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THE HONG KONG POLYTECHNIC UNIVERSITY

SCHOOL OF NURSING

A COMMUNITY-BASED

AND

FAMILY-CENTERED CARE APPROACH

FOR STROKE SURVIVORS IN WUHAN CITY OF CHINA

LI SI JIAN

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE

REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

UNDER THE SUPERVISION OF PROFESSOR SAMANTHA PANG

& PROFESSOR THOMAS WONG

OCTOBER, 2005

PART II



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Chapter Six

Multiple Care Issues

Home care problems have been consistently reported in the previous studies (McLean et al. 1991, Davis & Grant 1994, Grant 1996, Pound et al. 1998, Subgranon & Lund 2000, Bakas et al. 2002, Cassells & Watt 2003).

These recurrent issues are reported as nutrition, hygiene, elimination, medication, care of environment and mobility, emotionalism and communication, poor sleeping, backache and weight loss, respite issues, health education issues and hospital aftercare issues (McLean et al. 1991); lifting, transferring and bathing (Davis & Grant, 1994); preparing meals, using the telephone, managing money, driving and participating in recreational and work activities for stroke survivors and bathing, dressing, transferring, walking, and feeding the stroke survivors for family caregivers (Grant 1996); difficulty with leaving the house, doing the housework, pursuing former leisure activities, inability to walk in the way they wanted, problems with communicating, washing, bathing and dressing, and with confusion and deteriorating memory (Pound et al. 1998); diarrhea, constipation, incontinence, trouble speaking, trouble eating or drinking, difficulty taking medicine, being helpless, pain, choking, convulsion, high sexual need, depression, anger, short temper, constant calling for help, immature behaviors, and confusion (Subgranon & Lund 2000); and incontinence (urinary or bowel) (Cassells & Watt 2003).

Bakas et al. (2002) also asserted that caregivers not only have to deal with care issues for stroke survivors, but also have to find a way to deal with their own physical, psychological and social problems, such as worrying about their health, sacrificing their social lives, and experiencing anger and frustration. All these studies have identified the most frequent problems encountered by stroke survivors and their family caregivers, but little is known about how they experience and live with these problems after discharge home over a period of six months.

This chapter firstly analyses *what* care issues were encountered and *how* the 18 families under study lived with them. Information regarding the ways they dealt with these issues over time is also provided.

Three major categories of care issues emerged from the cross-case analysis (see Table 6.1). They are: (a) care issues surrounding activities of daily living, (b) care issues surrounding the health problems of stroke survivors, and (c) care issues of the caregivers. Table 6.1 summarizes the three categories of care issues and shows the features of these issues by the three types of family well-being over six months. In the first category, seven care issues were raised in the three types of family well-being.

Eating and meal preparation was presented first, and four sub-categories were included. They were (a) eating difficulties, (b) change in food choice, (c) change in meal schedule, and (d) change in family meal practice.

Six families expressed issues of eating difficulties: of those, one (Mr. R) was from a family with optimal well-being, three (Mr. F, Mr. I and Mr. H) were from a functional family and two (Mrs. D and Mr. E) from a dysfunctional family. Five families had a change in food choice: of those, two (Mr. M and Mr. J) were from families with optimal well-being, one (Mr. I) was from a functional family, and two (Mr. A and Mrs. B) were from dysfunctional families. Three families had a change in meal schedule: of those one (Mr. P) was from a family with optimal and two (Mr. F and Mr. I) from families with functional well-being. None were found in families with dysfunctional well-being. Finally, two families had a change in family meal practice, one (Mrs. K) from an optimal family and the other (Mr. A) from a dysfunctional type of family.

Regarding safety issues, eight families had experienced incidences of falls and injury. Three of these (Mr. J, Mr. M, Mr. P) were from families with optimal well-being, three (Mr. F, Mr. H and Mr. I) from functional families and two (Mr. A and Mr. E) from families with dysfunctional well-being.

Concerning issues of mobility, three sub-categories were presented: (a) afraid to walk, (b) very eager to walk, and (c) reluctant to walk. Of those who feared walking, one survivor (Mrs. B) was in a dysfunctional family and the other (Mrs. N) was in a family with optimal well-being. And of the six survivors who were very eager to walk, three (Mr. P, Mr. J and Mr. M) were in families with optimal well-being, two (Mr. H and Mr. F) were in families with functional well-being, and one (Mr. E) was in a dysfunctional type of

family. Finally, of the four survivors reluctant to walk, three (Mr. M, Mr. O and Mr. R) had the optimal type and one (Mr. A) the dysfunctional type of family well-being.

In the issue of eliminating, three sub-categories evolved: (a) functional limitation in attending elimination need, (b) urinary incontinence, and (c) bowel incontinence. One survivor from a family with functional well-being (Mr. H) had functional limitation in attending to his elimination needs, but of those from families with dysfunctional well-being, one (Mrs. C) had urinary and another (Mrs. D) had bowel incontinence.

In the last of three care issues about skin care, expressing sexuality and dressing, three dysfunctional families (Mr. A, Mr. E and Mrs. C) had the issue of skin care, one stroke survivor (Mr. F) from a functional type and the other (Mr. E) from a functional type of family raised the issue of expressing sexuality. One survivor from a family with optimal well-being (Mr. J) had a problem with dressing.

The second category of care issues comprised two issues: (a) medication concerns and (b) management of physical discomfort. In medication concerns, five sub-categories were prominent. They were (a) issues of accessibility and affordability, (b) management of medications, (c) ambivalent attitude towards medication, (d) adherence to medical prescription, and (e) self-modification of medication regime.

As for issues of accessibility and affordability, seven families had complete medical coverage: of those, three (Mr. J, Mr. M, and Mr. Q) were from optimal well-being

families, two (Mr. G and Mr. H) from functional ones and one (Mrs. B) from a family with dysfunctional well-being. Five families had partial medical coverage, three (Mr. L, Mrs. N and Mr. P) from optimal families, one (Mr. F) from a functional one and one (Mr. A) from a family with dysfunctional well-being. Seven families had literally no medical coverage, three (Mrs. K, Mrs. O, and Mr. R) of them the optimal type, one (Mr. I) the functional type and three (Mrs. C, Mrs. D and Mr. E) the dysfunctional type of family.

In the issue of management of medications, three families with the optimal type of family well-being (Mr. J, Mr. L and Mr. P) and one (Mrs. G) with the functional type had orderly management of medications; four families had disorderly management of medications: of those, two (Mrs. K and Mr. P) were from families with the optimal type and two (Mr. A and Mrs. B) from those with the dysfunctional type of family well-being.

Furthermore, four families had ambivalent attitude towards medication. One of these families (Mrs. K) had optimal well-being and three (Mr. A, Mrs. B and Mrs. C) had the dysfunctional type of family well-being. In addition, three families were adherent to medical prescription, two (Mr. Q and Mrs. N) of the optimal type and one (Mr. I) of the functional type of family well-being. And four families had self-modification of medication regime, three of them (Mrs. K, Mrs. O and Mr. P) of the optimal type and one (Mr. F) of the functional type of family well-being.

In the last care issue of management of physical discomforts under the second category, eight families expressed their physical concerns. Of those, three (Mr. J, Mrs. K, and Mr.

P) were in the optimal type, one (Mr. F) in the functional type and four (Mr. A, Mrs. B, Mrs. C and Mrs. D) in the dysfunctional type of family well-being.

In the final category of care issues of the caregivers, two families (M's wife and Q's wife) had the optimal type of family well-being and one (I's wife) the functional type of family well-being. According to this information, the task of this chapter is (a) to examine how families live with multiple care issues, and (b) how they deal with them by the three types of family well-being over time.

Table 6.1. Three categories of care issues encountered by types of family well-being over six months

Categories	Sub-categories	Types of family well-being			
		Optimal	Functional	Dysfunctional	
Case issues surrounding activities of daily living					
Eating and meal preparation	Eating difficulties	R	F, I, H	D, E	
	Change in food choice	M, J	I	A, B	
	Change in meal schedule	P	F, I		
	Change in family meal practice	K		A	
Safety		J, M, P	F, H, I	A, E	
Mobility	Afraid to walk	N		B	
	Very eager to walk	P	H, F	E	
	Reluctant to walk	M, O, R		A	
Eliminating	Functional limitation in attending elimination need		H		
	Urinary incontinence			C	
	Bowel incontinence			D	
				A, E, C	
Skin care				E	
Expressing sexuality			F		
Dressing		J			
Care issues surrounding health problems					
Medication concerns	Issues of accessibility and affordability	Complete medical coverage	J, M, Q	G, H	B
		Partial medical coverage	L, N, P	F	A
		Literally no medical coverage	K, O, R	I	C, D, E
	Management of medications	Orderly	L, P, J	G	
		Disorderly	K, R		A, B
	Ambivalent attitude towards medication		K		A, B, C
	Adherence to medical prescription		Q, N	I	
	Self-modification of medication regime		K, O, P	F	
	Management of physical discomfort		J, K, P	F	A, B, C, D
Care issues of the caregivers		M's Wife, J's Wife	I's Wife	C's Husband	

6.1 Care issues surrounding activities of daily living

In the present study, according to the Barthel Index measurements of activities of daily living (ADLs), nine stroke survivors (ADLs>85) were able to return to complete independence in activities of daily living six months after stroke, seven with moderate residual disability (ADLs ranged 35-85) that left them partly dependent upon others and two with severe residual disability (ADLs <35) that rendered them completely dependent upon others in personal self-care. Table 4.6 in chapter 4 shows the distribution of the 18 cases by levels of residual disability and by types of family well-being. In collating the instrumental activities of daily living (I-ADL) scores with the ADLs, it is found that only Mr. L and Mrs. K could live independently without any assistance in daily activities. All other survivors needed some kind of care assistance. While eating and meal preparation issue are common care issues experienced by all families irrespective of the level of residual disability, safety and mobility issues are more prominent in survivors with moderate residual disability, and eliminating and skin care issues are more obvious in survivors with more severe disability. Two male survivors expressed sexuality needs when their condition became stable. What follows are descriptions of how the stroke survivors and their families lived with these issues.

6.1.1 Eating and meal preparation

Almost all cases frequently mentioned what they used to eat, how they ate and why they did it based on their own understanding of what is good for their health and well-being in day-to-day life.

When these families deal with their eating and meal preparation, their understanding of how to select healthy food and eat well is influenced by both traditional Chinese medicine and Western medicine in each family daily practice.

The influence of traditional Chinese medicine can be traced back from the early work to 1800 in the Tang Dynasty made by Wang Bing “the Yellow Emperor’s Classic of Internal Medicine” or “Yellow Emperor’s Canon of Internal Medicine” (黄帝内经). In this book, there was one dialogue between the Yellow Emperor and Shaoyu in which they discussed the five tastes (e.g. sour, salty, acrid, bitter and sweet) of food and diet, and in which the Yellow Emperor described the phenomenon of how these different tastes enter into the body (e.g. stomach) have impacts on different bodily functions (e.g. tendon, blood, energy, bone, muscle and heart) and lead to well- and ill-being in various ways.

Following is their conversation. The Yellow Emperor asked Shaoyu:

“When the five tastes enter into the stomach, each of them prefers to go to the viscus of its similar property and each of them causes the specific disease; such as, the sour

taste goes to the tendon, when one takes sour taste excessively, he will have dysuria; the salty taste goes to the blood, when one takes the salty taste excessively, he will be thirsty; the acrid taste goes to the energy, when one takes the acrid taste excessively, he will have the feeling of fumigation of the heart; the bitter taste goes to the bone, when one takes the bitter taste excessively, he will vomit; the sweet taste goes to the muscle, when one takes the sweet taste excessively, he will feel oppression of the heart” (Wu & Wu 1997).

Among the 18 families, survivors tended to eat light food and fruit instead of heavy and spicy food or hot or “fire” fruit (e.g. spicy or hot, pork meat, chicken, orange), such as bean curd, fish, duck, banana and water melon.

On the other hand, they also followed the diet and meal preparation principles prescribed by doctors in Western Medicine as the “three lows and one high diet”, referring to low sugar, low lipid, low protein and high vegetables.

As also indicated earlier in the review of literature, stroke is a family matter, which not only interferes with the stroke survivor’s life as an individual in physical and psychosocial aspects, but also has an impact on the whole family. Thus the findings in the present study showed how stroke influenced eating and meal preparation, resulting in eating difficulty and food choices at the personal level, and having an impact on meal schedules and family meal practices at the family level.

In the present study, there are four major changes facing stroke survivors and caregivers in dealing with eating and meal preparation: (a) eating difficulties, (b) change in food choice, (c) change in meal schedule, and (d) change in family meal practice. Change in food choice was the area mentioned most often by survivors, and change in meal schedule was the area of greatest concern to family caregivers leading to an increase in the burden of care.

Eating difficulties

Eating difficulties were experienced immediately by both the stroke survivors and their primary caregivers in the initial time after discharge home in the following families. Four of the survivors (Mr. F, Mr. I, Mr. R and Mrs. D) said they had difficulty in drinking water and choking on fluid; and some caregivers mentioned that they noticed the survivors' eating difficulties and attempted to modify their food consistency from time to time. These difficulties and some recognition of this problem are illustrated in the following verbatim transcriptions.

Mr. F, Mr. I and Mr. R described their experiences when choking on water from time to time. Mr. F said:

“Morning after getting up, I drink water, but cough, without stop, cough, I could not help, drink again, but cough more severe...”

Mr. I expressed his problem:

“I have to drink slowly, a small mouth once, If I am drinking too fast, I will cough, only slow down will be all right otherwise cough, cough, sometimes cough makes me very uncomfortable, my wife helps me pat my back.”

I's wife felt puzzled while observing her husband cough. She murmured:

“What is wrong with him, he used to drink a lot of water, 3 bottles a day, well, he takes water he should take it slowly, otherwise, cough, cough, without stop.”

R's wife recounted her experience of dealing with her husband's swallowing difficulties by selecting food and fluid carefully. She said:

“At first, rice/steam bread cannot be swallowed, only milk powder, so I can only give him milk powder with water (冲奶粉), another dish is curd soup, and egg with noodle...”

R's wife laughed when talking about her husband's behaviors when drinking water, she recounted:

“He is only able to drink a cup of milk (milk powder with hot water), like a baby, ha...every other day's morning, I buy tender curd with sugar (豆腐佬), he can eat a big bowl.”

D's daughter-in-law gave her observations and described how she dealt with her mother-in-law's eating difficulties, she said:

“She does not eat rice, any dry food, like pie, some other food she used to preferring it. I have to feed her water rice, adding some sugar, or sticky powder rice with hot water.”

Two survivors (Mr. H and Mr. E) had tooth problems while having difficulty with food. H's wife described his problems and said she had slowly recognized his difficulties with various kinds of food.

“He has difficulty in eating rice, having less and less, he says not easy in chewing food due to his teeth, no more teeth. So I give him porridge with curd (豆腐), and he likes that....He says he would not eat this or that due to little teeth and can't chew rice, well, I give him noodles with eggs, he may feel easy, or some soft pumpkin, He has false teeth, cannot bite hard things; when in hospital, he always had instant noodles three times a day.”

Mr. E recounted his deep frustration in managing his eating and meal preparation. He recalled his experience with a helpless sound:

“I am unable to make good food, I have to eat outside in the morning, a cup of water noodle and very simple meal at home. I am used to eating soft food like water rice or porridge, and curd (豆腐), others I can't bite them, I eat a little, you see I have only two teeth...”

Change in food choice

Five families (Mr. M, Mr. J, Mr. I, Mr. A and Mrs. B) mentioned their experiences of selecting healthy/good food and fruit based on both the ideologies of both Chinese medicine and Western medicine.

Based on the above understanding, they were concerned about the nature of food and the fact that it has different tastes that might make their body feel “fire”, “hot”, or “cold”, and might be harmful for their health and hinder their recovery from stroke.

Mrs. B said she could not take spicy or acrid food, even though this was her favorite kind, since it had “fire”, which might be harmful for her health.

Mr. A expressed his difficulty in dealing with his diet since he was fond of some fruits, but many of them were not suitable for him. He said he was told that orange was too “hot”, and duck was too “cold”, and pork was too “greasy” (i.e., full of cholesterol). All that remained for him to eat was balsam pear, towel gourd, and cucumber. All these food made him terribly hungry and lose body weight. This issue often created tension and conflict between survivors and their family members while they were eating food at the same table and cooked in the same “hollowware”.

At the same time, family caregivers expressed their confusion with using what was called cold food, light food in order to remain as healthy as possible. This confusion is demonstrated by the following cases.

A's wife explained how she was worried about selecting proper food and changing the taste frequently to meet her husband's preference on the one side, and making sure that it was either low in cholesterol or rich in nutrition, as reminded by a doctor, on the other.

A's wife said:

“He once expressed he was eager to have some meat, and I found duck is good for his health because it is cold food and with low lipid.”

Mr. A added in a hurry:

“I am too gluttonous, I want to have meat, she (his wife) bought a whole duck, it is so tasty that I eat half of it...later I admitted to the hospital, the doctor said ‘high cholesterol’.”

Mr. A voiced his frustration over his being fond of good food and the restriction of not being allowed to have this and that, such as some fruits like orange. He said: “She does not offer me any orange, and does not buy any pork...”

A's wife explained:

“No, no...perhaps eat too much at that time and he likes it very much, you see he is thin...Orange is not allowed because it has ‘fire’ my neighbors said. ”

Mrs. B described how she managed her food flavor and fruit selection based on her experience, mentioning particularly that before she was fond of spicy food, but now changed her habits to eating light meals. She recounted:

“I cannot have spicy dish, because of being afraid of too hot, as described by traditional Chinese medicine: spicy food may have ‘fire’ to body. Also, I cannot eat any cold stuff because cold food stimulates my cough. If I cough, I should drink hot water, no cold water, I must be hot water; for selecting of fruit, I have banana, and litchi, but orange no, it will make fire in the body, not good, you see.”

B's daughter added: “Too particular, too difficult to serve her satisfactorily.”

Mr. M described his problems in selecting soft food and food that was good for his health instead of hard food, because a number of foods were impossible for him to bite:

“Vegetable and meat are too hard to bite, I only can eat curd, only curd is a good dish for me, having many nutrition.”

M's wife added:

“He eats a little and many things he does not like them, only curd, he never gets tired of eating it (百吃不厌).”

H's wife was very careful to prepare food that would be suitable for managing Mr. H's diet and eating problems. She said: "His teeth are spoiled, he can't eat vegetable and fruit, so I just cook noodles, put some tender pork, milk twice a day, then banana."

I's wife described her dilemma in selecting good or healthy food. She said:

"I want to cook a duck soup with radish over a slow fire, duck belongs to cold food, and radish soup is a kind of ginseng soup as the old said, but I am afraid of having too much oil, yes, I will try to wipe out the surface oil and then he can have, am I right?"

In addition, I's wife also expressed her caution in cooking food selectively in order to ensure that he was getting low-fat food for his health. She recounted: "I cook different dishes for him everyday, avoid pork soup, and being too greasy."

J's wife also frequently talked about how to select a variety of balanced food, with low cholesterol and reducing the amount of food each time, but she was worried that this might cause Mr. J to be hungry and worsen his health. J's wife noted:

"I offer him egg everyday but I take off egg-yolk, give him only egg-white, right? Then give him pumpkin for meal, cannot give too much rice, doctor reminded. Since he can not eat too much rice, I decide to give him more vegetables so as to avoid him hungry, a small bowl of rice added a big bowl of fresh vegetable...Haha...this is my invention!"

Mr. J always said with a smile: “Yes, she gave me two bowls, let me eat more...but for herself, little left, she eats a little, am I right?”

K’s husband attempted to change his wife’s diet by seeking alternatives to manage low sugar food. He said:

“Since she had diagnosed with diabetes, it is heard that pumpkin is beneficial for one who had diabetes, then she starts to eat pumpkin every day as a medication, well, each meal has pumpkin for all of us...”

Change in meal schedule

A change in meal schedule apparently affected each of the following individual’s meal-times from the prior routine of three times a day to the present two to six times a day when stroke conditions become stable. The number of meals varies greatly based on their belief in health “the more the better” or “the less the better”. These changes are illuminated by the following three cases (Mr. F, Mr. P and Mr. I).

Mr. F described his experiences of eating twice a day after one week discharge home. He added that he had acquired this habit while living in the hospital. He believed that eating less would benefit his health. He said:

“Twice a day would be good, morning at 10 am, afternoon at 4pm, a friend living in the same ward who was a retired doctor told me, I think he should have his own sense to do so, I learn from him.”

Mr. P was very cautious about his diet since he had had a long time experience of diabetes and several episodes of stroke recurrence; he said bitterly about the reduced amount of food for him:

“Only give me a small bowl of rice, just tricky! Haha...but once a small bowl, but I can have more meals a day when I feel hungry, I have additional meal when I am hungry sometimes, I can take salty biscuit with sodium or have a cup of soya bean milk with no sugar, sesame powder...”

P’s wife described how Mr. P would have a small bowl of rice and recounted:

“Yes, it is a pity for him to control his meal by taking small bowl...we sometimes tease him ‘airs and graces’ (做作).”

I’s wife expressed how she was bored and experienced a burden of care in managing Mr. I’s food preparation several times a day, even though Mr. I felt very proud of having his meals five times a day. Mr. I said: “I have five meals a day, good appetite, and my energy is improved.”

But I’s wife described her work burden as not only taking care of Mr. I’s daily activities, but preparing the son’s family’s meals, as well as the whole family’s meals at weekends individually. She noted:

“Breakfast at 7-8 am, lunch at 12, 3 pm, supper, 6 pm and a snack at 9 pm, I eat hot-dry-noodle...five meals a day...I, not only cook for him, but also cook for son

and daughter-in-law, if dishes are not so tasty, they refuse to eat!....Particularly on Sunday, they all come back, I have to cook for more than ten people!”

Change in family meal practice

There were two families (Mr. A and Mrs. K) who would prefer to have the whole family eating together from the same dishes of the same taste. One family caregiver described conflicting feelings about the food prepared being undesirable to the survivor’s palate, and the other noted that other family members were considerate of her needs because the whole family could share her optional food (i.e., low salt and low cholesterol) as reminded by the doctors.

Mr. A said his wife’s preparation of his meals was unsatisfactory and was very upset:

“She always prepared the same dishes, no modification, and no taste. You see, she is reluctant to give me good food, always Gua-gua-gua (瓜-瓜-瓜) cucumbers, white gourd, towel gourd, and pumpkin...(here referring to the same pronunciation (寡-寡-寡) ‘little-little-little’ in local accent which means the word little-little-little) she is merely grudging me her food, but when son and daughter-in-law come back, she will cook varied kinds of dishes, like meat and fishes, and other so tasty food for them, isn’t it right?...”

Mrs. K emphasized that her dietary change was not only for herself, but meant changes for the whole family. She described this change as a matter-of-fact:

“Doctors said I should eat low salt and low sugar food. But we used to have a big meal for the whole family with strong taste food (local dishes usually spicy and strong). Now I cook light food with low salt and low sugar. You see, pumpkin, low sugar, every day. Pumpkin, good food for diabetes, my neighbors told me, it is also said pumpkin, good for adult and children, now we eat every day and every meal for the whole family, my family loves the way I cook.”

6.1.2 Safety

The issues of safety seem to be one of the most important issues in their everyday activities, and it gradually becomes part of their personal life to re-recognize, adjust and re-adjust their personal self from the previous familiar surroundings to the present situation of functional limitation, from unawareness to awareness of the importance of the individual's own ability in meeting his/her personal competence.

For those survivors who had experienced several falls, they started to be lost in functional independence, frustrated, hopeless and full of despair, which prevented them from maintaining normal activities of daily living. This phenomenon was systematically documented by Doolittle (1992) as an experimentation phase in the early stage following stroke. Doolittle noted that after four to five months following a stroke, survivors were actively engaging themselves in testing their abilities: the examples were illustrated by walking without a walker, walking in a new area unassisted, carrying large amounts (such as buckets full of water), mowing the lawn, and driving. It is suggested by Doolittle that

experimentation is critical because it is a process of adaptation for the survivor to master his/her important personal tasks and achieve or recognize his/her process of the recovery.

It is also important to recognize that the time point for their falls and injuries was usually in the first three months after discharge home. This was consistent with previous study (Grant et al. 2004), in which it was stated that safety was the primary concern and problem experienced by both survivors and primary caregivers, and that this might be related to functional deficits, emotional disturbance and limitation of social activities (for example, mood swings, memory loss, depression and frequently calling the caregiver).

Within the types of safety issue, lesion of injury and place of fall are of concern. In this study, one of the subjects (Mr. A) had injured himself while shaving. For the location of falls occurring, it included bedroom (Mr. E, Mr. F, and Mr. H), the corridor to the toilet (Mr. J, Mr. M), climbing stairs and outdoor walking (Mr. E, Mr. F, Mr. P). The falls mostly happened in the morning after getting up and while walking to the toileting. The problem caused stress to family caregivers as constant supervision of the stroke survivors was needed to prevent falls and injuries. This issue was documented by Davis and Grant (1994), who showed that family caregivers use practical situational vigilance for close monitoring of survivors' safety while walking.

These issues are the second most common problems encountered and reported by eight families (Mr. J, Mr. M, Mr. F, Mr. H, Mr. I, Mr. A, Mr. E and Mr. P), particularly in those having higher levels of independence and in the first three months following

discharge home in the present study. Such issues as blade injury, falls and ankle strain are described by the following cases.

Mr. A expressed his worries while he felt he was good at shaving his face once a week, the first time after discharge home, he cut his face with the razor. When he saw the blood, he was scared to death and sought help for the whole night, but he was disappointed that the clinic doctors paid insufficient attention to manage 'his bloody event'. Mr. A recalled the incident angrily:

“That evening when shaving, I didn’t know why, hand tremor, and hurt my kin, bleeding...we went out and saw doctor, he only gave me a cotton, but it was still bleeding...I was so scared due to blood...”

Mr. E expressed his feelings of helplessness while living alone, and said he had fallen several times at home and without anyone to offer him a hand at night. He said:

“Once I fall at home, I call my son, but they can not hear me, I have to sit down on the ground to wait. It is so cold and wet, until the next morning, when they pass by my room.”

Mr. H had one experience of falling while he practiced walking around the room. He said:

“Nothing particular, only when I was turning around, perhaps I was standing unsteadily, then I was sitting on the ground.”

But after this event, H's wife was very nervous, closely supervised his walking and never allowed him to move by himself independently. H's wife said: "Never leave him alone, follow him to walk every time, if he falls again, it will be terrible, I am scared ...I can not pick him up alone at home."

I's wife expressed how considerate her children were in taking care of Mr. I's safety issues after discharge home, and she said: "My son and daughter-in-law specially bought him a 'chair' (for the toilet); the four feet of the chair were wrapped to avoid slipping."

Mr. I added: "Every time when I go toileting, my wife will bring that chair for me, I just sit there, quite comfortable, it was bought by my son and daughter-in-law..."

Mr. J said he was in a hurry while going to the toilet, but was unable to control his affected leg to raise it up and down properly. He had falls several times, and his wife expressed her helplessness in trying to manage his walk safely. Mr. J stated:

"I used to get up early in the morning to get into the toilet. Now I am still in a hurry to get to the toilet. In the last incident, I wanted to walk faster, but my legs seemed not to listen to me, eventually I fell down on the ground."

J's wife described her difficulty in pulling her husband's body up from the ground. She said:

“I could not pull him up, he is big and tall, that morning, nobody at home, he had to sit down on the ground to wait for the helper’s coming. The only thing I could do was to stay with him, waiting...”

Mr. F lived alone, and he was extremely self-confident at the time when discharged home. But while he did exercises his ankle was badly sprained. He described his experience of five falls in the home environment. He hit his legs repeatedly and murmured sadly:

“Why you do not follow to instruction and my commanding...when my legs would have enough strength? Sometimes getting up in the morning, not standing firmly, I fell down and my back hit the bed edge, severe pain for many days...Toileting, the edge of the toilet room is too high, I walked and lost balance, sat on the ground...Walking on the stairs, I thought I was all right, both my hands were holding cabbage and radish, unable to be stable, slipped down and hurt my head badly,...then went to the hospital and had several stitches for the wound... I want to be improved quickly and gain more strength. That is why I do exercises twice a day. The first time in the morning after getting up at 5 o’clock, I stand in front of the window, practice up and down-20 times, right and left-20 times; the second time in the afternoon, the same.”

Mr. M recalled his falls one month after discharge from hospital with a fearful voice:

“I got up in the morning. I thought I must be so fine in taking care of my self. I held a basin hold in my hands, and walked slowly. While reaching the kitchen room I

bent to bring a hot bottle for water, but only a moment I could not stand still, and sat down on the ground, fortunately, I was not injured.”

Mr. P had problems in walking steadily in the initial period of discharge home, and he attempted to test his ability and recognized his personal competence in walking. He said:

“When first arrived at home, my leg couldn’t move, couldn’t walk, I tossed my leg, I told my self, if I didn’t move, I will be paralyzed. When going round nearby, first with stick, now, it is no need any more. Now I ride a bike to the park, bike becomes my stick, no problem, not a bit scared...”

P’s wife added: “I am afraid of his having accident outside when he rides bike, I follow him....yes, really greatly improved.”

6.1.3 Mobility

Mobility is also significant and valued by most survivors in order to reintegrate into their normal personal and social life. It has been hypothesized that stroke is a stigmatizing condition: as Sjogren states, based on the interviews with hemiplegic stroke survivors, 41% has suggested stigma as “people observe me”, “I am treated differently because of my stroke”, “people discussed my disability”. Another study conducted by Pound and Gompertz (1998) also stated the survivors’ reactions to their stigmatizing condition based on their concerns about age and gender differences. It is suggested that this may be an experience of younger people because stigmatizing might be strongly associated with old

age. Labi et al. (1980) asserted that feelings of stigma in respect to body image might be more likely to have an adverse effect on females in western cultures because of the traditional values attached to good feminine physical qualities.

The experience of the issues of mobility seems to be different from the previous literature and three interesting behaviors are manifested: (a) afraid to walk: being able to walk independently, but too afraid to walk, being fearful of the surroundings, (b) very eager to walk: strong willingness to walk but lacking awareness of protecting his own safety by himself (e.g. using a stick) or from the environment (e.g. high and steep stairs, dark), and (c) reluctant to walk: unwillingness to walk due to fatigue, previous falling experience and 'lazy' to move around. These three situations are illustrated by the following cases.

Afraid to walk

Two survivors (Mrs. B and Mrs. N) said that they were almost able to walk independently immediately after discharge home. But one (Mrs. B) frequently said she was fearful when anything or anyone would approach her and the other (Mrs. N) described she was afraid of walking outside due to inability to move smoothly with her legs.

Mrs. B said:

“Don’t touch me while I am walking. I am so afraid of hearing the voices of cars, they come to me, I will stand still for a long time...I am also afraid of unevenness road, scared of fall...”

Mrs. N said: “I have not moved out of my home after coming back, I am just worried while walking outside.”

Very eager to walk

Six survivors (Mr. E, Mr. F, Mr. H, Mr. P, Mr. J and Mr. M) described a strong desire to walk independently and actively. However, they lacked information on what had happened to their bodies to make it so difficult to move. Of these six, three of them (Mr. F, Mr. H and Mr. E) had fallen several times, as described earlier.

Mr. E and Mr. F were feeling alone and used to going out and about, but also experienced falls several times. Neither of them had used an assistive device (i.e., stick) properly and effectively. They said they were not well prepared to use it since they had not yet bought it.

The following cases indicate that how they walked and how they responded to assistive devices used.

Mr. E said:

“I am feeling so normal. The only problem is my poor eyesight (previously diagnosed by cataract, and doctors gave me some eye drops). Sometimes I see things unclearly as if there was something in my eyes.”

Mr. F stated:

“When I walked outside, I am not used to using stick. I know I am fine but I didn’t know why, something held my foot, I fell down, I could not get up by myself, I tried, but failed. Fortunately, thanks to a young man, he helped me to get up, and took me back home.”

Whether using an assistive device or not became a common concern for both survivors and family caregivers, but there was a lack of consensus among them. From the side of survivor, he expected to be able to walk independently and hoped the process of recovery would progress quickly. On the other side, the caregivers worried about falls and preferred to provide close supervision and vigilance while the survivors walked around. Mr. H’s family was an example of the discrepancy in the expectations of the rapid recovery.

H’s wife was so worried about Mr. H’s independent walking that she hid the stick from him, which upset Mr. H very much.

Mr. H said:

“I want to walk, walk, walking in the room, when I turned, I fell down! Only once, only once, no problem, if I can use the stick, I would not fall, this is her fault (his wife)...my stick was hidden by her...I could not find it!....She won't let me use a stick, she said it's not safe, she insisted that she had to help me...”

H's wife was so worried about his fall, she explained it:

“In case he falls again, I am alone, what I can do? No, no walk...the stick is on the back of the door, I don't mean I do not allow him to use a stick, I am afraid of his falling down when he is walking by himself.”

Mr. P was reluctant to use a stick in the initial time after discharge home; his wife encouraged him to use it since the stick would help to prevent him from falling while he was alone outside.

In the initial weeks after discharge home, Mr. P said: “I never stop walking, one patient (living in the same ward in the hospital) told me: once you stop walking, you will be finished (完蛋)...”

But Mr. P did not like to use a stick while walking out. P's wife recalled this experience and laughed at him:

“He is afraid of being teased by others: lame in one leg with a stick. Not good for a big man, is it? I tell him, that is not a bad look. You see, Premier Zhou-eng-lai's (周

恩来) left hand was injured where he put it on his abdomen in this way... And the National Father Sun-zhong-shang (孙中山) also used stick, he looked so handsome with stick, is it? They are all the greatest men in China, what are you worrying about?”

Mr. F was very wary of others’ attitudes when going out in the street. He spoke about the embarrassment of being perceived as a helpless and useless man in his walking, and of being helped across the road by others, and felt sad when others observed at him. He thought he might look so old and ugly. He said:

“When I use a stick to walk slowly in the street, the neighbors look at me, and observe me in another new and strange light, as if they see through me. After coming back, I look in a mirror, and find my face becomes disfigured, you look at me, is it true?”

J’s wife described how difficult it was for her husband to walk around. She said: “I had to help him raise his leg to move forward, his legs do not listen to me, it is hard and heavy for me to raise them to move.”

Mr. J added: “Yes, I do not know, they are not listening to me too, it is too stiff.”

Mr. M described his unsteady walking and his worries. He said: “While I am walking, I stay close to the wall and to be supported with hands...”

M's son added: "Why is his walking so staggered? What's wrong?"

Reluctant to walk

There were four survivors (Mr. M, Mr. R, Mr. O and Mr. A) who described their lack of motivation to walk because of fatigue and previous experiences of fall accident. But their caregivers often expressed their worries about survivors lacking motivation to move, which might contribute to worsening their physical health for future independent living.

Mr. A said that he was unwilling to walk because he felt fatigue and being afraid of being fall once more. A's wife described her husband at home and unwilling to walk. She worried that:

"Sitting down, no movement, he says he was tired if walk much, always tired he feels. But if we go to clinic for medication and injection, he is so capable and energetic. Provided he decides to go clinic, he is happy to go, fifteen minutes walk and up and down stairs. In one word, he stays at home, unwilling to walk or move, only a step."

Mr. A described his experience of walking outside: "My legs are so heavy for each step, you see my shoes are broken, because my legs is dragged on the ground."

Mr. M was afraid to walk in the first month after stroke. He said he easily became fatigued, so he preferred to stay in bed all the time. He said: "It is cold outside, dress too much, I cannot move, stiff legs."

M's wife urged him to walk more. She added: "Move more would be better for recovery, am I right?"

O's daughter mentioned her mother's little motivation to move and walk. She said: "My mother does not like to walk while getting sick, always lying in bed."

Mrs. O added: "Yes, I am tired."

R's wife used to praise Mr. R while did his exercises. She described how her husband walked around the room at home, but felt worried about his physical deterioration because most of the time, he preferred to sit down and watch TV. She felt problematic and said:

"He uses a chair helping him walk in the room, from this room to that room, and stand beside the window and see outside...then watching TV is his favorite... Everything he is fine, but only he is lazy to walk and move, all the time sitting there and watching TV, is this proper for him to sit down all day long? I condemn him and shout: bone idle, always sit, but love to eat and watch ...I urge him many times, but I feel it is useless..."

Mr. R added: "Yes, I am standing beside the window and say Hello to my old friends...Haha...at night, nothing to do, only TV, I love it."

6.1.4 Eliminating

Eliminating and incontinence issue in stroke survivors was examined by McLean et al. (1991), Subgranon and Lund (2000), and Cassells and Watt (2003). The findings revealed that the impacts of care recipient incontinence on their spouses were role change, financial cost, decreased intimacy, emotional responses, sleeping issues and social isolation. However, what issues they are concerned with and how both survivors and family caregivers experience and deal with this problem in the home care setting are unknown.

In the present study, three survivors had problems of incontinence. Mr. I had functional limitation in eliminating need, Mrs. C and Mrs. D had incontinence. Mrs. C had troubles in urinary incontinence and was taken care of by her husband, while Mrs. D had bowel incontinence and was cared for by her 38-year-old son. Mrs. D frequently expressed her feelings of being guilty while her son helped her clean her bottom. But Mrs. C had a bedsore on her back lumbar location at three months after discharge home, her husband had to learn to change her dressings every day and Mrs. C attempted to control her water intake in order to reduce the troubles of passing urine.

Functional limitation in eliminating need

Mr. H and his wife could not agree with each other. In particular, he was constantly complaining about his wife's slow movement and inability to get to him in time when he needed help.

Mr. H had a very hot temper and was easily irritated by his wife's slow reaction. He described he would go to the toilet and pass his stool after his breakfast. This was his habit. But now he had to be dependent upon his wife to help him get to the toilet. He said impatiently:

“I must go to toilet after taking milk, then I will ask her to help me, but she is so slowly to come, I ask her for many times, I am so angry at her unhurriedly coming...well, after losing my temper, I can not pass the stool easily...she made me constipated...upset...”

H's wife explained: “He always shouts me late, how quick? I have my own business, too fast, I am afraid of fall, he makes me bewildering, too quick or slow...”

Urinary and bowel incontinence

C's husband was patient while dealing with his wife's urinary incontinence. He was so considerate even though he recognized his wife was in an incontinent state, and he never

mentioned it directly. He used an easy tone and described how he proceeded when he was absent and had to leave Mr. C alone at home. He said:

“Every month I will buy several packages of diaper from supermarket, it is easy to use and clean. Change (diaper) three times a day. Why I am using it because I am afraid when I am out of home, nobody can help her.”

In dealing with her continence, Mrs. D never used this kind of diaper. She used to lie on a cloth pad with several layers. If she sensed a stool coming out, the helper would help her to add some tissues to the pad. Everyone knew that Mrs. D was fond of cleaning. Mrs. D stated: “I want her (the helper) to support me at the back so that I can sit down on the basin... I don’t like to be dirty....I love cleanliness.”

Once a neighbor mentioned that she had been such a clean person since she was young. Meanwhile, Mrs. D was extremely frustrated and feeling disgraced by the experience of her bowel incontinence. She was feeling so helpless, hopeless and desperate in this situation while her son managed her stool. She said she felt very embarrassed in front of her son. She said:

“Ay, my buns is just like a duck’s ass, passing stool any time, again and again, really upset and dirty!...in particular, while my son took care of me, he did such thing, I am feeling so bad, he is a male, my son, how could I let him help me to do such kind of things?...Where is my daughters? Why they not come? Everyone escapes from me...I know.”

6.1.5 Skin care

Skin care is so stressful for those with other chronic illness (i.e., diabetes), who cannot wash or take a bath and are highly dependent upon their family caregivers. The problems include: toe infection, body itchiness, and bedsores infection. These problems are illuminated by the following cases (Mr. A, Mr. E and Mrs. C).

Mr. A described his pain and fear when he experienced an infected toe. He cautiously described his health as follows:

“Because my swollen foot resulting from a stroke, and my shoes gradually became so tight while mobilizing and walking. You see, the front of my cloth shoes has broken, my left toe is painful like a needle inserting. One day my toe hurts, maybe it was because of the tight shoes, I have to use some antibiotic ointment instead of cleaning it, drug is fine, but it becomes worse, I am so scared to be infected. I once heard that if infected in the leg, the limb would do operation, like amputation. Am I right? Thus I went to the hospital and lived there, gain transfusion and disinfection, it was the infection in my leg that I really worry about!”

Mr. E looked so distressed and was lying on bed during the first time visit after discharge home. He said:

“Nothing is good, only lying on bed, cannot sleep or eat.....but itching days and nights...all over my body! I have to scratch, my skin is broken, still deadly itching.”

(Observation: He had been hospitalized for 28 days and it seemed that nobody had given him a good wash and clean or taken a shower following his stroke).

Mr. C was the only survivor whose bedsore was infected severely and badly because of urinary incontinence. She felt so painful in her sacrum while lying on the bed and was afraid of drinking water because it was 'troublesome'. C's husband showed his incompetence and helplessness to heal Mr. C's deep wound in the early visits, but he still insisted on changing the dressings of her bedsore wound every two days. He said:

"She sleeps all day long, without moving, the skin of her bottom hurts...it is expensive dressing changed in the hospital, about 10 dollars for one change, I can't help. Later I ask a clinic doctor to come home and help her to change dressing. Then I found I can do it by myself. You see, now I have bought some gauze, alcohol, and some antibiotic lotion. I clean the wound and I change bandage for her every other day after washing her body...I buy dressing, cotton, alcohol, and plastic in drug store, not expensive, but in the hospital, each dressing should be 10 Yuan for once, so I do it at home, now it is smaller than before."

6.1.6 Expressing sexuality

Sexual needs of stroke survivors have been rarely discussed in the reviewed articles as described in Chapter Three. Only one article by Subgranon and Lund (2000) addressed this issue.

In the present study, two survivors expressed their need for someone to accompany and take care of them in the home care setting. But expressing sexuality is not a common thing for Chinese people. Interestingly, two male survivors boldly disclosed their problems to the investigator openly and honestly. Both of them were widowers and stated that after they had suffered a stroke, they were eager to get married again because they needed somebody else to provide their day-to-day care activities in the earlier visits. After that they felt their children were not happy and supportive, especially when their views were strongly rejected by their children; eventually they said they gave up. They also felt hopeless and helpless because they recognized that to marry with a woman in their age (more than 70) would be too difficult to attain for them, as if they were trying to reach the sky. These feelings may be attributed to a sense of Chinese family dignity, as they should behave like a good father and grandfather in the family, as well as win face for the family from outsiders instead of losing it; if they remarried at this age, they would be regarded as face disgraced by the family on the one hand, as well as not paying due respect to their late mother and grandmother on the other.

This issue has become vulnerable and significant for their lives when their stroke conditions appear to be stable in the later visits. These two male survivors' concerns are illuminated by the following descriptions.

Mr. F was a strong-willed man and he explained that he never thought living in the world as a single person could be so painful for him due to losing a spouse. He said:

“My wife died in 1998, I re-married later, but that woman cheated me, took away all my money and left me, ...now I dare not think of re-marriage, afraid of being cheated again, my children also hated me in the last re-marriage experience, that is why my older son did not pay me a visit...(he sighed loudly) As spouses, cannot decide to be born on the same day, but we really hope to die together on the same day. It is such a pitiful life to be left alone in this world!”

Mr. E had a lower education in his young age and seldom thought about much. He used to say that he needed a woman directly and expressed his experiences of seeking women from outside problematically. He said:

“My wife died in 1995, I tried to re-marry, but was prevented by my daughter-in-law. She condemned me and disregarded me. My children think re-marriage would lose our family’s face. No way, I wish to have a wife...I am afraid of my daughter-in-law, she might not agree, afraid of being cheated by a new wife again, they do not allow me to re-marry... I have to seek women from the outside. Now every week, I seek outside services by paying (i.e., prostitute). I just go to seek sex, 20 Yuan for each time...weekly...what can I do? This is what I am fond of....This is the only thing I am interested in...I get old, and I am counting my days (过一天算一天).”

Even in this situation, Mr. E still expressed his desire for women. He said he was indulged in his sexual needs at three months after discharge home. Then he was seeing prostitutes twice a week. Mr. E said it quietly:

“I need a woman, I have to pay for them right now ...This is the only thing I indulge in...at present. Once I suffered a sexual disease, later I was treated and cured...I want it, I can't help.”

6.1.7 Dressing

Mrs. J described how their old couple had difficulty in making the bed in cold weather and how the couple worked together and made joint efforts to dress cooperatively so as to avoid catching cold and made up the bed for her paresis husband easily and smoothly. J's wife said:

“Every evening we need to schedule our time go to bed early in order to make the bed and get dressed quickly due to the cold weather...I undressed him, made the bed, after washing we started to sleep, anyway, never after 9pm. I helped him pass water, washed the jug, then helped him to get in bed...We both give up watching TV after 7:30pm in order to get up early in the morning....He is so fine and patient, never loses his temper, and ensures that I have enough time in the morning to pray.”

6.2 Care issues surrounding stroke survivors' health problems

As shown in Table 5.4 (p. 198), of the 18 stroke survivors, ten had recurrent stroke, three had one concomitant disease and 15 had two or more co-morbidities. The most common diseases were hypertension (n=17), coronary heart disease (n=9), and diabetes mellitus

(n=5). These diseases require long-term medications. Hence the most prominent care issue among these stroke survivors revolved around medication concerns, and the secondary care issue revolved around management of physical discomforts. The medication-related experiences varied widely among the 18 stroke survivors. Differences are noted in issues of accessibility and affordability, management of medications, ambivalent attitude towards medication, adherence to medical prescription and self-modification of medication regime. What follows is an exposition of the experiences of the medication-related care issues in families living with stroke over time.

6.2.1 Medication concerns

Medication concerns have been reported by the one article in the reviewed literature (Subgranon & Lund 2000) on stroke care, but it has been recognized widely as an issue of antihypertensive medication compliance in China (Guo et al. 2001, Huang et al. 2002, Gao & Cao 2004).

In the present study, medication-related care issues are prominent and multidimensional, and frequently articulated by the 18 families. Those who were non-adherent and used their self-modification regime might prescribe medication to themselves through self-monitoring and a self-modified regime with a variety of reasons, such as fear of side effects (e.g. drug toxicity) and worrying about efficacy; they also took drugs according to their own regime (e.g. taking drugs while feeling uncomfortable), or stopped taking medication due to medication shortage or being afraid of side-effects. Almost everyone

knows the popular saying that “one third of any medicine is poisonous (是药三分毒)”. Other families experienced an extreme problematic situation while managing multiple kinds of medications over a period of six months after discharge home.

In addition to using Traditional Chinese Medicine (TCM) for guidance in eating and meal preparation, they also chose herbal medicine based on the beliefs of TCM that herbs are able to stimulate blood circulation and Qi-channel connection (活血化郁). Thus they selected herbal drugs included Ji-ju-di-huang-wang (枸菊地黄丸) and chrysanthemum (菊花) to eliminate liver fire and maintain eye brightness (明目). These herbs are considered to be beneficial to health and well-being.

The five sub-categories of these concerns were: (a) issues of accessibility and affordability (e.g. having complete, partial or literally no medical coverage), (b) orderly and disorderly management of medication, (c) ambivalent attitude towards medication, (d) adherence to medical prescription, and (e) self-modification of medication regime. These are discussed below.

Issues of accessibility and affordability

In this issue, differences in medication-seeking behavior are then divided into the following three parts, which are based on the percentage of free medical care coverage (see Table 5.4, p. 198). They are (a) having complete medical coverage, usually 90% or

above, (b) having partial medical coverage, ranging from 50-80%, and (c) having literally no medical coverage, usually 10% or less.

Complete medical coverage

Six survivors (Mr. J, Mr. M, Mr. Q, Mr. G, Mr. H and Mrs. B) had complete medical coverage, but they complained of difficulty in obtaining medications over time, because of reimbursement issues, immobility, distance from hospitals, issues of accompaniment and lack of guidelines for proper and effective use of medications. These are demonstrated by the following cases.

Mr. J mentioned about stopping taking medications due to a shortage of drugs at hand after discharge home because of inconvenience access to hospital services. He said: “After using up Jiang-ya-ling (medication for anti-hypertension 降压灵), no more at home, blood pressure is OK, no particular feeling, and no need to take more.”

J’s wife was short and thinned but her voice was high while describing how difficult it was for her to have a medical check each time she requested medication, and she was overwhelmed with indignation. J’s wife described this experience while asking for the prescription as just like “begging food” (讨饭). She said:

“You can’t imagine how hard it is. Each script is only for 30 yuan, and I can only get one each time. You see this check, only a bottle of medication could not be afforded. In addition, I have to take bus, 60 minutes for double lines; but to take taxi,

30 Yuan for going there and back. Then there is queuing up for seeing doctors, prescribing, and offering me a medication price. You see, I am old enough and frail, I can't bear it for standing so long and getting in and out with such a crowd of people. Eventually one bottle of drugs, it is not counted at all (不划算)!”

Mr. H and his wife were living alone; their daughter was busy and came to see them once a week. Mr. H said he would like to have more medications, but nobody could help him to get to the doctor because the hospital was far from his home. Mr. H said:

“This is the only drug I take, you see it is effective for my stroke? Can you suggest me to use some other medications? If you give me the name of medications, I can ask my daughter to prescribe it from the doctors.”

