VI- Consent Form (Chinese)

香港理工大學
護理學院

## 參與研究同意書

### 研究題目: 一項對本港華人家屬在照顧中風病者時應變之研究

本人明白是項研究旨在探討華人家庭成員在照顧家中中風長者的需要。本人願意參與是項研究之問卷調查，並明白在整個研究過程中，本人可以要求刪除任何所提供的資料，及擁有隨時退出的權利。本人的個人資料會作保密處理。如有任何有關是項研究的疑問，本人可以致電李麗棠 2766 6388 或 莫孫淑冰博士 (研究指導老師) 電 話 2766 6410 聯繫。

本人，________________，(參與者)已閱畢/清楚明白上述資料，並對有關之問題已獲得清楚講解。本人願意參與是項研究之問卷調查，亦知道可以隨時退出。本人同意提供予是項研究的資料可能會被刊載在有關的文獻內，唯本人之姓名將不會被透露。

| | |
|---|---|
| ________________<br>參與者姓名 | ________________<br>研究員姓名 |
| ________________<br>參與者簽名 | ________________<br>研究員簽名 |
| ________________<br>日　期 | ________________<br>日　期 |

# Appendix VII- Field Note Sheet

Participant Code #

Interview date: Starting time: Ending time:

Pre-interview goals for interview

Location of interview

People present

Description of environment (including personal belongings. Etc.)

Non-verbal behaviour (e.g. tone of voice, posture, facial expressions, eye movement, forcefulness of speech, body movement, hand gestures)

Content of interview (e.g. use of keywords, topics, focus, exact words or phrases which stand out)

Researcher's impressions (e.g. discomfort of participant with certain topics, emotional responses to people, events or objects)

Analysis (e.g. researcher's questions, tentative hunches, trends in data, emerging patterns)

Technological problems (e.g. lost 5 minutes when tape turned)

# Appendix VIII- Interview Guide

Interviews were conducted face-to-face by using the interview guide with eight open-ended questions as follows:

1. Tell me how you became the family caregiver of your stroke-impaired elderly relative.
2. Please describe your present life in relation to caring for your elderly family member after hospital discharge.
3. Please tell me the routine of a day starting in the very early morning till you go to bed.
4. Are there any difficulties in providing care for your elderly family member after hospital discharge? What are they?
5. What are the things that have changed after the relative came home?
6. What are the things that were different from what you expected before the discharge?
7. Tell me about the community services that you have used during your caregiving.
8. What is the information that you think you need in providing care for the stroke-impaired elderly?

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Social Welfare Department

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本署傳真：[redacted]

香港理工大學
護理及醫療科學系
李麗棠講師

李講師：

有關「本港華人家庭成員在照顧家中中風長者一職上的經驗」研究

跟進與張凱茵同學及鄭慧思小姐於二月五日及三月一日的聯絡，我已發信給最新近登記成爲會員的二十多位護老者(照顧中風長者的家人）。現將沒有提出反對參與有關上述研究的會員資料(包括姓名、年齡、性別與聯絡電話)給你作聯絡用途，合共七位。由於有關資料涉及護老者的個人資料，請小心處理並安排銷毀。

2. 在寄給會員的信中，我已附上有關的「參與研究簡介」讓他們參考。有不少會員反對參與有關研究，有好一些很抗拒被安排與研究人員面談 / 家訪。雖然我已向他們交待大部份聯絡會透過電話進行，但照顧者們仍不願意被訪問。向會員所寄出的信當中不排除有些寄失了，有些照顧者可能確有收信但看不懂有關信內的內容；如有照顧者對其姓名及電話會被理工大學護理及醫療科學系知道而產生懷疑，不滿等，請你們立即向我反映，我會儘快跟進。如有照顧者反映本中心服務不妥善，也請他們可直接聯絡中心以便改善。名單當中亦可能包括患者不幸離世不久的照顧者，他們可能情緒較不穩，在訪問過程中請給與多些時間及情緒支援以讓他們減輕哀傷。

3. 爲幫助中心改善服務和更瞭解照顧者的經驗與需要，中心萬二分期待可以參考有關的研究報告。

4. 如有任何疑問，請與我聯絡：[redacted]。

祝　工作愉快

護老者支援中心主任
（[redacted]）