Mr. Q was the oldest among the 18 survivors. He had two sons. Both of them were taxi drivers. Every month, on a fixed date, one of his sons would accompany him to see the doctors and have some medications prescribed. Mr. Q said:

“I obtain drugs in OPD each month. Each time the drug fee will be no less than 500 yuan, usually one kind one bottle, I have three to four kinds. And my coverage can be reimbursed at once, no delay for me.”

(He is an old carder and had joined the Red Army in his youth. Thus he is treated very well by the government.)

B's daughter described her mother's behavior in doctor shopping as blindly going “from one hospital to another”. B's daughter felt puzzled and said:

“My mother always attempts different hospitals, sometime this hospital is more effective than the other. She will make a comparison among them. But she will visit hospitals once a month. You see, this time she first visited the doctor and had regular medications, then she saw her eyes’ problem in another hospital because she thought that one is famous in healing eye’s disease.”

M’s son comes back home to help his father to take regular medications in the out-patient department. M’s wife said:

“He is no need to see doctor in person, the son will help him to bring medications, only bring along his father’s medical record (prescribed by doctor before discharge home) and show it to the doctor. My son will do it once a month, and do reimbursement in his work unit every six months.”

Mrs. G managed her medications and reimbursement alone. She had to prepare medication regularly in advance. She said:

“I have full medical coverage, but I seldom use it. Because I am at home, and work unit is far from here. Every time I reimburse my medical fee, it will take a long time to go and I have to ask my daughter to accompany me. In fact I can read the explanation of each medication I use. Thus I buy them nearby, such as drugstores. It is cheaper and more convenient.”

Partial medical coverage

Five survivors (Mr. A, Mr. F, Mr. L, Mr. N, and Mr. P) had partial medical coverage. The most frequent problems for them were the cost of medication fee, confusion about the price and efficacy of the medication chosen, and distance concerns. These are illustrated as followings.

A's wife expressed her extreme difficulty in buying various kinds of medications to deal with Mr. A's multiple chronic problems and illness. She stated that she should prepare a large amount of money for medications and to be ready for hospital readmission. She was distressed at their family's financial situation. She noted:

“My son gives me 300 yuan per month, but last time he was admitted to the hospital and spent about 3000 yuan for about 10-day hospitalization. Only 50% can be reimbursed but we have to wait for six months in getting the money back. Now you see, he has five types of chronic illness, at least one type one medication, it is really not enough...Now I have already borrowed money from my relatives for about 2500 yuan, I am so worried if next time he would be hospitalized...”

Mr. L was a newly retired worker with a lower income. He expressed his great resentment at the high cost of medication prescribed by doctors in the hospital. Mr. L described the burden of medication costs:

“Whoever wants to take medicine everyday? For medicine, it is a great burden for me, the doctor said I had to take medicine at least 200 yuan a month, how can I

afford to pay? I select medications and they should be cheap and high quality. An effective medication should be affordable, with a good price, and of good quality. I am used to selecting a cheap and efficacious drug. Every month I spent no more than 200 yuan.”

Mr. F was a persistent man who used to try a lot of alternative ways to test the efficacy of his medication. But he frequently expressed his bewilderment and asked questions about why doctors commonly prescribed medications that were so expensive. In addition, he felt puzzled that each time he was in outpatient department, he met different doctors. This time doctor A gave him one kind of medication (e.g. anti-hypertension). But next time doctor B gave him another kind of medication with the same function (e.g. anti-hypertension). He wondered: “I should follow which doctor’s order? And why they prescribe medication so differently?”

Couple N was honest and quiet. Both of them were retired workers, and their work unit could not cover their full medical costs. N’s husband said he would like to go to the unit clinic to get his wife’s medications because it was either nearby or cheaper. He nodded his head constantly and added: “We seldom visit hospital, yes, we are taking drugs in the clinic, that is enough.”

Couple P was very active and open-minded. They said they had a long history of taking/using medications and were very familiar with the efficacy of the medications they used (Mr. P had about a twenty-year history of diabetes and one episode of stroke

recurrence). They said: “We buy medications in the drug store nearby, the persons working in this store are so familiar with us, they always have medications that we need, we like it.”

Literally no medical coverage

Seven survivors (Mrs. K, Mr. O, Mr. R, Mr. I, Mrs. C, Mrs. D and Mr. E) had literally no medical coverage. All of them used to work in enterprise units that had collapsed since they retired. Thus they selected health care services carefully, or worse, they defaulted medications.

Mrs. C, Mrs. D, Mrs. O, and Mr. E reported they had seldom used health care services since their discharge home. This did not mean that they never took medications, but that they took medications which their relatives bought for them from the drug stores.

Mr. R had a sister working in the hospital as a doctor, and she used to prescribe relevant drugs for him if needed. R’s wife said: “His sister will help him prescribe medications regularly, she is a doctor.”

I’s daughter-in-law was a laid-off worker. Her responsibility was to provide help in getting prescribed medications from the hospital once a month (just like Mr. M’s relative, she also brought Mr. I’s medical records and asked for his prescription). The cost of the medications was usually shared by their children.

Orderly/disorderly management of medication

Eight survivors and their family caregivers (Mr. L, Mr. P, Mrs. K, Mr. R, Mr. A, and Mrs. B) described how they dealt with medications. Of those, four (Mr. J, Mr. L, Mr. P, and Mrs. G) could manage their medications in an orderly manner; and four (Mrs. K, Mr. P, Mr. A and Mrs. B) failed to deal with them effectively. These issues are illuminated in the following cases.

Orderly management of medication

The methods that were frequently used included (a) making a schedule in order to take medications punctually, (b) trying alternative ways to obtain medications in the long run, (c) reading and understanding the proper usage of medication, and (d) preparing enough medication in advance.

Mrs. G described how she managed to take several medications every day. She made a schedule to manage her medication:

“I took these medications once a day in the early morning since it helps me to relieve my constipation. I took the other medications three times a day for controlling my blood pressure.”

J's wife expressed their difficult care situation with regard to access to health care services, but said they could deal with by the situation in their own and alternative way:

“He really can’t get down stairs to see doctor, so I just go down to ask a private doctor to help him measure blood pressure and blood sugar...”

Mr. J added:

“My wife is also weak and can’t walk to hospital, it’s too far away. We cannot get the same pills for blood pressure after finishing the stock. We read from the newspaper that some medications are good for stroke. My wife goes to dispensary to get those medications in need.”

Both Mr. L and Mr. P had a high school and college education. They indicated that they loved to read. Mr. L said he paid attention to carefully and regularly taking medication, but he felt concerned due to his fear of the side-effects of drug toxicity, and the physical discomforts each time he took drugs. And he said:

“I am used to taking notes after having medications so I would not miss taking them. Otherwise eating less or more is not good for health. There is a popular say that ‘one third of any medicine is poisonous’.”

Mr. L could also deal with the problem of abdominal distension problem effectively. He said: “I walk around after meals, then it (abdominal distension) would be improved.”

Mr. P felt capable of handling multiple drugs, but he expressed his lack of proper information about how to properly change drugs in order to avoid side-effects. He said:

“All the medicine is arranged by myself, if blood sugar goes up, I eat less rice. If blood pressure goes up, and I have some particular feeling, I’ll take xin-tong-ding (心痛定) , the dose, more or less, I can manage, please see this, this is my personal diary, I write down a lot of things, such as value of blood sugar, blood pressure, normal and abnormal range, making notes are important for me to remember.”

Couple P explained how they planned for their medication needs at home in advance:

“Buying medicine in the hospital, expensive and cannot be compensated, OK, I just go to the dispensary next door monthly, what he needs (e.g., medicine for hypertension, diabetes) and what we need, such as for common cold, disinfection, I always reserve some, to meet accidental or urgent need,you see, all the medicine for my family are put in this closet, all tidy and in order...this closet was previously a book shelf, how convenient it is! Haha...”

Mr. P also said:

“Yes, she always prepares first, all kinds of medications including Traditional Chinese Medicine Ji-ju-di-huang-wang (枸菊地黄丸), my favorite, have been kept there...”

And P’s wife also described how she closely observed the expressions on Mr. P’s face for changes of blood pressure. She frequently mentioned her husband’s long history of illness experience and gave great consideration to his health. She said:

“He was suffering from the third attack of stroke, his right side of the body felt frequently numb and weak. His blood pressure was unstable while he made efforts to do some housework at home. I no longer allowed him to do any housework even though he could not remain quiet at home. As soon as I found his face turning red, I knew that his blood pressure might be rising....in the past, he loved to plant flowers every day, but he had to give up nowadays, due to his body’s function and unstable blood pressure, not doing any work at home, truly...”

Disorderly management of medication

Five families (Mrs. K, Mr. P, Mr. H, Mr. A and Mrs. B) said it was problematic to deal with medications in an organized manner. These problems included: (a) multiple kinds of pills need to be taken from once a day to three or more times a day, (b) taking drugs irregularly and blindly (e.g. not remembering, based on physical comforts or discomforts), and (c) misplacing medications. These problems were illuminated by the cases below.

Couple A was busy with abundant drugs and all drugs were placed on the table. If Mr. A wanted to take medications, he preferred to be offered them by his wife. A’s wife expressed her “big head” while dealing with so many bottles of drugs and worrying about misplacing them. She said: “He takes some twice a day, some three times a day; if he took more, it would be toxic, but less might not be enough, who can remember exactly?”

Mr. A's voices frequently said:

“How can I know how many kinds of medicine I am using? A big tank, too many kinds, just can't remember. Only my wife remembers....I rely on her. But the other day, she said she had already given me, but actually she didn't, then my blood pressure went up...become so high...”

Mrs. B was a meticulous woman. She showed the investigator a drawer containing various kinds of medications. She said:

“I take drugs like having a meal; if I feel hungry I will have it. That is to say if I have a headache, I will take anti-headache drugs. But one day, I quarrel with my older daughter, I am so angry, then I feel very uncomfortable. I think it must be my high blood pressure. I took three tables at once (usually one tablet) but the headache prevailed. At last I went to see doctor.”

She smiled and added: “The doctor says, you are used to be high blood pressure or low blood pressure? I pause for a while and guess: take too much and now I become ‘hypotension’.”

But she felt problems that sometimes it seemed better to take Western medication and sometimes Traditional Chinese Medicine - herbs. She was afraid of adverse interaction between the two. She said, for example: “Just take these seven bags of herbs, go and see! Then, I have to pay attention to taking hypertensive drug.”

Mr. H frequently described his dissatisfaction with the medication and said that it was stored wrongly by his wife. He said: “One time here, another time there, putting them in different places made me unable to take it on time.”

H’s wife explained: “All the medication was put on the shelf, but he couldn’t find it himself, and then he would be irritable.”

Mrs. K often calculated her medications carefully, but she quitted her drugs on her own will. She said:

“Now my condition is improved, no need to take more medications, but I would like to keep them, in case my condition becomes worsen. If I feel uncomfortable, I will still take them. But now most of the time, I am feeling fine, I am keeping the drugs and saving money.”

R’s wife was a capable woman and managed her family’s expenses precisely. But she was worried about her husband’s way of taking medications. She said: “You see, he used to take them today and forget tomorrow; in this regard, taking medications is meaningless for his health.”

Ambivalent attitude towards taking medication

Four families (Mrs. K, Mr. A, Mrs. B and Mrs. C) suffered tremendous confusion regarding how to take their medications in the home care setting. These issues are demonstrated by the following cases.

Mrs. A was very distressed and upset when she described Mr. A's unpredictable behaviors in taking medications by "sometimes eating or not eating even at midnight", resulting in a conflict between them. She said since Mr. A had four chronic diseases (e.g. coronary heart disease, hypertension, asthma and diabetes), there were more than ten kinds of drugs to be administered each day. On the one hand, Mr. A was strictly adherent to his doctors' prescriptions based on the time and dosage before or after meals. On the other hand, he was extremely scared by the drugs' side-effects, and therefore sometimes took medications according to his own preferences.

He said:

"I always follow the doctor's orders, I never take any other medicine, I'm afraid of being intoxicated...How can I know how many kinds of medicine I am using? A big tank, too many kinds, just can't remember. Only my wife remembers....The other day, she said she had already given me, but actually she didn't, then my blood pressure went up...become so high."

Mrs. B thought that Western medication must conflict with traditional Chinese Medicine (TCM) and worried about the side-effects of combined medications. She preferred to take one kind at a time. She said: “Just take these seven bags of herbs, go and see! Then, I have to pay attention to taking hypertensive drug.”

B’s daughter recounted: “She said there might be conflicts between all these drugs, so I quit them all. Today, I again dig them out for her.”

Mrs. C was worried about addiction while taking sedative pills because she could not sleep at night. She said: “Can this kind of sedative tablets be taken? I dare not, afraid of being addictive, but I am unable to sleep...”

Mrs. K expressed her attitude toward whether high or low prices of drugs were considered as good or effective drugs. She said:

“People say good medications must be expensive. That means good quality and efficient drugs. I want to eat good drugs, but if expensive, I can’t afford it, I don’t like to take cheap drugs, because it must be low quality, am I right?”

Adherence to medical prescription or self-prescription of alternative therapeutics

Adherence to medical prescription and therapeutic regime appears to be significant to maintain an optimal state of health and prevent stroke recurrence. It is interesting to show

that medications are prescribed differently after discharge home. One method is adhering to medical prescription and the other is self-prescription of alternative therapeutics.

Adherence to medical prescription

Three survivors (Mr. Q, Mr. N and Mr. I) expressed their willingness to adhere to doctors' order in taking medications. They provided their experiences below.

Mr. Q described how he followed his medical prescription and was proud of his good health. He said: "I strictly follow the prescription, never missing them, never forget them, you see how strong I am."

Mr. I described his experience of taking medications and was very proud of the improvement in his health while strictly followed doctor's order with regard to medications. He said:

"I cannot recognize the instruction words on the bottle instruction because they are too small for me to read, so my medicine intake is all arranged by my daughter-in-law. I have gained an experience of my condition improvement, one of the important lessons is to follow the medications, insist and persist, the body will be better."

N's husband was a kind and warm old man. He used to smile and talk actively, and he strictly followed the doctor's prescription. He said:

“I bring each pill of medications for my wife from the clinic, each time I went out to get them because her mobility was not so well. I do it, no problem. Now you see, this drug is right for her? How about that one? ... She is better, right?”

Self-modification of medication regime

Four stroke survivors (Mrs. K, Mr. O, Mr. P and Mr. F) modified their medication regime according to their own free choices, as illustrated in the following.

Mrs. K took her medications based on her personal feelings, and prescribed her drugs by herself. She said: “Usually I take one pill per day, no particular feeling, blood pressure is all right; if I feel uncomfortable, I’ll take an extra one.”

Mr. F expressed his distrust of the doctor’s prescription due to its high cost but low efficacy, he said:

“The medicine prescribed by this hospital is expensive and not effective, what’s wrong? Now I prescribe all by myself, from medicine shop, buy Chinese herbs, the advertisement in street said ‘ling-zhi’(fungus glossy) was good, buy three doses, an extra one would be given free of charge, see, this costs more than 600 yuan.”

O’s daughter was a considerate person. She brought her parents to live with her family and assured them that this would be better for her mother’s health. They never paid a visit

to the doctor after discharge home, and dealt with the medications in their own way. She said:

“My mother had been diagnosed with diabetes. But when she took this drug for diabetes, she was sweating heavily. Then I stopped it, she no longer takes this medication now. Now she takes medications obtained from my elder sister. She bought it from the drug store and someone recommended that drug would be good for her.”

Mr. P was an upright piano worker (good at fixing pianos). He called himself a good family doctor due to the long duration of his illness (久病成良医) and to cure a dead horse as if it is alive (死马也当活马医) (20 years of diabetes). He showed the investigator his pill-case, which was placed in his bedroom. He said:

“All kinds of drugs are here, from catching cold to my personal use for the whole family, I bought them from drug stores. I understand them so well and had a lot of experiences on how to use them.”

6.2.2 Management of physical discomforts

Physical discomforts include a variety of pains (i.e., shoulder pain, tooth-ache, joint pain, headache), dry cough, eye problems, physical fatigue and body numbness in eight cases (Mr. J, Mrs. K, Mr. P, Mr. F, Mr. A, Mrs. B, Mrs. C and Mrs. D). Shoulder pain was of most concern among the survivors. How they experienced these problems and managed them is illustrated by the following.

Mr. J described how his shoulder upset him and the helper assisted him to deal with his shoulder pain through massage. He said: “When my shoulder hurts, he (the helper) massages for me, then I feel at ease.”

Mr. A added to his shoulder problems, saying: “My shoulder hurts badly, I can’t move...When my head ache appears, I am very concerned of recurrent stroke...”

Mrs. K felt distressed during the night while her tooth was so painful. She said: “Last night I had tooth pain the whole night, this, see, swollen, they said there’s ‘fire’...My eyes also in trouble, they said it was caused by ‘fire’.”

Mr. P said the numbness in his leg troubled him while walking. He said: “This leg has numbness, no sensation at all, I just knock my leg...”

Mr. F said his fatigue was overwhelming in the earlier visits, which made him feel he needed someone to accompany him. He said:

“To have treatment in the hospital, I run out in the morning and came back at 12 (noon time). I am exhausted and feel sick while climbing the high stairs (he was living in the sixth floor).”

Mrs. B said: “My cough is very annoying; I have taken lots of medicine and had injections, but not effective...”

Both Mrs. C and Mrs. D had frequent pain in their legs: they said their legs were in extreme pain all the time, and particularly disturbing at night.

Mrs. C said: “I have terrible pain in my leg, pain attacks at the interval of several minutes, I myself can’t sleep well, I interrupt my old partner’s sleep too.” And C’s husband nodded his head helplessly: “Always.... always... pain, no stop...not dare to take any pills.”

Mrs. D described her pain and the hard time she had at night. She said: “I cannot asleep and close my eyes, there must be someone helping me massage my left leg, then I can sleep for a while...the neighbor is noisy you know...” And D’s daughter-in-law murmured sadly: “She always asks someone to accompany her, stand beside her, whatever days and nights.”

D’s helper, 38 years old was kind and sympathetic to Mrs. D’s constant pain at night. She offered to massage Mrs. D’s leg so as to relieve her suffering. She added: “I must touch her left leg in a soft manner, anyone either too light or too heavy she will yell, only me she said it is comfortable to her...”

6.3 Care issues of caregivers

The experience of providing care for survivors had an impact on the caregivers' lives in their daily activities, particularly in the management of their own physical and psychosocial health. Not only did the family caregivers have to deal with multiple care issues for survivors, but they also had to find ways to deal with their own safety issues and physical and psychosocial disturbance (Bakas et al. 2002).

In the present study, four primary family caregivers (M's wife, I's wife, J's wife and C's husband) talked frequently about their safety issues and physical problems in taking care of their spouses in 24 hours a day.

M's wife (70 years old) had an accident. Her left leg was badly burned and she had to have the dressing changed every other day in the hospital. She could not move and had to lie down in bed for over one week. She was still scared by this experience because her leg was so painful at that time. The following are her recollections.

She recalled her experience with a severe burn on her left leg near the ankle. She mentioned that it had happened in the first week after Mr. M was discharged from the hospital.

“...When pouring boiled hot water from kettle (the kettle is on the stove, and the stove is fired by coal on the ground floor), I bent down and wanted to pour water into the thermos bottle, my eye sight was no good due to steam water, suddenly, the

kettle turned upside down, hot water burned a large part of my leg,...it really hurt and caused great pain,...my son took me to emergency department, then I couldn't walk for a whole week...my left leg was burn by boiling water. The pain was just like a needle plunging into my skin, my feet even could not touch the ground for a whole week, oh, you don't know how painful it was..."

M's son added: "You don't know, my mother was extremely afraid of pain. That is why she did not come to see doctor, she dislikes hospital."

Initially, her sons took complete care of her, but later there were no other family caregivers available to give her a hand.

In addition to this issue of safety, three primary caregivers were confronted with their own physical discomforts in this long process of care experience, and worried about their own health conditions. These issues are also significant and should not be overlooked because they are the primary sources and the only services for survivors after discharge in the home care setting, and more significantly they themselves could become another potential 'sick person' if not given enough attention after their patients' discharge from hospital.

I's wife expressed her emotional disturbance and said that her social life was restricted by offering care on a 24-hour basis. She said: "He really tortures me, always calls me again

and again, to go to toilet, he needs help, he will shout 24 hours, I am fully occupied, it makes me bored...”

And she further described her problems with sleeping disturbance. She said:

“Sleep, I can not sleep well, very tired, call me....call me for a while, everything calls me....Day time at home without going outside anywhere...I feel sleepy, but I can not fall asleep...what can I do?”

J’s wife expressed her exhaustion while taking care of her husband day and night:

“During this period I have been taking care of him, it makes me collapse. If I want to go to hospital, I am not able to walk, my legs are very tired.”

P’s wife described how busy she was doing housework and taking care of the other family members’ competing needs, like taking care of their grandson living with them as well as her stroke survivors at the same time. She expressed her physical discomforts in a low tone:

“You see, I have to do all housework, he would like provide me a help, but I am afraid of his illness to be recurrent, I do both inside (e.g. cleaning room, cooking and washing) and outside (e.g. go to supermarket, picking up grandson from the school in the morning and afternoon)...As soon as I sit down, I feel back ache, cannot move; this hand, you see maybe tendonitis, fingers look like disfigured.”

C's husband appeared very distressed while talking about his night hours taking care of Mrs. C over the six months after discharge home. He said with deep and sunken eyes:

“I am used to sleeping so well even though there is a thunderstorm outside. But now I cannot sleep even for a while due to her constant callings and complaining of her leg pain. I have to watch TV for the whole night...what can I do?”

6.4 Coping with stroke-related residual disability and multiple care issues

As stated earlier, effective strategies and skilled care are a necessity, as is an understanding of the increasingly complex and multiple care issues (Shyu 2000, Mumma 1986). More importantly, readjustment to the changes related to a stroke-related residual deficits and disability is essential for adapting to a variety of losses (Doolittle 1991, 1992, Folden 1994).

Stroke-related residual disability is associated with the limitation of the activities of daily living involving personal activities of daily living such as eating, bathing, grooming, dressing, bowel and bladder, toileting, transferring, mobility and stairs; and instrumental activities of daily living like handling money, working or housework competency, shopping, hobby, simple housework, preparing meals, knowing one's affairs, discussing, remembering and using transportation. It needs a long process of recovery for stroke survivors to cope with their stroke-related residual disability on the one hand, and it is necessary for family caregivers to cope with their multiple care issues on the other.

Orelando (1972) stated that the process of individuals interacts with each other. This process involves the individuals' reaction including their perceptions, thought and feelings. Then an action selected by each individual in response to this reaction. In this study, when the stroke survivors and family caregivers act and manage their stroke-related residual disability and their activities in daily living and daily care hassles, the coping process transpires. Any behaviors were observed from the stroke survivors can be viewed as a sign of realigning their competences in their activities of daily living and daily care hassles, indicating he or she could find out one's own immediate needs and meet them, while these behaviors were observed from the interaction between the survivors and their family caregivers can be considered as a signal of active and proactive management of multiple care issues, showing that their family caregivers could figure out the stroke survivors' immediate needs and meet their needs properly.

When the stroke survivors' coping behaviors are observed as an accurate recognition and active action of their abilities in dealing with their activities of daily living, the survivors' functional and emotional status, and social activities were improved over time, it represents that they are able to completely realign their competences in their activities of daily living, thus the realignment in activities of daily living occurs. These families could sustain optimal family well-being living with stroke at six months after discharge home. When the stroke survivors' coping behaviors are only observed as an active action, but there is a lack of an accurate recognition of their abilities in dealing with their activities of daily living, the survivors' functional and emotional status, and social activities were less improved over time, it denotes that they are partly capable of realigning their

competences in their activities of daily living. These families could maintain functional family well-being living with stroke at six months after discharge home. However, when the stroke survivors' coping behaviors are observed neither as an active action, nor an accurate recognition of their abilities in dealing with their activities of daily living due to the high levels of stroke-related disability (Mrs. C, Mrs. D), the lack of awareness of the functional limitation (Mr. A), over meticulousness (Mrs. B), lack of family support (Mr. E), either the survivors' functional, or emotional status, or social activities were deteriorated over time, it notes that they fail to realign their competences in their activities of daily living, and these families could end up with dysfunctional family well-being living with stroke at six months after discharge home.

While the interaction of their management of their care issues between the survivors and their family caregivers is observed actively, particularly both stroke survivors' and their family caregivers' care issues are met, the active and proactive management of care issues occurs. These families could sustain optimal family well-being at six months after discharge home. Although the interaction is observed actively, either the survivors' or their family caregivers' care issues were not met, such as eliminating issues related to functional limitation (Mr. H), issues of caregivers' need (Mr. I), multiple issues related to living alone (Mr. F, Mrs. G), these families could maintain functional family well-being at six months. However, the interaction is observed actively or passively, neither the survivors' nor their family caregivers' care issues were not met, such as eating and meal preparation (Mr. A, Mr. E), eliminating issues (Mrs. C and Mrs. D), expressing sexuality

(Mr. E) and disorder management of medications (Mrs. B), these families could end up with dysfunctional family well-being at six months.

The following discussion focuses on how these 18 cases perceived their post stroke and care experience and how they acted to deal with their activities of daily living and care issues by the three types of family well-being. Two parts are delineated: realignment of personal competence in activities of daily living and active and proactive management of daily care hassles

6.4.1 Realignment of personal competence in activities of daily living

Optimal well-being of the family living with stroke

J's wife was a considerate old lady. She described how her husband used to keep himself busy doing housework tasks, but right now he had to readjust himself to his reality. He accepted his new role (successful transformation of his caregiving role into his care-receiving role) actively and met his own needs. He was sitting still (walking dependently), enjoying reading newspapers and discussing national affairs. She stated: "Watching TV news and weather broadcast at seven o'clock in the evening. That is his favorite. While he is watching, I make bed for him."

Mrs. K described a sense of numbness in her affected hand and leg after discharge home. Both she and her family members recognized her limitation in activities of daily

housework tasks (e.g. meal preparation, shopping). Mrs. K had therefore actively adjusted herself to doing fewer tasks, and her daughter-in-law's actively provided her assistance. Mrs. K recounted: "She (daughter-in-law) washed, and prepared, then I cooked."

Mr. L attempted to readjust himself to his ability from running to slowly walking after suffering from a stroke. He was conscious to actively do exercises so as to maintain his body's strength and health. He said: "I used to run and play foot ball, I love sports. But now I have to walk, slow walk around the playground after a meal, never stop."

Mr. M had experienced a couple of falls. At six months after discharge he said he felt better and had had no more falls because he recognized how to protect himself from falls and was cautiously aware of safety issues. He described his experience as "Place my hand on wall...no more falls again."

Mrs. N was a quiet old lady. She used to talk little and sat calmly. She said she used to do all the housework tasks both inside and outside. But right now she only worked inside and assigned the outside tasks to her husband. N's husband recounted this change as "She is in the kitchen only, I go out to the market for buying things."

Mr. P described his problem with long walks outside due to fatigue. In order to insist on going for a stroll, and to conserve more energy, he said he could get more exercises by riding a bicycle than going around outside on foot.

Mrs. O and Mr. R managed their inability to walk and move around effectively due to fatigue by “sleeping and resting more” in order to conserve energy.

Functional well-being of the family living with stroke

Mr. F, 72 years old, was living alone and used to be good at running and in a good state of physical health. He was an extremely active man and could not stay still at home for long. When he was diagnosed as having stroke, he could not accept and recognize correctly the diagnosis made by his doctors. He denied it and insisted on his own understanding and diagnosis. He was reluctant to use a stick when climbing the stairs (he lived on the sixth floors), and did his exercises vigorously. As a result, he had fallen down several times and gone to the emergency room to have his wounds sewn, his ankle by overdoing exercises. He was active but he was suffering from secondary injuries due to lack of awareness of his personal competence at present. He recounted the change and attempted to draw his lessons from his falls on stairs:

“Climbing the stairs slowly, and holding the banisters tightly. But sometimes I cannot control my body and balance. I hit my head and ask it why you do not give me a signal?”

Thus readjusting oneself to his new competences and being aware of the change are crucial, especially for newly diagnosed stroke survivors.

Mrs. G described her walking in the street, which might not be so safe without her daughter accompanying. She said she would do exercises on a platform at home. “Firstly, I am standing still, then slowly moving up and down repeatedly.”

Mr. H had a hot temper because of staying at home all day long. He could not manage his temper well and easily become irritable. He actively practiced walking at home and went at a fast pace. But H’s wife complained that he was unable to control his body safely and prevented him from walking. H’s wife expressed her worries frequently as “I am fearful for his falls”.

Mr. I was unable to stand steadily in the first month after discharge home. He actively did exercises on the corridors and gradually recognized how to increase his exercises effectively from short to long distance. He said: “From one floor to two floors, now go downstairs and walk around this building, persistently.” His functional status was improved over time, however, he partly failed to perform his self-care activities, such as toileting, simple housework tasks (e.g. make tea). At six months, his wife complained of an increasing burden of care because of her own physical discomforts.

Dysfunctional family well-being living with stroke

Mr. A was actively to do things for himself. He used to shave his face by himself, but his face was injured by the blade, he was scared and repeatedly said: “No more shave, I am so scared ...”. After that he was reluctant to perform his self-care tasks and dependent

upon his wife completely. He thought he should be taken care by his wife and his son because of fostering the sons for future supporting of the father (养儿防老).

Mrs. B was a very capable old lady, but she was passive to do anything (she was independent in her functional status). She said she could not do any housework activities because she needed rest following her stroke. She hired a young helper and depended upon her completely in her housework activities. She recounted her avoidance of doing work as “no doing any work; if tired, be recurrent again.”

Mrs. C and Mrs. D lay in bed day and night, they were completely dependent upon others because their functional status was completely limited (ADL rating ranging from 20 to 30). They were lying helpless in bed and asking: “When I could be getting up?”

Mr. E actively dealt with his self-care activities, but he had great difficulty eating and preparing his meals. His sons seldom offered him a help. He had to take simple food like porridge (water rice 稀饭) and curd (豆腐) every day because “I am unable to make good food”.

6.4.2 Active and proactive management of care issues

Optimal family well-being of the family living with stroke

Couple J frequently worked together to get dressed on and undressed, as well as for meals and to choose proper and healthy food on a daily basis. They made joint efforts to help each other “make the bed and get dressed quickly due to cold weather”. J’s wife managed her husband through change in food choice, which she properly used their knowledge of the benefits of avoiding eating a high-fat diet - “take off egg-yolk, give him only egg-white” - in order to maintain good nutrition and prevent stroke recurrence. Meanwhile J’s wife described their difficulty in accessing to health care services, and considered such as going to the dispensary to get that medicine instead. In this case, J’s wife was active and proactive management of her husband’s multiple care issues in eating and meal preparation, dressing her husband and medication properly.

K’s husband smiled while explaining how a change in family meal practice happened when Mrs. K began to adhere to the principles of the doctors’ orders to eat food according to the ‘three lows’ rule (e.g. low fat, low sugar and low salt), which meant the whole family had to eat “all light food with low salt and low sugar”. In this case, Mrs. K and her family members (e.g. her husband, sons and daughters-in-law) were active and proactive management of care issues (e.g. eating and meal preparation, medication) and supported each other in physical and psychosocial aspects.

Mr. L had partial medication coverage and engaged in orderly managing his medications by “selecting a cheap and effective drug”, “walking around” in order to achieve the goal of a long-term medication taken for high blood pressure, and decreased his abdomen distension following the side-effects of a drug. In addition, he also provided his assistance for his family when his function was improved over time. In this case, Mr. L was active and proactive management of multiple care issues not only for his self-care activities, but also for his wife (e.g. meal preparation) and his daughter’s family (e.g. picking up his grandson’s from the kindergarten) at six months after discharge home.

Mr. M had complete medication coverage and insisted on follow-up by taking prescribed medications regularly with the assistance of the family (e.g. his sons and wife). As mentioned above, “the son will help him to bring medications”, which assisted him to be able to adhere to the doctors’ prescription even though he had limited motion. M’s wife was careful to prepare soft food for him because of his eating problems and he was satisfied with her wife’s arrangement. In this case, M’s wife and sons actively participated in managing Mr. M’s multiple care issues (e.g. medication, eating and meal preparation) and Mr. M’s condition was improved over time.

Mrs. N had partial medication coverage too, and N’s husband would help her to management her medication orderly and in the long run by “seldom visiting the hospital and taking drugs in the clinic”. In this case, N’s husband actively helped his wife to see doctors and get proper medications, and he was active and proactive management of

housework tasks which he was seldom involved in the past. Mrs. N was very satisfied with him and her condition was improved over time.

Mrs. O had no medication coverage, and seldom used health care services for medication. Her daughters would obtain medications from the drug stores based on their self-prescribed medication, so as to ensure that Mrs. O took her medication for long-term management of her blood pressure and diabetes. In this case, O's daughters were active and proactive management of their mother's multiple care issues (e.g. eating and meal preparation, medication) and daily care hassles (e.g. providing emotional and financial support). Mr. O's emotional status was dramatically improved over time (from depression to normal status).

P's wife described her husband's long history of illness and how couple p engaged in managing the medications orderly, such as using closely monitoring, making personal notes making and remembering so as to accurately monitor change in blood sugar and blood pressure. Furthermore, they also handled multiple drugs in an alternative way: some might be adherent to their doctor's prescription and others relied on their own prescription based on their own monitoring and recording, as mentioned by "arranged by myself" and observing the change of blood pressure from the color of Mr. P's face. In this case, couple P was active and proactive management of multiple care issues (e.g. medication, eating and meal preparation) and Mr. P's condition remained stable over time.

Mr. Q had complete medical coverage and closely adhered to the prescribed medications as he mentioned previously “I obtain drugs in OPD each month”. In this case, Mr. Q was mercy father who treated his sons and sons’ families properly (e.g. offering financial and emotional support for the two sons’ families). In turn, his two sons and daughters-in-law were active and proactive management of multiple care issues (e.g. medication, eating and meal preparation) and Mr. Q’s condition was improved over time.

Mr. R had literally no medical coverage due to his work unit being bankrupt. They overcame their shortage of medications through seeking help from R’s sister, who was “working in the hospital as a doctor”. R’s wife constantly reminded her husband to manage medication orderly. In this case, R’s wife were active and proactive management of care issues (e.g. eating and meal preparation, mobility, mediation issues) and daily care hassles (e.g. providing emotional support).

Functional well-being of the family living with stroke

Mr. F lived alone, had fallen five times, and tended to over-exercise, which had resulted in a bad ankle sprain. He was very worried about his future and hit his legs repeatedly, murmuring “why you do not follow to instruction and my commanding...”. He had partial medical coverage and actively went to see the doctors. In the later visits, he felt doubt about the efficacy of the medication. He attempted to modify the medication regime by his own choices. In this case, Mr. F was active management of care issues, but

sometimes he dealt with them less smoothly. He continued to deal with them and drew lessons from his experience over time.

Mrs. G had complete medical coverage and she described how she took several kinds of medicine every day. She said she made a schedule to manage her poly-pharmacy orderly. She was active and conscious to deal with care issues by herself. But she felt uncomfortable to live with her daughter's family because of her son-in-law's cold attitude.

H's wife was very careful and active in preparing food and seeking alternative ways to manage her husband's diet and eating problems: "I just cook noodles, put some tender pork, milk twice a day, then banana". Mr. H suffered functional limitation in eliminating need because he perceived her wife's movement which was too slow. He always complained about his wife who did not incorporate his requirements immediately. Mr. H had completely medical coverage but nobody could help him to get to the doctor and the prescribed medications.

I's wife said how considerate her children had been to take care of Mr. I's safety after discharge home: "specially bought him a 'chair' (for toilet seat)". She also managed his diet through change in meal schedule, which was always careful in scheduling meals for Mr. I's good health, eating the more frequently, the better, such as "five meals a day". I's daughter-in-law assisted him to get prescribed medications from the hospital regularly. But with the time went by, she started to complain about preparing a big meal for "more than ten people!" at the weekend and this made her extremely exhausted. In this case,

even though Mr. I's condition was improved over time, I's wife's emotional status became worse at six months after discharge home.

Dysfunctional family well-being of the family living with stroke

Mr. A had several chronic health problems. His diet was strictly controlled as doctors prescribed. A's wife actively attempted to manage his eating and meal preparation, Mr. A complained about the change in his food choices as too "cold" or too "greasy" or too "little". He had a razor bleeding accident and a fall experience. He had partial medical coverage and actively got his prescribed medications. Couple A had difficulty in managing multiple kinds of pills and dealing with them orderly. They also expressed the extreme financial burden to see doctors and admit to the hospital. Mr. A constantly complained about his wife's improper administration of many kinds of drugs. And his wife found it difficult to manage his poly-pharmacy every day in order to control Mr. A's high or low blood pressure. In this case, Mrs. A was active management of his husband's care issues, and felt difficult to manage them well. Mr. A felt incapable to take care of himself (e.g. reluctant to walk) and completely depended on his wife. Even though Mr. A's functional status was improved over time, his emotional status became deteriorated over time.

Mrs. B had complete medical coverage and was proud of having plenty of good drugs and both Western medicine-herbs and TCM-herbs. B's daughter felt puzzled as "from one hospital to another" and "blindly". She actively managed her medications, but she

could not manage them orderly because she was only relying on her feelings of comfort or discomfort instead of according to the doctors' prescription. In this case, Mrs. B failed to manage her medication orderly and had an ambivalent attitude towards taking medication.

Mrs. C had a urinary incontinence and a big bedsore on her back, and she was afraid of drinking water due to urinary incontinence. C's husband actively dressed the bedsore wound by himself her at home, but the wound was deteriorating. Mrs. C had literally no medical coverage and seldom went to see doctors and obtained the prescribed medications after discharge home. C's husband could not manage his wife's physical discomforts (e.g. leg pain) and both of them suffered a disturbance of sleep.

Mrs. D had bowel incontinence and was helpless about stool coming out on the bed; she felt disgraceful when her son offered her help. She had literally no medical coverage and did take any prescribed medications after discharge home. She was completely cared by for the helper and other family members involved less and less. The helper could not manage her physical discomforts (e.g. leg and back pain).

Mr. E had been widowed for more than five years. He felt extremely lonely and was eager to seek female company. He described himself as seeking his own solutions for his sexual needs. He was affected by transmitted sexual disease once and cured in a local clinic. He was active to walk and had falls for several times. He had difficulty in eating

and meal preparation and he had his very simple food (water rice) every day. He had literally no medical coverage and he failed to take any prescribed medications.

The above three cases (Mrs. C, Mrs. D and Mr. E), the families failed to manage care issues actively and proactively and daily care hassles over time. These stroke survivors' health conditions became deteriorated at six months after discharge home.

6.5 Summary

Both the stroke survivors and their family caregivers identified three major areas of care issues surrounding activities of daily living related to stroke-related residual disability and care provided by families. These issues were: (a) care issues surrounding activities of daily living, (b) care issues surrounding health problems, and (c) care issues of caregivers.

Two major strategies were properly and successfully adopted by the 18 families to cope with these issues over time. They were (a) realignment of personal competence in activities of daily living, and (b) active and proactive management of care issues.

However, *how* the survivors and family members interacted with each other, *what* effective personal coping resources they mobilized to cope with these care issues, and how the well-being of the family was sustained over time need to be further examined and explained, thus these issues form the basis of the following detailed discussion in chapters seven, eight and nine.

Chapter Seven

Family Dynamics in Caring Work Organization

Doolittle (1988) stated that personal background could help us understand how social action is personified, and provided us with a great deal of insight into the details of individual-cultural interplay. The personal life is substantially constructed by the realities of stroke (Davis & Grant 1994), and it fosters insights regarding the complex nature of the post-stroke experience and care experience (Doolittle 1992) in each unique individual and family.

Suchman et al. (1998, p. 9) stated that “Each of us has a personal philosophy that shapes our perceptions, interpretations and actions”. His/Her work addressed questions such as why things happen, what is right and what is wrong, and why are here; our personal philosophies give rise to our own individual ways of being in the world and also frame our goals and expectations.

Williams (1987) further stated that the value of the role expectation is significant, since the value of the individual acting out his or her daily tasks is frequently associated with the kind of the role that is valued and expected by the society they are living and interacting in. Thus what the stroke survivors and their family caregivers value in context influence their acts and behaviors.

Culture specifies the prescribed roles and responsibilities of each member within the family, and also decides who should be the family caregiver and how the care should be provided (Dai & Dimond 1998). Sung (1995) further stated that filial piety is a significant cultural concept that influences the ability of family members in the process of caregiving.

Filial piety is also a significant concept in Chinese society which can be addressed by a set of role requirements and responsibilities prescribed by the basis of three dominant links and five cardinal relationships (三纲五伦) (Tang 1993, Anonymous, 2004).

The three dominant links imply ruler being superior to minister (君为臣纲), father superior to son (父为子纲) and husband superior to wife (夫为妻纲), which reflected by the same situation, in which son is regulated by father, and wife is ruled by husband in the family internal relationship. In this perspective, everyone should act as a prescribed role. That is ruler must act as a ruler, minister must perform as a minister, father must operate as a father, and son must behave as a son. For detail, minister must serve for ruler, son for father and wife for husband. The prescribed role responsibility is strictly required that minister must be loyal to his ruler (“loyalty” “忠”), son must pay due respect to his parents (“filial piety” “孝”), and wife must be obedient with her husband (“obedience” “从”) (Tang, 1993).

On the other, the five cardinal interpersonal relationships deemed as the strengthened the above three dominant links. Besides the above three dominant links, it adds older brother and younger brother, and friend and friend. Among these five relationships, three of them (father-son, husband-wife, and older brother-younger brother) express intra-familial relationship, and the father-son relationship is primarily ahead of the relationship between the ruler and minister (Anonymous, 2004). Furthermore, the other two relationships (ruler-minister and friend-friend) are considered as the extended and enforced intra-familial relationships. In this sense, the prescribed role obligation is regarded that older brother and younger brother (“sequence” 长幼有 “序”), and friend and friend (“诚”信, faith).

Filial piety and the prescribed traditional value of family role responsibilities are values upheld in the three dominant links and five cardinal relationships. This principle requires that the father must operate as a father, the son must behave as a son, and wife must be obedient to her husband (Tang, 1993).

Based on this understanding, the principle of these three links and five relationships requires that the father must operate as a father, the son must behave as a son, and wife must obedient to her husband. This principle is important in regulating family stability and harmonization in traditional Chinese family. There are two aspects needed to be considered. One is obedient and the other is sacrificing. The family members are expected to devote themselves and to sacrifice their own interests in physical, financial

and social aspects to maintain their elderly parents', husbands' and children's basic needs and well-being on the one hand, they should also respect and care for their older parents and other sick family member on the other. Parents are also required to behave themselves, be broad-minded and fulfill their responsibility by raising, loving and educating their children. The personality of the parents is very important; if parents set a good example, then they will win the love and respect of their children.

This may not always happen. There are several studies addressing the significance of the transformation in family role responsibility in the family caregiving process over time.

Skaiff and Pearlin (1992) have suggested that as the new caregiving role commences, one can assume that some reorganization of daily activities and tasks will happen. Thus the individual's previous activities can be transformed or altered by caregiving activities.

Jongbloed (1994) also analyzed one couple's difficult experience of their role responsibilities in allocating day-to-day tasks at home. And Robinson-Smith and Maboney (1995) examined seven older couples who had different experiences in their marital relationships. Some noted benefits and others drawbacks.

Fraser (1999) examined two daughters' experience and how stroke had changed their close relationship over time due to the increasing burdens of care (e.g. demands on time and energy spent to take care of stroke survivors at home).

Finally Secret (2000) examined different primary caregivers (e.g. spouses, mothers and daughter). It is noted that most primary caregivers expressed a greater connection and congruence with stroke survivors with respect to what made the other happy. Although these studies show the significance of personal transformation in the family caregiving process, little is known about *how* the family members interact in this post-stroke and care experience, *what* they value greatly, and ultimately *how* caring work be organized over time.

In the present study, as analyzed and shown in Table 5.3 (p. 192), five types of family structure are identified in the 18 cases under study. Of the 18 families, 14 families had maintained the traditional type of the Chinese family structure. Of those, eight families had two or three generations living together in the same household, which modeled a traditional Chinese extended family, and six families shared their daily living in part, with four two-generations families having meals together although not living under the same roof (modified nuclear family), and two two-generation families living under the same roof but not having meals together (modified extended family). Finally, only three families belonged to the nuclear family category, and one survivor lived by himself. Table 4.5 (p. 167) in Chapter four categorizes these 18 families in five types of

family structure by the three types of family well-being, which shows that whether the families living with stroke can have the family well-being sustained is not dependent on family structures. Indeed, the Chi-Square analysis as shown in Table 5.3 (p. 192) revealed no significant difference in the five types of family structure by the three types of family well-being ($p>0.05$).

Against this background, the task of this chapter is divided into two parts: (a) to examine the dynamics of the family relationships that constitute the different patterns of caring work organization in families living with stroke, and (b) to scrutinize how the three types of family well-being are developed based on the three patterns of caring work organization. Drawing on qualitative content analysis (e.g. the field observation notes and interview transcriptions), the interactions among the members within each family under study were analyzed for the different patterns of caring work organization. They were cooperative, compromising and disengaged organization of caring work. The followings are expositions of how these three patterns of caring work organization manifested in the 18 families. And then the dynamics of family relationships were discussed by the interactions between lateral (the wife and the husband) and vertical level (the parent and the children) to look at whether prescribed traditional role expectation could be fulfilled and role responsibilities could be transformed.

7.1 Cooperative organization of caring work

Cooperative organization of caring work was found in those families who could perform prescribed family role expectations harmoniously or make their personal transformation successfully over time. They were: (a) meeting traditional Chinese family role expectations, and (b) transforming family role responsibilities.

7.1.1 Meeting traditional Chinese family role expectations

Five families (Mrs. K, Mr. M, Mrs. O, Mr. Q, Mr. R) were able act and perform their prescribed family roles and meet their expected and mutual needs by upholding traditional family values. These values included: the wife taking good care of her husband and being obedient to her husband in need (夫唱妇随), parents loving their children and treating them kindly (上慈), and children acting as filial sons and daughters (下孝).

Mrs. K's family demonstrated how these values were upheld by their sons and daughter-in-laws. Mrs. K was 65 years old. She and her husband lived on the 6th floor with their second son's family and two unmarried daughters. The total income of the old couple was 800 yuan. She was independent in activities of daily living at the four time points (ADLs: 100). And she was able to live independently in the community. In addition to stroke infarction, she was diagnosed with diabetes.

In the first week after discharge home, the whole family had been worried about her situation since she had had no previous medical problems. Two of her daughters-in-law took turns to cook, and the oldest son was responsible for accompanying her to see her doctors for prescribed medications once a month. One month after discharge home, the old couple would go shopping and prepare meals for the whole family in order to support their children's full-time jobs, and the relationship between the family members was harmonious. She expressed her satisfaction with the whole family's concerted efforts and said: "They are used to coming back home late, but I wait for them and make sure they eat well, either fresh or warmed up, because they work hard."

K's husband was an old worker. While talking, he inhaled deeply on a cigarette in his fingers, and added with a contented expression:

"To offer love to our children and grandchildren, gives us very great satisfaction and happiness...we have five children, they are all very kind, if one offers a little heart of filial piety, then I will have five hearts of filial children, you see I receive and enjoy filial love every day."

Mr. M's family demonstrated how his obedient wife and filial sons acted over time. Mr. M was 65 years old. The couple had four sons and one daughter, and was living in their own flat and with two sons' families. One was on the third floor and the other on the second floor. Their total income was 800 yuan. His stroke disability rating went from severe limitation of function to moderate over time (ADLs: T1:45, T2:45, T3:55,

T4:55), and he was dependent upon others at home and in the community (I-ADL: T2: 25, T3: 24, T4: 26). Besides his first ever stroke, and he had several chronic illnesses (e.g. advanced hypertension, coronary heart disease, chronic renal disorder).

The couple's living surroundings were dark, poorly equipped. They slept in a short double bed. M's wife was 65 years old, illiterate, and a typical housewife. She was always busy in and out, while taking her responsibility for her husband. She had become bent and hunchbacked. (Observation: Mrs. M. seemed never to be worried, always satisfied, used to taking care of others, comfortable, and smiling peacefully. She was diligent, cooking on the stove, bending and working almost without rest. Besides caring for her husband, she also cooked for the whole family, working hard and enduring hardships, regardless of criticism). The relationship between the family members was harmonious. She described her obligation calmly:

"I am used to getting up early in the morning and then going to the market because fish and meat would be so fresh at that time. We have four sons, two sons' families were living with us. We have one meal together each day in the evening, Our sons take turn to help him (Mr. M) get medications from doctors and accompany him to visit the hospital, the younger son has a car...not his own, working unit car...The other sons frequently come back to visit us."

Mrs. O's family demonstrated how these traditional values were acted out by her filial daughters, particularly her second daughter over time.

Mrs. O was a 76-year-old housewife, and she was illiterate and jobless. She and her husband depended on their daughters for a living. They had four daughters and always felt regret at being unable to bear a son to continue the family line. To fulfill their wish, they fostered their nephew as their stepson. Poverty-stricken, Mrs. O had been in poor health and suffering from various chronic diseases (e.g. chronic asthmatic bronchitis, hypertension, non-insulin diabetes). Her stroke disability rating was from severe limitation of function to mild (ADLs: T1:45, T2:70, T3:95 T4:95) at the four time points after discharge home. This indicated that her physical function improved with time, though she was still dependent at home and in the community over time.

While Mrs. O was in the hospital, her nephew was involved in a street fight and was suddenly stabbed to death. The sad news completely overwhelmed her and caused her illness to worsen. She had lost all hope in life and buried herself deep in desperation, saying: “Let me die, don’t waste money and treat me anymore, I don’t want to live in this world any longer.”

Mrs. O’s second daughter, 37 years old, was sitting besides her mum during each time. While talking about her mother’s life, she expressed her deep appreciation for her mother’s hard time in taking care of the whole family, and described her mother’s long history of picking up second-hand stuff in order to raise them. The daughter said:

“She is so pity and poor in her young age, my mum, she has devoted all her life to take care of her four daughters, taking good care of her is my responsibility and I will never give it up.”

Later, under the careful tending of her daughters, Mrs. O regained confidence bit by bit, recovered from her illness and once again lit the flame of life. She had finally realized that in modern times having sons or daughters makes no difference, and what matters is that they should have a loving heart.

Mr. Q’s family demonstrated how the above traditional values were acted out by a merciful and old father in treating his sons kindly and generously. Meanwhile, in return, filial piety was observed by the two sons over time.

Mr. Q was an 82-year-old, older anti-Japanese army soldier. Q’s wife was frail too. Besides cerebral infarction, he was diagnosed with the advanced hypertension. His stroke disability level was independent when discharged home, and he was dependent at home and in the community. His monthly pension was 1400 yuan. He had two sons. He was a kind old man and made decision on his own. He and his wife lived with each son’s family for six months at a time. He was very satisfied with this arrangement for living with the two sons’ families alternately. Their family relationship remained harmonious. He said:

“I have brought two cups of the same level (两杯水端平) at the same time... There are two advantages, one, we are old and need someone to take care of us; second, I am able to compensate them some money when I live with them. If I lived with the one, the other one would be unhappy. Thus I live with one at one time, and the other at another time right now. Now my two sons are jobless and they share a taxi to earn a living, I give them some money, 1000 yuan a month; I also buy breakfast for my grandson... Both of them can obtain my subsidy. My sons and daughters-in-law are very kind; that is when the elderly treat the younger ones well, the younger will be also filial to the elderly, eventually we are living happily, I love them and also win the respect.”

Mr. R's family demonstrated these traditional values acted out by his wife over time. Mr. R and his wife were unemployed and both 44 years old. Mr. R had no medical coverage. He used to be a driver and his wife used to be an accountant. They had a 17-year-old daughter who was a high school student. Besides being diagnosed with multiple infarctions, he also had hypertension III stage, and coronary heart disease. His level of stroke disability was from severe limitation of function to moderate at the four time points after discharge home (ADLs: T1:35, T2:60, T3:70, T4:80; IADL<5). From this observation, it indicated that his physical performance had improved with time, though he was still dependent at home and in the community.

Mr. R was depressed during the initial visits and expressed his extreme worries about his wife and daughter's future life in a low voice, tears flowing from his eyes: "If I died, how you two (R's wife and his daughter) are surviving?"

R's wife comforted her husband and attempted to find ways to make him feel happy and relieved. She hid her feelings and had tears in her eyes, gently stroked his head and comforted him, and tried to joke with him. Their family relationship remained harmonious.

"Nothing to worry about, we still have half of our house to sell, (tears flowing).

Don't worry about our life. Furthermore, we can move to my mother's house to live with them (weeping), please don't worry, don't worry...I buy a telescope for you, you can play with it while you are alone at home, ok?"

7.1.2 Transforming family role responsibilities

Transforming is a multidimensional concept. Regardless of context, transformation literally means a forming over or restructuring (Wade 1998). It can refer to the changing of character, substance or function (Williams 1991). The Oxford English Dictionary defines the change as a metamorphosis (DK illustrated Oxford dictionary 2003). A person or thing can experience transformation. Transforming here defines the transformation of family role function and performance. That is his or her previous caregiving role responsibilities transformed into the care-receiving ones after a stroke.

Four families (Mr. J, Mr. L, Mrs. N and Mr. P) attempted to alter their prior roles in order to adjust to the changes resulting from a stroke. Their family responsibilities were primarily shared, but after a stroke, the wife's duties were primarily laid on her husband (Mrs. N), or the husbands' duties were mainly transferred to their wives (Mr. J, Mr. L and Mr. P). Sometimes the caregiver could actively engage in the caregiving process and ensure that the survivor's care issues were managed adequately through constantly adjusting their role responsibilities to meet the needs of the situation. At other times the survivor recognized his/her changes and attempted to perform his/her activities of daily living independently as much as possible; particularly when the conditions became stable, they would offer their help to assist their spouses or other family members in order to share day-to-day care and household tasks or activities.

Mr. J's family demonstrated how J's wife took over all care and household responsibilities which had been almost completely shouldered by Mr. J before his stroke.

Mr. J was 70 years old and his wife was almost the same age. J's wife was frail, thin, and short, and she had coronary heart disease and hypertension, while Mr. J was tall and strong. In addition to cerebral infarction, he had been diagnosed with diabetes. His level of stroke disability remained moderate limitation of function over time (ADLs: T1: 45, T2: 50, T3: 50, T4: 50). This indicated that his physical function was stable with time, though he was still dependent at home and in the community living (I-ADL>5). They

had a male helper at home immediately after discharge home and he was 40 years old.

The family income was about 2000 yuan.

The couple lived together. They had two sons, the elder of whom had died in a car accident in 1995. As Mr. J explained, since the elder son passed away suddenly, a shadow had been cast over the family. The younger son's family was living in the same flat with the parents but ate separately because their meal schedule was different. And the grandson came to say hello to Mr. J every day and this gave them great comfort.

J's wife had worked as an accountant in a company after retirement. She always recalled the time when her husband helped her do all the housework and cared for her wholeheartedly. Due to Mr. J's limited mobility, he was completely dependent upon his wife in activities of daily living most of the times after stroke. When the couple was asked how they dealt with their daily care situation, J's wife recounted how they had both reconstructed their new roles to take care of each other after the stroke. She described how they helped each other proudly:

“You don't know, I learn all these household tasks only after he got sick, before that I never did any housework, he handled all household affairs. He bought soap, toilet paper, rice, oil...everything. And I was never worried about it. He was the admiration of everyone living around...he used to take care of me, never...never tired of doing it, at present, I should take care of him...Ha-ha...”

Mr. L's family demonstrated how Mr. L had recovered from his stroke soon after and then became actively involved in helping his wife and daughter to take all care and household responsibilities, as well as the care of his grandsons, which was previously carried out by L's wife alone.

Mr. L was 55 years old. He worked up through the Party school and factory; he was a "middle-level cadre". He suffered from stroke infarction (first-ever) and hypertension. His stroke disability rating was independent over time (ADLs = 100) at discharge home. He was also independent at home and in the community (I-ADL<5).

They lived on the fifth floor, and the younger daughter's family lived with them. The family pension was totally 1000 yuan. Due to his perceived low monthly income, he was very worried about being unable to afford his treatment and medication; this was absolutely unacceptable. But after repeatedly thinking and learning, he finally found his proper position, and more important was that he mastered how to adjust and solve the problem in the present reality so as to happily and peacefully shared his late life with his beloved family. He said he constantly readjusted to his new roles in the family and helped other family members with great satisfaction. He expressed his experience of transition to his new roles:

"I was very busy working in the factory before my retirement. My wife took care of all household affairs by herself. Two daughters were completely taken care by her alone...So difficult...I feel indebted to her, now I would like to make up my loss for

her care and for the whole family...I accompany her to watch TV at home. She also loves to play majiang (麻将) with a group of people in my home. I never disturb her, I just sit there and watch them play, in fact, I myself do not like it, I like reading novels and I like to play football instead...I have two little grandsons, one is three years old and the other four. Very cute, when I get better, I will take the older one to and from the kindergarten so as to help my daughter. I will do it, my daughter is busy.”

Mrs. N's family demonstrated how her husband could successfully accept his new role responsibilities to properly take care of Mrs. N's care issues and of the household tasks, which were mainly undertaken by Mrs. N before her stroke.

Mrs. N was 69 years old. Her diagnosis was multiple lacunar infarctions and hypertension. Her stroke disability rating was from severe limitation of function to mild at the four time points (ADLs: T1: 45, T2: 70, T3: 95 T4: 95; IADL>5). This indicated that her physical function improved with time, though she remained dependent at home and in the community.

N's husband was 70 years old. The old couple was living together and had four sons, and all of whom were married and living elsewhere. They said they were busy and seldom came home to visit them. The old couple was accustomed to this type of quiet,

careless and casual life in a cooperative way. The family monthly income was 800 yuan.

N's husband could not read many words from the instructions of the medications, but he was attentive when seeking medical advice and he tried hard to remember everything he heard in order to deal with Mrs. N's medications and daily care. He said:

“My wife was so capable before she was sick, she took care of everything, I had never been involved. But now I am doing all things because she is so sick, and our sons are not living here. I just come back from the market and buy some soya beans for her, and I take medications from the doctors, three times a day, this pill.”

Mr. P's family demonstrated how he attempted to assist his wife in managing household tasks and actively dealt with his own care issues so as to reduce the burden of care for his wife.

Mr. P was 66 years old. He had recurrent cerebral infarction and several chronic illnesses. These were hypertension with extremely high risk, such as diabetes, old cerebral infarction and coronary heart disease. His stroke disability rating was independent at the four time points (ADLs: 100), and he was dependent at home and in the community (IADL>5).

P's wife's voice was high and sharp. She was a singer before. She said she never allowed Mr. P to do any housework works because she was worried about his stroke recurrence. In fact, Mr. P frequently wanted to engage in household tasks in order to help his wife actively to clean and wash. P's wife was often proud of Mr. P's excellent management of his medications by making in observation notes. P's wife said:

“He is good at dealing with all his medications, he can accurately remember different kinds of medicine. But one thing he is not good, he always keeps himself busy, go to kitchen to wash bowl...bring a mop to wipe out the floor, ...I am worried, in case the blood pressure increased because of his doing this and that, that would be finished...I don't want him to do any work at home.”

7.2 Compromising organization of caring work

Compromising organization of caring work is characterized by those families who can maintain their harmonious family relationship in daily care activities but in a less smoothly interaction over time due to increasing illness and care burdens and a complex family care situation. There are two forms provided by the following cases. These were: meeting the family role expectation with increasing illness and care burdens (Mr. H and Mr. I), and being helpless in the changed family role responsibilities (Mr. F and Mrs. G).

In the home and family care situation, differences existed between children and spouses caregivers. Children were more often faced with the needs of their own jobs and needs of their own family. Spouse caregivers were confronted more often with their physical burden. These are illustrated by the following cases.

7.2.1 Meeting the family role expectations with increasing care and illness burdens

In two families (in Mr. H and Mr. I), the wives attempted to act according to their prescribed role expectations as good wives who were obedient and took good care of their husbands. But Mr. H was feeling unhappy all the time due to the increasing burden of his illness over time even though his wife made an effort to meet her husband's needs by providing proper care for him and hiring a helper at home to accompany him 24 hours a day. In Mr. H's case, there was constant conflict. His wife had to tolerate and succumb to her husband's temper over time.

I's wife felt they were working hard to manage her husband's care issues but later she felt alone and was unable to take all the responsibility for the household tasks and daily care activities, because she sensed she was lacking recognition from her husband, sons and daughters-in-law. No one could share the provision of physical care for Mr. I and herself over time. She became easily tired. She found it difficult to take care of her

husband alone at her age. In Mr. I's case, his wife was constantly complaining and unsatisfied because of the increasing burden of care provided by her alone over time.

Mr. H was 76 years old. He was suffered from a second stroke infarction and had had hypertension for eight years. From the investigator's observation, he spoke fast but could not be heard clearly. The movement of his limbs was limited. He was restless, irritable, often complaining the care provided by his wife. His stroke disability rating was from severe limitation of function to moderate at the four time points after discharge home (ADLs, T1:35, T2:55, T3:65, T4:65; IADL>5). This indicated that his physical function had improved with time, though he was still dependent at home and in the community. His emotional status was reflected by depression one week after discharge (CES-D: T1:19, T2:26, T3:33, T4:38). He looked anxious due to his limited movement in walking independently, and felt pain in his affected shoulder and hand.

H's wife was 76 years old, and moved slowly, while Mr. H had a hot temper and frequently wanted to do things quickly. The old couple lived together, and the total family income was 2000 yuan. After discharge home, they hired a 16 year old girl as a helper. They had one daughter who was married and lived in her own house. Mr. H constantly complained that his wife was disobeying him and failed to meet his caring needs. Sometimes he shouted at his wife loudly using bad words in front of the investigator. H's wife wore a helpless expression and felt wronged:

“No, no, I always help him, sometimes I am doing something else, I should finish it and then, come to help you, I do have my own business. Right? You always worry and are in a hurry, you see, he wants me to undress him but he says I hurt his arm,...he is lying on bed, he senses his elbow and shoulder are pressed by me...he is always unsatisfied...but I help him all the time, help him, without any conditions. Our words never work...I take care of you, and you do not appreciate.”

Mr. H added:

“I myself am all right, you see, my brain, my heart all OK! The main problem is that this leg is cold, walking not so freely as before. And this hand, a little tremor. Why, she forced me this and that (very much unsatisfied)...I hate her (wife), she did not just listen to me...My wife is such a person, she always stands against me.”

Mr. I was 75 years old and his diagnosis was cerebral infarction and brain atrophy. His stroke disability rating was from severe to moderate limitation of function at the four time points (ADLs: T1:45, T2:55, T3:80, T4:90; I-ADL>5). This indicated that his physical function had improved with time, though he was still dependent at home and in the community.

I's wife, an illiterate woman in her 70s, lived with her sick husband. They had three sons and two daughters, all married and were living in separate homes. The couple lived on the second floor, and the youngest son's family lived in the opposite building.

The son and his family, daughter-in-law and grandson came to have dinner with them every day. Both of his son and daughter-in-law were unemployed. The grandson was ten years old. He was studying at primary school.

The couple lived with 800 yuan per month, and supplemented with some deposits. In addition, they had financial support from the elder son, which allowed them to meet their basic life needs. The hospitalization cost was mostly paid by the elder son.

I's wife was 75 years old and their living room was bright, tidy and clean. Her attitude toward her husband seemed to be close and intimate in the earlier visits. Sometimes the old couple even unconsciously held each other's hand. She was very proud of how she took care of the family's father or master of the family (老子 or 一家之主) so kindly at home, and each of their children praised her and paid visits to her in the first month after discharge home. Once the topic turned to the 24-hours household tasks and activities, the out-going I's wife became so sad and tears fell from her eyes. She mentioned impatiently in the later visits:

“All work belongs to me, he is their (children) father, five children's father...I am old enough now, someday I was sick, who will take care of me? I am really bored, 24 hours a day...He deadly tortured others, gossip, going to toilet he will shout, again he wants to get up, he calls me again and again asking for help, he makes me upset!”

7.2.2 Being helpless in the changed family role responsibilities

In two of the families (Mr. F and Mrs. G), some of the children attempted to act according to their prescribed role expectations as filial daughters and sons who tried their best to take good care of their parents. But Mrs. G's son was more concerned with the needs of his own jobs where he worked far away from his mother's home, and Mr. F's elder son mostly met the needs of his own nuclear family. Both of their sons were unable to live with their parents and offered them timely help. Both Mr. F and Mrs. G said it was problematic and they felt helpless when they lived alone (Mr. F) or with the daughter's family (Mrs. G).

Mr. F was 72 years old and had been made a widower in 1998. His wife died of esophagus cancer. His monthly pension was 400 yuan. He had suffered from his first-ever stroke, and his level of stroke disability was from mild limitation of function at the four time points (ADLs: T1:95, T2:100, T3:100, T4:100; I-ADL>5) to independence. This indicated that his physical function had improved with time, though he was still dependent at home and in the community.

Mr. F had two sons and one daughter. Both the elder son and daughter were unemployed. The younger son was a business man, and occasionally paid his father's medical fees. But the older son appeared to be avoiding him since he returned home. Mr. F said sadly:

“He no longer pays me a visit even though he accompanied me during the night while I was hospitalized. He told me at that time he would pick me up to his family and lived with them, but he ate his words and did not keep his promise... You know he is the first son (长子) in the family. I told him, your family name cannot be changed, you have my blood that cannot be changed too.”

Mr. F felt so lonely while lying sick in bed. He described his suffering and feelings of isolation:

“What does the meaning of pain? I don’t know before. Pain is nobody help, nobody concern, and nobody cook for you, you cannot even get a cup of water...what does happiness mean? Happiness is someone with you, accompany you, concern you, cook for you, somebody being present with you, now I am a solitary lonely old people who have sons and daughters but in an empty nest (有儿有女的孤老).”

Mrs. G was 79 years old. She had a monthly pension of 1000 yuan. She was diagnosed with lacunar infarction and cerebral atrophy. Her stroke disability rating was independent at the four time points (ADLs: 100, I-ADL>5). But she was still dependent at home and in the community.

After discharge from hospital, she lived with her second daughter’s family. The daughter was kind and expressed her concerns about her mother’s condition. It was noted that her children were all very enthusiastic to help, some offered money, some

offered other help, and they often discussed their mother's situation and described the situation during hospitalization. She frequently mentioned her only son, who was working in Xian and how he treated her well when he paid her visits through offering her emotional and financial support.

But Mrs. G appeared to hide her feelings because she felt guilty living with her daughter's family and being unable to live with her son's. This made her son-in-law very unsatisfied. Once G's son-in-law blamed her and impolitely shouted:

“What? You are still unsatisfied with the care? We are all taking good care of you, especially during hospitalization, cooking for you, sending meals for you...all around you.”

At that time, Mrs. G hung her head and was expressionless, said nothing, and it seemed nothing happened. After the son-in-law left, she silently wiped away her tears and murmured: “When can I go to my own house?...I want to go back home...”

She continued to talk about her bitter life when her husband passed away and when she was alone and took over the responsibility of raising the five children. Every time she touched on this experience tears fell from her eyes. She thought living in another's home was like living under another's roof (寄人篱下).

7.3 Disengaged organization of caring work

Disengaged organization of caring work was found in five families (Mr. A, Mrs. B, Mrs. C, Mrs. D and Mr. E) who failed to sustain their harmonizing family relationship in daily care activities with difficult interaction over time due to conflicting value of care responsibilities and role expectations, and unbearable burdens of care over time.

There are two kinds of manifestations: one is condemning family members who are not able to meet the role expectations (demonstrated by three families, those of Mr. A, Mrs. B, and Mr. E) and meeting the family role expectations with unbearable care burdens (illustrated by two families, those of Mrs. C and Mrs. D). These are described in the following five cases.

7.3.1 Condemning family members who are not able to meet the role expectations

Mr. A was extremely upset by his only son and frequently felt irritated by his son's "un-filial behaviors", constantly accusing him of infrequent visits and greetings when his son and daughter-in-law came back home. On the other hand, Mrs. B seemed to be arrogant towards her children because she felt herself wealthy enough so that her voices could be spoken somehow louder than those of others'. Then her children totally ignored her. For example, once her son and daughter-in-law did not greet her on the street she was on the way home. She blamed their acts on an absence of filial piety. In Mr. E's case, the sons always found plenty of excuses to not fulfill their responsibilities

to manage the daily care issues and household activities for their father, and prevented him from getting married. They attempted to obtain his money by “stealing” his bankbook. Mr. E was very angry with his sons’ unfilial behaviors.

Mr. A was 58 years old, and he had a long history of several diseases. His wife described her husband’s situation with a sad face:

“I understand, he was suffering from many illnesses, bad physical health, he had 32 years of asthma, insisted on injecting aminophyllin. But, later, when the son paid less visits to parents, particularly with a critical events happening in this family, my daughter-in-law admitted to hospital and all family’s concerns were paid to the daughter-in-law and the newborn baby in the hospital.”

Mr. A became more irritable. He frequently lost his temper and shouted about his son’s “paying less visits” behavior. He said:

“He was busy? But he still has time to play majiang, even no phone call at all. It is you who has spoiled him. Raising a son is no better than raising a dog...”

A’s wife expressed her frustration and her heavy responsibility that was not being acknowledged. She said cautiously:

“He, quarrelling, scolding, even beating me, and argued that he is right all the time...My daughter-in-law is in hospital, my son is so busy with his work, I have to go to the hospital to take care, after arranging for my husband, I must go out, but he

is so...even shouted to me ‘Get out...roll your egg’. Where on earth can I roll? His behavior makes our home restless and a mess...”

Mrs. B was a 67-year-old semi-illiterate woman because she described she could recognized more than 1000 words. She did not go along well with her husband. She thought she had made a great contribution in raising the children, but they failed to show any gratitude by acting as filial sons and daughters-in-law. She complained that all the children “protect the old guy (father)”; she was always in the minority 6:1 and this brought tears to her eyes, and fire to her heart. She said:

“If only fighting between us two, it will be OK, I can tolerate but six to one, this is intolerable!!! ”

Mr. E was 75 years old, was living with his two younger sons’ families, but prepared his meals separately and ate alone. His sons ignored him and they were reluctant to provide help for their disabled father. Once E’s second son was met by the investigator at the door, he actively talked about his father’s bad temper and strange behaviors, which seemed like finding an excuse to avoid offering assistance to “their poor and old father”. E’s son said:

“He often loses his temper, only for tiny things, shouting...bellowing as if the earth would shake...We are all afraid of him, try to avoid him...leave him alone...No one knows, in the past my mum took care of him wholeheartedly...now nobody can help him...”

Mr. E was unhappy most of time, but the big question for him was, in his words:

“Why am I treated by my sons in such a way?...Why is that? I have been taking good care of my family. Why don't they follow suit? ...If my wife were alive, I should be better, I might not suffer from stroke, she used to take good care of me, but she left me alone...it really drove me crazy. I need a woman, I have to pay for them right now ...This is the only thing I am indulged in...”

7.3.2 Meeting the family role expectations with unbearable care burdens

Because the nature of stroke is long lasting and requires a constant course of care, the burden of care was unavoidably increasing over time if primary caregivers' physical needs were not met and they could not get enough rest and support from the other family members. Some family caregivers described how their physical discomfort distressed them on the one hand, and psychosocial suffering on the other, made them feel unbearably tortured. This was described by them frequently, saying “Patient suffering painfully by illness, and carer torturing heavily by caring burden (活人磨命, 病人磨死)”. This actually reflected the heavy burden of illness in survivors and the heavy burden of care in primary caregivers after discharge home over time.

C's husband used to take complete responsibilities for taking care of Mrs. C. But at the six months after discharge home, he expressed his great frustration and helplessness in the endless road of care. He said:

“All dependent on me, even you do a little, that would relieve my burden and I will be better. I never expect you to help me, never! Now look, see yourself, see your sons. The younger son no longer comes back, I know he does not like to go home; I myself, 24 hours a day, nowhere to go, only staying at home, tomorrow, if I were sick, who can help you?”

Mrs. D was a retired textile worker. After the death of her husband at 37, she had to raise their three children on her own independently with her low 40 yuan monthly income. She had stool incontinence and was lying in bed 24 hours a day, and feeling pain in her whole body. In particular, her incontinence was unbearably painful; her description of it was: “Just like squeeze tooth paste, squeeze out...” D’s only son talked about his mother and acknowledged her contribution to the whole family,

“In her whole life, she is diligent and loves to be clean and tidy. To earn a living, she even collected garbage to supplement family need. She has a bitter life.

Therefore, I really appreciate her, but we have no money to stay in hospital, even at home I’ll still take good care of her, but I am really feeling bad when she constantly calls me 24 hours a day for help.”

But he said he had never taken such care of a patient for such a long time, and the only experience he had of providing care for others was when his wife gave birth in the hospital.

7.4 Harmonization of intra-familial relationship

The findings in the present study was consistently supported those of previous studies. Stroke is a family matter and an ongoing process that is shaped by personal, socioeconomic and political context (Williams & Wood 1988). It involves the individual's role transformation, and his/her personal belief and value (Jongbloed 1994, Robinson-Smith & Mahoney 1995, Fraser 1999, Secrest 2000, Anderson et al. 1995, Nieboer et al. 1998, Forsberg-Warleby et al. 2001, Williams 1987, Doolittle 1988).

Self-sacrifice and a strong sense of devotion for filial acts are respected and praised by Chinese society. It is a common belief that filial piety or filial duty, stability and harmonization are the key elements to preserve a good state of family well-being and actualize the ideal of “respecting the old and fostering the young” in the family context.

According to the information presented in the first part, family dynamics of caring work organization is revealed by three patterns in the present study. These are cooperative, compromising and disengaged patterns. Some families could organize their caring work in a cooperative way and sustain optimal family well-being while meeting the traditional Chinese family role expectations and transforming family role relationships over time. Other families organized their caring work in a compromising way and retain functional family well-being while meeting the family role expectation with increasing illness and care burdens, and being helpless in the changed family role

relationships over time. In other cases, families organized their caring work in a disengaged way while condemning family members not able to meet the role expectations and meeting the family role expectations with unbearable care burdens over time. These families ended up with dysfunctional family well-being. The different outcomes of these three types of family well-being are illustrated in the following 18 cases.

7.4.1 Optimal well-being of the family living with stroke

Mr. J started to accept his role of being dependent on his wife. J's wife was actively and carefully engaged in helping her husband in all ways after his stroke, even though she said her husband used to do everything at home and took care of her because she had heart disease. But she started to learn, as she said: "I learn all these household tasks after he got sick".

In this case, both their roles (Mr. J and his wife) have been transformed successfully after the stroke event.

Mrs. K had two sons and two daughters. The couple lived with the son's family and the daughter-in-law helped Mrs. K cook for the whole family after her discharge home. The couple was proud of describing themselves as "receiving and enjoying filial love every day". In this case, all members in the family are able to perform their prescribed family

roles, such as the son accompanying his mother's to visit doctors, daughter-in-law providing timely assistance in kitchen activities. Thus all family members are able to meet their traditional Chinese filial role expectations.

Mr. L felt guilty because he could not offer the family's help while he got sick immediately after his retirement. As soon as he felt his health had improved, he actively provided assistance in household tasks (meal preparation) and picked up his grandson from kindergarten. In this case, Mr. L is eager to compensate for his earlier failure to assist his family. He actively modifies and transforms his role from "being taken care of by his wife" into "taking care of others". As he said: "I feel indebted to her, now I would like to make up my loss for her care and for the whole family."

When Mr. M got sick, his wife undertook most of his care at home. She described how the family came together everyday for dinner together, saying: "we have one meal together per day in the evening" and how his five children came back home in turn and shared the responsibilities of taking care of their father. In this case, each member of the family attempts to meet the traditional filial sons' role expectations to care for and respect their parents.

Mrs. N was a housewife and used to take care of her husband. After she had a stroke, N's husband was very considerate of her health, and actively took all care responsibilities for her. As he said: "Now I am doing all things because she is so sick".

In this case, N's husband transforms his role successfully from a receiving care role into one of providing care.

Mrs. O had four daughters but no son and was once full of worries about the future. Her second daughter took her parents to live with her family after Mrs. O was discharged from hospital. O's second daughter made every effort to care for her sick mother and managed to assure her mother that even without a son, as she said: "Taking good care of her is my responsibility and I will never give up".

In this case, O's daughter meets the traditional filial daughter role expectation in all ways.

Mr. P had a long history of multiple chronic illnesses (e.g. diabetes, three times of stroke recurrence and coronary heart disease) and was cared for by his wife. He also actively involved in helping his wife in daily household activities such as cleaning the house and washing clothes. P's wife murmured about his health: "I don't want him doing any work at home".

In this case, P's wife attempts to meet her filial wife role expectation, while Mr. P transforms his role relationship to one of helping others in the family.

Mr. Q was an old Communist party member since joining the Army at the age of 16. He was kind and behaved as a complete kindhearted father in the family. He described how to manage family harmonization, and said: “I have brought two cups of water, and make the water in both cups in the same level (两杯水端平) in the same time”.

In this case, Mr. Q always behaves in such a way as to meet his merciful father role expectation, as indicated by “Love one’s sons and win their respect”.

Mr. R was not so willing to accept his severe stroke at his age of 45. He was so depressed in the initial time after discharge home. In order to comfort her husband, R’s wife tried to find fun to relieve his burden of illness through her efforts and consolation, she said: “Buy a telescope, he can play while he is alone at home”.

In this case, R’s wife made efforts to meet her traditional filial wife role expectation. From the above observation, meeting the traditional prescribed roles and transforming family role relationship are important to sustain a family with optimal well-being.

7.4.2 Functional well-being of the family living with stroke

Mr. F had two sons and one daughter. He believed in fostering the sons for future supporting of the elderly (养儿防老). However, he was seldom visited by his elder son. He was so disappointed that he disregarded his elder son as an unfilial son. He described his son who could not disown his father up by recounting sadly that “Your family name could not be changed, you have my blood that can not be changed too”.

In this case, Mr. F feels helpless in the face of his changed expectation of his son acting according to his filial role responsibility.

Mrs. G had only one son but he lived in Xian which was far from Wuhan. She had to live with her daughters’ families in turn, but one of her son-in-law felt unhappy about her living with them. Mrs. G described her situation as saying: “When can I go to my own house?...I want to go back home...”. She felt she was living under another’s roof.

In this case, Mrs. G also feels helpless in being unable to change the family relationship in which she, as a mother-in-law, has to live with her daughters’ and son-in-laws’ families.

Mr. H had suffered from a stroke and his wife described his husband’s irritability due to the illness burden. She attempted to help him, but Mr. H frequently expressed his

dissatisfaction as described by H's wife as "He is always unsatisfied...but I all the time help him, help him, unconditionally".

In this case, Mr. H has difficulty in transforming his role from receiving care and being dependent upon others. He is helpless in the changed family role transformation.

Mr. I's condition was improved over time, but I's wife perceived her burden of care as increasing over time. She explained that all care provided was laid on her shoulders, and that she felt tired of performing all the necessary tasks. She said: "All works belongs to me...I am old enough".

In this case, I's wife is more than 70 years old, and even though she attempts to fulfill her expected role as a filial wife, she perceives an increasing burden of care to be completed on her own.

According to the above information, increasing the burden of care and being helpless to change one's role expectation are significant for a family to fail to sustain a family with optimal well-being over time.

7.4.3 Dysfunctional well-being of the family living with stroke

Mr. A always expected his son to respect him by paying him visits everyday. But due to the son's nuclear family (the son's wife was pregnant) and devote attention to his busy job, he seldom offered his father a visit. Mr. A shouted about his son's behaviors, saying "Raising a son is no better than raising a dog..."

And his wife did not understand how he could do so by saying "Where on earth can I roll?" In this case, Mr. A is overwhelmed by negative affects by condemning his family members who are unable to meet his role expectations as a filial son.

Mrs. B had two sons and three daughters. She was so upset with his sons because they did not pay her any visits when she was hospitalized, and never paid due respect to her. She described all of them as "'Protect the old guy' but fighting with her 'six to one'".

In this case, Mrs. B is very angry about her sons' less filial behavior and condemning her family members as not being able to meet her role expectations as filial sons and daughters-in-law.

Mrs. C had urinary incontinence and was taken care of by his husband completely. With the time went by, C's husband became very stressed. He said: "All dependent on me... 24 hours a day, nowhere to go."

In this case, C's husband is holding an unbearable burden of care even though he attempts to act according to the prescribed traditional merciful father and husband role.

Mrs. D had bowel incontinence and he lived with her only son's family. D's son was distressed in dealing with his mum's problems due to "in such a long time", even though they expressed his willingness to act as a good and filial son.

In this case, D's son is carrying an unbearable burden of care even though he attempts to act according to the prescribed traditional filial son role expectation.

Mr. E had four sons. He was initially cared for by his grandson (19 years old). After one month, his grandson left and E's only daughter paid him a visit and helped him every week. But his sons could not give him any care when he was in need. In this case, the sons living with him actually do not act according to the expected traditional filial sons' roles to take care of their "old and frail father".

Based on the illustration of the above cases, being unbearable burden of care and keeping constantly complained about the others are essential that ended up with a dysfunctional family well-being over time.

7.5 Summary

Based on the quantitative information regarding the comparison of the five types of family structures and qualitative content analysis, three patterns of caring work organization emerge. They are cooperative, compromising and disengaged organization of caring work. Each pattern of caring work organization is divided as follows.

The pattern of cooperative organization of caring work involves (a) meeting the traditional Chinese family role expectations, and (b) transforming family role relationships. In the compromising pattern, they were (a) meeting the family role expectation with increasing illness and care burdens, and (b) being helpless in the changed family role relationships.

And the final pattern of disengaged organization of caring work include (a) condemning family members not able to meet the role expectations, and (b) meeting the family role expectations with unbearable care burdens.

In a sum, for those who are able to meet the traditional Chinese family role expectation and transform family role relationships, caring work can be organized in a cooperative way; for those who are still able to meet the traditional Chinese family role expectation, but are helpless due to being unable to change family relationships and increasing

illness and care burdens, caring work can be organized only in a compromising way; ultimately, for those who are unable to meet the traditional Chinese family role expectations due to an unbearable burden of care and fail to transform their roles due to overwhelming negative affects through condemning family members' unfilial behaviors, caring work fails to be organized smoothly but rather in a disengaged pattern.

From the findings it is indicated that the interest in caregiving research expands the research scope from a limited focus on the negative caregiving burden to the whole constellation of both positive and negative impacts of family dynamics.

Chapter Eight

Personal Coping Resources in Living with Stroke

Stroke-related residual disability associated with activities of daily living (e.g. eating, dressing, bathing, mobility, walking) is the most common consequence following a stroke (Evans et al. 1992). The impact of stroke on both stroke survivors and family caregivers was described intensively in the changes of the bodily', emotional, and social functioning (Doolittle 1991, 1992, Grant 1996, Periard & Ames 1993, Silliman et al. 1986), particularly emphasized in their losses of their daily activities, personal abilities, characteristics and identity, and independence (Mumma 1986, Doolittle 1992).

This complex nature of losses and changes required a constant adaptation to personal capacity to cope with them effectively (Doolittle 1992, Folden 1994). In the aspect of the survivors' physical adaptation, Doolittle (1991, 1992) used clinical ethnography in observing different phases of bodily recovery as: having a dramatic loss of automaticity over a period of six months, experiencing plateaus in recovery at two to three weeks, waning improvement at seven to 12 weeks, experiencing the possibilities at 15 to 20 weeks (four to five months), particularly when survivors became daring and experimental, and finally discharge home, undergoing transformation as a result of familiar surroundings in the home setting. In the aspect of their psychosocial adjustment, Folden (1994) emphasized how stroke survivors accepted the reality, maintained hope, preserved energy and increased their personal control over recovery.

Gains were also reported for the family caregivers through constructing a positive recovery, reconstituting family life, maintaining family patterns, creating a safety net, and redoubling self-reliance (Burman 2001), remaining positive, adapting to change, comparison with others who were worse off, changing their employment status, humor, switching off, and using family support (O'Connell & Baker 2004).

The above illustrations provided a number of coping strategies utilization based on personal views, perception and belief. Doolittle (1991, 1992) stressed that this belief was grounded by one's personal, family and social background, such as specific cultural and their particular experiences. As Suchman et al. (1998, p. 9) further stated:

“Each of us has a personal philosophy that shapes our perceptions, interpretations and actions...This process—a gradual assimilation of attitudes and values from our families, culture, education, and life experience—tends to be so subliminal that we may not recognize our core beliefs as beliefs at all, and instead simply accept them as ‘reality’”.

The following discussion is based on the above understanding on each individual's belief and culture. The 18 cases were examined by scrutinizing their thinking, attitudes and behaviors to cope with their stroke-related residual disability and multiple care issues in the home care setting. The analysis shown in Tables 5.7 (p. 204) and 5.8 (p. 205), which reveal that stroke survivors in the families with dysfunctional family well-being had significantly higher Center for Epidemiological Studies Depression

Scale (CES-D) scores than those in the families with optimal well-being one month after discharge home. Analysis of the CES-D subscales indicates that the former had more negative affect and somatic symptoms. Table 4.8 (p. 175) in Chapter four lists the CES-D scores and self-evaluation of general health (SEGH) scores of each stroke survivor and primary family caregiver by types of family well-being at one week and six months for an overview of the changes in emotional status and self-perceived health status among the 18 cases.

It is noted that families in the category of optimal family well-being had less experience of negative emotions and had higher ratings of general health regardless of the levels of post-stroke residual disability. Based on the interview transcriptions of both stroke survivors and family caregivers who had maintained a good emotional status over time, the ways in which they perceived their care-receiving and care-giving experience to impact on the emotional status were analyzed. The analyses yielded interesting findings of how individuals used different positive personal coping resources in dealing with stroke-related disability and daily care hassles. They are (a) cultivating the moral self, (b) appealing to spirituality, (c) ascribing positive meaning to life adversities, and (d) acting as a folk healer.

The first part of this chapter describes how stroke survivors and family caregivers used these positive personal coping resources, and examines the reasons inhibiting some stroke survivors and their family members from mobilizing these personal coping

resources. The second part examines how these families deal with these care issues by the three types of family well-being living with stroke.

8.1 Cultivating the moral self

Cultivating the moral self is one of the personal coping resources utilized by both survivors and family caregivers in the home care setting. Survivors acted as Confucian scholars, upholding the principles of self-reliance and upholding a Communist ideology to deal with their residual disability regarding their activities of daily living and health problems (e.g. falls, eating and meal preparation, mobility, eliminating, skin care, expressing sexuality, medication management and physical discomforts). They were competent to require themselves to be optimistic, and accept the reality in a positive way. These were manifested by acting as a Confucian scholar, upholding the principle of self-reliance and upholding the Communist ideology. They are illustrated by the cases below.

8.1.1 Acting as a Confucian scholar

Confucian followers believed they would care for others and have a right in behaving themselves. They followed the law of Confucian scholar that is “Jen” or “Ren” (仁) (authoritative or benevolent) and “Yi” (义) (significant or righteous) (Chen 2001).

In this sense, the Confucian culture emphasizes “Ren” (仁) which indicates two persons’ relationship. In order to create a good personal relationship, “behave oneself” gives it top priority: it is considered that a person should first be a good and righteous man “Yi” (义), then he will be able to create himself with an optimal state of health and well-being. Forgiveness is to love others, pardon other’s mistakes. If they lack forgiveness, the relationship between people will be tense and destructive. In the present study, it is found that they behave according to the principle of “being generous to others and being strict to oneself”, which it means that less trouble made towards others, and more self-reliance made by himself, even though very difficult care situation is encountered. They believe to be necessary in order to become an upright person and maintain a good state of mind. This idea has become the basis of planning one’s life and dealing with people and their problems. This is demonstrated by couple J’s case below.

Mr. J had a moderate degree of his residual disability at the four time points according to his Barthel rating (ranging from 45 to 50). He was taken care for by his wife and a

part-time male helper immediately after discharge home. Sometimes the helper was out of keeping with Mr. J's schedule, such as late coming in the morning and early leaving in the afternoon. J's wife was unsatisfied with the helper's work and discussed with Mr. J whether they would change a new one. Mr. J did not agree and said this helper had some strong points in assisting him to wash his feet and relieve his shoulder's pain like message. J's wife was touched by her husband's broad-mindedness. She shared her deep feelings and thoughts:

“He is such a person always be generous towards others, and strict towards himself, even though he was suffering from recurrent stroke, he had to be dependent upon others completely, he frequently shows his consideration to others.”

8.1.2 Upholding the principle of self-reliance

Upholding the rules of self-dependence was guided by their views of such common words as “where there is a will, there is a way” towards human life. They believed that as long they could be independent, their function and the process of recovery would be improved over time. Upholding the principle of self-reliance reflected the writings of one of the most famous writers in China, who wrote an article which highlighted the fact that the spirit of human behavior must have a strong will and self-reliance. “Never bend one's noble head just flattering for a bag of rice” was one of Tao Yuan Ming (陶渊明) sayings. He was 376-427 AC and a famous poet in the East Jin Dynasty. He

found it impossible to bend his back or to cringe for five pecks of rice which was the regulation salary.

In the Western culture, Mumma (1986) indicated that self-reliance and independence are powerful values. Jongbloed (1994) further stated that these are strength and responsibility. However, Phillips (1985) asserted that perseverance is more valued. All the above information stressed the significance of self-reliance and self-help which reflects the personal value and attitudes towards life. This is demonstrated by the following six cases (Mr. J, Mr. F, Mr. L, Mrs. G, Mr. I and Mrs. N).

J's wife praised his husband's capacity of his self-reliance. She said:

“He is a person who always helps himself, and never bends his noble head just flattering for five pecks of rice...”

Mr. F had a high sense of self-esteem and he was very proud of his self dignity and his strong will in helping self, he attempted to talk lightly while cooking meal in the stove even though he felt so difficult to do it. He said the following words just like he was singing a song:

“Force me and force me, to be in high spirits, take care, be stable and be stable.

Where is a will, there is a way ...Everything should rely ...on myself!”

When dealing with his fluctuating emotions, he had ways and theories for dealing with the situation by himself:

“It’s normal that sometimes happy and sometimes not, I must be easy-going, usually in the morning after doing exercises, I could walk better, then in the afternoon, after 4pm, the leg became heavy and weak, spirit got down, thinking about something sad, I’d try to adjust. Usually in the whole day, happy times were more than sad times. Anyway, I have been familiar with such situation, I have to be bold, to cheer up...sometimes I have to encourage myself. When the TV program made you laugh, you just try to laugh, sometimes try to sing, I sing! While listening to the radio, I sing by myself, amusing myself!”

Mr. L expressed his feelings of how he tried to be independent and relieve the burden of care. He said:

“I will help myself and I don’t want to become their burden. You see before I retired, my wife took care of me and the children, because I was busy with my work. Now I am retired, but I get sick, she has to take care of me too. I am feeling guilty, so I should depend on myself and provide her help.”

Mrs. G recounted her independent life in the past forty years since her husband passed away, and said she would still maintain it after her stroke. She stated:

“I have raised five children by myself, we were not rich then, my children and I were enduring hardship together, now our life is better, I hope I would rely on myself and they will live a happy life.”

Mr. I recalled his post stroke experience and felt a great improvement six months after discharge home. He said he had successful experience drawn from his improved recovery by saying that:

“Two points are important, one is to do regular exercises, every day, insist on doing that by myself; the other is adherence to medication prescribed by doctors, this is my good experience, in doing all the above, I do rely on myself to do it.”

Mrs. N recounted her experience after discharge home and attempted to relieve the burden of care shouldered by her husband. She said:

“He has been taken care of by me since we got married, now even though he can help me a lot, I still want to rely on myself, now you see, I am better.”

8.1.3 Upholding the Communist ideology

Communist believers had a full of appreciation of their new life in comparison with life in old China and attributed this to the great leadership of Chairman Mao since 1949. They also believed that numerous martyrs had sacrificed themselves for the sake of people's interest.

Mr. Q joined the Red Army when he was 16 years old. Mr. Q was an old soldier, he recalled his wartime life peacefully and proudly:

“During the War time, I had seen many persons died in the battlefield, I never feared, because I am a fighter, I joined the Army when I was 16 years old age and have followed the Community Party, ...I believe only the Community Party can save China, I have nothing worry.”

Mr. Q has joined the Communist Party. After the long period of hardship furnace, he was very satisfied with current life and situation, and be proud of leadership of community party. Sometimes he would quote Chairman Mao’s words:

“Thinking of such deeds, we, the survivors, are fortunate enough, are extremely lucky, why should we be so serious about our illness? (既来之, 则安之).”

The core meaning is since the disease had happened, one has to accept it, and there is absolutely no need to be worried; just listen to the doctor’s advice, and one will improve gradually. His belief made him optimistic for the future and full of confidence to deal with his difficulties.

8.2 Appealing to spirituality

The beliefs based on Buddhist teachings focus on the “law of cause and effect” (Zhou, 1994). It is believed that one does kind deeds, one would get good return, goes to

heaven after death, on the contrary, one would get punishment or consequence (因果报应) such as being hit by thunder, and going to hell after death. This is called “transmigration”. That is to encourage people to do good and right things and then receive goodness in return (Zhou 1994). According to this law, helping others and doing kind deeds (“In” 因) enable one to gain heavenly peace, great joy and ultimately gain merit (“Guo” 果). By contrast, those who uphold the naturalist belief of letting-it-be, they could keep in harmony with nature, be broad-minded, show high ideals, and not seek fame and wealth, so as to maintain their mind in a peaceful state (Li 2000).

Davis and Grant (1994) pointed out that the search for value was an effort to relate their illness and care experiences to a larger, philosophical, spiritual or religious meaning, as family caregivers demonstrated in their study showing that “my Christian beliefs support my doing this”. Subgranon and Lund (1996) also stated that religious beliefs of Buddhist and Islamic caregivers encouraged some family caregivers to maintain good care for their elderly stroke relatives at home.

In the present study, it found that there was that five families (J’s wife, Mrs. B, Mrs. K, H’s wife, I’s daughter, P’s wife) reported appealing to spirituality: through practicing Buddhist rituals and holding the naturalist beliefs in letting-it-be. They managed their care issues smoothly and were able to reduce the burden of care effectively. Those survivors and caregivers who practiced Buddhist rituals could relieve their suffering

and pain, and show their gratitude to their lives, while the caregivers also regained merit. These were illustrated by the following cases.

8.2.1 Practicing Buddhist rituals

From the following cases, J's wife and Mrs. B strongly believed that spiritual power enabled them to face difficulties and problems in the post stroke and care experience. They prayed in front of Buddha and begged for peaceful life and better future.

J's wife was thin but her mind was strong. The corner of the couple's living room had a prayer table. Although the couple evaded the sensitive topic of what had happened in this family in 1995. They lost their elder son due to a car accident, dealing the family a fatal blow. It was clear that J's wife's pain still remained in her heart. Mr. J had never had any religious belief in his life, and supported his wife in all ways. He stated:

“My old spouse has been ill for so long, it's a pity, she gets up everyday early in the morning and prays, I never disturbs her, just let her pray.”

And J's wife described how she insisted on this practice in every day:

“I used to getting up late, I can't get up so early, but it was said, the earlier one prays, the better the result would be.”

Mrs. B, 65 years old, was semi-illiterate. When the investigator met her in the first week after discharge, she was sitting with her daughter. Her daughter recounted her outside activities in visiting a number of temples immediately after discharge home. B's daughter said:

“She was busy all the time, the first day to Gui-yuan Temple (归元寺), the second day to Hong-shan Pavillion (洪山宝塔), the third day to ... Her next step is to climb Tai Shang (泰山)...It is said there is a big temple there.”

When the investigator paid Mrs. B the last visit, she wanted to show what a pious Buddhist she was, showed a special red notebook to the investigator and said mysteriously “this is my Gui-Yi-Zheng (归银证)”. The Gui-Yi-Zheng refers to certifying that she is the formal member of a Buddhist believer.

8.2.2 Holding the naturalist belief of letting-it-be

The following cases hold a belief in naturalism, which is considered to mean they would be obedient to the heaven and natural changes, thus keeping the mind at peace.

Mrs. K described how her tooth ached and tortured her a lot, but she did not seek any medical help from doctors. She said:

“Me, just like this, everything just letting nature taking its course. This is natural changes you cannot prevent it. For me, tooth pain, terrible pain, if it drops off, just let it go... just neglect it...”

H's wife was short and fat. She used to do things at her own slow pace. This made Mr. H always complaining of her movement in “slow rhythm”. But she still continued doing things unhurriedly and said:

“No worry, too quick might cause accident, in case falls, I have my own way, what for, in such a hurry? Just take it easy, take your time!”

I's youngest daughter-in-law was not amused by her mother-in-law when they sat in the same room and she was asked how she could take care of her father-in-law during his hospitalization twice a day. She described her experience with deep feeling:

“Every person will get old and get sick, this is a nature I will be getting old and sick, I will need to be taken care of by others someday...”

P's wife was open-minded. She used to mention their life in an easy way. She comforted her husband with an appreciating heart for the natural world. She stated:

“You see, after surviving a great disaster, one is bound to have good fortune in later years (大难不死, 必有后福), you were so sick this time, but you can still survive, you should be contented, I am contented, every man will die sooner or later, nobody can escape, take it easy and let it be.”

8.3 Ascribing positive meaning to life adversities

Ascribing positive meaning to life adversities was the third positive coping resource appraised by both survivors and family caregivers. Two major subcategories were included: using humor and interpreting personal meaning.

They described using humor as one of the essential ways of coping with stroke-related residual disability for survivors and surviving in the caregiving role. Humor has been used as a strategy to teach patients and families to adopt positive coping mechanisms in Bakerman's (1997) study. O'Connell and Baker (2004) also suggested that the use of humor should not be underestimated as an effective coping strategy for family caregivers and stroke survivors in dealing with their home care problems.

Searching personal meaning was also important for both survivors and caregivers about the value and significance of their post stroke and care experience. Davis and Grant (1994) state that a search for personal meaning reflects an individual effort to find their personal meaning and purpose in one's own experience, which they illuminated their example by "something good will result from this experience".

In the present study, these two coping resources were demonstrated by the five families (J's wife, R's wife, Mr. M, Mr. F and Mr. L) below.

8.3.1 Using humor

Keep smiling and all the sorrow and grief would be diminished according to their beliefs. This attitude was illuminated by the following cases.

J's wife frequently mentioned her experience of difficulty in helping her husband stand up and walk around. She said:

“He is tall and heavy. He is eager to walk. Once he had a fall and sat down on the ground, he looked at me, and laughed loudly as if nothing had happened...Sometimes I dress him, he laughs...he laughs at least twice a day...Sometimes he bursts into laughter and even makes me impossible to work anymore and tears flow out...He makes me laugh.”

R's wife frequently mentioned their experience of hardship during the acute stage in the hospital, and how the couple joked with each other in order to overcome their difficulty. She recalled:

“He is lying in bed alone, and does not speak at all. If I want to make him talk, I have to make a joke. Once I asked him why you always looked at the door during hospitalization rather than me? I asked him to turn his head to me, but he always looked at the opposite side, why you did so? Then he opened his mouth and talked to me: ‘Why asking me to turn to your side and looked at you? There were so many young and pretty nurses over there’. He joked why should I look at your ‘ugly

wrinkled leaves'. I am also joking, I shout: Why, me, 'ugly wrinkled leaves'? Look at you, 'old tree bark'...Ha-ha-ha..."

Mr. M was full of wit and humor. When asked him how about the effect of a drug tonic, he immediately imitated a verse from a TV advertisement slogan as follows, making everybody sitting around him laughed. "Tasty and in high spirits (好精神, 好味道)."

8.3.2 Interpreting personal meaning

Two survivors (Mr. F and Mr. L) attempted to give meaning of their illness and tried their own way to deal with the problems. These were demonstrated as follows.

Mr. F was living alone and struggling in his limited circle, a circle full of physical and mental pain. He always raised questions and seriously structured answers for themselves, so as to pacify their wounded flesh and soul, and gain energy for sustaining life. He frequently described his desire to deny the diagnosis made by the doctors and gave his own meaning and diagnosis of stroke. He said:

"I want to cancel the diagnosis of stroke, I am not suffering from stroke, it was because the other day, very hot, I slept under the fan, too windy, it is the wind that caused the disease, doctor's diagnosis of stroke? No, I rejected it, never accepted it!!! Eliminating wind from my body, this would be an effective way!"

Mr. L was a person who was good at thinking and had an independent viewpoint. Although he was unsatisfied and had much contradictory thinking in medical help-seeking, he could often release his pressure and maintained an optimistic mood. Mr. L attempted to give his life as a whole the new meaning of establishing a better relationship with his daughter and wife on the one hand, and he also actively arranged his time, made his life colorful (e.g., playing with his grandson, going fishing and enjoying sunshine, and reading novel) on the other in order to reduce the shadow of the burden of illness on himself:

“Now I am paying back the debt I owed them, because when I was young I didn’t take good care of them!”

8.4 Acting as a folk healer

Acting as folk healer is another important form of upholding positive coping resources in the present investigation. This was mentioned by seven families (Mr. J, Mr. L, Mrs. O, Mr. Q, Mr. F, Mrs. B, Mr. P) and was used in particular by families with optimal well-being living with stroke. Some cases valued and believed in their self-care abilities and activities, which merged both traditional folk beliefs and modern western medicine practices. They retained the knowledge handed down by the family’s ancestors to heal their own pain. They also conveyed this message to others, sharing the happiness of this healing process.

They sought medical knowledge and information from health providers, television programs, and newspapers, and found the most effective drugs on their own. Some survivors had experienced a long history of diabetes and several stroke events. They seemed to understand every signal of such diseases, particularly the warning signs. Due to this experience, they frequently became part-time advocates for their neighbors and were very proud of it. Two major measures were adopted: improvising therapeutic measures and applying folk healing formulae. This was illuminated by the cases below.

8.4.1 Improvising therapeutic measures

Four survivors (Mr. J, Mr. L, Mrs. O, Mr. Q) frequently followed advice found in newspapers or told by their neighbors. “Drink vinegar regularly, vessels can be softened”. They believed that vinegar could be beneficial for their health because of its softening function for blood vessels. Another survivor (Mr. F) had his own method of using magnetic needle and water to relieve physical discomfort. These measures are illuminated below.

Mr. L used to dunk eggs in the bottle with vinegar and eat them every early morning. He said:

“Every week I will make two bottles, one for myself, the other is for my-son-in-law. I know this method from reading a newspaper. It is said eating vinegar egg regularly would be beneficial for your blood vessels. This will

indirectly improve hypertension. My relatives also tell me that they eat egg vinegar every day. It is effective. This has become part of my regular work, every morning, ‘vinegar egg’.”

Another two survivors had different methods of taking vinegar but for the same purpose. Mr. Q took a spoonful of white vinegar in the morning; whereas Mr. J took vinegar primarily with beans.

Mr. F said he had difficulty while drinking water in the early morning and coughed without stop. Then he used magnetic needle and magnetic water and found it was effective. He said:

“Morning, after getting up, I drink magnetic water—benefit to my health, then cough without stop. First, I press the points on my finger’s area or my throat area hard. If there was no improvement, I would use magnetic needles on the finger points, my cough would improve.”

Mrs. O seldom talked and frequently lay in bed. O’s daughter always helped her mother to answer all the questions, and she said:

“My mum uses her own way of healing herself. That is sleep! She said when her mum was young and got sick, she would be dependent upon sleep to cure her problem; it always works, she said!”

8.4.2 Applying folk healing formulae

Two survivors described how they behaved in their own ways according to their own therapeutic regime, and how family formulae helped them and neighbors to cope with their problems.

Mrs. B frequently expressed her good medical experience in healing the others since she had her family formula to cure the disease. She stated:

“My neighbor came to visit me for help many times because of her mastitis, eventually I offered help to her. She recovered. I knew medicine that passed down from my family...”

Mr. P had his own way to deal with his multiple chronic illnesses, he said:

“I understand their illness, and able to answer all the questions and all the time...my neighbors, someone has a headache, they will ask me how much blood pressure should be a normal range; some one may not understand the drug they take, they will ask me how to take it, and what is better. I always remind them, don't stop to take medications if you have a hypertension, it is dangerous for stroke!”

8.5 Reasons for failure to mobilize personal coping resources

Kinney et al. (1995) observed that individuals who were able to appraise their daily hassles both positively and negatively. Those who appraised them more positively, they were able to cope with their problems effectively; whereas who appraised them more negatively, they would fail to cope with their problems successfully. Furthermore, the problem of severity of stroke related residual disability may lead to higher level of burden of care which could not be overlooked by health care professionals (Anderson et al. 1995, Nieboer et al. 1998, Forsberg-Warleby et al. 2002). Thus the issue of appraisal and the reality of the burden of illness and care played a significant role in the process of adjustment.

In the present study, seven families were unable to deal with their difficult care situation because of: suffering from unbearable illness and symptom burden, and being overwhelmed with negative feelings of being treated unfairly by others and/or by heaven. These were illustrated by the cases below.

8.5.1 Suffering from unbearable illness and symptom burden

Four families described their difficulty in dealing with stroke-related disability and multiple care issues over time. This was found in particular at the three months and six month. This is frequently indicated in popular Chinese saying such as “even a person of

deep filial piety would no longer tolerate the long-lasting heavy burden in care-giving (久病床前无孝子)". This means filial children no longer existed beside parents' beds in the long run of an illness.

Mr. F felt very lonely while lying sick in bed. He described his feelings of isolation. Mr. F said:

"What does the meaning of pain? I don't know before. Pain is nobody offers help to you, nobody concerns you, and nobody cook for you, even without a cup of water...I cannot sense any happiness."

Mr. H was taken care of by his wife, but he complained a lot about his sudden loss of ability to take care of himself. And his wife could not meet his care needs on the one hand, and let him feel bad on the other. He said:

"I walked around every morning by myself, go to park...I was a manager, I did a lot by myself, what a pity now, my shoulder is painful, and I cannot move, you see her long and tired face, what a day."

Mrs. C lay in bed all day totally dependent on others in taking care of her. She described her pain with a little voice as if she was a small cat. She said:

"The pain in this leg terribly hurts, the whole night is sleepless, it also tortures my husband. What can I do? No way, just waiting to die... patient suffering painfully by illness, and carer torturing heavily by caring burden."

The care for Mrs. D relied totally on the helper's shoulder at six months after discharge home. Her daughters and son had become less and less involved in the process of care of Mrs. D, and Mrs. D was extremely distressed and hopeless. She said:

“I don't know why I cannot fall asleep, my eyes just gazing at the clock!....I can't live long, where shall I die, just disappear in a fire? No need to rescue me, Let the doctor give me an injection and let me die earlier... Let me go, I don't want to be their burden...this daughter doesn't come, that daughter doesn't come, they all leave me alone...”

8.5.2 Being overwhelmed with negative feelings of being treated unfairly by others and/or by heaven

Some survivors doubted their sudden attacks of stroke and tried to explain they had never done anything bad in their lives, and they should not be punished by the heaven.

Mr. A insisted that life was unfair to him. He regarded himself as a kind person and always kind to everybody. And he has never hurt anybody. He said:

“Oh, heaven above my head, I never argue with anybody outside, I never do anything bad, Even I never even step on an ant on the ground, but, why let me suffer such a horrible pain!... I'm a nice person. I have been kind and honest to everyone throughout my life. I have been taking pains bringing up the children and caring for the family. Is this what I have had in return? Now I'm sick and useless.

My days are numbered and I'm just waiting to die, maybe, this winter or next spring, who knows! Give me a piece of rope! That would be quick!"

Mrs. B had a tense relationship with her children, frequently complaining that her son and daughter-in-law did not even greet her when meeting them on the street. She was so upset and angry about it. She said:

"Why I send 'spring wind', but I never get any 'night rain' in return ...in my life, I have five children, but my husband protects the children all the time, all of them make trouble with me, all fight against me! Even the grandson loves my husband and stand with him, I work hard for them for my whole life, but at the end, I got no return and being treated badly."

Mr. E described his lonely experience as an isolated bird receiving no attention from his sons. He was so upset and said repeatedly:

"Why am I treated by my sons in such a way? Why is that? I have been taking good care of my family. Why don't they follow suit?...If my wife were alive, I should be better, I might not suffer from stroke, she used to take good care of me, but she left me alone...it really drives me crazy..."

8.6 Mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles

The previous studies have mostly emphasized the negative impact of stroke on both stroke survivors' and family caregivers' lives in day-to-day activities. In the present study, both positive and negative aspects of coping were addressed, in particular nine kinds of positive personal resources emerged over time. They were: (a) acting as a Confucian scholar, (b) upholding the principles of self-reliance, (c) upholding the Communist ideology, (d) practicing Buddhist rituals, (e) holding the naturalist belief of letting-it-be, (f) using humor, (g) interpreting personal meaning, (h) improvising therapeutic measures, and (i) applying folk healing formulae. And the two reasons for failure to mobilize these resources positively were: (a) suffering from unbearable illness and symptoms, and (b) being overwhelmed with negative feelings of being treated unfairly by others or by heaven.

When integrating the mobilization of both positive and negative personal resources by the 18 case studies in the present study, some families could successfully mobilize these positive personal coping resources and sustain an optimal family well-being. Others failed in part to mobilize these positive personal copying resources and retained a functional family well-being. And the families who completely failed to mobilize these positive personal coping resources could end up with dysfunctional family

well-being. The different outcomes in terms of these three types of family well-being are illustrated in the following 18 cases.

8.6.1 Optimal well-being of the family living with stroke

In Mr. J's family, both Mr. J and his wife had used a number of positive coping strategies to deal with the issues of mobility and falls, eating and meal preparation, medication concerns and physical discomforts. Five positive coping resources were mostly utilized by them: (a) acting as a Confucian scholar "strict to himself and generous to others", (b) upholding the principles of self-reliance "never bend his noble head just flattering for five pecks of rice", (c) using humor while sitting on the ground because of falls was mostly used by Mr. J, whereas (d) practicing Buddhist rituals was used by J's wife most frequently, and both of them adopted (e) improvising therapeutic measures through taking vinegar beans.

In Mrs. K's family, Mrs. K was frequently mentioned her ways of holding the naturalist belief of letting-it-be in dealing her care issues (eating and meal preparation, physical discomforts-tooth pain) through "just let it go... just neglect it".

Mr. L often mentioned how he had difficulty in managing medication issues, but he frequently used improvised therapeutic measures, such as taking vinegar egg regularly so as to soften his blood vessels, and upholding the principle of self-reliance and

helping other family members relieve the burden of care (i.e., eating and meal preparation). In addition, he often interpreted his personal meaning in dealing with his functional limitation through regaining his self-strength (actively doing exercises to enhance physical strength in walking).

Mr. M had problems walking and moving independently because he had a lack of energy. However, he frequently used humor to make others happy and relieved the burden of illness and symptoms with a single brilliant catchphrase “tasty and in high spirits”.

Mrs. N frequently acted like a normal person walking and cooking for her husband, in order to relieve the burden of care on her husband by proving herself to “be better” through upholding the principles of self-reliance.

O’s daughter was unemployed and confronted with financial problems in paying the medications. Mrs. O frequently described how capable her four daughters were of working together in the family to obtain medications through improvising therapeutic measures creatively and economically in their own ways.

Mr. P and his wife believed that they could appreciate their problem by living with the long-term illness. They learned how to apply folk healing formulae effectively like

“curing a dead horse as if it is still alive” and holding the naturalist belief of letting-it-be, “one could live better in his later years”.

Mr. Q attempted to take fewer medications in order to reduce the side-effects and toxicity: he improvised therapeutic measures by taking one spoonful vinegar in the morning to heal his blood vessel problems. He also upheld the Communist ideology toward illness like a brave soldier “going through fire and water”.

Couple R was the youngest among the 18 families and their daughter was only 16 years old. R’s wife felt Mr. R sometimes had a problem in communicating and was depressed. She would encourage him to talk and lighten the atmosphere of family life by using their special humorous metaphor of “ugly wrinkled leaves”.

8.6.2 Functional well-being of the family living with stroke

Mr. F lived alone and felt his emotional state fluctuating during the day. He used to apply a number of ways to deal with the burden of his illness and symptoms, which sometimes overwhelmed him. The strategies he most often used included upholding the principles of self-reliance in managing his eating and meal preparation, and interpreting his illness in an acceptable way, such as “denying the doctor’s wrong diagnosis of brain-stroke but utilizing his self-diagnosis of wind-stroke”.

Mrs. G was widowed and had to live with her second daughter's family temporarily. She was not welcomed by her son-in-law and she felt stressful in dealing with this situation. She constantly did exercises and upheld the principles of self-reliance because she had a hope that "I would rely on myself and live in a happy life", and that she could go back to her own house sooner if she could completely depend upon her self.

Mr. H was irritable and depressed after discharge home. His wife patiently dealt with Mr. H's temper by holding the naturalist belief of letting-it-be. They frequently comforted each other that getting sick could not be solved in such a hurry as "recovery takes time".

Mr. I attempted to keep his mind at peace and preferred to speak less. He insisted on doing exercises through upholding the principles of self-reliance: "I do rely on myself". But I's wife frequently expressed her dissatisfaction with Mr. I's silence and the fact that her work was less acknowledged by the whole family. I's daughter-in-law was unemployed and frequently offered her help to her mother-in-law by affirming the naturalist belief of letting-it-be as "getting old is natural".

8.6.3 Dysfunctional well-being of the family living with stroke

Mr. A was demanding in eating and meal preparation, and expressed immature feelings by condemning his son and his wife for not acting as a filial son and obedient wife. He blamed that “raising a son is no better than raising a dog! Wild birds flying mad, chickens running everywhere ...”. And his wife complained helplessly:

“He, quarrelling, scolding, even beating, and argued that he is right all the time...”

Mr. A was also overwhelmed with negative feelings of being treated unfairly by his family and heaven. His behaviors also made his whole family members feel helpless and hopeless.

Mrs. B was considered to be a strong and independent woman in her family and always provided others with ‘goodness’, but received nothing in return. She blamed her daughter-in-law: “when meeting her daughter-in-law on the way, she even did not greet to her-mother-in-law”. She was overwhelmed with negative feelings of being treated unfairly by her unfilial sons and daughters-in-law. She complained that despite sending ‘spring wind’, she never got any ‘night rain’ in return.

Mrs. C used to depend on her husband before her stroke; now she was paralyzed and lay in bed all day long. Mrs. C was overwhelmed by the burden of her illness and symptoms, such as leg pain “I was so upset I am tortured to death”. And C’s husband

had to take all responsibilities for caring for her without a break: “24 hours a day, nowhere to go”, which he perceived to be unbearable burden of care. Thus both of them were suffering from unbearable burden of care and burden of illness and physical discomforts after six months in the home care.

Mrs. D was extremely distress and helpless when lying in bed with constant bowel incontinence, and begged for death to come “Let the doctor give me an injection and let me die earlier”. She was suffering from an unbearable burden of her illness and symptoms, and begged for death to come and relieve her pain.

Mr. E (widowed) had five children, none of whom could provide him with practical help, particularly in eating and meal preparation. He was also overwhelmed with negative feelings of being treated unfairly by his sons, shouting: “Why am I treated by my sons in such a way?”

8.7 Summary

The findings from this part detailed the post stroke experience of survivors and the care experience in family caregivers, as well as the way they dealt with their problems in daily care hassles in the first six months after discharge home. Personal coping resources utilization was divided into the positive personal coping resources and the reasons for failing to do so. The positive personal coping resources involved (a)

cultivating the moral self included upholding Confucius scholars, communist ideology, and the principles of self-reliance, (b) appealing to spirituality included practicing Buddhist rituals and holding the natural belief of letting-it-be, (c) ascribing positive meaning to life adversities including using humor and interpreting personal meaning, and (d) acting as a folk healer including improvising therapeutic measures and applying folk healing formulae. The reasons for failure included suffering from unbearable illness and symptom burden and being overwhelmed with negative feelings of being treated unfairly by others and/or by heaven. Finally mobilization of these personal coping resources was examined by optimal, functional and dysfunctional well-being of the families in living with stroke.

Chapter Nine
Towards an Empirically-based Theory of Family Well-being
in Living with Stroke

Evans and colleagues (1992, 1994) have detailed information on post-stroke family functioning disrupted by maladjustment to stroke, showing that stroke can be devastating to interpersonal relationships and can cause several kinds of personal problem within families. Paralysis and cognitive deficits resulting from stroke have been shown to adversely affect marital relationships, family members' health, and social functioning, and particularly to limit social interaction. They suggested that stroke-related disability usually interacts with changes in family functioning (Evans 1994). Although studies have pinpointed some actual or potential problems following stroke, they also indicate that a majority of families function well after the stroke and that in some cases gains are also made within the family. But those studies on family functioning seem to fail to examine *how* and *why* some suffer a loss of functioning, while others could continue functioning in their own way.

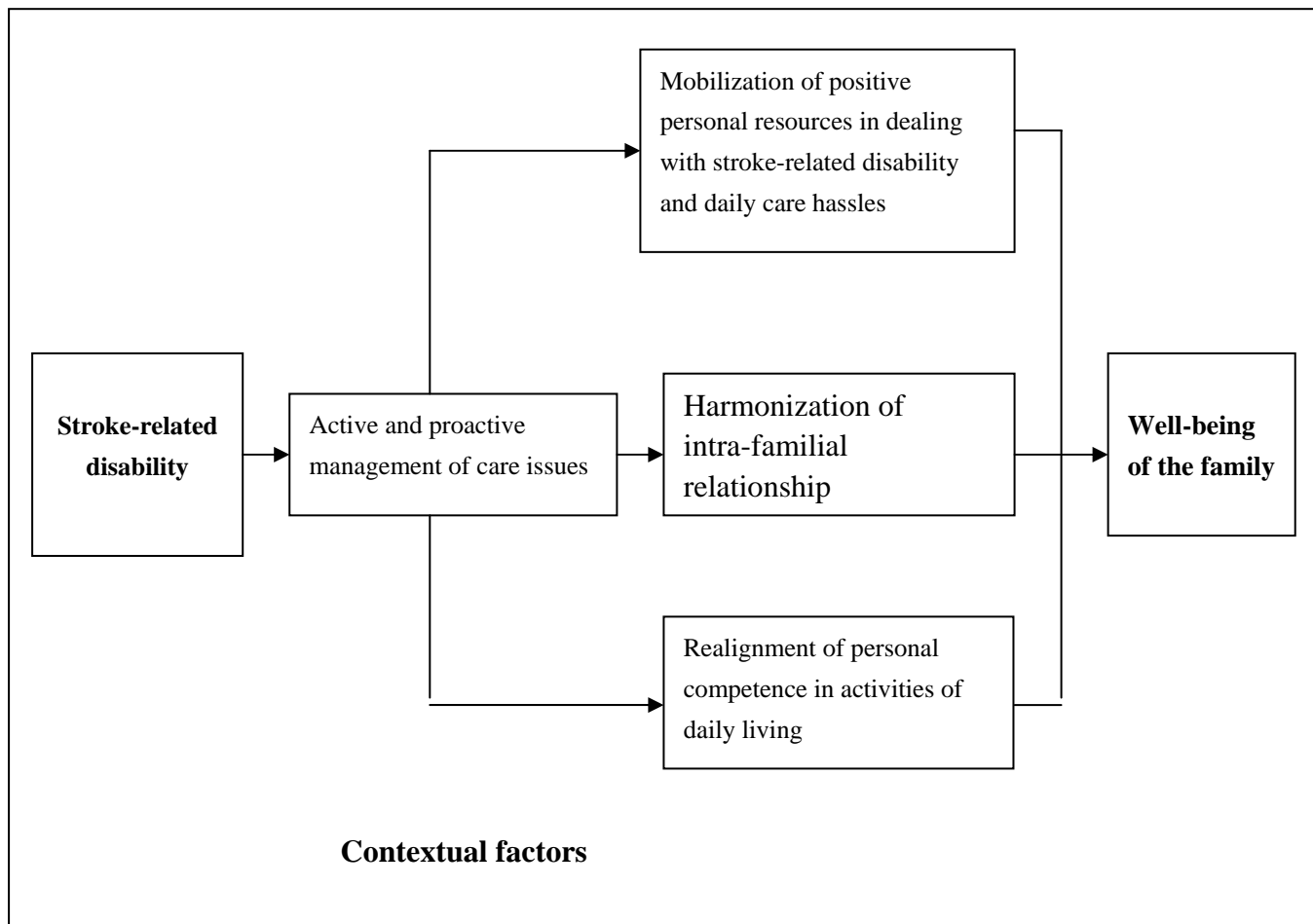
In order to answer these questions, this multiple-case study was designed according to the study proposition, which stated that the well-being of the family is dependent upon stroke-related residual disability and emergent care issues, perceived burdens in family care-giving, coping resources at the personal, family and community levels, and caring work organization.

The analyses of the 18 case studies as presented in Chapters five through eight provided empirical evidence of the commonality and variations among these 18 families in terms of their experiences in living with stroke. In re-examining the study proposition based on the findings as presented in Chapters six through eight, an empirically-based theory of family well-being in living with stroke is derived to attempt to explain *how* and *why* the well-being of the family living with stroke can be sustained. It is postulated that the well-being of the family living with stroke is dependent on: (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Families who failed in part or in whole to maintain these four features were considered as having functional or dysfunctional well-being. Of the 18 families, seven could maintain optimal family well-being and one remained functional during the study period. Ten families had their family well-being changed over time, with eight experiencing negative change and two positive changes.

The task of this chapter is to explain *why* the positive and negative changes occurred in the well-being of families living with stroke. The interplay of four constituent elements in optimizing the well-being of family living with stroke in Wuhan, China, is illustrated in Figure 9.1. It indicates that the well-being of family is determined by stroke-related disability, active and proactive management of care issues, mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles,

harmonization of intra-familial relationship and realignment of personal competence in activities of daily living.

Figure 9.1. The interplay of four constituent elements in optimizing the well-being of family living with stroke in Wuhan, China



9.1 Positive and negative changes of family well-being in living with stroke

Data analysis revealed that there were various types of change in family well-being change over time. It was also noted that of the 18 families, there were ten showing a pattern of change and eight remaining stable over time (see Table 4.9, p. 177).

Of the above two important patterns of change, two showed a positive change and eight a negative change. These changes are demonstrated by the following cases.

9.1.1 Positive change by types of family well-being

The following two cases demonstrated positive change: one from dysfunctional to optimal family well-being (Mrs. O), and the other from functional to optimal family well-being (Mr. R).

At the beginning of the first month, O's daughter, as the primary caregiver, struggled to manage the stroke survivor's eating and nutrition, as well as medication to control the newly diagnosed diabetes. Mrs. O had four daughters but always regretted being unable to bear a son to continue the family line. To fulfill their wish, the couple had fostered their nephew as their stepson. While she was in the hospital, her nephew was involved in a street fight and was stabbed to death. The sad news had completely overwhelmed

her and caused her illness to worsen. She was depressed and lay in bed all day long saying: “let me die”. O’s second daughter provided her constant caring, saying “I will never give up” and Mrs. O regained her confidence and improved her emotion.

In this case, a positive change emerged, with contributing factors being: (a) changes of family dynamics from a disengaged to a cooperative pattern because O’s second daughter persistently strived to meet the traditional Chinese family role expectations – the filial daughter role – by taking care of her sick mother wholeheartedly, and the fact that harmonization of familial relationship being attained, (b) O’s daughters working together to mobilize personal positive coping resources in dealing with stroke-related disability and daily care hassles: improvising therapeutic measures to deal with medication issues, and (c) O’s daughter’s active and proactive management of Mrs. O’s care issues, such as eating and meal preparation, and orderly management of medication. Thus, with her daughters’ careful care and support, the family worked together, and was eventually able to sustain optimal family well-being, and see a positive change from dysfunctional to optimal well-being at six months after discharge home.

During the initial interview, R’s wife was alone in providing care to her husband. Mr. R had previously worked as a driver, and felt depressed due to the initial shock caused by his stroke. This experience had made him constantly stay in bed, unable to move, worrying about a recurrence of stroke and despairing at home. R’s wife attempted to

talk to her husband by making jokes “ugly wrinkled leaves?” and “old tree bark”. R’s wife constantly comforted and supported him, and his sister provided help in medication prescription.

In this case, a positive change emerged, with contributing factors being: (a) changes of family dynamics from a compromising to a cooperative pattern because of R’s wife persisting in meeting the traditional Chinese family role expectations – the filial wife role – to take care of her sick husband, and the fact that harmonization of familial relationship being attained, (b) the couple working together to mobilize positive coping resources in dealing with stroke-related disability and daily care hassles by ascribing positive meaning to life adversities by using humor, and (c) active and proactive management of care issues, such as R’s sister’s involvement in managing medication issues. Thus with both R’s wife’s and sister’s patience and emotional support, such as buy his favorite gift with a surprise, and Mr. R’s depression was improved over time. Thus the family could sustain optimal family well-being of the family and see a positive change from functional to optimal well-being at six months after discharge home.

9.1.2 A negative change by types of family well-being

Of the eight indicating a negative change, five (Mr. A, Mrs. B, Mrs. C, Mrs. D, Mr. E) ended up with dysfunctional and three (Mrs. G, Mr. H, Mr. I) retained functional family well-being. These cases are illustrated below.

In the initial time after discharge, Mr. A praised his wife and son frequently, saying “My wife is extremely good, and everything is done by her: shopping, cooking, washing. My son is praised by all living around!” As time went by, A’s son was busy with his job and paid fewer visits to his parents, particularly when critical events occurring in his own family and the daughter-in-law was pregnant. At that time, the whole family’s concerns were directed towards the daughter-in-law and newborn baby. Mr. A turned his anger toward the daughter-in-law and newborn baby and lost his temper frequently. He accused his son and wife, saying “raising a son is no better than raising a dog!” “Chickens running everywhere...”. A’s wife was sad and complained, “He, quarrelling, scolding, even beating me, and argued that he is right all the time”. In addition, Mr. A lacked the awareness of his limitation in his activities of daily living such as razor accident. A’s wife had problems in dealing with poly-pharmacy due to their misplace, saying “a big head”.

In Mr. A, it is indicated that a negative change evolved, with contributing factors being:

(a) changes of family dynamics from a cooperative to a disengaged pattern due to

condemning his son, daughter-in-law and his wife as not being able to meet their role expectations, and the fact that harmonization of familial relationship not being attained, (b) failure to mobilize their personal positive coping resources because of being overwhelmed with negative feelings of being treated unfairly by other family members and by heaven (c) failure to realign his personal competence in his activities of daily living and daily care hassles, and (d) less effective active and proactive management of poly-pharmacy on the part of A's wife. Thus the family could not sustain optimal family well-being of the family and see a negative change from optimal to dysfunctional well-being at the six months after discharge home.

Mrs. B was so happy when the investigator initially met her while she was sitting with her youngest daughter, and she described how she arranged her activities after discharge home through going out and visiting several temples as well as having all medical coverage for hospitalization reimbursed by her working unit immediately. As she said: "I am very pleasant these days." Later she expressed her frustration at being ignored by her sons and daughter-in-law since they did not pay her any visits in a long time. She had several fights with her husband and children because they were all taking sides against her and isolating her. Even though she was capable of doing housework, she refused to do any because of a fear of stroke recurrence. Finally, she decided to live in the temple and made detailed arrangements for her new life.

In the case of Mrs. B, a negative change evolved, with contributing factors being: (a) changes of family dynamics from a cooperative to disengaged pattern due to condemning her sons and daughter-in-law not able to meet the role expectations, and the fact that harmonization of familial relationship could not be attained, (b) failure to mobilize personal positive coping resources because of being overwhelmed with negative feelings of being treated unfairly by other family members and by heaven, even though she was able to practice Buddhist rituals by visiting Buddhist temples and attempted to apply folk healing formulae on the part of Mrs. B, and (c) failure to realign her personal competence in her activities of daily living such as cooking and washing, and (d) less effective active and proactive management of her own poly-pharmacy. Thus the family could not sustain optimal family well-being of the family, and see a negative change from optimal to dysfunctional well-being at six months after discharge home.

C's husband had an anxious expression and the couple was actively trying to find measures and was hoping that Mrs. C would recover someday when the weather became warmer. But as time went by, C's husband had to give up his part-time job and take care of Mrs. C full-time at home, frequently helping her change position, perform skin care, and changed her diapers, but little improvement was made. Mrs. C frequently complained of leg pain and sleeping disturbance. Finally, C's husband expressed helplessness in the face of the endless daily care activities, such as urinary incontinence and

her constant pain, and complained about her total dependence by saying “Totally dependent on me, I even want her to pass away quicker...Absolutely no hope...”

In the case of Mrs. C, a negative change emerged, with contributing factors being: (a) changes of family dynamics from a cooperative to a disengaged pattern due to meeting the family role expectations, but with an unbearable care burden (because of complete dependence in her activities of daily living, particular urinary incontinence) on the part of C’s husband, (b) failure to mobilize personal positive coping resources because of being overwhelmed with negative feelings of suffering from an unbearable burden of illness and symptoms on the part of Mrs. C, (c) Mrs. C failing to realign her personal capacity in her activities of daily living because she had a high level of stroke-related residual disability, and (d) less effective active and proactive management of multiple care issues in seeking alternatives for access to health care services on the part of C’s husband like bedsore dressing and urinary incontinence due to financial constraints (no medical coverage) and an unbearable burden of care. Thus the family could not sustain optimal well-being and see a negative change from optimal to dysfunctional well-being at six months after discharge home.

D’s only son, 37 years old, initially sat with his mother and pretended to conceal the fact that he was unemployed. Mrs. D suffered from bowel incontinence, saying “Just like squeeze tooth paste, squeeze out...”. D’s son said he was stressed that he had never taken such responsibility for a bedridden patient.

In the case of Mrs. D, a negative change evolved, with contributing factors being: (a) changes of family dynamics from a cooperative to a disengaged pattern due to meeting the family role expectations, but with an unbearable care burden (because of complete dependence in her activities of daily living, particular bowel incontinence) on the part of D's son, (b) failure to mobilize personal positive coping resources because of being overwhelmed with negative feelings of suffering from an unbearable burden of illness and symptoms on the part of Mrs. D, (c) Mrs. D failing to realign her personal capacity in her activities of daily living because she had a high level of stroke-related disability, and (d) less effective active and proactive management of multiple care issues in seeking alternatives for access to health care services on the part of D's son (e.g. physical discomforts bowel incontinence) due to financial constraints (e.g. no medical coverage) and an unbearable burden of care. Thus the family ended up with dysfunctional well-being at the six months after discharge home with a negative change from optimal to dysfunctional well-being at six months after discharge home.

Mr. E's wife had passed away and they had four sons. However, none of them could provide instrumental daily care for him. He was initially cared for by his grandson at one month, and then all day-to-day tasks were completed by him. He attempted to find a woman in order to re-marry, but all of his children rejected this idea, particularly his daughter-in-law. In order to find a balancing point, he thought the only way to get relief was prostitutes, and he was living in a "counting my days".

In the case of Mr. E, a negative change emerged, with contributing factors being: (a) changes of family dynamics from a compromising to a disengaged pattern due to being helpless in the changed family role relationship and condemning his sons and daughter-in-law as not being able to meet their role expectations, and the fact that harmonization of familial relationship not being attained, and (b) failure to mobilize personal positive coping resources in dealing with stroke-related disability and daily care hassles because of being overwhelmed with negative feelings of being treated unfairly by other family members on the part of Mr. E, (c) Mr. E failing to realign his personal capacity in his activities of daily living (e.g. eating and meal preparation), and (d) less effective active and proactive management of care issues in his family (e.g. issues of sexuality). Thus the family could not sustain optimal well-being and see a negative change from optimal to dysfunctional well-being at six months after discharge home.

Mrs. G, 79 years old, was still capable of helping herself. Even though she had four daughters and one son, she could only live with her daughters' families in turn. Once her son-in-law accused her terribly but she simply wept in silence. She frequently expected to recover and lived independently, saying "I want to go back home...".

In Mrs. G, a negative change grew, with contributing factors being: (a) changes of family dynamics from a cooperative to a compromising pattern due to being helpless in the changed family role relationships as Mrs. G was unable to live with her son's

family), and the fact that harmonization of familial relationship not being attained, (b) being able to mobilize personal positive coping resources in dealing with stroke-related disability and daily care hassles: cultivating the moral self by upholding the principles of self-reliance, acting as a folk healer by improvising therapeutic measures, (c) her realigning her competence in her activities of daily living, (active involving exercises), and (d) her active and proactive management of the issue of medication. Thus the family could not sustain optimal family well-being of the family, and see a negative change from optimal to functional well-being at six months after discharge home.

Couple H was almost 75 years old. They got a helper immediately after Mr. H was discharged from the hospital. Mr. H frequently showed his dissatisfaction with his wife's caring work, but he preferred to be assisted by the helper, 16 years old girl. The tension between them was remarkable because Mr. H shouted at his wife, while his wife was angry with the helper.

In Mr. H, a negative change emerged, with contributing factors being: (a) changes of family dynamics from a cooperative to a compromising pattern because even though H's wife met the Chinese role expectation, Mr. H perceived his needs unmet properly, and the fact that harmonization of familial relationship not being attained, (b) his realigning his competence in his activities of mobility, (c) his failing to mobilize his personal positive coping resources due to Mr. H's being overwhelmed with negative feelings of a burden of illness and symptoms, and (d) his wife active and proactive

management of dietary modification and meal preparation. Thus the family could not sustain optimal well-being, and see a negative change from optimal to functional well-being at six months after discharge home.

I's wife was thoughtful and she had tried her best to care for her husband. Mr. I also made efforts to do exercises in order to improve over time. As time went by, I's wife blamed Mr. I and took out her dissatisfaction and boredom on her daughter-in-law, even though Mr. I had made great progress in his personal care over time.

In the case of Mr. I, a negative change evolved, with contributing factors being: (a) changes of family dynamics from a cooperative to a compromising pattern because even though I's wife met the Chinese role expectation, but with an increasing burden of care on the part of I's wife, and the fact that harmonization of familial relationship not being attained, (b) his realigning his personal competence in dealing with stroke-related disability and daily care hassles (e.g. walking independence and actively doing exercises), (c) his mobilizing his personal positive coping resources by upholding principles of self-reliance, and (d) her wife and daughter-in-law's active and proactive management of care issues related to dietary modification and meal preparation, and orderly management of medication. Thus the family could not sustain optimal well-being, and see a negative change from optimal to functional well-being at six months after discharge home.

Overall, optimal family well-being could be sustained in families meeting the above four constituents. Functional family well-being could be maintained in families meeting part of the above constituents. However, dysfunctional family ill-being could emerge in families which failed to meet these four constituents.

9.2 Summary

All cases revealed characterization of the above four constituents. They are: (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence to activities of daily living and daily care hassles, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Families who failed in part or in whole to maintain these four features were considered as having functional or dysfunctional well-being.

Both positive and negative changes are analyzed. Of the 18 families, seven families could maintain optimal family well-being and one family remained functional during the study period. Ten families had their family well-beings changed over time, with eight families experiencing negative change and two families positive change.

This finding provides an empirically-based theory for research on the post-stroke and family care experience, and nursing actions to assist both stroke survivors and family

caregivers dealing with stroke-related disability and daily care hassles and managing multiple care issues in Wuhan, China.

Chapter Ten

Conclusion and Study Implications

In this final Chapter, conclusion and study implications are presented including issues of generalizability of the empirical-based theory of family well-being in living with stroke, the multiple-case study as an optimal choice for investigating the well-being of the families living with stroke, and the need and strategies for designing an organized and planned stroke care community-based health services. Finally, the study limitations and suggestions for further study are delineated.

10.1 Generalizability of the empirically-based theory of family well-being living with stroke

The lack of generalizability has been the most pertinent question remaining because “case study research is used mainly to investigate cases that are tied to a specific situation and locality, and hence this type of inquiry is even less readily generalizable than other qualitative research” (Holloway & Wheeler 2002, p. 222) and quantitative research (Dale 1995, Gray 1998), in which the findings cannot be applied to the sample under study.

Platt (1992) suggested that this problem arises due to difficulties in defining a representative sample, or because the case sample is small. Mitchell (1983) contended

that the generalizability is high as the research is conducted in a real situation thus enhancing the believability of the research. Thus the case study is favorable because the real experience can be described intensively, and in depth and in harmony with the reader's experience, so that the reader or readers can have his or their empathy with the case (Platt 1988, Stake 1983). Such believability enhances the internal validity, and this is intensified by a real event (Stoecker 1991).

Yin (1994) responded to the critique of the shortfall of case study that understanding the distinction between two types of generalizability – statistical and analytical generalizability – is the most important challenge in doing case studies. Statistical generalizability is a way of generalizing the results of the case, thus each case is selected randomly from the population underpinned by a sampling logic, and the final goal of the study is generalizable to populations or universes. Yin further explained that this is because an inference made from statistical generalizability is about the population (or universe) on the basis of empirical data collected about a sample (Yin 1994).

In contrast to statistical generalizability, analytical generalizability is based on a previously developed study proposition (Yin 1994). The study proposition has been used as a template to select each case; each case is seen as a single case analogous to a single experiment, and multiple cases are analogous to replicating the same phenomenon under different conditions underpinned by a replication logic. Thus the

short answer is that case studies, like experiments, are generalizable to theoretical propositions or expanding theories (analytical generalization), but not to enumerating frequencies (statistical generalization) (Yin 1994, p. 10). According to this replication logic and prior development of the study proposition, Yin's multiple-case (embedded) study design was used so as to overcome this problem.

Based on this justification, the aim of the present multiple-case studies was to establish a cause and effect relationship, in which one condition was shown to lead to other conditions through constant comparisons of commonalities and differences and the iterative nature of explanation-building across 18 case studies. Ultimately, the goal was to derive an empirically-based theory of family well-being living with stroke. The theory that emerged from the cross-case analysis in this study (see Figure 9.1, p. 385) appears suitable for explaining the well-being of families living with stroke. This illustrates what is meant by "generalizing to theory", which is the purpose of an explanatory case study. The empirically-based theory in this study is capable of answering the questions "*how*" and "*why*".

10.2 The necessity of developing a community-based family-centered care service in Wuhan, China

The findings from the present study delineated many care issues related to the post-stroke experience in survivors and the care experience in family caregivers over a

period of six months after discharge home. These issues, for both survivors and family caregivers, were consistent with reports in previous studies, characterized by being diverse, complex, and changing over time: from initially instrumental to later psychological (McKevitt et al. 2004).

The neurological impairment and stroke conditions were presented as (a) varied levels of neurological deficits in terms of hemiplegia, hemiparesis, and weakness, (b) more recurrent stroke, (c) most having two or more chronic illnesses, the most common being hypertension, coronary heart disease and diabetes. In addition, most primary caregivers had one chronic health problem such as anemia, kidney problem, musculoskeletal problems, coronary heart disease and others. In addition to health problems, a higher level of perception of economic burden was also noted. The study has also suggested that although stroke survivors made progress in performing activities of daily living, their psychosocial health did not improve over time. Moreover, the findings also showed that most survivors were living with family members after discharge home and needed the support and assistance of their families in the traditional form of extended family structures.

The study revealed a lack of organized and planned stroke care service either in hospital-based or community-based settings, and that many families did not seek medications prescribed by doctors but used their own therapeutic measures instead. Further, most families complained that these services were far from satisfactory

because of cost, professionals' attitudes, and the absence of a trusting relationship, difficulties such as inconvenience in terms of the lack of family members to accompany the patient, inability to walk independently (e.g. elevator not available), difficulties in transportation (e.g. located far from home, and afraid of falling), and lack of proper information.

The findings help the investigator to gain a comprehensive and culturally sensitive understanding of stroke-related residual disability, multiple care issues, family dynamics in caring work organization and personal coping resources of families living with stroke in Wuhan. These strategies are of theoretical importance because it is postulated that optimal well-being of the family living with stroke is characterized: (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living and daily care hassles, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Families who failed in part or in whole to maintain these four constituents are considered as having functional or dysfunctional well-beings.

Community-based family-centered care service is imperative to be developed in the prevention of stroke recurrence health promotion and maintenance in hypertension, coronary heart disease and diabetes, as well as being critical to the recovery of psychosocial aspects in the local Wuhan community. Particular attention should also be

paid to meeting family caregiving needs in the long run because these caregivers may otherwise become “hidden patients”.

It is important for nurses to understand and accept stroke survivors and family caregivers within their own family context, thus efforts should be made to appreciate the uniqueness of the families to whom we are going to deliver an optimal and individualized care. Therefore, a holistic assessment for the family as a unit of care is needed.

Because of the diverse nature of these issues, the development of community-based family-centered care strategies is essential for nurses working in the community. A multiple-case (embedded) study approach can be used which is enable to address how stroke survivors and their family members live with stroke and assist the investigator to design family-centered and community-based care strategies for them in Wuhan, China.

10.3 Multiple-case study as an optimal choice for investigating the well-being of the family in living with stroke

The multiple-case study has much to offer as a research strategy and method for investigating the complex phenomenon of nursing in its contemporary context because it is able to capture its diversity and accurately account for the reality of examining the

well-being of the families in living with stroke. The focus of this multiple-case study is the search for the commonalities and differences in both post-stroke and care experience over time. Since health and illness behaviors happen within a total real-life context, conducting case studies is vital to understanding the care issues encountered by the families living with stroke survivors, how they coped with these difficult care situations, and how they sustained their well- and ill-being of families in living with stroke over time in the home care setting.

Three types of case study were applied in the present investigation. These were exploratory case studies (aiming to test the feasibility of desired research procedures), descriptive case studies (aiming to present a detailed and thick description), and explanatory case studies (aiming to show a cause and effect relationship). Using multiple sources of evidence, establishing a case study data base, and developing a chain of evidence were desirable because these could strengthen the construct validity and reliability of the study in the process of data collection. Similarly, time-series analysis, pattern-matching and explanation-building techniques also enhanced internal and external validity in the process of data analysis.

Furthermore, a variety of data collection methods were utilized in the present study, such as chart review, structured questionnaires, in-depth interview and field observation, because this multiple-case studies revealed that each family is unique and the impact of stroke on survivors and family caregivers are broad and diverse, thus both

general and unique information were important. Chart reviews were essential to understand the nature of the illness condition, standard questionnaire could be undertaken to record the stroke recovery process over time, and the in-depth interview was particularly pertinent because the perspective of the individual's experience is different from that of the health care professional. Of these, understanding an individual's experience is significant because an individual's experience and background can help us understand how social action is personified and how the personal life is substantially constructed by the realities of stroke, so as to provide us with a great deal of insight into the detail of individual-cultural interplay and to foster insight regarding the complex nature of the post-stroke experience and care experience (Doolittle 1988, 1991, 1992, Davis & Grant 1994).

The multiple-case study has two remarkable advantages particularly relevant to designing community-based family-centered care strategies, one being the collection of multiple sources of evidence and the other that it allows the investigator to listen the voices and the perspective of the individuals studied.

10.3.1 Collecting multiple sources of evidence

The methods typically used to assess family well-being after stroke have been challenged and only recently have techniques been developed to quantify the assessment of family well-being in stroke (Evans et al. 1994). Many studies have

suggested that a combined approach to evaluating family well-being is preferable (Evan et al. 1994). Evan et al. (1994) further suggested that a combination of self-report questionnaire, interview measures and observation methods can be useful to gain intensive and in-depth information on family well-being after stroke.

In the present investigation, structured questionnaires were used to screen for level of cognitive deficits, general health status, characteristics of stroke survivors, family caregivers, and family surroundings, and health care service utilization both in hospitalization and post-discharge home; chart review was employed to identify characteristics of the stroke illness and medical conditions, and some medical observations were recorded.

The semi-structured methods were based on the question guides and were designed to yield more detailed information on the care issues encountered and how they were dealt, and to offer the advantage of the field observations.

Field observation and notes were sensitive and effective, but might need specific training and careful attention to methodological issues. Regardless of the methods used, the practice of collecting family information allows nursing professionals to learn more about the impact of post-stroke and care experience on family well-being over time and to plan more effective and efficient nursing intervention program.

10.3.2 Listening to individuals' perspective

This investigation has enhanced knowledge and understanding about the well-being of the family living with stroke. It has confirmed the perception of illness and care experience and patterns of organization of caring work that are critical in determining an optimal, functional and dysfunctional family's well-being. The findings have also shed light on how an optimal family well-being can be enhanced through four features: (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living and daily care hassles, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. There is no doubt that such knowledge and understanding has significant implications for improving quality of care for the families living with stroke after discharge home. For instance, enhancing nursing professionals' awareness can create openness to individuals' experiences and their priorities, concerns, values, beliefs, and wishes regarding the process of the post-stroke and care experience. Further, the quality of relationships between health care professionals and individuals living with stroke can influence family's well-being, which it enables them to share their experiences, our understanding what they care about, and our listening to their voices and stories.

10.4 Proposing community-based family-centered care strategies in Wuhan, China

The findings were informative in enabling nurses to derive culturally sensitive and community-based care strategies to help families living with stroke in Wuhan. However, before this discussion, it is necessary to give a brief introduction to research studies in the area of developing community-based health care services.

10.4.1 Previous studies on developing community-based health care services

There are a number of studies examining home care problems, the effectiveness of intervention programs, and the advantages and disadvantages of existing health care services provision.

The common home care problems include unmet psychosocial needs (McLean et al. 1991, Lui & Mackenzie 1999, Eaves 2002), uncertainty of caregiving role after discharge (O'Connell & Baker 2004), and the tension between the patient's goal of recovery and that of the professional (Lawler et al. 1999, Eaves 2002).

About the evaluation of the effectiveness of intervention programs, some studies reported a positive outcome in improving quality of life for family caregivers after discharge home (Mant et al. 2000), and others showed only a small improvement in

social activities (Forster & Young 1996), low impact on the improvement of psychosocial aspects (Glass et al. 2000), and only limited improvement of physical function (Taub & Morris 2001, Lincoln et al. 2000).

Regarding the examination of the existing nature of health care service provision, two major forms of these services are identified: institution-based service (Stone 1987, Forster & Young 1989, Mant et al. 2000, Lincoln et al. 2000, Taub & Morris 2001, Miller & Spilker 2003) and community-based service (Holmqvist et al. 2000).

Some researchers indicated that the scope of institution-based service (e.g. hospital-based care, geriatric day hospital) was comprehensive and health care staff could be experts in the rehabilitation area (Forster & Young 1989) and multiple forms of care provision such as rehabilitation, continuing care, and support of carers.

Other researchers have argued that the quality of interactive caring between stroke patients and health care providers is questionable in patients' physical and psychosocial well-being (Pound et al. 1995, Macduff 1998, Burton 2000b) because the characteristics of existing stroke rehabilitation services are underpinned by a two-phase model (e.g. in the acute and rehabilitation stage) but do not reflect the long-term nature of stroke recovery for individuals' needs.

It is also contended that institution-based service is an expensive resource that may prevent from optimal use, and also requires an expensive journey by ambulance. It was particularly difficult for stroke patients traveling a distance, which might lead to increased muscle tone and repeated transfers strengthening pain in the pre-existing frozen shoulder (Stone 1987, Forster & Young 1989). Further, high cost and limited access have led to less effective and efficient utilization after discharge home (Muro et al. 2000).

By contrast, in community-based service, many researchers have demonstrated the potential role of nurses in promoting quality of care after discharge home (Gibbon 1994, Forster & Young 1996, Snape & Burton 2002), particularly in organization of services, providing counseling and education to promote psychosocial recovery. Several nursing research studies have been conducted.

Mumma (1986) pointed to two strategies that facilitate the survivor's independence: (a) being an advocate for patient goal-setting and decision-making, and (b) assisting the patient to be as involved as possible in the rehabilitation program in the early stages.

The PREP system of nursing interventions aims to develop the preparedness (PR), enrichment (E) and predictability (P) of family caring (Archbold et al. 1996), based on role theory and recognition that caregiver stress often results from caregiver's difficulty in performing their new roles. PREP promotes an understanding of how caring

develops longitudinally, thereby affording many opportunities for greater professional involvement. Professionals can use a number of strategies to enhance the preparedness of caregivers, to establish mutuality, to enrich the care-giving relationship, and to develop a sense of predictability in the care-giving situation.

Dorsey and Vaca (1998) outlined several strategies to ease the caregiver's negative reactions and support the caregiver, such as respecting survivors and allowing them to maintain as much control over their own lives, listening by the caregiver which may help to ease suffering by the survivor, putting things in perspective, and validating their own importance and the importance of this episode in their lives. Importantly, it is essential that the caregivers take care of their physical needs and reserve time just for them. The caregiver may benefit from building a network of personal support and allowing others to help them in time. Lessons of faith, words of scripture, hymns of assurance, and teachings of nature also may help the caregivers to find hope.

Pierce (2001a) also outlined caregivers' strategies for successful caring: (a) identifying actions, such as establishing a daily routine, reasoning and looking for answers, reading, watching television or movies, listening to music, (b) the social aspect, such as taking time to relax, calling someone one on the telephone, making plans to go out, using respite of other family members, doing something that is fun, and visiting close friend, (c) the physical aspects in the sense of going someplace, such as shopping at the mall, going walking, and maintaining good nutrition, and (d) the spiritual aspect: reflecting

on one's feelings, saying prayers, reading the Bible or religious books, and asking God for strength.

Eldar (2000), and Lubben and Damron-Rodriguez (2003) also conducted comprehensive and systematic reviews of various issues and the implications of integrating institution-based and community-based rehabilitation services. Eldar made a clear comparison of both institution- and community-based services through demonstrating their advantages and disadvantages (see Table 10.1). Eldar noted that the role of such rehabilitation services can be acted as an integration form which aims at reducing the functional deficits and limitation. However, other aspects appear to be neglected (e.g. psychosocial function and activities).

Even though Eldar viewed integrating medical rehabilitation services as creating a continuum that spans all types of services needed, it is only restricted from the perspective of health care providers, and less in individuals living with stroke-related residual disability and their psychosocial needs and concerns in the home care settings.

Table 10.1. Comparisons between institution- and community-based rehabilitation services

Institution –based rehabilitation services	
Hospital-based rehabilitation	This can be provided on medical or surgical wards as therapeutic interventions by individual therapist, but is often applied without a clear rehabilitation strategy. Some general hospitals have specialized rehabilitation units with comprehensive programs based on coordinated team work, but highly specialized.
Inpatient rehabilitation	The goal is to provide early rehabilitation care, to estimate the final level of patient functioning, to decide on the most appropriate setting to achieve this and to fulfill requirements for discharge from hospital to the most appropriate setting as soon as possible. But it is artificial and different from home, the amount of rehabilitation treatment is often limited, and it is very expensive.
Community-based rehabilitation services	
Day hospitals	These allow patients to live at home and be observed for several hours during the day, and to receive multidisciplinary treatment with accessibility to hospital resources. They are both therapeutic and social environments, providing long-term support and temporary relief to families. They are less expensive than inpatient rehabilitation. But there is a need for transportation which is related to distress, discomfort, complications and expenditure; that patients living at a distance may arrive late and leave early.
Ambulatory rehabilitation	This allows patients to live at home in a familiar environment and it is appropriate to not require admission to inpatient wards or day hospitals. It is also less expensive. However, it requires travel. There are various forms: (a) ambulatory rehabilitation: offers more treatment than inpatient setting or day hospitals, but less closely integrated than in day hospitals and little social interaction is offered, (b) institutes for physical medicine and rehabilitation: these may be part of general hospitals or free standing. Skills and resources are available and multidisciplinary treatment is possible, and less expensive, but its accessibility and comprehensiveness are difficult to coordinate, (c) secondary care setting: this is a large health care center or clinic that has an x-ray, laboratory and physiotherapy and medical/surgical specialists. But the availability of skills and resources and the possibility of multidisciplinary therapy are limited, (d) primary care setting: this is a health center based on Primary Care (PC) teams (i.e., general practitioner or family physician, nurses, or social worker), rehabilitation provided by PC teams. Expenditure is lower than in all previous settings because the setting is nearer to the homes of the patients and travel is shorter. However, the availability of skills and resources is limited.
Domiciliary rehabilitation	There is no need for transport or travel, the environment is familiar, providing emotional security - the patient is the center of a treatment program in which family members can be involved and trained according to the patients' need. However, a full range of skills and resources is not available and a multidisciplinary therapy cannot be implemented.

Source: Eldar R. (2000) Integrated institution-community rehabilitation in developed countries: a proposal. *Disability and Rehabilitation* 22(6):266-274.

More recently, Lubben and Damron-Rodriguez (2003) have proposed an international approach to community health care for older adults based on the research conducted by the World Health Organization Kobe Center for Health Development (WKC). The goal of the WKC approach aims at integrating health and social services and spans health

promotion, primary care and long-term care and meeting the competing needs of the older adult, the family and formal service providers. Lubben and Damron-Rodriguez (2003) further contend that “the WHO’s Kobe Center for Health Development (WKC) has fostered the development of a new approach to community health care. The imperative for this new paradigm is based on both the values and the preferences of older persons and their families, as well as important fiscal and policy issues” (Lubben & Damron-Rodriguez 2003, p. 339) concerning the chronic care needs of older adults, such as people in the community with their families following a stroke.

In addition, they have attempted to develop a new approach to community health care which is particularly suited to developing nations that because they “cannot afford expensive institutional care models...the new approach complements cultural norms of filial piety strongly held by many ethnic populations” (Lubben & Damron-Rodriguez 2003, p. 339). Thus, four prototypes are suggested and a comparison of these approaches has been made based on their particular characteristics and on a global review of approaches to organizing community health care. These approaches include communal, marketplace, case management, and managed care. Of these four approaches, it is suggested that the communal care and marketplace approaches are the most common in developed nations, and the managed care organization approach is the least common, but the case management approach can increasingly be found because it is an economical one.

As Lubben and Damron-Rodriguez (2003) suggest the case management approach is of special interest because the goals of managed care and nursing case management are considered to be quality care and cost-efficiency in healthcare resources utilization. This discussion focuses on the following major characteristics of the case management models in formalizing the community health care service coordination function (see Table 10.2).

Table 10.2. Characteristics of case management models

Elder's role	Case manager moderates older person's discretion
Self-care	Case manager will encourage and facilitate
Social network	Case manager encourages and helps coordinate
Agency care	Mostly autonomous agencies, but some collaboration
Payment source	Often some coordination of payment sources
Payment type	Fee for service
Coordination	Semi-formalized

Source: Lubben J. E. & Damron-Rodriguez, J. (2003) An international approach to community health care for older adults. *Family and Community Health* 26(4):338-349.

Besides these seven characteristics, this model also proposes a new and expanded professional role of case manager assigned to a nurse and a social worker. Lubben and Damron-Rodriguez (2003) stated that nurses and social workers can play an important role in organizing a case management team. They are not only limited to providing direct services (e.g. knowledge and skill of care), but also can be hired to perform as case managers. Further, the case manager not only arranges formal services, but also attempts to mobilize the information support systems where appropriate.

An ideal community-based health care practice and services have been shown in the framework of the case management model (Damron-Rodriguez 2000) because the

multiple layers of a community health care system are illustrated and included, and multiple levels of support within this model can be supplemented by informal and formal supports in the community.

10.4.2 Suggestions for designing strategies toward a community-based family-centered care services for families living with stroke in Wuhan

This part takes a look at the strategies toward a community-based family-centered care service which can be provided as a vehicle in following three aspects: case management, nursing process and sustainability of an optimal well-being.

Case management

The community health care service coordination model proposed by Lubben and Damron-Rodriguez (2003) can guide the development of the present community-based family-centered care strategies. The work of the Case Management Society of America (CMSA) produced a definition of case management in 1994: “case management is a collaborative process which assesses, plans, implements, coordinates, monitors, and evaluates options and services to meet an individual’s health needs through communications and available resources to promote quality, cost-effective outcomes” (Powell 2000, p. 5).

Case management is particularly a team effort and likely to expand a number of health care services ranged from hospital-based to home-based services and it is necessary to collaborate multiple providers (Surgit 1997) which it highlights the interaction among them (Hall & Weaver 2001). Surgit (1997) points out that the disciplines of nursing and social work can work together and each of them is able to utilize knowledge and skills of different categories of professionals and to offer a comprehensive and continuing care in the community.

For nurses, they must be able to utilize the nursing process to provide direct, comprehensive and continuing individualized care. This process should include (a) organizing, understanding and analyzing data regarding their characteristics (e.g. stroke survivor and family caregivers, the family), their general and health information, as well as stroke conditions, the level of stroke-related residual disability and their psychosocial well-being, (b) making decisions about the intervention programs based on their personal needs, concerns, values and beliefs, (c) planning the procedures (e.g. objectives, contents, time, forms), (d) evaluating the effectiveness of the programs.

While for social workers, they should contribute to a service manager and coordinator as indicated by Surgit (1997), which they could provide (a) service prescription or arrangement, (b) coordination of services from multiple providers, (c) budget planning for service units, time periods, (d) reassessment of needs, (e) monitoring of delivery and quality of service, and (f) support the family.

The common goal is to sustain an optimal well-being of the family in living with stroke in the community. Within the framework of the empirically-based theory of family well-being in living with stroke, all activities enable and facilitate the optimal well-being of the family encompassed. The four major strategies toward a community-based family-centered care approach for families living with stroke are suggested as follows: (1) Promoting and maintaining health. This strategy is aimed at recognizing risk factors for stroke and other chronic illnesses, such as heredity, age, hypertension, hyperlipidaemia, diabetes mellitus and cigarette smoking. This represents a change from the traditional approach, where clients are considered as passive and less involved in health care, and lack of self-awareness and responsibilities for his/her personal health. The mutual recognition of the above points is encouraged, (2) Preventing stroke recurrence. This strategy guides the family to closely monitor early signs and symptoms, urge medication adherence, properly use health care service in order to have an early identification, diagnosis and treatment, (3) Fostering an optimal well-being of the family in living with stroke. This strategy provides adequate and appropriate education and opportunities for skill development so that family members can positively interact and communicate with each other for effective use of resources in personal and family level in order to sustain an optimal well-being of the family. These skills include active and proactive management of care issues, realignment of personal competence to activities of daily living, mobilization of positive personal coping resources in dealing with stroke-related residual disability and daily care hassles, and harmonization of intra-familial relationship, and (4) Building community-based

family-centered care policy. This strategy involves all in health care to ensure that health and well-being becomes incorporated into all health care policy decisions. Both multidisciplinary and interdisciplinary collaboration is needed in order to recognize that the policies of other parties, such as social welfare, education, health care and urban planning also affect and are affected by each other for guiding the development of family and community health.

It is also essential to be aware of changes in family structure and value of traditional culture, like the reduced number of available family caregivers, increasing burden of care at home, and conflicting of the family role expectations and generation gap. It is important for community nurses and social workers to mediate, enable and facilitate the adaptation process of post-stroke and caregiving experience in their perspective that can be mobilized to achieve their own goals of well-being. McMurray (1999) advocates that multiple partnerships should be formed for change, in order to engage in the immediate community, understand and respect the family, immediate dynamics and needs. And it is an approach that “requires resourcefulness, information exchange, receptivity to new ideas, a tolerance for difference, a willingness to change” (McMurray 1999, p.20).

As a community nursing practice, nursing process is important to guide nursing care programs regarding of using nursing assessment, problems identification, the objectives and the nursing care plan, nursing implementation and nursing evaluation.

Nursing assessment, problems, objectives and nursing care plan, implementation and evaluation

The ongoing collection of detailed information should include the profiles of family, encompassing the following aspects: (a) characteristics of stroke survivors, primary family caregivers, family structure, and health care service utilization in hospital stay and after discharge home, (b) the severity of stroke-related residual disability regarding physical performance, emotional and social status, and cognitive state by using ADLs and IADL, C-ESD, SPMQ (c) perceptions of the post-stroke and the care experiences based on the study proposition, like care issues encountered, coping resources utilization, and the organization of caring work. Based on the objective and subjective information, case-based and cross-cased analysis should be undertaken in order to identify major problems for the family.

After recognized nursing problems, the objectives and nursing care plan should build. The goal is to achieve an optimal well-being of the family in living with stroke. And the nursing care plan will address to provide a comprehensive, continuing and individualized care; low cost with a broad coverage and convenient access for everyone in the family; and high-efficiency aiming to improve quality of care and quality of life. Nursing implementation aims to health promotional and maintenance, prevention of stroke recurrence and fostering the family well-being in living with stroke. And finally nursing evaluation of family well-being in three levels is conducted. That is for those who can fulfill the above four features, well-being of the family can sustain in an

optimal type; for those fail in part or whole, well-being of the family will be functional or dysfunctional.

Sustainability of an optimal well-being: family as a care of unit

Sustainable optimal well-being is wellbeing that endures over time (McMurray, 1999).

McMurray first states the interaction between the environment and individuals living in the community, that encompasses not merely the current state of health in a family, but also the factors in the context of the social-economic environment will influence the individual development and behavior, and the ability to communicate well. And second, McMurray points out that the key to sustain an optimal well-being depends on a *commitment* to the notion of health which is *holistic* and *dynamic*. The commitment refers to a common notion of health that can be shared by family members included as well as health professionals. Health is valued and people are valued in a climate of trust and mutual respect that extends to all facets of life. When people are healthy, they have the potential for achieving higher levels of wellness and perceive themselves as having the ability and responsibility to manage their personal health.

A holistic view of health focuses on the whole, not just the physical components, but it also refers to mental, social and spiritual factors. The dynamic or action-oriented nature of being healthy and wellbeing is also acknowledged because health is not a static entity, but it is ever changing.

Having this shared understanding of healthiness and well-being, our premise is to assess a family's capacity for sustaining an optimal well-being in living with stroke in accordance with the empirically-based theory that requires the understanding of characteristics of stroke survivors, family caregivers and other family members, family characteristics in terms of family structure, multiple care issues encountered and how the families deal with them with respect to (a) mobilization of positive personal resources in dealing with stroke-related disability and daily care hassles, (b) realignment of personal competence in activities of daily living and daily care hassles, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. In addition of the above crucial information, we can direct toward understanding of the family culture, family risk factors, of how family members behave, interact and support with one another, and how they perceive their well-being and ill-being over time in order to sustain an optimal well-being in living with stroke.

10.5 Study limitations and suggestions for further study

10.5.1 Study limitations

Before considering the implications of this investigation, there were two major limitations addressed. First, this exploratory, descriptive and explanatory, multiple-case study used a purposive sample. Although the selected cases covered both stroke survivors and family members (primary and secondary caregivers) from a broad geographic range in local community of Wuhan, only Wuhanese survivors and family caregivers were recruited. The findings should be understood within this context, but it may not represent the views of non-Wuhanese speaking of survivors and family caregivers. Thus the findings may not be generalized to the other cities of China. Second, the quantitative findings could not be inferential because of the small number of the cases. However, the aim of these findings was to assist the investigator to describe the profiles of the 18 families living with stroke. After combining this information with the field observation notes and interview transcriptions, this multiple sources of evidence enabled the investigator to produce the more rich description and explanation for sustaining optimal family well-being living with stroke over time and to help design community-based family-centered care strategies in Wuhan, China.

Because this study targeted the care issues encountered by the family living with stroke-related disability, replication in other illness and care situations is needed to

establish similarities and differences across families after discharge home. Also, as all participants were living in local Wuhan city of China, the generalizability to the other cities in China needs to be further studied. In spite of these limitations, this study has proposed the necessity of establishing a community-based family-centered care service approach for nursing practitioners that is growing in importance as families becoming increasingly responsible for delivering multiple care to stroke survivors. The service helps families living in the community to sustain optimal family well-being and resolve the multiple care issues through delivering specific community-based family-centered care service after discharge home in a comprehensive, systematic and planned way.

10.5.2 Suggestions for further study

Further research is needed to test the empirically-based theory with larger samples and over a longer period of time. Also, further research should include other types of stroke with other kinds of deficits, such as stroke hemorrhage, aphasia, and cognitive impairment in order to validate this empirically-based theory. Religious beliefs, views and cultural concepts related to care issues encountered, family dynamics in caring work organization, and personal coping resources should be further studied in depth.

Further consideration in nursing research and practice is proposed by the following questions based on the following reason. The findings reveal that mobilizing positive personal coping resources and harmonizing familial relationships is challenging for the

provision of community-based family-centered health care services. In the present health care delivery system, most of the care is only provided by the hospital-based health care service, of which most of the emphasis is on the bio-medical perspective. That is, only acute medical care and nursing management has been given for a limited time and during a short stay in hospital setting. Little attention has been paid to psycho-social aspects of care, such as how family dynamics and personal coping resources can be attained and mobilized in sustaining family well-being.

This study raises several questions. Will these multiple care issues exist among families living with stroke after discharge home over time? Will these personal coping resources existing in other families living in different environments? Will these personal coping resources be employed by other families living with other health care problems? It may also be time to evaluate interventions that will enhance an optimal family well-being through mobilizing positive coping resources and maximizing cooperative organization of caring work. How can nurses support families so that dysfunctional family well-being is minimized and avoided?

Community-based family-centered care service is pertinent in the development of direct and coordinate care, and should emphasize preparation, training, and support for the family as a unit of care, particularly in the local community of Wuhan, China. Community nursing practice is critically important in providing help and support for the families, especially those living with stroke, who are in need of many types of

assistance. Most significantly, further study will focus on finding the effective interventions to enhance optimal family well-being in terms of reducing the burdens of care and illness, and preventing the negative changes of family well-being from optimal to functional or dysfunctional levels.

Further study would increase the nurse's understanding of the readjustment process for the post-stroke and care experience in living with stroke. In a short, stroke has a severe impact not only on the well-being of stroke survivors, but on the family as well. It is suggested it is necessary, therefore, to study the experience of survivors and caregivers living with an increasing sample size, the more types of chronic illness and disability and over a longer period of time.

10.6 Summary

In applying the multiple-case (embedded) study, the analytic generalizability has been achieved because “how” and “why” questions were answered. Most survivors had some degrees of stroke-related residual disability after discharge home. They were living with their families and depended upon their family's care. There were multiple care issues encountered. Both survivors and family members managed these care issues through family dynamics of caring work organization and mobilization of personal coping resources. Characterizations of optimal family well-being were revealed: (a) mobilization of positive personal resources in dealing with stroke-related disability and

daily care hassles, (b) realignment of personal competence to activities of daily living and daily care hassles, (c) harmonization of intra-familial relationship, and (d) active and proactive management of care issues. Families who failed in part or in whole of maintaining these four features were considered as having functional or dysfunctional well-beings. Of the 18 families, seven families could maintain optimal family well-being and one family remained functional during the study period. Ten families had their family well-beings changed over time, with eight families experiencing negative change and two families positive change.

The findings are informative for nurses to derive culturally-sensitive and community-based care strategies in helping families living with stroke in Wuhan city. However, a more conscious endeavor is needed on the part of designing community-based family-centered care service.

Further research questions also might include: How can optimal well-being of a family in living with stroke be sustained? How can changes in family well-being be observed and monitored by community nurses for families at risk? Such as those families who have potential problems and need timely and accurate care and support in the home care setting? How can the most effective nursing interventions be assessed, planned, implemented and evaluated by community nurses? What approach can be taken to provide proper psycho-social support from community-based family-centered care service for families living with stroke after discharge home in Wuhan, China?

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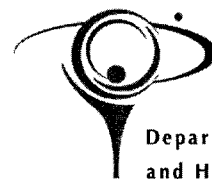
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Appendix 1 Information sheet and consent form



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學



Department of Nursing
and Health Sciences

護理及醫療科學系

本研究介绍

中风病人及其家庭照顾状况访谈

我是香港理工大學研究生李斯俭，誠邀您和您的家庭成员參加此項研究计划。

這項研究的目的是了解中风病人出院后的家庭照顾以及社区健康资源状况的基本情况。访谈将以问卷和询问的方式进行。每次需要花費您约1-2小時时间。访谈将在6个月内共分4次完成。希望這些資料能有助於医疗护理人员对中风病人出院后家庭照顾的理解，从而为武汉的中风病患者建立良好的社区医疗保健服务提供依据。

凡有关您的个人资料均會保密，全部访谈的資料只有研究人員知道。您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不正常的代遇或責任追究。

如果您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 AG426室轉交)。

如果您想獲得更多有關這項研究的資料，請與李斯俭女士電話8787聯系或香港理工大学副教授彭美慈(我的指导导师)电话00856-2766联系。謝謝您有興趣參與這項研究。

李斯俭 研究生



參與研究同意書

中风病人及其家庭照顾状况访谈

本人 _____ 同意參加由 李斯俭 負責執行的研究項目。

我理解此研究所獲得的資料可用於未來的研究和學術交流。然而我有權保護自己的隱私,我的個人資料將不能洩漏。

我對所附資料的有關步驟已經得到充分的解釋。我理解可能會出現的風險。我是自願參與這項研究。

我理解我有權在研究過程中提出問題,并在任何時候決定退出研究而不會受到任何不正常的待遇或責任追究。

中风病人姓名 _____.

中风病人簽 _____.

中风病人家屬姓名 _____.

中风病人家屬簽名 _____.

研究生姓名 _____.

研究生簽字 _____.

日期 _____.



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學



Department of Nursing
and Health Sciences

護理及醫療科學系

INFORMATION SHEET

Towards a community-based and family-centred care approach for stroke survivors in Wuhan City of China

You are invited to participate on a study conducted by LI Sijian, who is research student of the Department of Nursing and Health Sciences in The Hong Kong Polytechnic University.

The aim of this study is to better understand the care issues encountered by the family caregivers and stroke survivors in the community. The study will involving completing a questionnaire and interview which will take you one to two hours each time for 4 times in a period of six months. It is hoped that this information will help to understand caregiving experience for persons with stroke for the development of community-based care services for both family caregivers and stroke survivors in Wuhan city of China.

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 interview without penalty of any kind.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Miss Milly Koo, 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 AG426 of the University).

If you would like more information about this study, please contact Dr. Samantha Pang, my direct supervisor, on tel. no. 00852-2766 or Ms Li Sijian on tel. no. 8787

Thank you for your interest in participating in this study.

Ms. Li Sijian
Research Student



CONSENT TO PARTICIPATE IN RESEARCH
**Towards a community-based and family-centred care approach
for stroke survivors in Wuhan City of China**

I _____ hereby consent to participate in the captioned research
conducted by LI Sijian .

I understand that information obtained from this research may be used in future research
and published. However, my right to privacy will be retained, e.g. 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 subject _____

Signature of subject _____

Name of the informant caregiver _____

Signature of the informant caregiver _____

Name of research
student _____

Signature of research
Student _____

Date _____

Appendix 2 Record of clinical information during hospitalization

住院病情和医护资料

1. 入院时间：____年____月____日

2. 入院后状况：

2-1. 医疗处理包括(意识评估,病情轻重程度治疗措施和原则等)_____.

2-2. 护理计划(特护,病危,一级,二级或三级护理等)

_____.

2-3. 试验室检查:(血,尿,大小便)
_____.

2-4. 放射检查(X-ray, 胸片)_____
_____.

2-5. CT扫描_____
_____.

M.R.I(核磁共振)_____.

2-6. 入院诊断:(脑梗塞类型)

左侧脑梗塞 -- 腔隙性(多发性 单个性)

右侧脑梗塞 -- 腔隙性(多发性 单个性)

2-7. 肢体瘫痪:

左侧肢体瘫痪

右侧肢体瘫痪

3. 出院诊断(预后评估,出院指导,出院注意事项,药物等)

_____.

4. 住院天数_____.

5. 医疗费用合计_____.

6. 其它附语说明_____
_____.

病 情 记 录

病 情	检 查 结 果	医 疗 处 理	护 理 措 施	时 间/日 期	备 注

Appendix 2 Record of clinical information during hospitalization

Chart review of health conditions and medial management

2. Data of admission : ____Year____month____day

2. Conditions after admission :

2.1 Current status

2.2 Past history

2.3 Physical examination: CT scan, Lab, etc.

2.4. Medical management (cognition assessment, muscular assessment)

2.5 Nursing management

2.6. Diagnosis (types of infarction)

Side of lesion: left or right; Affected body: left or right.

3. Discharge planning (diagnosis, pre-discharge planning)

_____.

4. Length of hospital stay

_____.

5. Medical expenditure _____.

6. Others, specified_____.

Health condition recording during hospital stay

Condition	Result of test	Medical management	Nursing management	Time/data	Others

Appendix 3A 中风病人首次访谈部分

访谈 1(出院后一周)

病人编码 _____

1.个人和社区健康资源资料

- | | |
|------------------|----------------------------------------------------|
| 1. 性别 | 男
女 |
| 2. 你今年几多岁? _____ | (或)你于哪年出生?
_____. |
| 3. 你在武汉居住了多少年? | 少于1年
1年至7年
7年以上 |
| 4. 你现在的婚姻状况是: | 已婚
丧偶
分居
未婚 |
| 5. 居住状况 | 獨居
與他人同住:
配偶
子女
配偶及子女
親友
子女及其家人 |
| 6. 住屋种类 | 单位住房(已买)
单位住房(未买)
私人住房
租住房间
其它 _____. |
| 7. 你的教育程度是: | 没有正式上过学
小学程度
初中程度
高中程度
大专程度
硕士或以上程度 |

- 8.测试阅读能力(戴眼镜也包括在内)阅读1遍健康资讯
- 不可以
部分可以(在不能阅读部分打圈)
完全可以
- 9.你的视力如何?
- 清晰
模糊
- 10.你有否配戴眼镜?
- 有
没有
- 11.听力如何(观察)?
- 差(需要提高声量)
好(平常交谈语调)
- 12.你有否使用助听器?
- 有
没有
- 13.你有什么宗教信仰?
- 无
拜神/祖先
佛教
道教
天主教
基督教
其他宗教 _____
- 14.你是否仍工作?
- 是,现在职业 _____
否,退休前职业____
家庭主妇
- 收入来源:
- 是 没有
- 15.工资收入
- 16.家人资助(子女)
- 18.储蓄
- 19.退休金
- 20.单位补贴
- 21.其他(如:股票_____)
- 22.请问你每月的总收入约多少钱?
- <200
201-500
501-1000
1001-5000
>10,000

23. 你每月平均开支约多少钱？
 100-200
 201-500
 501-1000
 1001-5000
 >10,000
24. 你每月是否有节余？
 有节余
 刚刚够
 不足够
25. 如果有额外的开支(如医疗费用),
 你会担心钱不够用吗？
 擔心
 不大擔心
 不擔心
26. 如果你一旦不够钱用,你会最先向
 哪个求助？
 自己/配偶
 子女
 亲戚
 朋友/邻居
 政府,如所属单位
 其他,请说明_____
27. 你自己有没有办理医疗保险？
 有
 没有
28. 你或你配偶有没有公费医疗保障?(如:单位/企业职工)?
 有
 没有

當你在生病時，誰可依靠？

可依靠什麼？如經濟、家居照顧、覆診

29. 配偶

30. 兒子

31. 女兒

32. 媳婦

31. 女兒

33. 女婿

34. 孫

35. 非直系親屬(如

干兒子/干女兒)

36. 朋友/鄰居

37. 其他 (例如:靠 自

己、政府)

38. 整体来说,你满意你目前的身体健康状况吗? 10分是非常满意, 1分是非常不满意,你会给多少分?

10	9	8	7	6	5	4	3	2	1
----	---	---	---	---	---	---	---	---	---

2. 精 神 状 况 (简易精神状态检查 -- 记忆能力)

以下是一些简单的问题,看你是否还能记得住。请尽量回答。

	正 确	不 正 确
1)今天是星期几?	_____	_____
2)今天是多少号?	_____	_____
3)谁是现任国家主席?	_____	_____
4)谁是上一任国家主席?	_____	_____
5)20减去3,再减去3,一直减下去,减5次,答案是什么?	_____	_____
6)你的电话号码是多少?(如无,问下题)	_____	_____
6a)你的地址在哪里?	_____	_____
7)你的住址属于哪一区?	_____	_____
8)你有多大年龄? _____岁。	_____	_____
9)你何时出生的?		
_____年_____月_____日	_____	_____
10)日 本 侵 略 中 国		
_____年_____月_____日	_____	_____

总 分: _____.

功 能 状 况 ** _____.

**共10项,答错一项得1分,总分为10分。对结果的判断标准:

得0—2分者为正常;3—4分者为轻度认知障碍;5—7分为中度;8-10分为严重认知障碍.

3. 情绪状况

我现在将念下列句子，它们表述了哪些人的感受和行。请问在过去1周内，你有多少天有同样的感受和行？*注意：在记录总分前先*将4, 8, 12, 和16题的分数由低到高重新按照大小排列顺序。

	从无<1天	1-2天	3-4天	5天-7天
1.你为一些小事担心	0	1	2	3
2.你不太想吃东西，胃口甚差	0	1	2	3
3.你虽有家人或亲戚劝解，仍觉得闷闷不乐。	0	1	2	3
4.你觉得自己同其他人一样好	0	1	2	3
5.你没办法专心做事	0	1	2	3
6.你觉得心情很不好	0	1	2	3
7.你做事提不起劲(没精神做事)	0	1	2	3
8.你觉得未来充满希望	0	1	2	3
9.你觉得你这一生是失败了	0	1	2	3
10.你觉得很担心，害怕	0	1	2	3
11.你睡不安稳(半夜醒来后难以入睡)	0	1	2	3
12.你觉得很快乐	0	1	2	3
13.你说话比平时少	0	1	2	3
14.你觉得很寂寞，孤单	0	1	2	3
15.你觉得人人都不友善	0	1	2	3
16.你热爱生命，很享受人生	0	1	2	3
17. 你曾经哭过几次。	0	1	2	3
18.你觉得很悲哀	0	1	2	3
19.你觉得别人 不喜欢你	0	1	2	3
20.你觉得你所做的每件事都很不顺利。	0	1	2	3
总 分				
功 能 状 况 **				

**指数数值越大，说明精神遭受的压力越大，该老人患有忧郁症的可能性也就越大。文献上常用CESD 指数为16作为界限，CESD指数大于或等于16者被归为忧郁症。

4. 日常活动量表 (ADL 和 IADL 能力)

改良巴氏指数评定表(ADL 能力)

项目	评分标准和评定时间	得分
1. 吃饭	0分=依赖他人 5分=需要部分辅助(夹菜,盛饭,切面包,抹黄油) 10分=全面自理	
2. 洗澡	0分=依赖他人 5分=自理	
3. 修饰	0分=需要帮助 5分=独立洗脸,梳头刷牙,剃须	
4. 穿衣	0分=依赖他人 5分=需一半辅助 10分=自理(系,开纽扣,开闭拉锁和穿鞋等)	
5. 大便	0分=失禁或昏迷 5分=偶尔失禁(每周<1次) 10分=能控制	
6. 小便	0分=失禁或昏迷或需由他人导尿 5分=偶尔失禁(每24h<1次,每周>1次) 10分=控制	
7. 用厕	0分=依赖他人 5分=需部分辅助 10分=自理	
8. 转移(床和椅间)	0分=完全依赖别人,不能坐 5分=能坐,但需大量(2人)辅助 10分=需少量(1人)帮助或指导	

	15分=自理	
9. 活动(步行)(在房间及其周围,不包括走远路)	0分=不能步行 5分=在轮椅上能独立行动 10分=需1人辅助步行(体力或语言指导) 15分=独立步行(可用辅助器)	
10. 上楼梯(上下一段楼梯,用手杖也算独立)	0分=不能 5分=需帮助(体力或语言指导) 10分=自理	
总分		
ADL 缺陷程度**		

**ADL能力缺陷程度: 0--20分=极严重功能缺陷; 21--60分=严重功能缺陷; 61--90分=中度功能缺陷; 91--99分=轻度功能缺陷; 100分=ADL能自理.

功能活动评估 (IADL 能力)

项 目	得分*
1. 处理金钱(如算钱,找钱,付款)	
2. 患者工作能力或做家务能力	
3. 能否到商店买衣服,杂货和家庭用品	
4. 有无爱好,如下棋,打麻将或扑克	
5. 会不会做简单家务,如点炉子,泡茶	
6. 会不会准备饭菜	
7. 是否了解最近发生的事件(时事)	
8. 能否参加讨论和了解电视,书和杂志的内容	
9. 能否记住约会时间,家庭节日和吃药	
10. 能否自己搭乘公共汽车	
总分	
IADL 缺陷程度**	

* 每个项目的评分标准: 0分=正常或从未做过,但能做; 1分=困难,但不能单独完成或从未做过; 2分=需要帮助; 3分=完全依赖他人.

** ≤5分为正常; ≥5分表示该患者在家庭和社区中不可能独立.

5. 面谈指引

1. 请告诉我任何有关最近发生在您身边的事情, 具体来说, 您是如何照顾中风病患?
2. 您遇到不顺利的事情或问题吗? 有哪些呢? 您是如何看待这些事情和问题? 举例说明.
3. 您在处理这些照顾问题时候, 你感觉(感受)如何? 举例说明一下.
4. 如果你能解决面临的问题和困难, 您是采取和利用哪些途径或方法来解决? 举例说明.
5. 如果你不能解决, 遇到得最大障碍是什么? 举例说明.

Appendix 3A. The first interview of the stroke survivor

Interview 1 (1 week after discharge home)

Patient number _____

1. Data of the individual and the community health sources

1. Gender
Male
Female
2. How old are you this year? _____ (or) In which year were you born? _____.
3. How long have you been living in Wuhan?
Less than 1 year
1 to 7 years
More than 7 years
4. How is your present marital status?
Married
Widow or widower
Live separately
Single
Living alone
5. Living status
Living with others:
Spouse
Children
Spouse and children
Relative
Children and their relatives
6. Types of housing
House of the unit (bought)
House of the unit (not bought, rent)
Private house
House renting
Others _____.
7. Your educational background:
Not formally educated
Primary school
Junior middle school
Senior middle school
2-4 year college
Master degree or above
8. Comprehensive reading test (including reading with glasses)
Read something about health information
Unable
Partly able (mark the part of unable)
No problem
9. How is your eyesight?
Clear
Subtle
10. Do you use glasses?
Yes
No
11. How is your hearing ability? (Through observation)
Poor (available when raising voices)
Good (Communicable with ordinary voice)
12. Do you use hearing aid?
Yes
No
13. Do you have any religious belief?

	No	
	Worship god/ancestor	
	Buddhism	
	Taoism	
	Cathedral	
	Christian	
	Others _____	
14. Are you still working?	Yes, present job is _____	
	No, your job before retirement _____	
	House wife	
Income from:	<u>Yes</u>	<u>No</u>
15. wage/salary		
16. family support (children)		
18. savings		
19. wage of retirement		
20. subsidy from unit		
21. others (e.g., stockings _____)		
22. Please tell me total income per month	<200	
	201-500	
	501-1000	
	1001-5000	
	>10,000	
23. How much, on the average, is your monthly expenditure?	100-200	
	201-500	
	501-1000	
	1001-5000	
	>10,000	
24. Do you have enough money per month?	Enough	
	Just enough	
	Not enough	
25. If you have any extra payment (e.g., medical expense), are you worried about money?	Worried	
	Not much worried	
	Not worried	
26. If you do not have enough money, who is the <i>first one</i> you might ask for help?	Self /Spouse	
	Children	
	Relatives	
	Friends/ Neighbors	
	Government, such as your unit, specified _____	
27. Do you have medical insurance?	Yes	
	No	

Yes
No

What to rely on? Such as finances, home care, follow-up?

A horizontal number line with tick marks at every integer from 1 to 10. The numbers 1 through 10 are written above their respective tick marks.

2. Short Portable Mental Status Questionnaire-SPMSQ

We will ask you some simple questions to know about your memory. We do not expect everyone can remember the answer. Please try your very best to answer the questions.

	Correct answer	incorrect answer
1) What day of the week is it?	_____	_____
2) What is the date today?	_____	_____
3) Who is the Chairperson of China?	_____	_____
4) Who was the Chairperson before him?	_____	_____
5) Subtract three from twenty and keep subtracting three from each number, all the way down	_____	_____
6) What is your telephone number? Or 6a) Where do you live?	_____	_____
7) What is your street address	_____	_____
8) How old are you?	_____	_____
9) When did you born? _____Year_____Month_____Day	_____	_____
10) When Japan invaded China? _____Year_____Month_____Day	_____	_____

Total scores: _____.
Value: **_____.

**Altogether 10 items, giving one incorrect item, adding one score, total scores are 10. The criteria: ranged 0-2: normal; 3-4: mild disturbance; 5-7: moderate disturbance; and 8-10: severe disturbance.

2. Depression Indicators (The Center for Epidemiologic Studies Depression Scale: CES-D)

Now I am going to read some statements about some way people act and feel. On how many of the last seven days did this statement apply to you?

	None<1day	1 or 2 days	3 or 4 days	5 or more days this last week
1.I was bothered by things that usually don't bothering me	0	1	2	3
2. I did not feel like eating my appetite was poor...	0	1	2	3
3. I felt I could not shake off the blues even with help from my family and friends	0	1	2	3
4.I felt that I was just as good as other people	0	1	2	3
5.I had trouble keeping my mind on what I was doing	0	1	2	3
6.I felt depressed	0	1	2	3
7.I felt that everything I did was an effort.	0	1	2	3
8.I felt hopeful about the future	0	1	2	3
9.I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11.My sleep was restless	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get "going".	0	1	2	3
Total scores				

CES-D: it is not intended as a clinic diagnostic tool, it is interpreted in terms of level symptoms which accompany depression, not in terms of rates of illness. The scale is valuable to identify high-risk groups and to study the relationships between depressive symptoms and many other variables. An appropriate cutoff scores for depressive screening is 16.

4. Activities of daily living (Barthel index and Instrumental activities of daily living)

Barthel Index (Total 0-100)

Items	Assessment	Scores
1. Eating	0=unable 5=needs help 10=independent	
2. Bathing	0=unable 5=independent	
3. Grooming	0=unable 5=independent	
4. Dressing	0=unable 5=needs help 10=independent	
5. Bowl	0=incontinent; 5=occupational accident (once a week); 10=continent.	
6. Bladder	0=incontinent or catheterized and unable to manage alone; 5=occupational accident (maximum once per 24 hours); 10=continent.	
7. Toilet Use	0=dependent 5=needs some help but can do some things alone 10=independent	
8. Transfer	0=unable, no sitting balance 5=major assistance, can sit; 10=minor assistance 15=independent	
9. Mobility	0=immobile; 5=wheelchair independent, including corners; 10=walks with help of one person 15=independent but may use an aid (e.g., stick)	
10. Stairs	0=unable 5=needs help 10=independent	
Total scores		
Severity of disability**		

**Degree of disability: ranged 0--20 = much severely; ranged 21--60 =severe ; ranged 61--90 =moderate; ranged from 91--99 =mild; and 100 scores =Independence.

Instrumental activities of daily living (IADL)

Items	Scores [*]
1. Handling your own money	
2. Working or housework competency	
3. Shopping for grocery, or personal items	
4. Hobby, eg., chess, Majing, or playing cards	
5. Simple housework, etc. make tea,	
6. Preparing meal	
7. Knowing the affairs	
8. Participating in discussion or TV	
9. Remembering the appointment, family gathering and taking medication	
10. Using public transportation	
Total scores	
IADL ^{**}	

* Criteria : 0 =Normal; 1 = difficulty, but never do it; 2 = need assistance; 3 = completely dependent upon others

** ≤5: normal; ≥ 5 Independent living in the community

Part three: interview guide.

1. Please tell me anything what happened to you recently, specifically, how to you take care of family member who has had a stroke?
2. Have you ever met anything less smoothly with you? What are they? What do you think about it and how do you deal with them? Could you give me an example?
3. How do you manage care issues encountered? Could you give me an example?
4. Can you deal with them successfully? What methods you have used to solve them? Could you give me an example?
5. If you are unable to deal with them, what difficulty have you encountered? Could you give me an example?

Appendix 3B 中风病人随访部分

随访(共3次)

(出院后1月,出院后3月,出院后6月)

病人编码 _____

1.个人和社区健康资源资料

在过去的1周,1个月,2个月和3个月,你采用以下

有

沒有

什么方式取得中风医疗健康知识:

1.个别接触医生或其他医护人员

2.醫療機構的健康講座

3.參加支援小組

4.社區中心

5.電台/電視

6.報章

7.書刊

8.朋友

9.家人

10. 其他, 請註明:

在过去的1周,1个月,2个月和3个月,你因中风你曾使用那些醫療健康服務?

有

沒有

11.自購藥物(药店)

12. 普通科門診(政府/单位医务室)

13. 普通科門診 (私家)
14. 專科門診(政府)
15. 專科門診 (私家)
16. 急症室 (政府)
17. 急症室 (私家)
18. 住院(政府)
19. 中醫藥(政府)
20. 中醫藥(私家)
21. 針灸(政府)
22. 針灸(私家)
23. 其他治療如按摩，氣功，推拿等(政府)
24. 其他治療如按摩，氣功，推拿等(私家)
25. 其他，請註明： _____

26. 在過去的1周,1個月,2個月和3個月, 100-200
 你用在中風病治療費用約多少錢? 201-500
 \$:_____ (1周) 501-1000
 \$:_____ (1個月) 1001-5000
 \$:_____ (2個月) >10,000
 \$:_____ (3個月)

有 無

27. 一般來說：你在尋求醫護服務時，有沒有遇過困難？

如果有，原因是：(可選擇多1項) 是 不是

28. 經濟問題(收費太貴)

29. 不知到有那些醫療服務

30. 交通困難，不便

31. 對醫療服務沒有信心

32. 行動不便

33. 無人陪同

34. 其他_____

35. 整体来说,你满意你目前的身体健康状况吗? 10分是非常满意, 1分是非常不满意,你会给多少分?

10	9	8	7	6	5	4	3	2	1

36. 整體來說，你滿意現時所使用的醫療服務嗎？10分是非常滿意，1分是非常不滿意，你會給多少分？

10	9	8	7	6	5	4	3	2	1

原因：

37. 你希望醫護服務应该如何有效地帮助中风病人?(建议)

2. 精 神 状 况 (简易精神状态检查 -- 记忆能力)

以下是一些简单的问题，看你是否还能记得住。请尽量回答。

	正 确	不 正 确
1)今天是星期几？	_____	_____
2)今天是多少号？	_____	_____
3)谁是现任国家主席？	_____	_____
4)谁是上一任	_____	_____
5)20减去3，再减去3，一直减下去，减5次， 答案是什么？	_____	_____
6)你的电话号码是多少？(如无，问下题)	_____	_____
6a)你的地址在哪里？	_____	_____
7)你的住址属于哪一区？	_____	_____
8)你有多大年龄？____岁	_____	_____
9)你何时出生的？ _____年_____月_____日	_____	_____
10)日 本 侵 略 中 国 _____年_____月_____日	_____	_____

总 分 _____.

功 能 状 况 **_____.

**共10项，答错一项得1分，总分为10分。对结果的判断标准：得0—2分者为正常；3—4分者为轻度认知障碍；5—7分为中度；8-10分为严重认知障碍.

3. 情绪状况

我现在将念下列句子，它们表述了一些人的感受和行为。请问在过去一周内，你有多少天有同样的感受和行为？注意：在记录总分前先将4, 8, 12, 和16题的分数由低到高重新按照大小排列一下。

	从无<1天	1-2天	3-4天	5天-7天
1.你为一些小事担心	0	1	2	3
2.你不太想吃东西，胃口甚差	0	1	2	3
3.你虽有家人或亲戚劝解，仍觉得闷闷不乐.	0	1	2	3
4.你觉得自己同其他人一样好	0	1	2	3
5.你没办法专心做事	0	1	2	3
6.你觉得心情很不好	0	1	2	3
7.你做事提不起劲(没精神做事)	0	1	2	3
8.你觉得未来充满希望	0	1	2	3
9.你觉得你这一生是失败了。	0	1	2	3
10.你觉得很担心，害怕	0	1	2	3
11.你睡不安稳(半夜醒来后难以入睡)	0	1	2	3
12.你觉得很快乐	0	1	2	3
13.你说话比平时少	0	1	2	3
14.你觉得很寂寞，孤单	0	1	2	3
15.你觉得人人都不友善	0	1	2	3
16.你热爱生命，很享受人生	0	1	2	3
17.你曾经哭过几次。	0	1	2	3
18.你觉得很悲哀	0	1	2	3

19.你觉得别人 不喜欢你	0	1	2	3
20.你觉得你所做的每件 事都很不顺利。	0	1	2	3
总 分				
功 能 状 况 **				

**指数数值越大 ,说明精神遭受的压力越大 ,该老人患有忧郁症的可能性也就越大。文献上常用CESD指数为16作为界限 , CESD指数 大于或等于16 者 被归 为忧 郁症。

4. 日常活动量表 (ADL 和 IADL 能力)

改良巴氏指数评定表(ADL 能力)

项 目	评分 标准 和 评定 时间	得 分
1. 吃 饭	0分 =依 赖 他 人 5分 =需 要 部 分 辅 助 (夹 菜 ,盛 饭 ,切 面 包 ,抹 黄 油) 10分 =全 面 自 理	
2. 洗 澡	0分 =依 赖 他 人 5分 =自 理	
3. 修 饰	0分 =需 要 帮 助 5分 =独 立 洗 脸 ,梳 头 刷 牙 ,剃 须	
4. 穿 衣	0分 =依 赖 他 人 5分 =需 一 半 辅 助 10分 =自 理 (系 ,开 纽 扣 ,开 闭 拉 锁 和 穿 鞋 等)	
5. 大 便	0分 =失 禁 或 昏 迷 5分 =偶 尔 失 禁 (每 周 <1次) 10分 =能 控 制	
6. 小 便	0分 =失 禁 或 昏 迷 或 需 由 他 人 导 尿 5分 =偶 尔 失 禁 (每 24h <1次 , 每 周 >1次) 10分 =控 制	
7. 用 厕	0分 =依 赖 他 人	

	5分 =需 部 分 辅 助 10分 =自 理	
8. 转 移 (床和 椅间)	0分 =完全依赖别人 ,不能坐 5分 =能坐, 但需大量(2人)辅 助 10分 =需 少 量 (1人)帮 助 或 指 导 15分 =自 理	
9. 活 动 (步 行)(在 房 间 及 其 周 围 ,不 包 括 走 远 路)	0分 =不 能 步 行 5分 =在 轮 椅 上 能 独 立 行 动 10分 =需1人 辅 助 步 行 (体 力 或 语 言 指 导) 15分 =独 立 步 行 (可 用 辅 助 器)	
10. 上 楼 梯 (上 下 一 段 楼 梯 ,用 手 杖 也 算 独 立)	0分 =不 能 5分 =需 帮 助 (体 力 或 语 言 指 导) 10分 =自 理	
总 分		
ADL 缺 陷 程 度 **		

**ADL 能力缺陷程度: 0--20 分 = 极严重功能缺陷; 21--60 分 =严重功能缺陷; 61--90 分 =中
度功能缺陷; 91--99 分=轻度功能缺陷; 100 分 =ADL 能自理.

功能活动评估 (IADL 能力)

项 目	得 分 [*]
1. 处理金钱(如算钱,找钱,付款)	
2. 患者工作能力或做家务能力	
3. 能否到商店买衣服,杂货和家庭用品	
4. 有无爱好,如下棋,打麻将或扑克	
5. 会不会做简单家务,如点炉子,泡茶	
6. 会不会准备饭菜	
7. 是否了解最近发生的事件(时事)	
8. 能否参加讨论和了解电视,书和杂志的内容	
9. 能否记住约会时间,家庭节日和吃药	
10. 能否自己搭乘公共汽车	
总 分	
IADL 缺陷程度 ^{**}	

* 每个项目的评分标准: 0分=正常或从未做过,但能做; 1分=困难,但不能单独完成或从未做过; 2分=需要帮助; 3分=完全依赖他人.

** ≤5分为正常; ≥5分表示该患者在家庭和社区中不可能独立.

5. 面谈指引

1. 请告诉我任何有关最近发生在您身边的事情,具体来说,您是如何照顾中风病患?
2. 您遇到不顺利的事情或问题吗?有哪些呢?您是如何看待这些事情和问题?举例说明.
3. 您在处理这些照顾问题时候,你感觉(感受)如何?举例说明一下
4. 如果你能解决面临的问题和困难,您是采取和利用哪些途径或方法来解决?举例说明.
5. 如果你不能解决,遇到得最大障碍是什么?举例说明

Appendix 3B. The follow-up interviews for stroke survivor

Follow-up (three times)

(After one month, three month, and six month)

Patient number _____

1. Data of the individual and the community health sources

In the past one month, three month
and six month, how could you
obtain stroke knowledge?

Yes

No

- 1.consultant from doctors or other
health care providers
- 2.Health talks in medical
institution
- 3.Supporting group
4. Community center
- 5.Radio/Television
- 6.Newspaper
7. Books
- 8.Friends
- 9.Family members

10. Others, please specified: _____

In the past one month, three month and six month, what
kind of health care service has been used due to stroke
related problems?

Yes

No

11. Pharmacy (drug store)
12. OPD (government/ clinic affiliated with unit)
13. OPD (Private)
14. Specialized OPD (government)
15. Specialized OPD (private)
16. ER (government)
17. ER (private)
- 18.Hospitalization (government)
19. Herbal medicine (government)
- 20.Herbal medicine(private)
21. Acupuncture (government)
22. Acupuncture (private)
23. Others: e.g., massage, Qi-gong, (government)
24. Others: e.g., massage, Qi-gong, (private)
25. Others, please specified _____

26. In the past one month, three month, and six

100-200

month, how much money have you spent in using	201-500
therapeutic approach for dealing with	501-1000
stroke-related problems?	1001-5000
\$: _____ (one month)	>10,000
\$: _____ (three months)	
\$: _____ (six months)	

Yes No

27. In general, have you ever had any difficulty in seeking health care service?

If yes, the reasons are: (please select one more choices) Yes No

28. Financial problems (high cost)

29. unknown where to go

30. Transportation problems and inconvenience

31. Lack of trust in health care service

32. Mobility problems

33. Nobody accompany

1. Others _____

2. In general, are you satisfied with your current health status? 10 are very satisfied, and 1 very unsatisfied. What you will give to yourself?

10	9	8	7	6	5	4	3	2	1

36. In general, are you satisfied with the present health care service? 10 are very satisfied, and 1 very unsatisfied. What you will give to yourself?

10	9	8	7	6	5	4	3	2	1

The reasons:

3. Would you have any suggestions to improve the present health care services?

2. Short Portable Mental Status Questionnaire-SPMSQ

We will ask you some simple questions to know about your memory. We do not expect everyone can remember the answer. Please try your very best to answer the questions.

	Correct answer	incorrect answer
1) What day of the week is it?	_____	_____
2) What is the date today?	_____	_____
3) Who is the Chairperson of China?	_____	_____
4) Who was the Chairperson before him?	_____	_____
5) Subtract three from twenty and keep subtracting three from each number, all the way down	_____	_____
6) What is your telephone number? Or 6a) Where do you live?	_____	_____
7) What is your street address	_____	_____
8) How old are you?	_____	_____
9) When did you born? _____Year_____Month_____Day	_____	_____
10) When Japan invaded China? _____Year_____Month_____Day	_____	_____

Total scores: _____.
Value: **_____.

**Altogether 10 items, giving one incorrect item, adding one score, total scores are 10. The criteria: ranged 0-2: normal; 3-4: mild disturbance; 5-7: moderate disturbance; and 8-10: severe disturbance.

2. Depression Indicators (The Center for Epidemiologic Studies Depression Scale: CES-D)

Now I am going to read some statements about some way people act and feel. On how many of the last seven days did this statement apply to you?

	None<1day	1 or 2 days	3 or 4 days	5 or more days this last week
1.I was bothered by things that usually don't bothering me	0	1	2	3
2. I did not feel like eating my appetite was poor...	0	1	2	3
3. I felt I could not shake off the blues even with help from my family and friends	0	1	2	3
4.I felt that I was just as good as other people	0	1	2	3
5.I had trouble keeping my mind on what I was doing	0	1	2	3
6.I felt depressed	0	1	2	3
7.I felt that everything I did was an effort.	0	1	2	3
8.I felt hopeful about the future	0	1	2	3
9.I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11.My sleep was restless	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get "going".	0	1	2	3
Total scores				

CES-D: it is not intended as a clinic diagnostic tool, it is interpreted in terms of level symptoms which accompany depression, not in terms of rates of illness. The scale is valuable to identify high-risk groups and to study the relationships between depressive symptoms and many other variables. An appropriate cutoff scores for depressive screening is 16.

4. Activities of daily living (Barthel index and Instrumental activities of daily living)

Barthel Index (Total 0-100)

Items	Assessment	Scores
1. Eating	0=unable 5=needs help 10=independent	
2. Bathing	0=unable 5=independent	
3. Grooming	0=unable 5=independent	
4. Dressing	0=unable 5=needs help 10=independent	
5. Bowl	0=incontinent; 5=occupational accident (once a week); 10=continent.	
6. Bladder	0=incontinent or catheterized and unable to manage alone; 5=occupational accident (maximum once per 24 hours); 10=continent.	
7. Toilet Use	0=dependent 5=needs some help but can do some things alone 10=independent	
8. Transfer	0=unable, no sitting balance 5=major assistance, can sit; 10=minor assistance 15=independent	
9. Mobility	0=immobile; 5=wheelchair independent, including corners; 10=walks with help of one person 15=independent but may use an aid (e.g., stick)	
10. Stairs	0=unable 5=needs help 10=independent	
Total scores		
Severity of disability**		

**Degree of disability: ranged 0--20 = much severely; ranged 21--60 =severe ; ranged 61--90 =moderate; ranged from 91--99 =mild; and 100 scores =Independence.

Instrumental activities of daily living (IADL)

Items	Scores [*]
1. Handling your own money	
2. Working or housework competency	
3. Shopping for grocery, or personal items	
4. Hobby, eg., chess, Majing, or playing cards	
5. Simple housework, etc. make tea,	
6. Preparing meal	
7. Knowing the affairs	
8. Participating in discussion or TV	
9. Remembering the appointment, family gathering and taking medication	
10. Using public transportation	
Total scores	
IADL ^{**}	

* Criteria : 0 =Normal; 1 = difficulty, but never do it; 2 = need assistance; 3 = completely dependent upon others

** ≤5: normal; ≥ 5 Independent living in the community

Part three: interview guide.

1. Please tell me anything what happened to you recently, specifically, how to you take care of family member who has had a stroke?
2. Have you ever met anything less smoothly with you? What are they? What do you think about it and how do you deal with them? Could you give me an example?
3. How do you manage care issues encountered? Could you give me an example?
4. Can you deal with them successfully? What methods you have used to solve them? Could you give me an example?
5. If you are unable to deal with them, what difficulty have you encountered? Could you give me an example?

Appendix 4A

病人家属的首次访谈部分

访问 1(出院 第一周)

家人编码 _____

1. 个人和社区健康资源资料

1. 性别

男

女

2. 你今年几多岁? _____

(或) 你于哪年出生? _____

3. 你在武汉居住了多少年?

少于 1 年

1 年至 7 年

7 年 以上

4. 你现在的婚姻状况是:

已婚

丧偶

分居

未婚

5. 居住状况

獨居

與他人同住:

配偶

子女

配偶及子女

親友

子女及其家人

6. 住屋种类

单位住房(已买)

单位住房(未买)

私人住房

租住房间

其它 _____.

7. 你的教育程度是:

没有正式上过学

小学程度

初中程度

高中程度

大专程度

	硕士或以上程度	
8.测试阅读能力(戴眼镜也包括在内)阅读1遍健康资讯	不可以	
	部分可以(在不能阅读部分打圈)	
	完全可以	
9.你的视力如何?	清晰	
	模糊	
10.你有否配戴眼镜?	有	
	没有	
11.听力如何(观察)?	差(需要提高声量)	
	好(平常交谈语调)	
12.你有否使用助听器?	有	
	没有	
13.你有什么宗教信仰?	无	
	拜神/祖先	
	佛教	
	道教	
	天主教	
	基督教	
	其他宗教 _____	
14.你是否仍工作?	是,现在职业 _____	
	否,退休前职业 _____	
	家庭主妇	
收入来源:	<u>是</u>	<u>没有</u>
15.工资收入		
16.家人资助(子女)		
18.储蓄		
19.退休金		
20.单位补贴		
21.其他(如:股票 _____)		
22.请问你每月的总收入约多少钱?	<200	
	201-500	
	501-1000	

- | | | |
|---------------------------------------|--------------------------------------------------------|-----------------|
| | 1001-5000
>10,000 | |
| 23. 你每月平均开支约多少钱? | 100-200
201-500
501-1000
1001-5000
>10,000 | |
| 24. 你每月是否有节余? | 有节余
刚刚够
不足够 | |
| 25. 如果有额外的开支(如医疗费用),
你会担心钱不够用吗? | 擔心
不大擔心
不擔心 | |
| 26. 如果你一旦不够钱用,你会 <u>最先</u> 向
哪个求助? | 自己/配偶
子女
亲戚
朋友/邻居
政府,如所属单位
其他,请说明 _____ | |
| 27. 你自己有没有办理医疗保险? | 有
没有 | |
| 28. 你或你配偶有没有公费医疗保
障?(如:单位/企业职工)? | 有
没有 | |
| 29. 你患有某种慢性病吗? | 有
没有 | 如有请注明
_____. |
| 30. 你需要定期看医生或吃药才能控制
病情? | 有
没有 | |

當你在生病時，誰可依靠？

可依靠什麼？如經濟、家居照顧、覆診

31. 配偶

32. 兒子

33. 女兒

34. 媳婦

35. 女婿

36. 孫 _____
37. 非直系親屬 (如 干 儿 _____
子/干 女儿) _____
38. 朋友/鄰居 _____
39. 其他 _____
(例如:靠自己、政府)

40. 整体来说,你满意你目前的身体健康状况吗?(10分是非常满意,1分是非常不满意),你会给多少分?

10 9 8 7 6 5 4 3 2 1
| | | | | | | | |

2. 情绪状况

我现在将念下列句子,它们表述了一些人的感受和行为。请问在过去一周内,你有多少天有同样的感受和行为? 注意:在记录总分前先将4, 8, 12, 和16题的分数由低到高重新按照大小排列一下。

	从无<1天	1-2天	3-4天	5天-7天
1.你为一些小事担心	0	1	2	3
2.你不太想吃东西,胃口甚差	0	1	2	3
3.你虽有家人或亲戚劝解,仍觉得闷闷不乐.	0	1	2	3
4.你觉得自己同其他人一样好	0	1	2	3
5.你没办法专心做事	0	1	2	3
6.你觉得心情很不好	0	1	2	3
7.你做事提不起劲(没精神做事)	0	1	2	3
8.你觉得未来充满希望	0	1	2	3
9.你觉得你这一生是失败了。	0	1	2	3
10.你觉得很担心,害怕	0	1	2	3
11.你睡不安稳(半夜醒来	0	1	2	3

后难以入睡)				
12.你觉得很快乐	0	1	2	3
13.你说话比平时少	0	1	2	3
14.你觉得很寂寞，孤单	0	1	2	3
15.你觉得人人都不友善	0	1	2	3
16.你热爱生命，很享受人生	0	1	2	3
17.你曾经哭过几次。	0	1	2	3
18.你觉得很悲哀	0	1	2	3
19.你觉得别人不喜欢你	0	1	2	3
20.你觉得你所做的每件事都很不顺利。	0	1	2	3
总 分				
功 能 状 况 **				

**指数数值越大,说明精神遭受的压力越大,该老人患有忧郁症的可能性也就越大。文献上常用CESD指数为16作为界限, CESD指数 大于或等于16者 被归 为忧 郁症。

第三部分：面谈指引

1. 请告诉我任何有关最近发生在您身边的事情,具体来说,您是如何照顾中风病患?
2. 您遇到不顺利的事情或问题吗?有哪些呢?您是如何看待这些事情和问题?举例说明.
3. 您在处理这些照顾问题时候,你感觉(感受)如何?举例说明一下
4. 如果你能解决面临的问题和困难,您是采取和利用哪些途径或方法来解决?举例说明.
5. 如果你不能解决,遇到得最大障碍是什么?举例说明

Appendix 4A. The first interview of the primary family caregiver

Interview 1 (1 week after discharge home)

Family caregiver number _____

1. Data of the individual and the community health sources

- | | |
|----------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
| 1. Gender | Male
Female |
| 2. How old are you this year?_____ | (or) In which year were you born?
_____. |
| 3. How long have you been living in Wuhan? | Less than 1 year
1 to 7 years
More than 7 years |
| 4. How is your present marital status? | Married
Widow or widower
Live separately
Single
Living alone |
| 5. Living status | Living with others:
Spouse
Children
Spouse and children
Relative
Children and their relatives |
| 6. Types of housing | House of the unit (bought)
House of the unit (not bought, rent)
Private house
House renting
Others_____. |
| 7. Your educational background: | Not formally educated
Primary school
Junior middle school
Senior middle school
2-4 year college
Master degree or above |
| 8. Comprehensive reading test (including reading with glasses
Read something about health information | Unable
Partly able (mark the part of unable)
No problem |
| 9. How is your eyesight? | Clear
Subtle |
| 10. Do you use glasses? | Yes
No |
| 11. How is your hearing ability? (Through observation) | Poor (available when raising voices)
Good (Communicable with ordinary voice) |

12. Do you use hearing aid?	Yes No	
13. Do you have any religious belief?	No Worship god/ancestor Buddhism Taoism Cathedral Christian Others _____	
14. Are you still working?	Yes, present job is _____ No, your job before retirement _____ House wife	
Income from:	<u>Yes</u>	<u>No</u>
15. wage/salary		
16. family support (children)		
18. savings		
19. wage of retirement		
20. subsidy from unit		
21. others (e.g., stockings _____)		
22. Please tell me total income per month	<200 201-500 501-1000 1001-5000 >10,000	
23. How much, on the average, is your monthly expenditure?	100-200 201-500 501-1000 1001-5000 >10,000	
24. Do you have enough money per month?	Enough Just enough Not enough	
25. If you have any extra payment (e.g., medical expense), are you worried about money?	Worried Not much worried Not worried	

26. If you do not have enough money, who is the *first one* you might ask for help?

Self /Spouse
Children
Relatives
Friends/ Neighbors
Government, such as your
unit, specified _____

27. Do you have medical insurance?

Yes

No

28. Do you or your spouse have free medical care? (e.g., unit/staff of enterprise)

Yes

No

When you fall ill, who will
you rely on?

What to rely on? Such as finances, home care,
follow-up?

29. Spouse

30. Son

31. Daughter

32. Daughter-in-law

33. Son-in-law

34. Grandson

35. Non-direct relative (such as
adopted son or adopted daughter)

36. Friends/Neighbors

37. Others (e.g., rely on self,
government)

40. As a whole, are you satisfied with your present health status? 10=very much satisfied, 1=very much
unsatisfied, what score will you give to yourself?

10	9	8	7	6	5	4	3	2	1
----	---	---	---	---	---	---	---	---	---

2. Depression Indicators (The Center for Epidemiologic Studies Depression Scale: CES-D)

Now I am going to read some statements about some way people act and feel. On how many of the last seven days did this statement apply to you?

	None<1day	1 or 2 days	3 or 4 days	5 or more days this last week
1.I was bothered by things that usually don't bothering me	0	1	2	3
2. I did not feel like eating my appetite was poor...	0	1	2	3
3. I felt I could not shake off the blues even with help from my family and friends	0	1	2	3
4.I felt that I was just as good as other people	0	1	2	3
5.I had trouble keeping my mind on what I was doing	0	1	2	3
6.I felt depressed	0	1	2	3
7.I felt that everything I did was an effort.	0	1	2	3
8.I felt hopeful about the future	0	1	2	3
9.I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11.My sleep was restless	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get "going".	0	1	2	3
Total scores				

CES-D: it is not intended as a clinic diagnostic tool, it is interpreted in terms of level symptoms which accompany depression, not in terms of rates of illness. The scale is valuable to identify high-risk groups and to study the relationships between depressive symptoms and many other variables. An appropriate cutoff scores for depressive screening is 16.

Part three: interview guide

1. Please tell me anything what happened to you recently, specifically, how to you take care of family member who has had a stroke?
2. Have you ever met anything less smoothly with you? What are they? What do you think about it and how do you deal with them? Could you give me an example?
3. How do you manage care issues encountered? Could you give me an example?
4. Can you deal with them successfully? What methods you have used to solve them? Could you give me an example?
5. If you are unable to deal with them, what difficulty have you encountered? Could you give me an example?

Appendix 4B

病人家属的随访部分

随访(共3次)

(出院后1月,出院后3月,出院后6月)

家人编码 _____

1. 情绪状况

我现在将念下列句子,它们表述了一些人的感受和行为。请问在过去一周内,你有多少天有同样的感受和行为? 注意:在记录总分前先对4, 8, 12, 和16题的分数由低到高重新按照大小排列一下。

	从无<1天	1-2天	3-4天	5天-7天
1.你为一些小事担心	0	1	2	3
2.你不太想吃东西,胃口甚差	0	1	2	3
3.你虽有家人或亲戚劝解,仍觉得闷闷不乐.	0	1	2	3
4.你觉得自己同其他人一样好	0	1	2	3
5.你没办法专心做事	0	1	2	3
6.你觉得心情很不好	0	1	2	3
7.你做事提不起劲(没精神做事)	0	1	2	3
8.你觉得未来充满希望	0	1	2	3
9.你觉得你这一生是失败了。	0	1	2	3
10.你觉得很担心,害怕	0	1	2	3
11.你睡不安稳(半夜醒来后难以入睡)	0	1	2	3
12.你觉得很快乐	0	1	2	3
13.你说话比平时少	0	1	2	3
14.你觉得很寂寞,孤单	0	1	2	3
15.你觉得人人都不友善	0	1	2	3
16.你热爱生命,很享受人生	0	1	2	3
17.你曾经哭过几次。	0	1	2	3
18.你觉得很悲哀	0	1	2	3
19.你觉得别人不喜欢你	0	1	2	3
20.你觉得你所做的每件事都很不顺利。	0	1	2	3
总 分				

功能状况**				
--------	--	--	--	--

**指数数值越大,说明精神遭受的压力越大,该老人患有忧郁症的可能性也就越大。文献上常用CESD指数为16作为界限,CESD指数大于或等于16者被归为忧郁症。

2. 健康状况

整体来说,你满意你目前的身体健康状况吗?(10分是非常满意,1分是非常不满意),你会给多少分?

10	9	8	7	6	5	4	3	2	1

3. 面谈指引

1. 请告诉我任何有关最近发生在您身边的事情,具体来说,您是如何照顾中风病患?
2. 您遇到不顺利的事情或问题吗?有哪些呢?您是如何看待这些事情和问题?举例说明.
3. 您在处理这些照顾问题时候,你感觉(感受)如何?举例说明一下.
4. 如果你能解决面临的问题和困难,您是采取和利用哪些途径或方法来解决?举例说明.
5. 如果你不能解决,遇到得最大障碍是什么?举例说明.

Appendix 4B. Follow-up interviews for primary family caregiver

Follow-up (3 times)

(1 month, 3 months and six months after discharge home)

Primary family caregiver number _____

1. Depression Indicators (The Center for Epidemiologic Studies Depression Scale: CES-D)

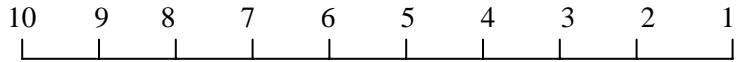
Now I am going to read some statements about some way people act and feel. On how many of the last seven days did this statement apply to you?

	None<1day	1 or 2 days	3 or 4 days	5 or more days this last week
1.I was bothered by things that usually don't bothering me	0	1	2	3
2. I did not feel like eating my appetite was poor...	0	1	2	3
3. I felt I could not shake off the blues even with help from my family and friends	0	1	2	3
4.I felt that I was just as good as other people	0	1	2	3
5.I had trouble keeping my mind on what I was doing	0	1	2	3
6.I felt depressed	0	1	2	3
7.I felt that everything I did was an effort.	0	1	2	3
8.I felt hopeful about the future	0	1	2	3
9.I thought my life had been a failure.	0	1	2	3
10. I felt fearful.	0	1	2	3
11.My sleep was restless	0	1	2	3
12. I was happy.	0	1	2	3
13. I talked less than usual.	0	1	2	3
14. I felt lonely.	0	1	2	3
15. People were unfriendly.	0	1	2	3
16. I enjoyed life.	0	1	2	3
17. I had crying spells.	0	1	2	3
18. I felt sad.	0	1	2	3
19. I felt that people disliked me.	0	1	2	3
20. I could not get "going".	0	1	2	3
Total scores				

CES-D: it is not intended as a clinic diagnostic tool, it is interpreted in terms of level symptoms which accompany depression, not in terms of rates of illness. The scale is valuable to identify high-risk groups and to study the relationships between depressive symptoms and many other variables. An appropriate cutoff scores for depressive screening is 16.

2. Health status

In general, are you satisfied with your current health status? 10 are very satisfied, and 1 very unsatisfied. What you will give to yourself?



Part three: interview guide.

1. Please tell me anything what happened to you recently, specifically, how to you take care of family member who has had a stroke?
2. Have you ever met anything less smoothly with you? What are they? What do you think about it and how do you deal with them? Could you give me an example?
3. How do you manage care issues encountered? Could you give me an example?
4. Can you deal with them successfully? What methods you have used to solve them? Could you give me an example?
5. If you are unable to deal with them, what difficulty have you encountered? Could you give me an example?

Appendix 5 Case Illustration

Mr. A's Family

Stroke survivor characteristics

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

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

*CT scan: left brain-stem infarction.

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

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

Length of hospital stay: 15 days, 3300 Yuan for hospitalization fare, 80% compensated by public health service.

Observation: He was cared by his wife and he discharged hospital by walk with a stick..

His educational level: middle school. Mr. A's salary was 460 Yuan.

Primary caregiver and family

The couple lived together. A's wife, 58, primary education, a retired textile worker, shouldering the whole care of the family.

A's son, 32, not living together, was the dean of a primary school, daughter-in-law, pregnant for 3 months, had 2-time abortions in the past, rest at home. Being the dean, the son was very busy, had to take particular care of his wife. The son had a meal once a day in parents' home, 300 Yuan was given to parents per month.

A's wife salary, only 290 Yuan. Because her working unit was belonging to the government-run enterprise which was broke, the wage not available for 1 year, only got paid recently. Their family income in each month: 1050 Yuan. Educational level : middle school.

They lived at 5th floor, the flat was distributed by their unit. With another elderly couple's family, they shared the flat. The neighbor's husband had hemiplegia after stroke, the wife died of cerebral hemorrhage suddenly later.

There were 3 rooms for Mr. and Mrs. A owned had their own toilet and kitchen. One room was the room for their son's marriage, though the son bought a new house, this room still specially remained for him. The room was well-decorated, an erecting-style air-conditioner, a big double-bed with high-quality silk cover. A dining table and a big sofa were in the middle room, the room with a broad window toward south, very bright was also remained for their son showing their expectation of their son's often visits. Now let's see the room of the elder parents, no windows at all, dark, only two doors, Mr. A hate darkness, due to asthma attack he always complained the poor ventilation causing him choking.

Health care service utilization

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

Health care service utilization included:

- a) General dispensary : common medicine (constipation, external use)+medication consulting.
- b) Clinics of their units : I.V transfusion, acupuncture, common medicine).
- c) Private clinics
- d) OPD of the hospital : (Important medicine) emergency (uncomfortable at night)
- e) Hospitalization : (provincial traditional hospital : afraid of being infected or being worsened)

Attitude toward medical service: family members tried their best to satisfy, stroke survivor also actively sought hospital service. He believed that hospital was the only place to trust, sought hospital service at any cost (including borrowing) : consulting doctor + hospitalization (overly dependent on medical service, excessively and unwisely utilization of health care services)

Qualitative content analysis

Case issues

Activities of daily living

A's wife was very cautious when Mr. A was walking, in particular when going up or downstairs, she just stood behind him to protect; besides, she helped him undressing. As mentioned above, Mr. A had bronchial asthma for 32 years and then in early 1990s, coronary heart disease and diabetes occurred, all these made him (once a strong soldier for 8 years) very thin and weak. Mr. A had to tolerate the pain brought by diabetes for long, for this, he always complained of food not tasty.

But A's wife definitely answered: My son does not permit me to buy pork for him, because it was too greasy. Mr. A was extremely unsatisfied, he shouted: how can I live without pork, without pork soup. Now, I want to eat anything, and I dare not eat anything. For diet control, A's wife was very much satisfied, she thought the blood sugar was under control (6-7mmol/l, within normal range).

Mrs. A doing cooking, offering meals, preparing hot water, washing for Mr. A, tried her best to arrange properly. She tried to serve food with more nutrition, like fish soup, milk powder without low sugar, after then, she went out to buy medicine, repair the sphygmomanometer, and at the same time, she would consult others about medical knowledge.

She was already very busy, what she asked for was just a rest at night, but this least demand could not be met. In recent days, she even could not have a peaceful night. She argued that, usually, she would be wakened 2-4 times for drinking, watering, taking medicine. But, recently, Mr. A could not fall asleep, he would feel uncomfortable here or there, he also had very strange thoughts, nightmare, fear, restless, the most boring thing was that he frequently asked for measuring blood pressure, sometimes, even every half an hour. Mr. A thought his blood pressure would go up at 3-4 o'clock, therefore, he would ask.

Mrs. A get up, measure for him. This was absolutely unacceptable for Mrs. A, she considered that all the necessary medicine was used, why still repeatedly ask for measuring blood pressure and taking medicine?

Health problems

Mr. A has suffered constipation for a long time, he said the longest period was that when he was in the hospital (more than 10 days), you see, 6 patients in a ward, without any screen, as for the toilet, he just couldn't squat down, finally, he really couldn't bear any more, he asked to go home to solve the problem. So far, this was still an everyday problem. He drank a big glass of water early in the morning, then some medicine, and repeated medicine for several times. Well, but he was worrying how about the next time, always dependent upon medicine he could be able to pass stool. He always wondered if medicine might cause intoxication!

With this problem he went to consult the doctor, but he became more hopeless, because the doctor told him: this kind of constipation needs an enema, if enema still doesn't work, then operation, oh, I was so frightened to death! If it is really like this, then I won't live in this world any more, to live like this makes me exhausted, and also causing trouble to my dear ones, I really can't stand it!!! Because of such a long period of illness, Mr. A was extremely concerned and sensitive to his situation, he had a series of theory about his illness and medication. Once the weather has some change, he would put on thick cap and scarf even at home, he explained: I can't stand wind, it must lead me to catch cold. Once he got a wound in his toe, he would put some ointment on the wound, and said: it can't be infected, mustn't have inflammation. He was also very cautious in taking medicine, seriously followed the doctor's order, carefully read the instruction. He insisted on taking medicine on time. He repeated: too much medicine, no, it might be poisonous; too little, no, it might be ineffective. Mrs. A joked at him: he got so many diseases, he was spoiled by diseases, he was too cautious!"

For his 4 kinds of disease, much medicine was filled up in a big box, some were wrapped, some in the bottles, bottles and bags, more than 10 kinds. Once Mr. A felt dizziness, he wanted medicine to lower his blood pressure, unfortunately, the more anxious Mr. A was, the more upset Mrs. A was, and at that very moment, Mrs. A really couldn't find it, so the whole night both of them were busy for nothing, and the next day his blood pressure went up, so they had to meet doctors in emergency room at night. Mrs. A showed a reluctant expression, she said: at first long-acting hypotensor was used, then short-acting ones, later, in the hospital the doctor had a change, a new kind was cheaper. Finally, the other doctor said this medicine has been taken for half a year, it has to be changed. Oh, so many kinds, today this, tomorrow that, changing all the time, what a mess, I was muddle-headed!

Coping resources

Cognitive

Son is the center of the family, ‘Son is a apart of my heart’ raise up the son is to serve elderly parents’. Furthermore, he loved his son wholeheartedly, he loved his family, but by the end, when father was sick in bed, the son didn’t care him, just like a stranger. Even more unbearable was that his beloved wife stood on the son’s side. He was well enough tortured by the disease, now that he “lost” his son, this shock shook the axial position of father, the son even refused to stay at home and moved out, and the wife damaged the traditional way of obedience to husband, always acted against him, the series of pain made his emotion tortured, even collapse. All these absolutely destroyed the peaceful calm family, all the traditional morale and rules were smashed by the son’s getting out of the family and all those modern concepts. The original patience, compromise and tolerance were replaced by complaining, quarrelling, and hurting, and could not get the way out. While doing all these care issues, Mrs. A sighed and said: ‘What can I do? Stir the whole family into a tempest! It’s he that damages our peaceful family!’

He insisted that life was unfair to him. He thought he himself was so kind, kind to anybody. And he has never hurt anybody. “Oh, heaven above my head, I never argue with anybody outside, I never do anything bad, Even I never step on an ant on the ground, but, why let me suffer such a horrible pain!....”. “I’m a nice person. I have been kind and honest to everyone throughout my life. I have been taking pains bringing up the children and caring for the family. Is this what I have had in return?! Now I’m sick and useless. My days are numbered and I’m just waiting to die, maybe, this winter or next spring, who knows! Give me a piece of rope! That would be quick!” The poor old man is eager to attract others’ attention and win sympathy from other people. In his mind, hospital is a better place than home because he could talk to nurses and doctors there.

Life is painful and enduring he described. The patient has many chronicle diseases and has been hit three times by stroke. Now he is suffering from a total nervous breakdown and is highly sensitive to any discomfort in his body. A slightest symptom might throw him off balance and bring him down with constipation, insomnia and high blood pressure. His bad temper has made his son and daughter-in-law move out and his wife’s counseling only adds to his discomfort and resentment. “If I have enough money, I would rather live in the hospital because I feel happier there than at home. Now that I’m old and sick, no one cares about me. My son has left me. Should I be more painful, lonely and pathetic?”

Affective

Stroke, and so many complications and physical discomforts made not only seriously hurt himself but also feels guilty putting too much burden on wife and family members, he said: What a pity, my illness has knocked her down ! I am exhausted, I can do nothing, I get them in trouble...”

Too much to worry about: stroke, diabetes, hypertension, constipation...

The most boring problem leads him go mad is that he thought he had a ‘rebelling’ son, he shouted: I would rather raise a dog than this son !

So many fears he had. Like fear of death, fear of recurrence of stroke (repeated and frequent measuring BP at night causing his wife restless).

Mr. A always mentioned about his hopeless situation which he had to face death. He said he could live not longer than this winter or next spring....“Give me a rope and I’ll hang myself....I’ll jump out from the window, what if I fell on the roof, fracture but not dead, no, no...even more painful!”

Overly demanding and overly cautious, as mentioned above: Once the weather changes, thick scarf and cap would be put on; a little wound would make him take special measure to cure.

Organization of caring work

At the Time 1 interview, stroke survivor was very satisfied with his functional improvement and his relationship going smoothly with his family members which provided adequate care to manage diet and eating, medication issues. The stroke survivor said: (Case 1) “She, extremely good! Everything is done by her: shopping, cooking, washing. My son, very good too, really, my son is praised by all!

His wife also added: I understand, he was suffering from many illnesses, bad physical health, he came from rural area in 1958, joined the army in 1961. 8-year soldier, too tired and living a hard life. He contracted typhoid. There were 7 children in his family, he was the third. He had 32 years of asthma, insisted on injecting aminophyllin. This time the 2 kinds of disease were the most boring ones: diabetes and cerebral infarction, could not ‘escape’ from so many diseases.

At this time, they understood each other well and manage multiple care issues such as multiple chronic illness and medication without any complaints.

But, later, when the son paid less visits to parents, particularly with a critical events happening in this family-daughter-in-law admitted to hospital and all family's concerns were paid to daughter-in-law and newborn baby in the hospital, the stroke survivor became more depressed. When asked how often did the son come back to visit them? The primary caregiver replied: "he is pitiful, too busy, daughter-in-law was pregnant" . But the survivor shouted: "he busy? But he still has time to play Ma-jiang, even no phone at all. It is you that spoil him. Raising a son is no better than raising a dog!"

During the Time 4 interview, when asked how they managed their care issues with medication, eating and diet, the primary caregiver said cautiously and quietly. However, the stroke survivor said: "Always fighting, he is stirring the whole family into a tempest".

On the other hand, his wife, while working hard on housework, sighing and being sad, and said: "He, quarrelling, scolding, even beating, and argued that he is right all the time....My daughter-in-law is in hospital, my son is so busy with his work, I have to go to the hospital to take care, after arranging for my husband, I must go out, but my husband is so.....even shouted to me 'Get out... roll your egg 'Where on earth can I roll? Why is he still unsatisfied with me? His behavior makes our home restless and a mess..." It is indicated that negative change contributing to negative factors as case 1 illustrated. It was from optimal to dysfunctional change over time; initial stage after discharge, he was happy (son's financial support, 300 per month) and satisfied with the care situation (PSP managing medication, diet and nutrition), as well as he himself felt as an old saying it means: if one survives an accident, one will have luck in the rest of his life.

At one month after discharge, he gradually felt unsatisfied with his son's unable to accompany him and not coming home to visit him regularly. Besides, he constantly complained his constipation as a trigger and attempted to find an excuse to return to his hometown in the countryside, his real intention was to attract the whole family's attention to his need. But the son and PSP were reluctant to carry out his plan due to safety problem on the journey. Then the conflict became white hot. In this case, his wife had to obey and compromise to accompany him to go to countryside. After 10 day-stay in the countryside, he came back proudly, because of his successful trip. But, at the same time, his son was hurt, tried to avoid meeting and almost had no communication with his father.

At the third month after discharge, his daughter-in-law stayed at home for pregnant rest due to a history of three-time abortion. Naturally all family members paid greater concern to daughter-in-law and expected her safe pregnant. As a father-in-law, he was unhappy because less attention was paid to him. His son no longer visited him; his wife always talked about and phoned their daughter-in-law.

At the sixth month after discharge, his daughter-in-law was admitted to the hospital due to pregnant hypertension. His son stayed in the hospital at night and his wife stayed there during day time. He complained: "Nobody was at home to take care of me". He shouted and made accusation to his wife, and threatened to get divorced, smashed the chairs around the floor, but his wife still carefully avoided conflicting. His wife said: "I looked at him and smiled, well, smiled...what can I do? I got everything ready for him before leaving home, and then went to the hospital. My son was very busy, I must help him to look after my daughter-in-law including preparing tasty meal, seeing doctor and discussing with doctor about both the health of mother and child, if I did not give a hand, who could help him at this critical moment? I have already done my best to take care of him, why is he still not satisfied? ! Endless complaints and hard words all the time, my head is going to burst out I can no longer stand it !

*CT scan: computerized tomography scan.

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

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

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

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

Family background

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

Health care service utilization

A number of health care services had been used.

Stroke-related disability

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

Care issues

They included constipation, mobilizing (walking), sleeping disturbance due to fear to death, physical discomforts (leg pain and numbness, swollen and skin rash) and medication concerns.

Coping resources

- a) Thinking dominated by him was his wish to get everybody around him. Mr. A insisted his authority as a father and husband. Father should dominate the family. However, in the later stage, things went to the opposite direction. Because the center of the family was no more the original father, instead, it shifted to the daughter-in-law and grand son; he perceived that they were not fulfilling the prescribed filial son and filial wife role responsibility (e.g., either children or spouse not acting as their prescribed role, traditional value of getting return from children)
- b) Being treated unfairly by heaven;
- c) Perceived burden of illness
- d) a number of negative affects (emotional disturbance) included guilty, worry, irritability, fear (death, high BP and stroke recurrence, constipation and cancer, to be overlooked and sneered by neighbors), self-pity, hopeless, isolation, demanding, immature feelings, accusation, upset, over dependent and self protection and concerns.

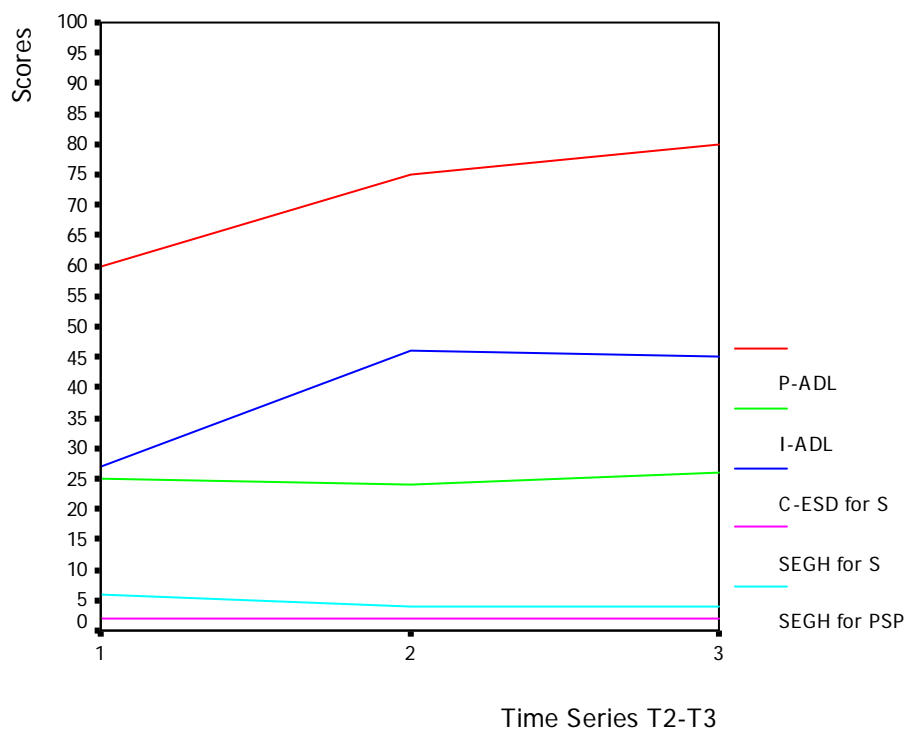
Organization of caring work

At first husband sang and the wife followed, the atmosphere was harmonious. But one month later, with the change of the family affair (daughter-in-law pregnant), Mr. A's temper went up, the family conflict emerged. At this stage, wife and son still tried to comfort him and exercised tolerance so as to maintain peace in the family. Six months later, with the birth of the new-born baby and some other factors, the family conflicts became more serious. The son tried to avoid meeting his father, the wife had much more time in the hospital taking care of the mother and child. Mr. A seemed to be isolated, his anger and rage burst out, he even threw hard words and beat his wife and shouted he wanted to divorce. Ultimately, his wife and son started to strike back, they argued with him at high pitch, the family relationship was at the volcano's edge.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Well-being of the family from T2-T4 for Mr. A



Mrs. B's Family

Stroke survivor characteristics

Mrs. B, 67, being hospitalized on June 4, 2001, because of “weakness of left lower limb and intermittent convulsion of limbs”.

P.E. BP: 140/100 mmHg, musculus tonus of left limbs: upper limbs grade V, lower limbs grade V, extension of tongue pointed left, both-side knee reflex weakened, left Babinski sign (+).

CT scan: lacunar cerebral infarction in the right basal nodule region.

Past history: hypertension, the highest being 150/100mmHg and cerebral infarction; a long-term heavy smoker (1-2 packages per day). Complications (coronary heart disease, chronic bronchitis).

Diagnosis: recurrent cerebral infarction with secondary epilepsy.

Length of hospital stay: 38 days, 10,000 Yuan for hospitalization fare, enjoyed free medical care service (95%), compensated twice a year.

Observation: during hospital stay, she was cared in turn by the second and third daughter. most time she was able to walk in the ward, when going out she needed a hand to support.

Her educational level: no formal education, A Buddhism believer, often visited temples, an able woman with clear- and keen- mind.

She had retired wage, 800 Yuan monthly, besides, she owned a house and had monthly rental income. She once ran a snack shop, had some deposit. Therefore, she had enough money to pay for visiting doctor. Her unit had a clinic. It was said she was poor in her childhood, illiterate, believed Buddhism after her parents. After liberation, she joined a 100-day literacy class, learned 1000 words. A smoker, 3 packages a day, she admitted that it was because of emotionally upset.

Primary caregiver and family

B's youngest daughter, 37 years, high school level, working in a laundry of a university hotel.

Mrs. B, lived alone (separated with her husband) and the flat was assigned by the working unit, has lived with this helper for 2 years. A TV set and air-conditioner were in his bed room, she had his own toilet too. The helper also helped B's husband and youngest daughter do some washing. Mrs. B usually quietly sat at the gate or watching TV and enjoy air-conditioner. She owned a flat at ground floor, had a play ground and many trees in front of the room giving her fresh, cool air and shade. Music and broadcast often came from a nearby middle school.

B's husband, 70 years old, a retired laundry worker, still working in the laundry and helping the youngest daughter. He lived with the daughter's family.

The couple had married for 40 years; also they argued and quarreled for 40 years. During the “fighting” years 7 children were born (4 sons and 3 daughters), the 4 sons had no connection with their father at all. The parents always argued and quarreled for children's affair, no compromise at all, sometimes, even beat each other. The power of allocating finance was separated, as mentioned above, Mrs. B was much richer, she was proud of it, occasionally she would show mercy and gave some money to this or that causing the whole family very unsatisfied, they were jealous, their hard words or fight. Therefore, Mrs. B became a heavy smoker due to bad mood. At present, Mrs. B didn't live with her husband, and Mr. B lived with daughter nearby, however, at meal time, the whole family came together and shared the dishes.

Health care service utilization

90 %of her hospital payment could be compensated at a period of 1 year. As she has enough deposit she could afford to pay for all the medical expenditures. Her medicine was obtained from the university clinics; sometimes she consulted the doctor of a Vehicle Hospital and brought back the prescription still fetching medicine in the university clinics.

Qualitative content analysis

Care issues

Activities of daily living

Mobilizing describe by her was Unable to walk alone. Afraid of cars and walk at night, on uneven street, afraid of falling down, Sleeping disturbance, Convulsion at night, headache after arguing and quarrelling. And eating and meal she used to mention by preferring favorite fruit (beneficial to tooth), Cannot eat spicy food because of causing her coughing, particularly, her mention about her hearing and eye sight decreased after discharge home (poor eye sight)

Health problems

Physical discomforts1: convulsion at night, about coughing, I want to cough, but unable to cough (1 month) When windy, my bone hurts, cough.

She thought that Western medication must be conflicted by TCM. She preferred to take one kind at one time. Mrs. B: “Just take these 7 bags of herbs, go and see! Then, I have to pay attention to taking hypertensive drug”. Daughter: “She said there might be conflicts between all these drugs, so I quit them all. Today, I, again dig them out for her.”

On the other hand, she was afraid of over dosage of medication leading to side effect Mrs. B: “This morning, headache, I could not get up. Because I didn’t sleep well last night. In the previous days, I quarreled with my elder daughter, I angrily smashed something. Well, dizziness, I thought, Blood pressure might go up, I immediately swallowed 3 pills of jiang-ya-ling (verticil) at one time, and 3 times a day, Oh, who knows, dizziness became more serious, doctor measured my blood pressure, telling me, only 90/60 mmHg, he wondered whether I were hypertension or hypotension! I burst into laughter, Ha-ha... of course hypertension. Now I know, this is the outcome of over dosage. Oh, I’ll never take them again, stop it, this medicine caused me great trouble”

Coping resources

Cognitive

“Why are the children all turned against me?”

The patient is a 67-year-old semi-illiterate woman and a pious Buddhist. She suffers from stroke infarction accompanied by epilepsy but can still take care of herself. The patient thinks of herself as a smart and capable woman, which gives her a smug and complacent feeling. When in her prime, she used to take care of everything at home. Now she and her husband live in separate rooms. She has almost no contact with her four sons and their families. When she was sick in hospital, two of her three daughters took turns to look after her. Unable to bear the lonely and cold life at home, she has chosen to move out and live in a Buddhist temple in pursuit of a quiet, peaceful and independent life.

“Why are the children all turned against me? Whenever I have a fight with my husband, they all stand up for him. 8 to 1 for over 30 years! Why is that? I have been taking good care of my mother-in-law and I have set up a good example for them. Why don’t they follow suit? Why couldn’t they just pay a teeny, tiny bit back for my dedication to the family all these years? Whenever I think of that, it really drives me crazy. I smoke a lot – one and a half packets a day. The more upset I feel, the more I smoke. I know I can’t be like this forever. I’m an independent woman and I’m capable of anything. Now everything will be over and I will be out of all these. As the saying goes, ‘out of sight, out of mind’.”

Affective

Her going to see the doctor, it seemed I’d be looked down upon. complaining the relation with all family members, seeking medical care (went to the hospital to get medicine regularly), seeking spiritual comfort (religious belief+ arrangement of life after leaving home to exhibit her specialty).

Organization of caring work

When meeting her in the first week after discharge, she was sitting with her daughter, extremely happy to accept my taking picture for them. The daughter said: “She was busy all the time, the first day to Gui-yuan Temple, the second day to Hong-shan Pavilion, the third day, to get the rent, the forth day, to Taishan...Mrs. B said: “I am very pleasant these days. You see, others have to wait for one year to get compensation of medical fare, see, I, by chance, immediately solved the problem, why not happy?”

One month later, when meeting her again, daughters, helper and husband were all busy, only Mrs. B, sitting alone silently at the gate, smoking. During lunch time, nobody talked, she was the first to finish, again sat at the gate, smoking, then went back to her own room.

Three months later, she told me she just came back from a temple, she went there with the helper,

stayed there for a period, she planned to live there for the rest of her life. She said she had got all the necessary information, she would stay together with a 80-year old grandma and hire a servant(in charge of bringing water, washing, cooking...100 yuan per month), it seems she has already had a perfect arrangement for her future life.

Six months later a visit to her at 9am, she still stayed in bed, edema at face. She told me : » yesterday her elder daughter came, a white hot quarrel, because of financial problem, a daughter had a traffic accident, they need money, the younger daughter and her husband stood on her elder daughter's side, they were all against her. She was so angry that she smashed a glass, flied in to a rage, then, blood pressure went up, again, she swallowed 4 pills of hypotensive drug, and headache became more serious...when I said good bye to her, she spoke in a very low voice : next time when you come, you might not meet me, I have already got well prepared, including all my clothing, medicine. I will go away, I will live a independence and quiet life.

During the whole process, she used to repeat following theme which reflected how complicated situation she was in the family.

She thought of her great contribution to the family, but they not only didn't show any gratitude, all of them 'protect the old guy', she was always the minority 6 :1; this made her tears in eyes, and fire in heart. She said "If only fighting between us two, it will be OK, I can compromise, but 6 to one, then can not tolerable !!! " In the past 30 years she got used to the endless fighting, and she used to smoking to diminish her sorrow, but , now, I will strike back, I will be fierce enough to give them a lesson.

After saying this, a depressive expression turned up, hopeless and helpless, she inhaled deeply the cigarette and slowly expired a long stream of smoke, with deep sigh, she said : » In my whole life, they cause me angry and upset...the whole family, nobody is good to my daughter-in-laws, daughters...all of them turn a deaf ear to me...how can I tolerate ! How can I compromise to them! Never! That's why I want to go to Qian-Jiang.

On the other side, she was very happy and proud to tell about her "grand" past: other than the story mentioned above, she continued: "at home and outside, everything was on her shoulder, she respected her father-and mother-in-law, she raised 5 children, besides, she understands some folk medicine knowledge and gave help to others without asking for return. "Whenever she mentioned all these "brilliant" deeds, she, from deep in her heart, burst into great laughter".

Statistical analysis and time-series analysis for Mrs. B's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mrs. B						
1	SPMSQ	0	--	--	--	--
2.	CES-D					
3	ADLs	90	90	100	100	
4	I-ADL	--	21	16	13	
5	SEGH	2-3	2	2	2	
B's daughter						
Category	Scales	T1*	T2*	T3*	T4*	Others
1	CES-D	0	0	0	0	
2	SEGH	4	NA	NA	NA	

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. B, 67, medical conditions were not severe, the blood pressure was high (180/90mmHg); besides infarction, she had coronary heart disease and hypertension, chronic bronchitis.

Family background

She was separated with her husband, and living with a young girl helper, but eating with his daughter and husband. She had free medical care coverage, financial status was satisfactory; this is modified nuclear family.

Health care service utilization

The community hospital, the third hospital of Wuhan and Hubei Medical No 1 Hospital after discharge home. 5000 Yuan had been spend in the past six months.

Stroke-related disability

Functional status showed increasingly improved over time, but she had to be completely dependent upon family members after discharge home. She had no indication of depression. But a lot of negative affects. Such anger, irritability, Meanwhile, her self evaluation of general health was remained low (2), and his daughter gave her evaluation only at T1 and T2 for scores of 5.

Care issues

They included meal and diet, physical discomforts (headache) sleeping disturbance, mobilizing (walking) and medication concerns.

Coping resources

Her wish to get return from his children and not acting as prescribed children's role. Negative affects included complaining and anger.

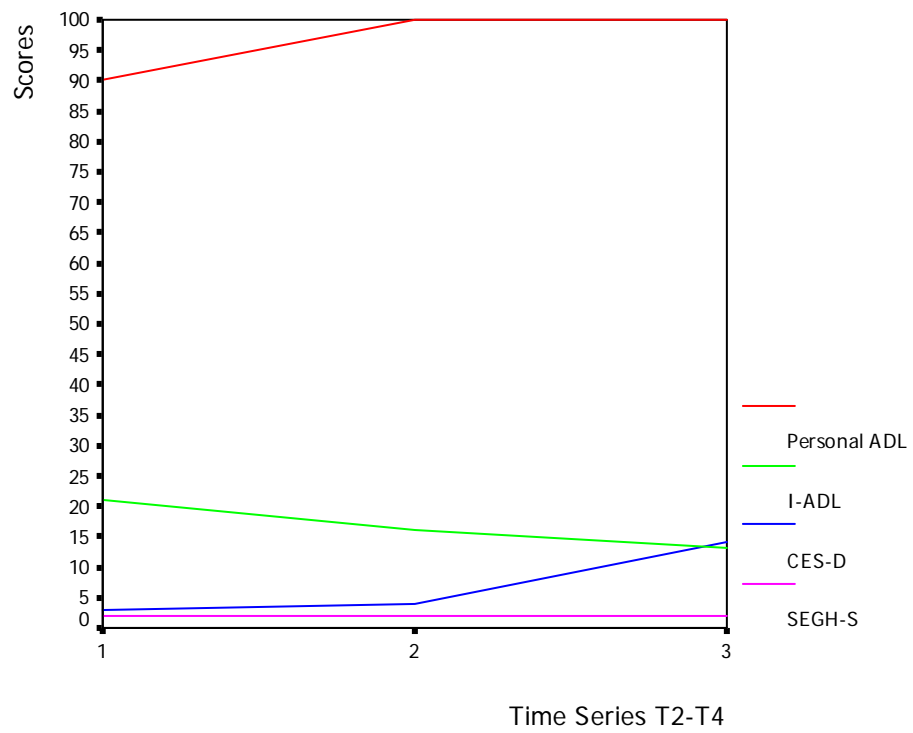
Organization of caring work

All family members kept distance with her, her sons did not pay any visits even her hospitalization, only the helper talked to her, she was isolated in this family. Finally she said she had been well prepared to live in a temple outside of Hubei Province in the rest of her life. Patterns of caring work was demonstrated as below.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Well-being of the family from T2-T4 for Mrs. B



Mrs. C's Family

Stroke survivor characteristics

Mrs. C, 56 years, being hospitalized on Nov. 4 2001. Because of 'short breath and chest distress occurred 1 week ago', her relatives said when closing eyes symptoms became released. Besides, she had weakness in limbs, difficult in swallowing, losing weight, seriously lean.

P.E. BP 90/60 mmHg, No cough, no pain at anterior pectorial region, no incontinence. Pain in lower limbs in the past history and was treated in hospital. muscular tonus increased, left, grade 0, right, grade I. Sensation of right limbs decreased (paralysis).

CT: "infarction in both basal nodule region".

Past history: Lower limb pain and admitted to the hospitals three times in the past one year.

Diagnosis: Stroke infarction, respiratory difficulty to be confirmed.

Length of hospital stay: 13 days, 3000 Yuan for hospitalization fare, no free medical care coverage.

Observation: she was cared wholly by her husband, and discharged hospital by carrying. She frequently said: "Pain in lower limbs for 1 year, seeking medical service with no effect, health status worsened. Walked with difficulty at home before admittance, absolutely unable to manage house work."

Her education level: middle school, a retired worker, and her salary was 400 Yuan.

Primary caregiver and family

The couple was living together with their elder son's family. The house was primate and handed down from Mrs. C's ancestors.

C's husband, 56, middle school education, he is a retired worker and had two sons. The elder son was unemployed in recent years.

The couple, together had a wage of 890 Yuan. Because of poor financial statue, their unit did not compensate their medical fare, they had to pay all by themselves.

The flat they lived was an old, poor and plain. C's husband showed a happy expression, it was because he was once a volunteer traffic administrator with 100 Yuan additional income. That was the only channel communicating with the outside world, he was very fond of working there.

Heath care service utilization

No medical services at all have been used after discharge home due to unaffordable of medical cost. Very dissatisfaction (2 scores) with the health service use. Before this time hospitalization, at first they tried to seek medical care:" hospitalized in three large hospitals, at home, two small clinics" Medical payment 10000 in total.

Qualitative content analysis

Care issues

Activities of daily living

Stool incontinence “Long-term in bed, unable to use bed pan, diaper only. lied on the back, bedsore occurred, sometimes lied on the stomach, then see this hand, also so!”

Sleeping disturbance and medication concerns complaining pain and other physical problems, “Difficult to fall asleep, can I buy Valium, sleeping pills available outside?” C’s husband was eager to buy and use sleeping pills, but Mrs. C was worried: “afraid of drug-dependent, afraid of not available in dispensary, afraid of ...” C’s husband replied: “No medicine can cease her pain, is it nerve pain? No cure. Once the pain ceased, she’d be OK” Worrying about unavailable of sleeping pills, also afraid of being drug-dependent (3rd month, 6th month) bedsore. Bedsore repeatedly occurred “change bandage, is it so easy to master?(bed pan, hurt, put some medicine, then use diaper, ulcer again) (1 week)

Diet control and poor appetite: food---no energy, malnutrition, edema? (observation: 6th month, edema in both hands), C’s husband expressed proudly “Sometimes we just don’t know how to do! All by myself, right or wrong! I’ll manage her wound whatever I like (waving head), just do according to my own way!”

Health problems

With knitted brows Mrs. C would groan and moan at the interval of 10-15 minutes:” pain in legs, can’t move, please hold my leg,”.

C’s husband ,while holding her back, he told how they went to seek medical service, about her disease...something bad in her bottom...what is hysteria? I just don’t understand what hysteria is.”

C’s husband said: “The whole day and night, always pain, cannot fall asleep, only a short nap. I am not in a good mood, sleepless the whole night, again, pain in this morning. The old man went to buy breakfast, I can only force myself to eat a little! No way, not a single night sleep well!”

Coping resources

Cognitive

The couple expressed that they couldn’t afford to pay for the care her/her needs. Most of respondent’s care falls on me. The time when they got married, Mrs. C owned a private house, while C’s husband was pennilessly poor, therefore C’s husband was so grateful he thought she was really generous and kind, as return, he was willing to pay intimate attention and sincere care to his beloved wife for many years, sometimes he even forgot he was a “great male”, he would compromise and satisfy whatever she demanded. Mrs. C, being proud of her property and glorious family history, took it for granted and derived great pleasure from her humble husband’s behavior. Now the world turned up side down, the unpredicted disaster drew C’s husband into the abyss of suffering. He thought he had already done his best to take care of her, but now, her wife not only could not move, but everything was heavily put on his shoulder, from day to day, from day to night, just like taking care of a infant, ”milk and stool”, it was beyond his physical and mental ability. Well, at last, he shouted out: “What, everything is on me, how can I shoulder all these!” On the cross-road between morality and responsibility, he burst out his way to getting out from this crisis: “It is not me that haven’t done my best,, I have been tortured more than enough, I’ll surrender...well, she can’t move, OK, just don’t move, let her go (die), the earlier the better, than I will be relieved...I can no more take over the job of taking care of her, I have no money to pay for her medical fare, finished, everything finished...!!!”

Mrs. C expressed: “The pain in this leg terribly hurts, the whole night sleepless, it also tortures my husband. What can I do? N way, just waiting to die.....”

Affective

Extremely financial strain and uncertainty of medical diagnosis made her desperate and painful, guilty feelings in her personal life. Full of sadness and sorrow

Upset. Mrs. C: “I am upset, I can’t walk, I have pain....Oh, he is blaming all the time (angry expression), I am exhausted, also in bad mood! I don’t want to eat, also afraid of drinking, for fear of passing water. When I move, I have pain, so painful that I can’t fall asleep. If released from pain, I’ll be better, I am so anxious!

Mrs. C: “Just delay and play for time, to the day of my end! What can I do? Our unit is poor, I can not pay the hospital fare, I myself have already paid more than 10000 yuan, no more money to pay! Not a single cent. They have promised good will, if my unit has better profit, I’d not stay at home and suffer, I can stay in hospital! I also don’t want to go out, I am reluctant to let others look at me, in such an image!”

Organization of caring work

The first time I met the couple, from their anxious expression I could feel that they were actively trying to find means and ways, and was hopeful that Mrs. C would recover someday. C's husband said: "Maybe when the weather becomes warmer she'd be better...(now it was December, chilly winter), when spring comes, everything will get better...(hope for the future). They tried to seek cure, but no improvement. C's husband hold her up, gave her massage, using kind words to comfort her, they understood each other, care issues well arranged, 18 hours TV program, making her warm, changed bandage for her, bought diaper, when getting upset, they comforted each other. Mrs. C: "Beat the cat away, beat...I was so upset that I even hate my pet cat". Mrs. C:" I am tortured to death, he, too. Then he shouted and roared, I kept quiet. When I shouted , he kept quiet. In this way, both of us understood each other. What can we do other than that? When we were young we never quarreled, not red-faced for 30 years. Yes, my relative said:" Have a quick recovery, and you still can have 400 yuan a month!"

The last time I visited them, Mrs. C was almost too weak to speak, her eyes, dull and dark, as if she saw nothing, just gazing at the TV screen, murmured in a very thin voice:" Too long, time, too long, the pain made me numb and senseless, one day and the other, until the end..."

C's husband looked sad and hopeless, smoking without stop. I have never seen such a scene in the past period that both of them were in dead silence. I clearly remembered the first impression of C's husband: so smart, out-going, talkative and very good art of communication. But, now, what happened! a cigarette after a cigarette, sitting there like a statue, thick smoke filling and choking the room, a Pan-like stove with burning charcoal beside his feet, a lovely cat bending and sleeping soundly nearby. The sound from the TV and the music of hymn and prayer from the tape-recorder mixed together. They were silent, they were thinking deeply, it seemed they are forming some miserable ideas. When Mr. C sent me to the door and said good-bye, he told me: "I even want her pass away quicker..." and the last sentence at departure was: "Absolutely no confidence!..."

Statistical analysis and time-series analysis for Mrs. C

Category	Scales	T1*	T2*	T3*	T4*	Others
Mrs. C						
1	SPMSQ	0	--	--	--	--
2.	CES-D	7	14	16	19	
3	ADLs	20	20	20	20	
4	I-ADL		27	30	29	
5	SEGH	2	2	2	2	
C's husband						
Category	Scales	T1*	T2*	T3*	T4*	Others
1	CES-D	0	0	0	0	
2	SEGH	6	6	4.5	4	

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. C, 56, medical conditions were severe, she was paralyzed in her left side.

The couple was living together with his elder son's family, no free medical care coverage, financial burden was heavy.

Family background

Family structure: This is an extended family.

Health care service utilization

No health care services had been used after discharge home, due to no affordability problems (no free medical care coverage).

Stroke-related disability

Functional status showed very severely disabled, completely dependence upon family members after discharge home. After one month, she had depression. Meanwhile, her self evaluation of general health remained low (2), and his son gave his evaluation at T1 and T2 for scores of 5. Issues included urine and stool incontinence, mobilizing (carrying by others all the time), sleeping disturbance due to constant pain, physical discomforts (leg pain and numbness, swollen and bedsores) and medication concerns.

Care issues

a) Urinary incontinence, b) leg pain and sleep disturbance, c) caregiver's need

Coping resources

Thinking dominated by Mrs' C was that woman should be dependent upon her husband, ultimately she perceived heavy burden of illness (hopeless and helpless); while husband perceived severe burden of care. 2) Negative affects included complaining of pain and burden of care overwhelmed.

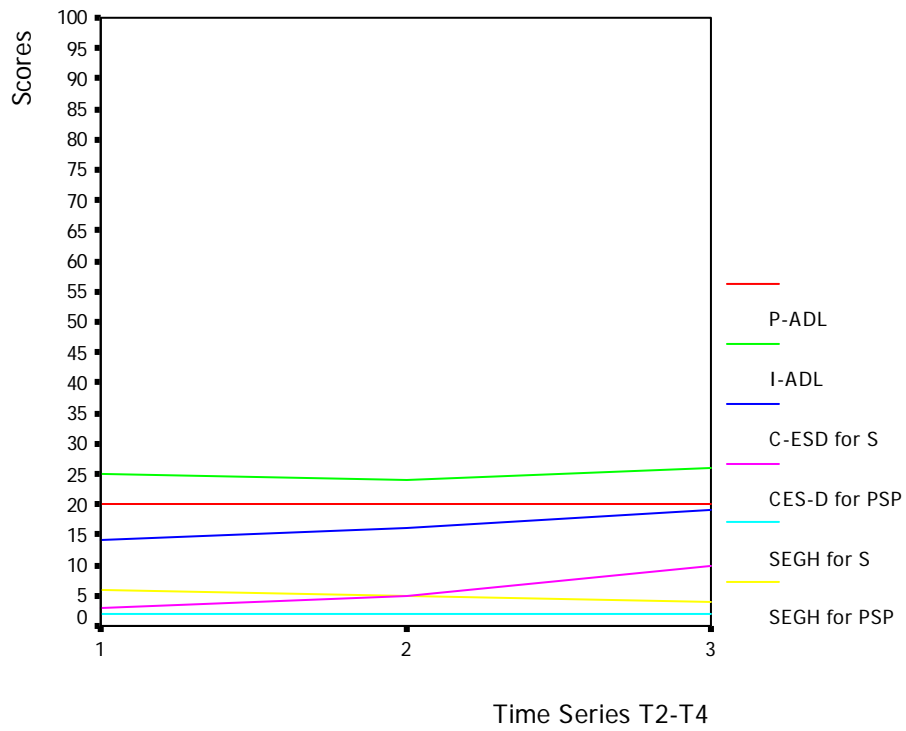
Organization of caring work

Husband could not bear any burden of care independently, his younger son did not come back home anymore, finally Mr. C lost his temporary job (part-time), felt extremely bored to continue taking care of her. He said he would prefer her to die, in which let their family be peaceful and quiet (See figure below)

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Well-being of the family for Mrs. C



Mrs. D's Family

Stroke survivor characteristics

Mrs. D, 65 years. Being hospitalized on Jan. 1, 2002. Because of 'a sudden attack of tachycardia of unknown cause occurred 13 hours before admission, with chest distress, short breath, abdominal discomfort, cough, white-bubble sputum, but no headache, vomiting and edema'. One hour later on the way to toilet, labial angle dropped, aphasia, weakness in right limbs, without unconsciousness, convulsion, incontinence, fever, hence consulting emergency department.

P.E.: BP 180/100mmHg, cyanosis, wet pale in both lungs, HR120/m, regular, consciousness, pupils equal sized, round, left nasal-labial sulcus shallowed, tongue extension pointed left. Muscular tonus of left limbs, grade I. ECG showed sinus rhythm, occasional arterial premature beat and cordial ischemia.

Cerebral CT scan: lacunars infarction in right, external posterior capsular region.

Past history: "Hypertension" 15 years, "coronary heart disease, heart 5 failure 5 years, denied diabetes. Length of hospital stay: 22 days. Expenditure 10,000 Yuan.

Diagnosis: "cerebral infarction, hypertension, coronary heart disease, heart failure grade III".

Observation: Spirit and appetite poor since the attack, poor sleeping, no stool, urine normal. BP 160/100mmHg.

Educational level: primary school, Textile worker, retired wage 530yuan, being widow at the age of 37.

Primary caregiver and family

Mrs. D, widowed, husband died in her 38 years old, had 2 daughters and 1 son. Living with her only son's family, a private flat with two floors, it was run by Mrs. D. Both her son and daughter-in-law were laid-off workers, the son drove motor to earn money, and his wife mended clothes in a shop. Grandson was 10 years old and studied in the primary school.

One daughter was a nurse but living in the suburb, the other daughter lived in the same city, they kept contact through phone call. After one month discharge home, a helper was hired (38 years old from countryside).

Health care service utilization

No medical services has been used after discharge home, because they were not affordable to pay the high medical cost. Very dissatisfaction (2 scores) with the health service use.

Qualitative content analysis

Care issues

Activities of daily living

Eliminating (stool Incontinence and constipation alternatively) Mobilizing (carried by others), sleeping disturbance due to fear of death (Sleepless and emotional disturbance: fear or need someone to accompany at night?)

Health problems

Medication concerns (Taking sleeping tablet, Leg pain and swollen, Pain fear, Skin rash.

Coping resources

Cognitive

She is born a stubborn woman, after the death of her husband at 37, she worked in a textile factory, besides, she collected wastes to earn a life for the family

Twenty-four hours lying in bed, pain in the whole body, incontinence made her unbearable painful, her description of incontinence as: "Just like squeeze tooth paste, squeeze out,...haemorrhoids also hurt, they crowded at anus, always want to pass stool, always need to clean, no end of trouble...They are all living a happy life, only me, alone, am suffering here..."

Affective

Two daughters, after my discharge, they are busy in their business, it made her very unhappy, crying while speaking:" It really hurts, son and daughter-in-law are human, daughters are human too, Why doesn't she bring me to their home? She just occupied my son. I am angry for it! I want her to take care of me, let you enjoy it!....."

Fear of taking medication and worry about cancer and constant pain, financial burden; hopeless by pain and upset for elder daughter; Afraid of eating due to stool incontinence, Feel debt to others by asking for massage at night; Blame self; (She looked hopeless, painful, out of control, burst into crying loudly).

Organization of caring work

During the first time visit, Mrs. D fell asleep soundly, D's only son talked about his mother: "In her whole life, she is diligent and loves to be clean and tidy. Being widow at 37, she alone raised two daughters and one son, no time to contact neighbors. To earn a living, she even collected wastes to supplement family need. She has a bitter life. Therefore, I'll respect her, we have no money to stay in hospital, but even at home I'll still take good care of her". He continued: "I am ready to do anything, run any risk, to sacrifice, anyway, not long,... not very long..."

During the second visit, D's daughter-in-law, while feeding Mrs. D some sweet rice soup she said: "Since she becomes ill, she becomes very talkative, just like a child, she wishes us be here 24 hours. When she is alone, she will shout...when we are here, she talks and laughs, she has changed to a new image....". She murmured and whispered: "She insisted that everybody is standing around her, gossip and gossip..."

At the third time of visit, her son and his wife went out, only a helper there. Mrs. D, again started to talk about her past: How she raised up the 2 daughters and one son, how strong and diligent she was! She said:" The marriage of the three children, all had a terrific and brilliant time at the party, I have not borrowed even a cent, all the expense was my own accumulation, you see, I just safe and safe! I am a strong person, I never ask others for help. I'd rather sacrifice by myself. See, for my grandson's 10-year-old birthday, I spent 2000 Yuan, that was also what I saved. I was a Youth league member, a league secretary, They wanted me to apply to join the Party, no, I won't, I don't like to flatter anybody..." Talking about the present days, the helper did not look down upon her, so Mrs. D was very grateful to the helper, she said:" The whole night, I just disturb her, but she doesn't mind, even smiled at me, Using the words of superstition, I'd say, you have done very good job, you would get good return in the future. The helper says she understands". Mrs. D was full of hope and imagination for the future, she said: "Haha, build a large house, let everybody come back and live together, what fun!"

The fourth visit: Mrs. D and the helper, she was in bed, looked extremely worried, pulling my hands, showed grieved and heart-broken expression, she said: "I don't know, why I cannot fall asleep, my eyes just gazing at the clock!...I can't live long, where shall I die, just disappear in a fire? Anyway, buried like that, I am not scared! Why I got paralyzed, if so, why brought me back?...No need to rescue me, let the doctor give me an injection and let me die earlier." She continued:" I hate them, not necessary to get me back, just let me die. The pain makes me upset. She finally added: "Let me go, I'd not be their burden...this daughter doesn't come, that daughter doesn't come, they are all my daughters, why they just leave me alone, and let my son alone, takes care of me?"

Observation: She looked very weak, this is the result of children all leaving her alone, they are far away, and she is suffering pain and insomnia, desperate, fear, darkness and has no way out. In short, Mrs. D is suffering the double grieved attacks: her physical pain plus her departed children, and can not find the way out.

Statistical analysis and time-series analysis for Mrs. D's family

Mrs. D

Category	Scales	T1*	T2*	T3*	T4*	Others
1	SPMSQ	0	--	--	--	--
2.	CES-D					--
3	ADLs	25	30	30	20	incontinence
4	I-ADL	--	25	29	29	--
5	SEGH	2	2	2	2	

D's son

Category	Scales	T1*	T2*	T3*	T4*	Others
1	CES-D	0	NA	NA	NA	--
2	SEGH	5	5	NA	NA	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. D, 64, medical conditions were severe, blood pressure was high (180/90mmHg); besides infarction, she had coronary heart disease and hypertension.

Family background

She was living and eating with his son's family, no free medical care coverage, financial burden was high. This was an extended family.

Health care service utilization

No health care services had been used after discharge home, due to no affordability problems (no free medical care coverage).

Stroke-related disability

Functional status showed very severely disabled, completely dependent upon family members after discharge home. After one month, she had depression. Meanwhile, her self evaluation of general health remained low (2), and his son gave his evaluation at T1 and T2 for scores of 5.

Care issues

Care issues included stool incontinence and constipation alternatively, mobilizing (carrying by others all the time), sleeping disturbance due to fear to death and noise from outside neighbors, physical discomforts (leg pain and numbness, swollen and skin rash) and medication concerns.

Coping resources

Thinking dominated by Mrs. D was her wish to get return from his children. Negative affects included fear to death, uncertainty, hopeless and helpless, anger were overwhelmed.

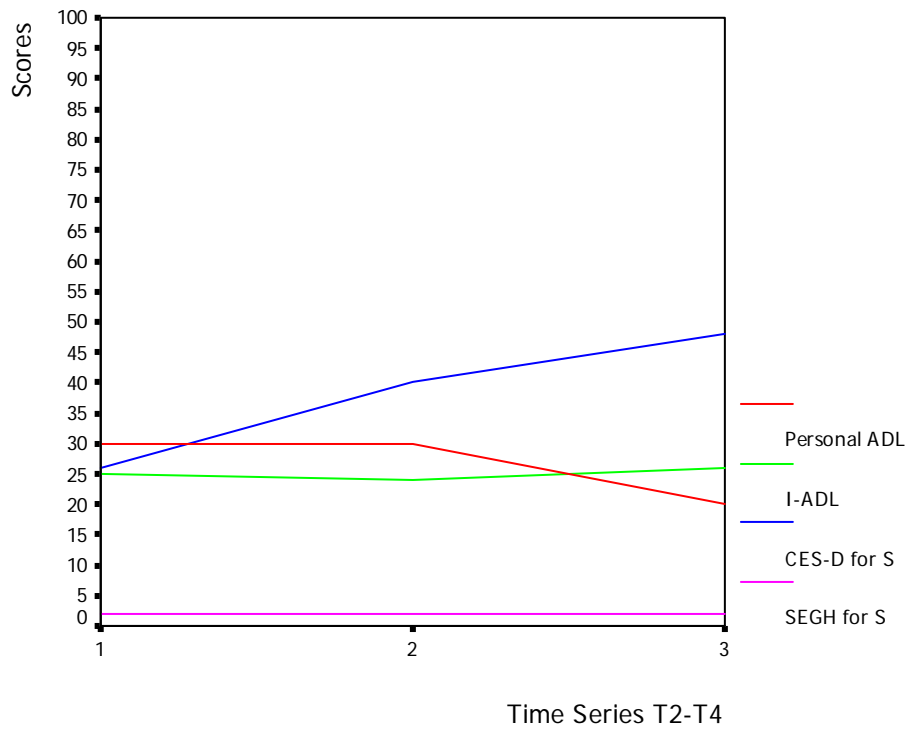
Organization of caring work

Organization of caring work: two daughters kept distance from her (one was living in the suburb and did not keep promise to pick her to her home; the other one was playing Majiang and came to see less frequently), her son was busy with his own business because he had to raise his own family (bread-earner).

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Well-being of the family from T2-T4 for Mrs. D



Mr. E's Family

Stroke survivor characteristics

Mr. E, 73 years. Being hospitalized on Dec. 9, 2001. because of 'sudden attack of aphasia with right limbs weakness for 5 days, walking unstable'.

P.E. BP140/90mmHg, consciousness, spirit poor, left pupil: 3mm, right pupil: 2.5mm. Light reflex dull. Muscular tonus of left upper limbs grade I, left lower limbs grade IV. Left limbs Babinski sign (+).

CT scan: Multiple lacuna infarction, softened foci in right capsid nucleus region, cerebral arteriosclerosis, brain atrophy.

Past history: hypertension, cataract.

Diagnosis: Cerebral thrombosis, multiple lacuna infarction.

Length of hospital stay: 28 days. Expenditure, more than 10000, free medical care coverage 50-60%.

Observation: He was cared in hospital with daytime by elder daughter; while at night time by his second son.

Educational level: no formal education at school. He was a retired worker, he used to be a head of Battery Factory. His monthly retired wage was 480.00 Yuan. Being widowed in 1995.

Primary caregiver and family

Mr. E, Widower, E's wife passed away in 1995 due to myocardial infarction, Mr. E had 3 sons and 1 daughter, lived with the younger son.

The third and fourth son lived in the opposite building, bright and clean, that might be the private property of Mr. E's whole life. 5 years ago, when his wife passed away, he himself moved to the old room, a previous kitchen from the better room. His wife died of heart disease. Since then, he became quiet, restless, depressed, without the care of his wife and without pleasure.

His income was low. His living condition is not as good as his sons' in the opposite rooms. His is small, dark and dirty, and with a moldy smell. His outlook is untidy with beard all over his face, finger nails are kept long, clothing and buttons are in a mess. His room has few pieces of worn out furniture.

E's grandson came to take care primarily of his daily life in the first month after discharge, and then he left for a job. His grandson (19 years old, with thin clothing in the chilly winter, sleeps in a small bed put together by several pieces of wood block, he is a graduate from middle school, introverted, sad expression (jobless).

E's daughter came to help him do washing and change bed sheet once a week.

He also felt that he was not as clear-minded as before, once he went shopping somebody cheated him giving him counterfeit bill. He was sad and desperate because of his physical deterioration and being unable to care independently, as well as to be the burden of his family members.

Although he had many children and lived with some of them, but they had meals separately.

In this household, only an 8-year old granddaughter came to talk with him after school. His elder son was living in the countryside with his family.

Health care service utilization

No medical services at all has been used after discharge home due to no affordability for medical cost. Unsatisfied with the health care services. Very dissatisfaction (2 scores) with the health service use.

Qualitative content analysis

Care issues

Activities of daily living

He often feels weakness in his limbs, he has fallen down many times, either at home or outside, I sometimes due to the uneven surface of the road due to his cataract. He sometimes used a stick while walking outside because he wanted to test his energy of walking. Once he fell down at home, and for half an hour nobody came to help. He had some limitations in his left hand and leg. And he was unable to dress, wash, toilet and cook.

He did not eat well and looked pale and weak. As he said “My teeth are not good, can only eat watery rice, twice a day. If I am hungry, I just buy an oil-stick, put it in the water, and buy a cup of milk, or a bowl of dumplings. I can’t eat vegetables, instead, I eat curd and dried fish”. On his table there were dirty bowls, chopsticks and pan, Some food were spread on the ground. Under the table there were coal. Some cookies were hung beside his bed where he can reach them.

He also frequently expressed that she needed a woman to take care of him, but he was afraid of his family members’ disagreement, particularly his daughter-in-law. They advised him that he would be cheated and teased, because the motivation of marrying him was the attraction of his money. He sought for prostitutes outside once a week, and once suffered from STD (sexual transmitted disease).

He also had difficulty to deal with managing his money, particularly it was easy for him to forget and lose his memory. He said he had twice lost his bank card and could not find it. After that, it was too troublesome for him to restart a new card. He had to wait to re-apply for it in one month.

Health problems

A number of physical discomforts (itching) he had, such as itching, sleeping disturbance, couldn’t eat well, poor sleeping, he had taken 10 packs of traditional herbs, shoulder pain, . Once he had constipation for twenty days, (related to food, habit...)

He did not take any medicine for blood pressure control, and never sought health care service after discharge home for six months.

Coping resources

Cognitive

He felt very lonesome: “A single person like me is just like a lonely wild goose, it flies alone, nobody takes care of it.”

The elder son did not permit him to live with them in the countryside, the other sons beside him did not respect him. He said: “If only my wife is still alive, I won’t be like this!”

During the new year, the elder daughter invited him to stay with them, but the old man did not like to listen to the gossip by the neighbor, he thought:” Neighbors will say, your hands can’t move, you’ll rely on your daughter! Hm! I am not happy, I have enough money to satisfy my need, I do not depend on anybody!”

“Why am I treated by my sons in such a way?”

“Why is that? I have been taking good care of my family. Why don’t they follow suit?If my wife were alive, I should be better, I might not suffer from stroke, she used to take good care of me, but she left me alone...it really drove me crazy. I need a woman, I have to pay for them right now...This is the only thing I am indulged in....”

Affective

“She died a sudden death, heart attack. She was hospitalized for 3 times, she came back and re-occurred, got 3 injections, got even worse, can’t eat, she died 5 years ago, in 1994, 1995”

“Nobody accompany me, nothing to do. I am afraid of gossip, I don’t want to stay with my daughter during new year...”

“The younger daughter-in-law is boring, the fourth daughter-in-law has gone already, so the grand son has nobody to take care of, always cries, the other older grandson always shouts at him, beats him”. Damned, she does not care the child and went away” “Sometimes I can’t fall asleep, I wake up and sit there, lie down again. Sometimes I fall asleep at 3am and wake up at 5am. It is because the bad daughter-in-law went away, I am angry about her.”

“I regret, cannot move freely, it’s a pity to be alone. I can walk, but cannot walk a long distance. Some neighbors said I look like a ghost. My disease, just stroke, will be better after using medicine. Raising children, what for? Who is better? Daughters? Sons? My second son is a teacher, a professor.

The other day, he asked me to stay with him, 3 days later, I came back, I don't like to stay in other's home, especially don't like to listen to gossip. Their parents were also there, they didn't care my business, they were not patient and kind to me. Now I am single, what a pity! I think of to end my life, life is not happy for me. To live is to suffer, oh, boring, that's enough..."

It was a chilly winter that I got the attack, fell on the ground for several hours, nobody in my family found me, he insisted that it was the reason why the disability remained so serious. His wife died in 1995, thereafter his life became a big problem, "I was 70 at that time, if only my wife were alive, I won't have this disease. Now, nobody cares me, she has gone for 5 years."

He was longing to get re-married, but the daughter-in-law strongly opposed. "I am afraid of her, she will strongly against me."

The 8-year old grand daughter was lovely and pitiful, but one year ago, her mother followed the other man and left us. The poor little granddaughter was so lovely, lonely and sorrow. Her future became a piece of stone choked in his throat. "It's a pity, I am worried, thinking of it, I cannot sleep. I hate that daughter-in-law."

Talking about his own future, single and lonely, very sad and sorrow," I don't know on which day I'll die. ., Oh, how boring!" (sigh)

Organization of caring work

During discharge, E's grandson (age 19) came to take care of him and living together. After one month, he left for a job. He was 19 years old, graduated from middle school, quit education and stay at home. He had been looking for a job, but failed before attending to his grandfather's home. During the first week and month after his leaving, his daughter came to help him in each week.

"The lovely granddaughter ran around grandpa, calling grandpa, grandpa, made the old man pleased and gave him great comfort. Mr. E said: "She is so young, most amusing!" He was very proud of his past, he was the boss and party secretary of a battery factory, he said: "I have been a cadre for more than 20 years, I was an able man, my work was excellent. Now, no more good, like a (sweet potato) dummy!"

The last time I saw him, there was a radio beside his bed, in quite good mood, also he was happy to tell his favorites in his life:" No 1, woman, whenever there is woman I will be happy, I like, I dream of it, (sigh), after that, I got released, I am not worrying any more! No 2, to watch Chinese opera, No 3, listen to radio. Besides, in the past, I am used to having a watch, once I had a watch worth 300 Yuan.

Oh, about re-marry, no suitable one, too old, I don't like, too young, it's dangerous, Ha-ha". Talking about the daughter who was always concerned about him, he was very grateful".

Mr. E also added: "My daughter is very considerate, my clothes, my sheets, all were washed by her. Nobody cares me except her. The daughter-in-law---get to the hell!". He continued: "Now I have to do everything by myself, I go shopping, I do cooking....but sometimes, out of control, the bowel will slip from my hands, bowels broken, my ground is dirty, what can I do, only one hand can handle. Oh, it's a pity, Why, I have sin?!" (Sigh), Anyway, I believe, if my wife is still alive, I won't be like this. Oh, she has gone for 5 years." "Oh, recurrence, just ready to die. Rely on others, impossible! How nice if I could do things all by myself!!!"

Life is still simple and bitter, but he has tried another way to find the balancing point, he thought the only way and place to get released is "prostitutes", that will make him forget everything, pain and sorrow. As a poem said: "Today I have wine, today I will be drunk", also as a saying expressed: 'One day being a monk, one day just beat the bell, life is but a dream! "Anyway, to have a balanced mood is much better than being sad all day long, right? "

Statistical analysis and time-series analysis for Mr. E's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. E						
1	SPMSQ	0	--	--	--	--
2.	CES-D	6	5	9	11	--
3	ADLs	45	55	85	85	--
4	I-ADL	--	16	15	15	--
5	SEGH	2.5	2.5	3.5	3.5	--
E's grandson						
1	CES-D	0	0	0	0	--
2	SEGH	4	NA	NA	NA	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. E, 73 years, medical condition was moderate, the blood pressure remained high, besides infarction, he had high blood pressure, and cataract.

Family background

He was living with two younger sons' families, but preparing meal and eating alone separately. This is a modified extended family.

Health care service utilization

No health care services have been used after discharge home, due to no affordability problems (no free medical care coverage).

Stroke-related disability

The functional status improved over time, but still completely dependent upon family members after discharge home. After one month, he had depression. Meanwhile, his self evaluation of general health remained low (2), and his son gave his evaluation at T1 and T2 for scores of 5.

Care issues

Care issues included mobilizing, fallen down, expression sexuality, physical discomforts (i.e., skin itchy, constipation), medication concerns.

Coping resources

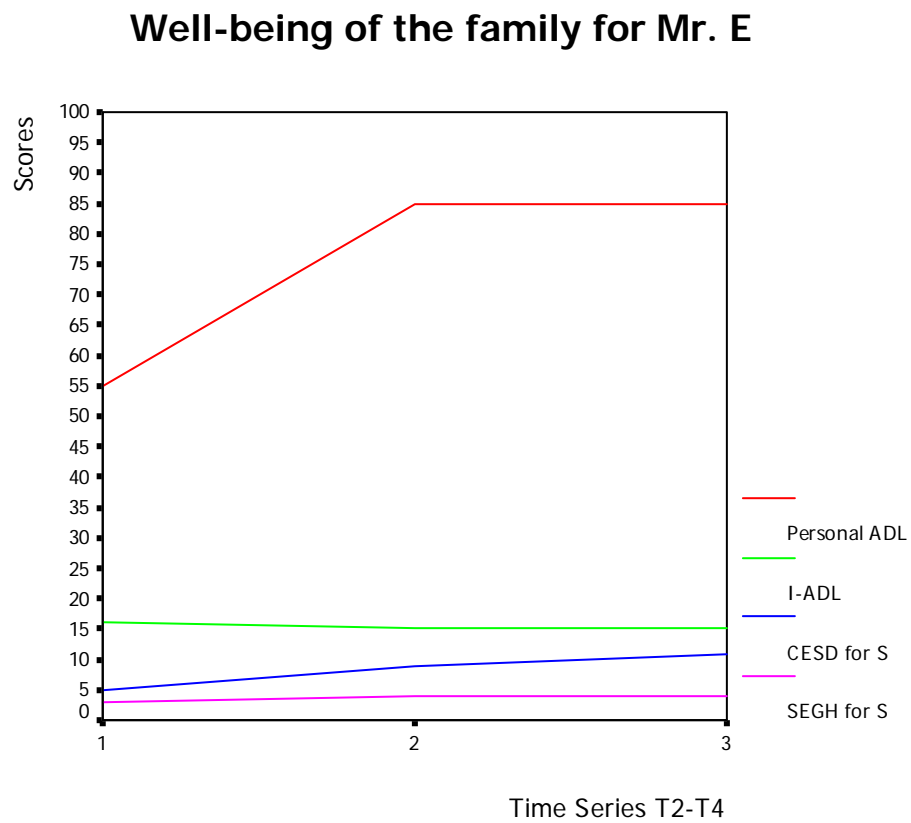
Thinking dominated by him was his wish to get return from his children and children not acting as prescribed role. Negative affects included isolation, hopelessness and helplessness, anger with his daughter-in-law were overwhelmed.

Organization of caring work

Initially he was cared by his grandson in the first one month. One month later, the grandson left for a job. Mr. E's daughter came to help him once or twice a week. Even he lived with two sons' families, but they did not pay any care for him after discharge home.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Mr. F's Family

Stroke survivor characteristics

Mr. F, 72 years old. Being hospitalized on July, 23, 2001. Because of 'sudden aphasia and weakness of left limb'.

PE: BP: 140/100mmHg, consciousness, right naso-libial sulcus swallowed, musculus tonus of left upper limbs: Grade III, right lower limbs: grade IV.

CT Scan: 1) Infarction of the right Radiation crown part of the right basal nodule region; 2) Arteriosclerosis of brain artery.

Past history: hypertension for 20 years, no hypertensive drug was taken, tuberculosis for 50 years, no cerebral infarction history.

Diagnosis: First attack of cerebral infarction.

Length of hospital stay: 15 days. Hospital payment 5000 Yuan, paid by the younger son. 50 % compensated by free medical care, paid every half year.

Observation: he was cared by his daughter during daytime, by his older son at night during hospitalization.

His educational level: high school. Retired wage: 400yuan per month.

Primary caregiver and family

Mr. F was a widow in 1998 (wife died of esophagus cancer). He had two sons and one daughter. Both elder son and daughter were laid off workers. The younger son did was a business man, and supported his father's medical cost occasionally.

He lived alone, a bed room and a kitchen, the toilet and the corridor were shared with the neighbor (so-called "united door household"). It was located at the 6th floor, the stairs were badly dark and steep.

Health care service utilization

The total medical payment 6 months after discharge was around 2800 Yuan (including medication and treatment), the main medical services were hospital OPD (emergence, Dept. of rehabilitation having acupuncture, physiotherapy and Traditional treatment, internal medicine), Private traditional doctor, (herb pills),dispensary, street-side advertisement (lingzhi herb) etc.,

Total expenditures for seeking services were 2800 Yuan after discharge home for six months. Which at T, T2 and T3 was 2040 (480/3=1440+600), at T4 (5M TCM herbs: 120) and 6M (640 lingzhikoufuye) was 760 Yuan.

Qualitative content analysis

Care issues

Activities of daily living

Daily life all cared by himself, two meals a day, because he thought when eating too much he would not have enough strength and could not do exercises. Be fond of meat, he happily said: “Not like others, my way of eating meat is just eat until you feel fed up, I can eat two bowls of meat, especially roasted meat or steamed meat”. When drinking water in the morning, he often coughs due to water getting into trachea. No need to brush teeth, all teeth were off as he described.

He expressed that he was very lonely, sometimes he saw some neighbor households, the whole family crowded together, he admired them, he said: “Look, they have wives, the living condition is much better, somebody cook for you, somebody does washing for you, but me, alone, everything is done by myself only. At home: me alone; going out: me alone; when enjoying something, me alone; when getting ill, again, me alone; Earlier, when not being stroke, I was still free, happy. Well, once stroke, being alone is much more painful, huh------(a long sigh)”

Three times he has fallen down after discharge home: 1) once hurt when doing exercises, ankle hurt. 2)The second time: Getting up in the morning, not standing firmly, I fell down and my back hit the bed edge, great pain for many days...3)Toileting, the edge of the toilet ground was too high, I walked and lost balance, sat on the ground...4) Walking on the stairs, I thought I was all right, both my hands were holding dishes, unable to be stable, slipped down and hurt my head badly, went to the hospital and had several stitches for the wound”

Health problems

He also described the medication fee was so expensive to him. He said: “This kind of medicine, 300 Yuan a month, because 33.4 Yuan a bottle, very expensive, every day half a bottle, plus hypertensive drug and herb, Oh, 10-20 Yuan a day! “Ah, I’ll ask that doctor, I want to know if his medicine can solve three problems? Can I run? Can I run fast? Can I be able to do labor work? Ha-ha...., I don’t think He can solve them: because I am easily be tired out, and my leg is so weak. Hope the three problems can be solved, otherwise, I ‘ll be tired and don’t like to move...!”

Coping resources

Cognitive

Mr. F said: “Force me to be in high spirits, take care, be stable, everything should rely on myself”

Just like a saying “Abite from a leech, it’ll suck your blood without stop” Mr. F wanted to express the idea that the relationship between family members are so close and that nothing can separate it, no way). He continued his philosophy of life: “Man should be loyal and honest, man mustn’t eat his words. The other day when I began suffering from stroke, my son promised me not to stay alone, move to live with them. But later, he ate his words, Oh, when one is getting old, nobody will pay any concern to your life...nut, anyway, you are my son, your surname is the same as mine, it can’t be changed...”(cough---a long sigh...)

He also expressed his burden of illness and caring feeling: “I am paralyzed in bed, if I don’t have any support from my children, OK, pick up a sharp knife and kill myself. Oh, using these cruel words, how sad (very bad mood, tears came out)”.” My older son even said he wanted to revenge me on my unfair treating him, how can I be so? He said when he got married he got less from me, while the younger son got more property from me. Oh, gossip, but the two marriages were not at the same time, one in the 80s, and one in the 90s, so my older son hated me. Well, both of you are my sons, it’s me that raise you up in the hard time, and now, I can’t move...”

“It is terrible to be a patient torturing others, there was a saying, ‘ when a patient being ill for too long a period, there won’t be anybody caring him’, really terrible!”

The burden of care: Mr. F. said: “The dilemma is that I want to die right now, impossible; I want to live well, also impossible! I want to see the doctor, I have to ask money from my son. I am weak, I am tired, I have no information about the outside world, there is no miracle in the world. I can eat, I can drink, only that I can’t move, oh that is the pain of stroke, and this is a disease only the rich man can be afford to suffer.”

Affective

In positive side, he had a strong self-reliance belief to depend upon himself and deal with the problems and difficult care situation in his own way. On the other hand, he also believed that he should get return from his children particular for his elder son’s dissatisfaction. He felt Anxiety, hopeless, he did not believe that the diagnosis is stroke. “Tell me the truth, can the disease be cured?” (sigh, sad, weeping)

Mr. F: "My wife died in 1998, I re-married later, but that woman cheated me, brought away all my money and left me, ...now I dare not think of re-marriage, afraid of being cheated again... We, my wife and I, cannot demand the same day of birth, but we really hope to have the same day to die together, leave me alone in this world, what a pity!"

Reminding the death of his wife and relating it to his fortune, Mr. F said: "What could she do? Her illness made her terribly thin, nobody could save her life, even one had lots of money....one week later, sputum choked her to death, she seemed to be snoring, then she died. I, my end, will be like this too! Her image at her last minute deeply pressed in my heart (a long sigh). Of course, the time with my wife, we had some conflicts, but we were companions. She went away, and no more companion. (weeping). Whom shall I talk to? To the wall? So Lonely. You see, I become a bachelor, a bachelor who had children!"

The No.1 thing to worry about was that :paralysis, hands cannot move, legs can not move, Mr. F's words "I ask heaven for help, I ask earth for help, but who can give me help???" "Then I'll sleep all day long, sleep until the last day comes".

Mr. F also was afraid of: meeting people, cars, walking on the street. Inferiority complex: Old and disabled, lower than ordinary man. Mr. F said: "I look at the mirror, what a image! Unhealthy and disabled! My neighbors also look down upon me. In the past they always praised me, but nowadays, they no more did so, furthermore, they belittle me, they showed me 'white eye', even they blame me... When they were happily playing cards, I envied them, I wished to join them, but how can I, I can't sit long, I have no stool, no money to buy, everybody is happily talking except me. I have hardship, but nobody to talk to....."

There is a saying: "If one is too anxious to get cured, one might seek anything from anybody, no matter effective or not" Mr. F: "Why, the more I get treatment, the more confused I will be?" Today he asked this doctor for treatment, tomorrow he saw another doctor to get new cure, finally, he got nothing, but was in the dilemma again.

Organization of caring work

Mr. F tall and well-built, used to be a vigorous sport activist. With his bright eyes and booming voice, he certainly doesn't look like a man in his 70s. His wife died several years ago and now he is living all by himself. After recovering from a stroke, he began to feel weak and easily became tired. To restore his strength, he tried doing some exercises, but unfortunately, he got a few bad falls and hurt himself. What worried him most was that he might become paralyzed and had to spend the rest of his life in bed. Besides, he noticed that people's attitudes toward him were also changing. Their admiring comments on his good health were gone and sometimes were replaced by certain measure of contempt and inconsiderate remarks. But Mr. Cai was not weighed down by these. He picked himself up, seeking effective medical treatment while maintaining a positive attitude and trying to restore his normal life. After experiencing a great deal of difficulty, he succeeded in conquering his fear and stress, and managed to lead a quiet and harmonious life.

One month after discharge, his second son installed a telephone for him.

"I began to feel weak and limp after the stroke. To build up my strength, I tried exercising, but overdid it and bruised myself many times. I was scared. How come if I had to spend the rest of my life in bed without being able to move an inch, doing everything in bed! What a trying experience! My wife was gone and the children have had their own families. I would be lonely. I would be a burden and nuisance to everyone. In my neighbors' and friends' eyes, I would have grown into a pathetic, poor old man. I would rather die than go on living like that. I used to be as strong as a horse and active in sports. I took part in the city's 10,000-meter run and came out the 20th. Everyone was envious of my good health and aliveness. How could I have a stroke? I left hospital in less than one week. My blood pressure was normal and I was still alert-minded and did not have any of those stroke patients' symptoms. After all, I was not *that* sick and had to make the best of what I had. I must pull myself up and learn to live in the present. Now that I'm old and sick and no longer as strong as I used to be, I must learn to let go of what I'm not capable of. There is nothing so difficult in this world if you only dare to scale. As the saying goes, 'where there is a will, there is a way'." They also use hot water, relaxation, exercise and taking aspirin for managing pain.

At the time of discharge, the perceived weakness on the left side made him feel fatigue and inability to stand and walk independently. During the initial period of discharge, his daughter insisted on persuading him to live in an elderly nursing home, but he rejected immediately as he described he was afraid of losing his freedom and independence. Over the process of six months following discharge home, there were multiple care issues and problems encountered while he took care of himself. They are diet and eating concerns, activity limitation, access issues to health care services and the psycho-social spiritual concerns.

The second visit: When looking upwards, there was a big and old clock on the wall, every 30 minutes

it would give off ‘dong-dong-dong’ to tell the time, in this room this was the only sound that always existed, besides this, deadly silence. When telling about his illness, he tried to speak in a light-hearted and take-it-easy way, his left hand unconsciously hit the injured leg heavily, making a clear and loud sound, ‘Pa-Pa-Pa-Pa’. He said: I say, I am not a very serious patient, mine is a rich man’s disease, a disease that one can eat, can drink but can’t move.” He was good at expressing his mind, but the words he uttered were not very clear and with a slight shutter, sometimes can be understood after 2-3 time repeating.

When encountering fluctuation of emotion, he had a series of way and theory to deal with: “It’s normal that sometimes happy and sometimes not, I must be easy-going”. He continued: “Sometimes, in the morning after doing exercises, I could walk better, then in the afternoon, after 4pm, the leg became heavy and weak, spirit got down, thinking about something sad, I ‘d try to adjust. Usually in the whole day, happy times were more than sad times. Anyway, I have been familiar with such situation, I have to be bold, to cheer up...sometimes I have to encourage myself. When the TV program made you laugh, you just try to laugh, sometimes try to sing, I sing! While listening, I sing!”

“Where there is a will, there is a way”

He, in particular, was afraid of being alone. he had to stay at home for a long time because he had lost the ability of running, walking, jogging in park, and he was upset if he was being treated coldly by the neighbor. He was worried about his future, being treated badly by children. Therefore he was trying his best to seek cure, even he was unsatisfied by the high price of the medicine; he was also trying hard to be self-reliance, in this course, he has fallen down for several times and hurt himself. Feeling alone as he was, he was not knocked down by stroke, he, from the beginning to the end, maintained hope, trying to seek any means and way to release his pain. Self-treatment, seeking acupuncture, asking for medicine or new information, doing exercises, forcing himself to be cheer-up, managing a regular life(meal, rest, news).... Pain and loss were treated by him as a kind of motivation and power to actively re-construct himself. His rich and complex inner world was full of hope and disappointment, happiness and sorrow, optimism and pessimism, love and hatred, bitter and joy. His life was colorful, an artistically knitted contradictive world. He was anxious to communicate with the outside world, eager to share the outside world with the elderly,. Sometimes he vigorously hated the complex world, because he wondered why the young generation behaved so cold to the wounded people. Love in nowadays seems to be as thin as a piece paper . Although he has long been badly tortured by his disease, he was still thinking deeply and trying to realizing the reality and be stronger and more courageous.

After discharge home, his daughter paid him a visit once a week, and his younger son helped him to install a telephone call at home. They told him he could call them any time needed. But after three months, he cancelled the phone call since the monthly fee was high for him (basic fee: 25 yuan per month). While he needed to buy medications, his younger son would offer him 500 Yuan to buy drugs and getting necessary treatment.

Statistical analysis and time-series analysis for Mr. F’s family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. F						
1	SPMSQ	0	--	--	--	--
2.	CES-D					
3	ADLs	95	100	100	100	
4	I-ADL	--	8	7	2	
5	SEGH	7	8	3.5	7.5	
F’s daughter						
1	C-ESD	NA	NA	NA	NA	--
2	SEGH	NA	NA	NA	NA	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. F, 72, medical conditions were stable, (130/90mmHg).

Family background

He was a widow, and living alone. He had one daughter, and two sons. There were 50-60% free medical care coverage, but reimbursement was paid for every half year. Financial burden perceived was high.

Health care service utilization

A number of health care services had been used. His total money for spending medication was about 2400 Yuan RMB in the past six months.

Stroke-related disability

Functional status improved over time, Meanwhile, her self evaluation of general health was from very satisfied to satisfied.

Care issues

Eating and meal preparation, mobility issues, expressing sexuality and medication concerns.

Coping resources

Both positive and negative affects existed. However, he could be able to adjust to his life smoothly. Being afraid of dependence on the others; The burden of illness. Both positive and negative thinking existed and mixed by him. Negative affects (emotional disturbance) included worry, fear (stroke recurrence, to be overlooked and sneered by neighbors), self-pity, isolation, social stigma. Loss of wife.

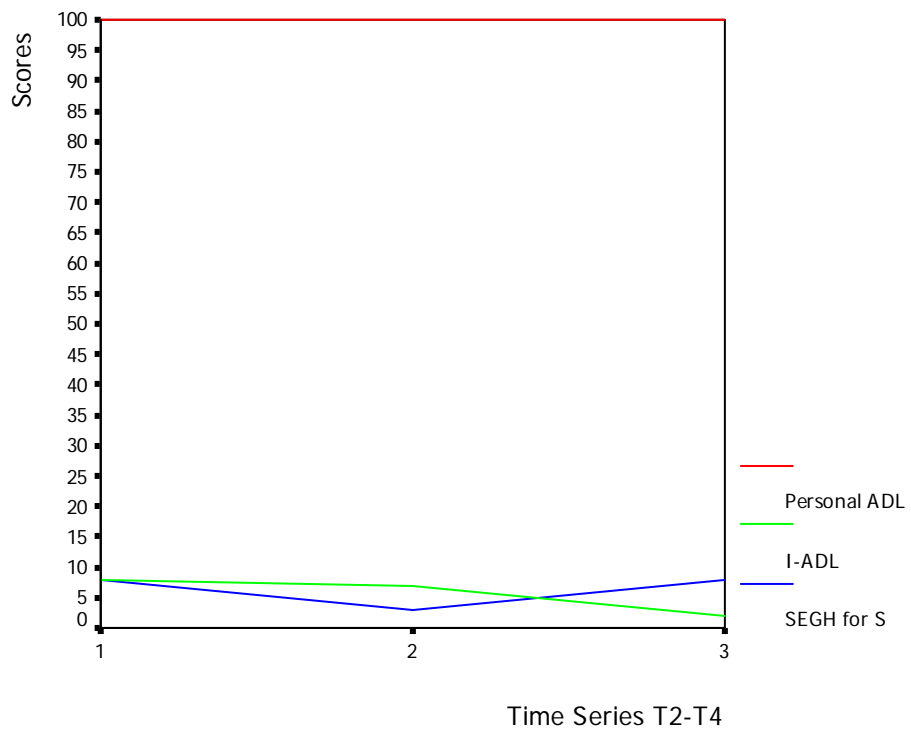
Organization of caring work

Self reliance was dominated by his thinking. Meanwhile, his daughter and younger son frequently provided their support, one is frequently paid by a visit once a week, the other offered financial assistance while he needs money in seeking medical help.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to dysfunctional
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Well-being of the family for Mr. F



Mr. G's Family

Stroke survivor characteristics

Mrs. G, 79 years, being hospitalized on Dec. 12, 2001, because when he was coughing, she found choking feeling in the throat 2 hours ago, with swallowing and drinking water difficulty, and saliva flew from the mouth, Head ache, aphasia when calling his relative for help.

P.E. BP 155/95mmHg, consciousness, both pupils equal size and round, 3 mm: BP155/95mmHg, light reflex (+), left naso-libial sulcus swallowed, tongue extension pointed left, aphasia. Musculus tonus: Left lower limbs grade V, left upper limbs: grade V, right lower limbs tendon reflex active. The musculus tonus of the four limbs not strong.

CT scan: Lacunar infarction in the basal nodule region, cerebral atrophy.

Past history: Hypertension for more than 10 years, took hypotensive drug (Kai-fu-te), Bp under control. Atrial fibrillation history, took herbs (dan-sen...) lacunar infarction attack 8 months ago, no obvious after effect, PG allergic history.

Diagnosis: The second attack of cerebral infarction

Length of hospital stay: 30 days. 7000 Yuan for hospitalization fare, 90% coverage by free medical care.

Observation: She was cared by daughters in turn. The main PSP was the second daughter. Bp 110/70 mmHg during the stay in the hospital.

She was a retired teacher from a primary school and fond of reading, with eyeglasses. She had a retired wage of 1000 Yuan.

Primary caregiver and family

She had 4 daughters and one son, she owned a house.

After discharge home, she lived with her second daughter's family, 2nd floor, private house, both of daughter and son-in-law were laid off workers, they had two sons, one was an undergraduate student and the other one is working.

She was clear-minded, she had her unique ideas about society, family, her future. She loved reading. Her children and grandchildren were kind to her and made phone call frequently. Meanwhile, the elder daughter came to visit and accompany her to play Majiang. Overall, she was satisfied with her present life, even though sometimes her son-in-law's words might hurt her badly.

Health care service utilization

A number of health care service has been used (drug store, OPD for prescribed medication, once a month). Medication fare was about 1000 Yuan RMB in the past six months.

Qualitative content analysis

Care issues

Activities of daily living

Health problems

Medication concerns: “Can the three kinds of medicine be taken together?”

Coping resources

Cognitive

Her son-in-law’s attitude toward his month-in-law always inpatient and unfriendly. This made her unhappy and kept silence. She thought she was the burden of their family.

Most of time, she relied on herself to take care of her basic living.

Affective

Fear for recurrence, expected to go back to her own home

Organization of caring work

After discharge from hospital, her daughter was worried about her mother’s condition. In order to pay a close attention and observation, the second daughter picked her mother to her family and lived with them. Her daughter was very kind and was a good assistant. But the mother felt that living in daughter’s home was not free enough, as she used to living in her own house. The kind daughter installed a special ring for her, and also put a sphygmomanometer beside her bed.

It was noted that her children were all very enthusiastic to help, some offered money, some offered other help, and they often discussed the situation of their mother and described the pain and bitterness during hospitalization. They don’t think hospital service was satisfied.

The mother mentioned about her bitter life that when her husband passed away, she, alone, took over the responsibility of raising the five children, every time when touching this experience her tears dropped.

She thought that her children, following her, suffered a lot. Before stroke attack, She lived alone, after stroke, she lived with children, she still kept her own house. She thought living in other’s home seems to be living under other’s roof.

Once her son-in-law blamed her in front of me while she expressed something dissatisfied with her daughter’s care. Her son-in-law impolitely shouted: “What? You are still unsatisfied with the care? We are all taking good care of you, especially during hospitalization, cooking for you, sending meals for you.....all around you..”

At that time, Mrs. G hung her head, expressionless in her face, said nothing, seemed nothing happened. After the son-in-law left, she silently rubbed her tears and murmured: “When can I go to my own house?...I want to go back home....”

Statistical analysis and time-series analysis for Mrs. G’s family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mrs. G						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	45	70	95	95	--
4	I-ADL	--	12	12	12	--
5	SEGH	4	4	5	5	--
G’s daughter						
1	CES-D	0	0	0	0	--
2	SEGH	5	5	5	5	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. G, 79, medical conditions were stable, (130/90mmHg).

Family background

She was a widow living with a daughter's family. They were extended family. She had one son, and four daughters. She had 95% free medical care coverage, but reimbursement was paid every half year. It was not convenient for her to come back to her unit to get her reimbursement. She lived in an extended family.

Health care service utilization

A number of health care services have been used (drug store, OPD for prescribed medications once a month). A total of 1000 Yuan RMB was paid in the past six months.

Stroke-related disability

Barthel index showed functional status improved over time, both positive and negative affects existed. However, she was able to adjust to the change of her life smoothly Meanwhile, her self evaluation of general health remained satisfied.

Care issues

Care issues included constipation and medication concern.

Coping resources

She maintained stable and less negative affects over time. upholding Self-reliance, Both positive and negative thinking existed and were mixed in Mrs. G's family On positive side, she had a strong self-reliance belief to depend upon herself and deal with the problems in her own way. On the other hand, her son-in-law blamed her staying in his home which made her stressful, sad and unhappy. But G's son-in-law felt unsatisfied with Mrs. G's long time living with them.

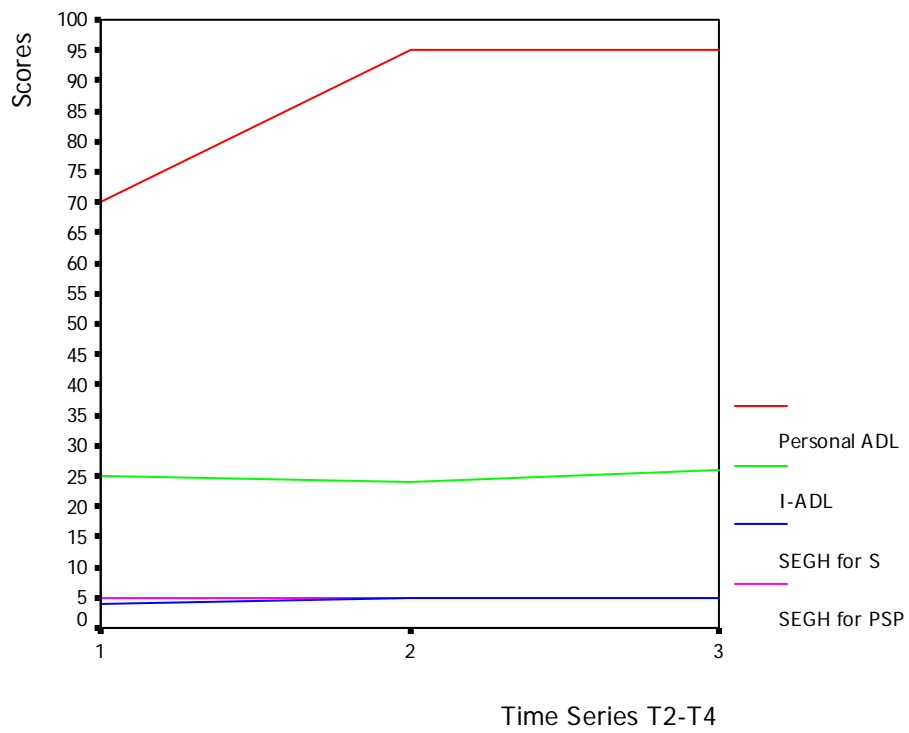
Organization of caring work

Her daughters tried to pick her up from one daughter's home to the other's. At six month, she felt happier than before and looked forward to go back to her own home sooner.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to functional
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Well-being of Mrs. G's Family



Mr. H's Family

Stroke survivor characteristics

Mr. H, 76 years, being hospitalized on August 29, 2001. Because of sudden attack one hour ago, left limbs weakened with aphasia, unable to walk independently.

P.E. : BP 130/80mmHg, consciousness, both pupils equal size and round, D=3mm ; light reflex sensitive, aphasia, left nasal-labial sulcus swallowed, muscular tonus of left limbs grade III, left upper limb V, left lower limb IV+, paralysis test : left limbs (+). Lab exam: renal function, CO₂CP 22.1mmol/L (23-31); BUN 2.8MMOL/L(2.1-7.9) ; Cr 70.3mmol/L (88.4-17.6)

CT Scan: multiple lacunar infarction, mostly old, cerebral arteriosclerosis, cerebral atrophy; ECG: 1) Sinus rhythm 2) Axis turn-left (mild) 3) myocardial damage.

Past history: hypertension for 7-8years, reached as high as 210/140mmHg, Oral hypertensive drug (Di-fu-da), maintained at 140/80mmHg. The first cerebral infarction in June, 2001, no sequel left.

Diagnosis: recurrent stroke infarction, and TIA.

Length of hospital stay: 61 days, 20,000 Yuan, enjoying free medical care 95%.

Observation: Speaking not clearly, in bed, limbs movement limited, could not handle daily activity; restless, irritable, often complaining about the food in hospital (false teeth, gingivitis), ate only instant noodles; His daughter sent meals, wife paid visits, a 24-hour male helper hired. Under the support of his daughter he walked out when discharge.

Educational level: high school, working as a carder before retired.

Primary caregiver and family

H's wife, 76 years, primary school, slow motion, subtle sight, listening ability all right. Usually not sociable, no communication with all the relatives. No religious believe for both of them, family income, 2000 Yuan. After discharge home, young girl (age 16) was hired by them as a helper.

Living in the 2nd floor, they had one daughter, married and lived in her own house.

Health care service utilization

No any health care services were used after discharge home. He also felt dissatisfaction with hospital service which made him troublesome during stay. He said: "I myself am all right, you see, my brain, my heart all OK! The main problem is that this leg is cold, walking not so freely as before., and this hand, a little tremor. Why, they forced me to stay in hospital (very much unsatisfied), I said, what for? I can walk, no need to be carried by others. Stay a few days, still I have to be back, then I might get some other diseases! (strongly reluctant to be hospitalized again).

"They just didn't listen to me (he felt upset many times while mentioned the experience in the hospital stay). Tell the truth, there are both good and bad doctors in the hospital. Lots of trouble: going to toilet, helper, eating, my teeth are false. If I were at home, anyway, I could have a bowl of rice. They tried to frighten me to let me obey. I said, mine is a chronic one, I just don't want to stay in hospital. Only very few medical workers are good. So many patients, how could they take good care? In a word I was forced to get in hospital, and I have no TV program to watch there, only several packages of medicine..."

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

Mr. H also described his false teeth and made him eat difficulty: “A spoonful of rice, just force me to eat...what dishes? Spinach, pumpkin...my false teeth couldn’t stand that. Fish, oh no, too many stings. Fruit, I couldn’t bite, it is hard. Only banana...there is numbness he was pointing his face), the false teeth were not convenient, oh very uncomfortable!”

Mr. H:” Yes, I took some, once, for my teeth, no effect after taking that medicine...it is in a bottle....(angry, they started arguing)...” Then in the shelf (he shouted), give me the stick, I’ll fetch it by n myself (anxious)why, lost? (dirty words)

H’s wife said: “He took once, no more, OK, you fetch it by yourself...That flat bottle...He just listened to the doctor, our words never work..”

H’s wife expressed her husband heavy cough “he has sputum, what medicine is effective? A ha-ha...sometimes common cold. Chloromycetin 甘草合剂 was taken, also in NO 6 Hospital, and brown mixture, syrup...”

Mr. H added: “Show them the medicine, also anti-infectious drug (asking his wife show all the medicine he is taking at present), can I take this or that? Just show them, and the syrup...”

H’s said: “Recently, cough, yes, at night, when the sputum was out , he’d be better. Yes, also common cold, when he coughs he was very upset. In daytime it’s better, only at night, disturbing sleeping.

Mr. H added: “Much better, running nose is better, the common cold is getting better....Another problem is that when I drink water, I’ll cough, so I dare not drink. My daughter asked me to drink. ...Especially when the weather is changing.

H’s wife said: “How can he eat? He said it is because of teeth. He was very unhappy with her wife’s overprotection and prevent him from practicing walking. He said: “he never allowed to walk alone, always follow me, in fact, I can, I can use stick, but she hid it from being used by me...”

Health problems

Mr. H expressed his difficulty in passing stool in the morning. He said “I used to go to toilet after my breakfast, but H’s wife used to be so slowly and busy with her own business. I shout and ask her to come and help me to go to the toilet, she seems not hear it! Then I am angry, well, too bad, I can not pass stool as well. She always in such a way, there are several days I did not pass stool...”

Mr. H expressed he had a severe should pain, but the young help (girl) was able to help him massage, he felt fine with it.

Coping resources

Cognitive

In his whole life, he was the leader to control others: once thehead of the drivers,, party member, and now, the role changes, he’d be under others’ control, self domination status was destroyed by the illness and inconsistence with his wife.

Mr. H consistently complained his wife disobey his will and unmet his need of care. His expectation of wife’s care is not only daily activities to meet his physical needs but his perception of care must be absolutely obedient. When this turned out not to be the case, he became depressed and angry and accused her wife as being ungrateful, dissatisfied and disobedient.

Meanwhile, the caring work done by Mrs H was percieved by Mr. H as overly protection and freedom-limitation. What she did let him feel confused, because he was used to freely living and commanding others, now he became a useless man, he felt unfair, He hate his wife didn’t understand

him, especially he hate that he himself became “powerless” and “disabled”, he was overly sad. Hundreds and thoudsands of hatred and sorrow all rushed into his heart causing him extremely unbalanced, hence the family became restless all day long.

Affective

Mr. H: “I, I, no future any more!.. I am living a bitter life! I can not move, my bitterness is endless!!! I am hopeless. I am already like this, if, someday, my wife collapses, what to do?! Oh, finished, everything finished, I even don’ want to eat. Oh, poor appetite, poor sleep, everything is poor”. Once I talk about it, I feel upset. When I was young I didn’t do housework, and when I get old, now I cannot do house work too, I owe you too much, what can I say? Just live and count my days!” “I have no freedom any more.....If, someday, others turn a deaf ear to me, they no more care me, then I’d jump down from the roof...”

Organization of caring work

After discharge home for one week, a young girl, a helper, arrived at Home to help them. It was observed that Mr. H was satisfied with the new-comer, but Mrs. H was not. Each time while Mr. H talked to me, Mrs. H added, Mr. H would shout loudly toward Mrs. H. While the helper added some words, Mrs. H would shout and upset toward her.

At one month after discharge, he use to shout his wife. He said: “When I speak, you just get out!...(scolding)...Her nature can’t be changed! I think just keep silent, take it easy! But, I have my temper, I am also restless, when you speak more, I’ll be upset. Recently, I am not in a good mood...I am not happy, my blood pressure: 150/70mmHg, I wake up at 4-5 am, I think, I can’t recover. My living setting, my environment, all are not good. And when I rest, all the diseases turn up, sleeping, eating, toileting, all finished...and all these I cannot do according to my own will, all are arranged by others. My wife is such a person, she always stands against me”, but she said: “I take care of you , and you do not appreciate.” Mr. H added: “she always blames me. I cannot pass stool, I cannot sleep well. She lets me have too thick cover, they are so heavy, I am very uncomfortable. If my temper goes up, I can’t pass stool. I ask for this, and she gives me that, the whole day, we have no peaceful life at all.....”

At six month after discharge home, Mr. H insisted on his own way, and his wife has to be obedient. Mr. H said: “I would do this way, and she insisted doing the other way, She was always against me...when I wanted to pass stool in the morning, she just did it slowly, she didn’t help me, after she finished her work and came, I have no stool to pass....why she did not help me earlier? She always blamed me being slow motion. Her temper went up just for a small thing. Who on earth did not have something to trouble others”.

Statistical analysis and time-series analysis for Mr. H’s family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. H						
1	SPMSQ	0	--	--	--	--
2.	CES-D	19	26	33	38	--
3	ADLs	35	55	65	65	--
4	I-ADL	--	25	28	28	--
5	SEGH	2	2	2	2	2
H’s wife						
Category	Scales	T1*	T2*	T3*	T4*	Others
1	CES-D	0	0	0	0	--
2	SEGH	4	4	4	4	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. H, 76, medical condition was severe, blood pressure was high (140/80mmHg); he suffered from stroke recurrence and this time was more severe than last time. Besides infarction, he had coronary heart disease, and hypertension.

Family background

The couple was living together, one daughter came to visit them frequently. They were nuclear family. The domestic help also lived with the couple. There were 95% free medical care coverage, but Mr. H was scared by re-admission to the hospital. He lived in a nuclear family.

Health care service utilization

No health care services used after discharge home, because of unable to walk from upstairs to downstairs.

Stroke-related disability

Barthel index showed improvement over time, but completely dependence upon family members after discharge home. After one month, he had depression. Meanwhile, his self evaluation of general health remained low (2), and his wife gave the scores of his evaluation of general health as 4 over time.

Care issues

Issues included constipation, mobilizing (walking), sleeping disturbance, shoulder pain, and medication concerns.

Coping resources

Thinking dominated by him was wife who should be prescribed as her obedient role, perceived burden of illness. To be treated unfair by the heaven. Her wife was quite positive, letting nature taking its course. But Mr. H negative affects (emotional disturbance) included, worry, irritability, fear (stroke recurrence), Pleading to death due to hopeless.

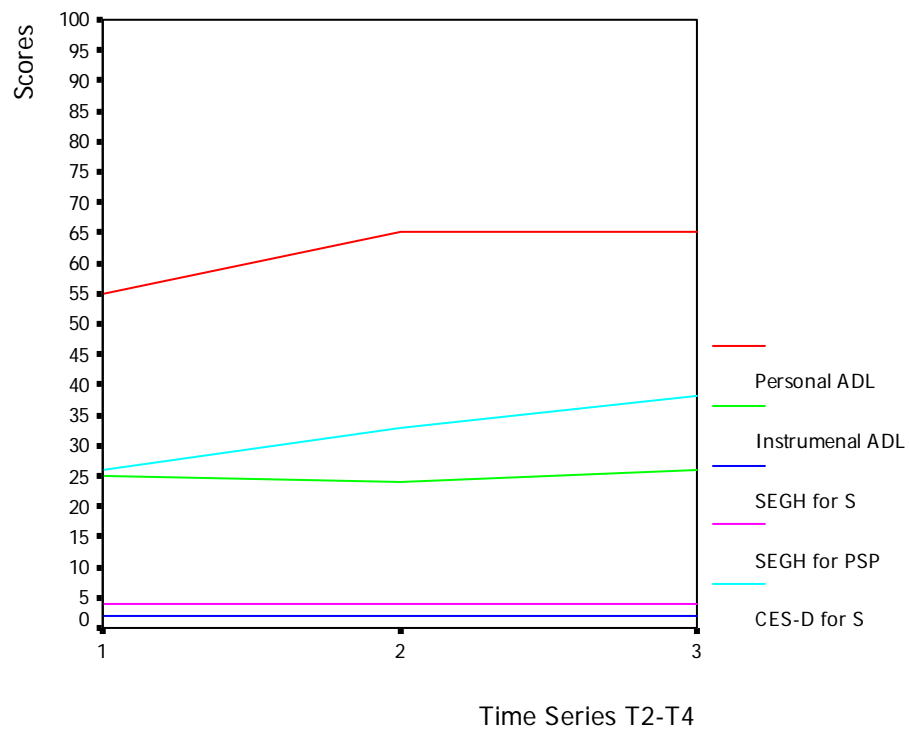
Organization of caring work

Mr. H appreciated for his wife's help and caring. One month later, due to the new-comer (domestic helper) the couple had different attitudes towards her. While Mr. H was satisfied, Mrs. H was always dissatisfied. All the time they were in the opposite position.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to functional
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Well-being of the family from T2-T4 for Mr. H



Mr. I's Family

Stroke survivor characteristics

Mr. I: 75 years, being hospitalized on June 14, 2001. Because of 'weakness in lower legs for 4 days, aphasia for 2 days, coughing when eating or drinking, with nausea and vomiting. He was

PE: BP 190/90mmHg, consciousness, neck soft, both pupils equal size and round, light reflex sensitive. Left naso-labial sulcus swallowed, upper limbs tonus grade V, lower limbs tonus grade V. No pathological sign.

CT scan: Left cerebral infarction, Brain atrophy

Past history: Cerebral infarction in 1990, no functional deficits left.

Diagnosis: Cerebral infarction, brain atrophy.

Length of hospital stay: 14 days, 2030 Yuan for hospitalization fare, no free medical care enjoyed.

Observation: Semi-reclining position in bed, apathy, silent. He was cared and accompanied by his daughter-in-law during day time. His wife was responsible for his meal three times a day. At night his three sons took care of him in turn.

Educational level: no school education, his retired salary was about 400 Yuan.

Primary caregiver and family

I's wife, an illiterate woman in her 70s, lived together with her sick husband. They had 5 children (3 sons and 2 daughters), all married and having separate homes.

The couple lived in the second floor, and the youngest son's family lived in the opposite building to them. They (the son and his family-daughter-in-law and grandson) came to have dinner with them everyday. Both of them (the son and daughter-in-law) were laid off workers). The grandson was 10 years old and studied in the primary school.

The couple together had 800 Yuan (retired wage), and some deposits, besides they had financial support from the elder son, could maintain basic life need. The hospitalization fare was mostly supported by his elder son.

Observation: The room was large and bright, tidy and clean.

Health care service utilization

His medicine was obtained OPD of the hospital and fetched by his daughter-in-law.

Qualitative content analysis

Care issues

Activities of daily living

Mobilizing and fatigue, numbness, meal and eating (preparation and dysphasia). Mr. I compared his arm while in the hospital, he said, “My hands are better, only when standing, the legs are not stable, enough”. While mentioned about assistance obtained from his son, he appeared to be happy and satisfied: “I was bathed by my elder son, I brush my teeth by myself, beard-shaving also by my elder son, my wife helps me dressing, helps to bring a “chair” when toileting. When sitting up, I need her help”.

I’s wife also made a joke for him: “when I heard he passed gas, I supposed he’d pass stool, but when I brought the “chair” to him, he had no stool at all.”

He also described his fear of falling down, he said: “now I can stand up, speak clearer, if standing up alone, I am afraid of falling down.”

I’s wife also described how she prepared meals everyday for Mr. I. I’s wife said: Breakfast at 7-8am, lunch at 12, 3pm, supper, 6pm and a snack at 9pm, I eat hot-dry-noodle....5 meals a day:....I bought a lot, he eats a lot, he doesn’t like too greasy food, (Mrs. I is very familiar about her husband habit), I want to cook some pork soup, but he doesn’t like” Meanwhile, she expressed difficulty in preparing meal for the whole family at the weekend. She said: “If all the members come back, I’ll be very busy. I buy and cook for them. Our neighbor said: ‘see, she is such an age and has to cook for so many people’. I also have to do cleaning of all the rooms (contradicting thinking, on the one side she expected them-sons and grandsons to come back, on the other hand, she does not want to be too busy working for many people; she thought of her sons, but she doesn’t like her sons because they always obey their wives’ orders). Usually sons with their families will pay their parents once a week for dinner at weekend, sometimes the dishes were delicious, but sometimes not. If not delicious enough, they won’t touch it. This upsets I’s wife badly.

I’s wife expressed her poor appetite and sleep disturbance frequently: “He eats bao-zi, I don’t want to eat. I have neurosis, ai-ai, I can’t sleep daytime at all, but he sleeps soundly all the time.....”

Health problems

I’s wife had a lot of physical discomforts perceived since taking care of Mr. I all day long. Such as

Fatigue, dizziness, weakness

Coping resources

Cognitive

Mr. I, after discharge, his function of limbs improved, in the 6th month he could walk by himself without any help, while at the beginning he needed other’s support. He had great improvement when going upstairs and downstairs, eating, strength...but at the same time, I’s wife complained that stayed at home all day long, repeatedly complained :” So lonely, so much trouble, so many hard words...”, she said:” The reason why I served him is because of thinking of the children’s ‘face’, you see, How I nice I have cared the old man...all the children should thank me”

I’s wife said angrily: “Why should I be the giver? Who cares for me when I’m down?”
“Why should I be the giver all the time? I don’t complain about having to take care of my husband. He is old, sick and needs caring. But what about me? Am I still young, in my prime and having inexhaustible energy? Does anyone show the slightest concern about what these 6 months’ nursing and household chores do to me? Does anyone know that I have trouble going to sleep all these days? Does anyone know that I have lost appetite for meals? Does anyone know that constant headache and dizziness have been bothering me all the time? No one cares about that as if I were born a giver. I care for the old chap and cook for the family. I feel like a candle being lit from both ends. What if I were burned down one day? Has anyone of you given the faintest thought of that?”

I’s wife also thought she had spent great efforts on caring the old man, but she got less and less concern and return from her children, this thinking made her angry, and she poured all the dirty water onto the ‘old father’. She blamed the patient was the fact, undermined was that she wanted to release her dissatisfaction and boring of the children (children are lacking respect to her). But Mr. I was self-reliant in the most of time.

Affective

I's wife complaining all the time: Complaining about the hard words of the patient; the support of children decreased; (6th month), complaining about 24 hours working around the patient (no time to visit her daughter and go to park), isolated with the outside world (no time to buy tapes, or chatting), Complaining about helping patient pass water 2-3 times a night; Complaining about the high price of medicine; Complaining about the financial support by children decreased (6th month).

Complaining about exhaustion Mrs. I: "He deadly tortured others, gossip, going to toilet he will shout, again he wants to get up, he shouts again asking for help, he makes me upset!"

Anxiety Mr. I expressed his worry: "I care for nothing, eat little, but many times, my colleagues sometimes come, sometimes not. I am upset, More than 70 (75), if the day of death will come, just come quicker. I am not worried, sometimes when I call with no response, it made me upset."

I's wife said: "Ai-Ai! His temper sometimes goes up, sometimes he is unsatisfied with children. Children are all right, sometimes not so good. Oh, young men, don't expect them to be too good, OK, they are all right."

Organization of caring work

At T1, I's daughter-in-law was participated in talking. One week after discharge, his feeling was all right, especially his emotional status, relax and peaceful, hands and legs began to gain strength. At home Mrs. I (75) was in charge of all his care issues. The youngest son's family lived in the opposite building, both younger son and his wife were laid off workers. They also had one son who was in primary school. Therefore, Mrs. I had to cook for the 5 members. I's wife attitude toward her husband seemed to be close and intimate, sometimes the old couple even unconsciously grasped each other's hand, she also prepared honey water for him. She persuaded her husband, explaining to him her theory of how to behave as a person one has to be, it means if you are the older generation, you should act as what you are, meanwhile, if you are the younger generation, you should behave as children. "上人要人做, 下人要人做", Once the topic turned to financial problem, the out-going Mrs. I would be sad and tears flew from her eyes.

Furthermore, stroke survivor's ADL improving rapidly. The care issues in the first one month were mainly dressing, transferring, walking and toileting, as well as preparing for adequate food, and medication administrating. While in the sixth month the survivor was able to walk independently, only cleaning for toileting needed help. Food and medication were still to be concerned with.

For survivor, he actively participated in physical exercises, such as climbing stairs and walking around outside in the morning; for primary caregiver, she tried to provide adequate nutrition. Such as providing 5 meals a day and various dishes in each day.

The 2nd time, 3rd time, I's wife was still very talkative, she talked without stop. I's wife was active and talkative. Mrs. I "My son and daughter-in-law specially bought him a 'chair' (for toilet seat), it was wrapped in the four feet of the chair to avoid slipping". Mr. I "Every time when I go toileting, my wife will bring that chair for me, I just sit there, quite comfortable, it was bought by my son and daughter-in-law....."

The 4th time: I's wife became silent and talked little, repeatedly yawned. She said: "You see, how nicely I treat him?! Everything is done by me. 24 hours a day around him, I do it just for 'giving the face' for the children. Later, when I could not move, see who was to help me?" Mr. I: "You buy and buy tapes", he blamed Mrs. I, but look deep into the problem, actually he was blaming daughter-in-law for their refusal of financial support.

But at the same time I's wife said: "I am upset by his words, always blaming me for the tapes, what did I buy? I am not spending your money, I buy nothing. That daughter-in-law doesn't do anything, in this family, they all depend on our wages! Hm, son! The grandson wants money, he is in middle school, he relies on us. Furthermore, the bills of water, electricity, around 100 Yuan a month. Ai, and the bathing -heater! If I mention this trouble, they just turned a deaf ear, ...Oh, about tapes, yes, the Hubei opera I like, very cheap, 2 Yuan each. Listen, many others, they play ma-jiang, I never play. I listen to tapes, what's wrong? You watch TV all the time, and you use much more electricity than I do..." Mr. I: "Give it to you, eat. You just go out all around. Why do you buy (tapes) (again, me I was unsatisfied)".

Overall speaking, Mr. I's condition in terms of physical and psychological aspects was stable, but his wife gradually became irritable and boring, as well as exhaustive in the process of caregiving. Finally the wife was not reluctant to provide him an additional meal and enough patience as she did before. More negative attitude and passive caring were illustrated in the side of primary family caregiver due to her old age and long-term workload and 24 hours intensive care or accompany by her own. Particularly while her daughter-in-law showed her aloof and detached attitude and less acknowledged her housework effort, she seemed to be extremely angry and intolerable to do such kind of care, not only for her husband, but for the other family members as well, such as son, grandson, and daughter-in-law.

Filed notes

Because of the limited space, during the interview, the patient and his family members were not separated, also to avoid unnecessary doubt and losing the trust of the patient.

Negative thinking resulted by following reasons mixed over time:

a) Taking a long time to stay at home for accompanying survivor, this made primary caregiver feel extremely bored after discharge home for one month, because the primary caregiver was afraid of falling down while she was absent. b) At the third month after discharge, his spouse perceived some physical and emotional burden while providing daily care and specific care, particularly deal with cleaning and washing, as well as medication preparing. c) In order to maintain a continuing medical treatment, medical cost was another important factor to be concerned with. Only 10% reimbursement could be provided by the work unit for hospitalization (that means: 2300 Yuan, paid by the unit merely 230 Yuan); the monthly medication fee was about 100 Yuan (monthly income for both of them is 800 Yuan) after discharge home. d) Their children have helped the family share most of burden encountered only in the initial period of time (in the first three months). For care issue, their sons did bathing for survivor in turn, buy a chair to be convenient and comfortable while toileting; they also helped them to pay medical fee during hospitalization. But in a long run, for primary caregiver, maintaining a constant care for survivor's recovery and good relationship with children are also important.

Mr. I fell ill and was hospitalized for intensive treatment. All the children and their family members came home to help. They took turns caring for the old man both in the hospital and at home. After three months, seeing their father recover steadily, the children withdrew from the nursing team and left all the chores back to I's wife, who was of the same age as her husband. Six months later, Mr. I was nearing a complete recovery. He could go about in the neighborhood without company or help, his strength and appetite being restored. In the meantime, however, Mrs. I was completely run down by the 6 months' nursing and household chores. Her problems were not only physical, but emotional as well. She grew tired of being a giver. She shed her resentment on both her ailing husband and her uncaring children, especially her daughter-in-law, who was laid off and supposedly able to help out more.

Statistical analysis and time-series analysis for Mr. I

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. I						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	45	55	80	90	--
4	I-ADL	27	27	27	27	--
5	SEGH	3	4	5	7	--
I's wife						
1	CES-D	0	1	6	8	--
2	SEGH	3	3	4	3	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. I, 75, medical conditions were moderate, the blood pressure was 140/90mmHg during the home visits; This was the second time of stroke infarction, he had hypertension.

Family background

The couple was living together, the younger son's family living opposite of their building and ate each other. They were modified nuclear family. They came back to eat with them every day for dinner. Mr. I had only limited free medical care coverage (5%), the elder son also provided assistance to them. He lived in a modified nuclear family.

Health care service utilization

OPD and drug stores were used once a month by buying medication through their daughter-in-law. 400 RMB were spent in the past six months.

Stroke-related disability

Barthel index showed improvement over time, but completely dependence upon family members after discharge home. And his self evaluation of general health was remained moderate (4), and his wife gave the scores of his evaluation of general health reduced over time (4 to 3) over time.

Care issues

Care issues included eating and meal, mobilizing (walking), sleeping disturbance, physical discomforts (fatigue and numbness) and medication concerns.

Coping resources

Thinking dominated by him was positive. Self-reliance, at T4, while Mrs. I was negative overwhelmed due to perceived burden of care and children not acting as a prescribed role, particularly her daughter-in-law. 2) Negative affects (emotional disturbance) dominated by I's wife was irritability, anger, fatigue, complaining of limitation of social activity and accusation, upset of Mr. I's over dependence at one month after discharge home.

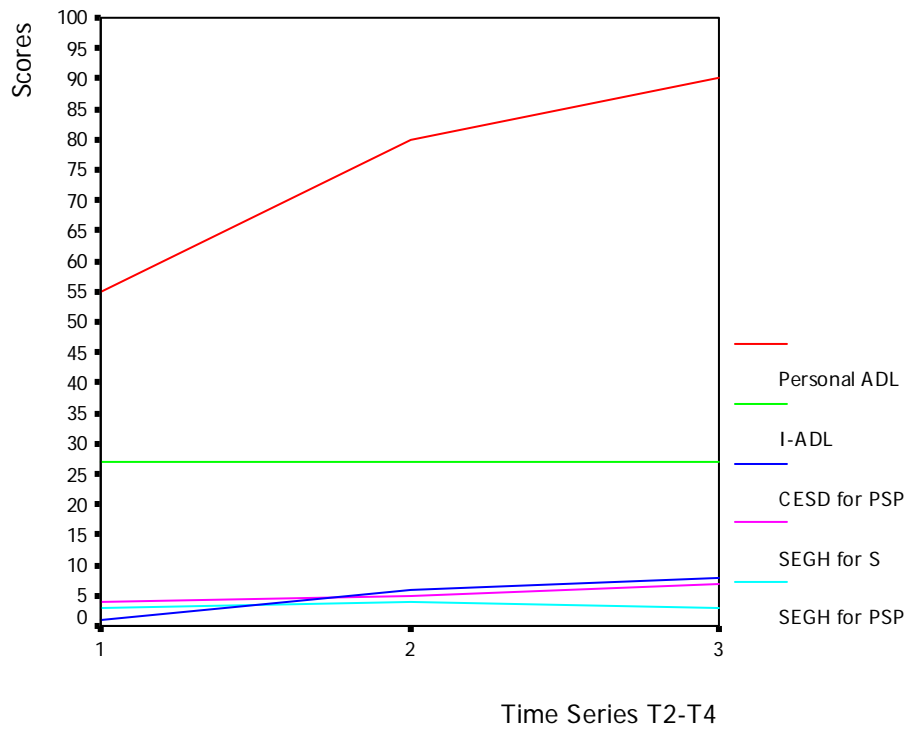
Organization of caring work

Mrs. I thought they would share financial burden of their family while they came for dinner every day, but they did not offer any cost for their own food. Mrs. I was very dissatisfied with her daughter-in-law. So she always lost her temper in front of Mr. I. But daughter-in-law showed the attitude of avoidance.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to functional
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Well-being of the family for Mr. I



Mr. J's Family

Stroke survivor characteristics

Mr. J, 70 years old. Being hospitalized on Oct. 2, 2001. Because of right limb weakness with numbness.

P.E.: Both pupils equal size, round, light reflex exists, right naos-labial sulcus swallowed, tongue extension pointed right, both lower limbs edema grade I. Muscular tonus of right upper limb grade IV, right lower limb V. Mild paralysis test (+). Blood sugar >8.9ug/mmol. (normal value: 5.8ug/mmol).

CT Scan: Lacunar infarction of left basal nodolar region, brain atrophy.

Past history: Hypertension for 30 years, Cerebral hemorrhage in 1998 (no functional deficit left)

Diagnosis: left cerebra infarction (right side hemipares) and diabetes type II.

Length of hospital stay: 50 days, 10,000 Yuan, enjoying free medical care coverage 90%.

Observation: During hospitalization a full-time helper was hired. Mrs. J cooked at home, brought meals to hospital fed Mr. J, came and went back between home and hospital.

Educational level: college, working as tax cadre. He had monthly retired wage: 1000 Yuan.

Primary caregiver and family

The couple lived together. Mrs. J's educational level: high school. Her retired wage was about 1000 Yuan. They had a helper at home immediately after discharge home. (Male, 40 years old).

Mrs. J was frail and small, she had coronary heart disease and hypertension. She used to work as an accountant for two years in a company after retirement. She always recalled the time when her husband helped her do all housework and cared for her wholeheartedly. She was also a sincere Buddhism and she used to getting up at 5:30am to pray in the morning. As Mr. J described since the elder son passed way suddenly, the shadow was overwhelmed in the family and his wife started to seek comforts from religious belief.

They had two sons, the elder son was dead of car accident in 1995. The younger son's family was living in the same flat with the parents but ate separately.

The family income was about 2000 Yuan RMB. "For the average family, the amount of money in annual month was enough for them, as compared with other families" the wife said.

Health care service utilization

Affordability: Monthly they bought medication for diabetes was about 500 Yuan RMB. Altogether they spent 3000 Yuan for buying drugs.

Difficulty in access to health care services included, particularly to see the doctor and doubtful about the treatment: inconvenience in motion, the helper carried Mr. J on the back, daughter-in-law borrowed a wheel chair; .traffic inconvenience; difficult when standing in line buying and paying for medicine in hospital; difficult in consulting the expert OPD: Lime limited, many patients, and reimbursement difficulty.

Because of mobile difficulty, Mrs. J eagerly hoped that medical workers could visit their home (brought medicine, checked blood sugar, blood pressure...)

Services utilization: including and selecting nearby drug store and private clinics to solve the issues of the medication shortage.

Qualitative content analysis

Care issues

Activities of daily living

He had fall for three times while walking in the morning and hurry to go to the toilet.

He no longer went downstairs since stroke recurrence due to stairs which prevented him from upstairs to downstairs without elevators. His wife mentioned that the difficult care situation is how to dress in and off during winter morning and night.

J's wife has sought a number of alternatives to assist him to eat well. Her menu was as follows: Vegetable as the major component, put some vinegar in vegetable; 1) Cai-tai (a special kind of vegetable); 2) cucumber with meat, 3) food offered in patient's hand; 4) eat while it is hot; 5) potato with 2 eggs (egg white only); 6) soup; 7) dishes renewed every day. Cared him carefully in every possible way. Breakfast: dumplings (bought outside), 10 am some milk powder.

Health problems: medication issues

There were a number of concerns to be dealt with after discharge home. This included diet and eating concerns which was different from the style as the son's family. They wanted to eat early and sleep early in the evening, tasty in slight instead of strong, soft rice instead of solid and etc.

J's wife mentioned that the difficult care situation was how to dress in and off during winter morning and night. "dressing him, is most difficult, why? I am small, while he stands up, he is tall, I have to get his body around dressing up and down, but he is unable to stand for a long while, I almost run and stretch around him...my hand is painful right now due to tendinitis".

The most anxious thing for his wife was to monitor blood sugar (diabetes) rather than hypertension. His wife described: "observing hypertension, it can be checked by blood-pressure meter, anti-hypertension drug can be obtained without much trouble. But diabetes, I have no experience about it, I have to seek help from others, but where can I find it? The hospital is far from my home, he is unable to walk there; is there any hospital staff coming out? No, big hospital, how can they come out and see patient at home?"

At T2 (one month later), they stopped taking any medication even they had no medicine at hands. Mr. Zhu said: "I do not take any anti-hypertension drug, because they have been eaten out...anyhow my pressure is not high, I can feel it, I have no headache, no discomforts...I don't care..."

His wife added: "to be honest, it is certainly difficult for both of us to walk out in a single step. Since he was ill severely this time, I am at a low ebb, my legs was too weak to move and uplift, I have nobody to expect, only wait and wait, if I go to the hospital, there is a long queue to stand, I can't stand for 1-2 hours, so...I am afraid of going to the hospital...I have to go to the drugstore nearby with stick slowly, without stick, I can't walk, I am waned since he is sick, waned and waned...". "Last month, I attempted to bring him to the hospital for check-up, but his leg was paralyzed, unable to move, such as walking stairs and taking taxi, I could not move him even in a single step, he was so tall, walking up and down the stairs and the transportation were so troublesome..."

Her wife mentioned about reimbursing issues of free medical care fee which was just like 'begging food', it was extremely tough to get a piece of reimbursing sheet from their working unit. For each sheet, it covered 30 Yuan RMB to spend. Two will be 60 Yuan. But each time only two pieces can be obtained for the maximum. His wife added: "for the sake these two pieces of 60 Yuan, I had to take a long queue for 2 hours, Oh, stand to death...I can't stand it".

At T4, Mrs. J: "During this period I have been taking care of him, it makes me collapse, if I want to go to hospital, I am not able to walk, my legs are very weak"

Coping resources

Cognitive

Mr. J was suffering from recurrent stroke, his right side of the body was affected, he had to be dependent upon his wife in his personal activities of daily living, such as dressing, transferring, walking etc. But he was still upholding Confucian Scholars "generous towards others, strict towards self", which means that less trouble made towards others, and more self-reliance. Even though very difficult care situation encountered, such as he fell down in the morning while walking, and his wife was unable to move him from the floor, he had to sit on the floor and waited for help. During this period, he comforted his wife by using a sense of humor. His wife described: "he looked at me, and laughed loudly as if nothing was happened....he laughs, at least twice a day...sometimes he burst into laughter and even made me impossible to work anymore".

When they discussed about future and death preparation, the husband showed his great emotion and deep hope attached to his wife's caring beside him and accompanying him while the terminal minutes approaching

him. His wife showed her sympathy and understanding of his husband feelings. She murmured: “Die-die is afraid of my death ahead of him. His biggest wish is hoping me to accompany and send him to the mountains in his final journey”.

However, *‘laughter is the best medicine’ has remained the major theme in their family.* To a sum, the old couple has been caring for each other throughout their lifetime. The old man went down with a stroke and was in hospital for nearly 2 months. During the time, the delicate, ailing old lady went to the hospital every day to take care of him. She felt it her duty to help the old man pull through the difficulties although it was sometimes totally beyond her ability. They formed positive attitude about their problems. They faced the challenge with both courage and care. They know their limitations and make the best of what they can do. Together they carefully plan and arrange their life and activities, making sure that the rest of their life is both joyous and colorful.

Mr. J said: my wife was just being economical. To her, every cent counts. She is not at all particular about her food. She comes to the hospital on foot every day. We all urge her to come by bus or taxi, but she does not listen. She does not care a bit about herself. She is having heart disease and high blood pressure. How could she afford to exhaust herself like this? Moreover, she does not take any medicine. She says she would only take it when the heart attack came. What if it came in the middle of the night? Who will take care of her? There will be nobody around!

J’s wife added: (chuckles smugly) Could you see what he means? What worries him most is that I would leave before him and his biggest wish is that I should be there when he breathes his last. “He always says laughter is the best medicine. At one time, he would burst into loud laughter several times every day. I was scared, thinking that he was developing some kind of mental problem. Then he told me, we should remain optimistic and form a positive attitude about life. Whenever we have trouble, laugh it away!”

Affective

I’s wife was worried about how to continue to take a good of care for her husband, such as medication buying and blood sugar monitoring. On the other hand, Mr. I was worried about his wife’s health. He said she had heart problem, once she suffered from heart attack at night, she could not even breath. “I am worried if she was attacked again at night, there would nobody could provide help even gives her medication to take. When they discussed about future and death preparation, the husband showed his great emotion and deep hope attached to his wife’s caring beside him and accompanying him while the terminal minutes approaching him.

A primary family caregiver described how they made joint efforts to dress on and off, and made an occupied bed for her paresis husband. “Every evening we need to schedule our time go to bed early in order to make the bed and dress the cloth off quickly due to cold weather...I undressed for him, made the bed, after washing we started to sleep, anyway, never after 9pm. I helped him pass water, washed the jug, then helped him to get in bed...We both give up watching TV after 7:30pm in order to get up early in the morning....He is so fine and patient, never loses his temper, and ensures that I have enough time in the morning to pray”.

Laughing toward Life: After discharge home, his wife described multiple difficulties and care issues encountered while providing day-to-day care activities. They are diet and eating concerns, activity limitation, multiple chronic health problems, sleep disturbance, physical discomforts, and access issues to health care services and their psychological fear. From the following vignette, it revealed that how stroke survivor and his wife coped with these multiple care issues through Seeking alternatives to diet and eating difficulties, working together, Rescheduling activities 彼此适应 and Considering alternatives for access to health care services to deal with medication issues, physical discomforts, access difficult issues by using nearby clinics and drug store.

*CT scan: computerized tomography scan.

Statistical analysis and time-series analysis for Mr. J's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. J						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	45	50	50	50	--
4	I-ADL	--	16	15	15	--
5	SEGH	2	3	4	4	--
J's wife						
1	CES-D	0	0	0	0	--
2	SEGH	2.5	2.5	3	3	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. J 70, medical conditions were stable. Besides infarction, he had diabetes (Type II), and history of hypertension, stroke infarction.

Family background

The couple and his son's family lived in the same flat but eat separately. They were modified extended family.

Health care service utilization

Only drug store nearby and one private clinic were used in the past six month. There were multiple difficulties and care issues encountered while providing day-to-day care activities. They are diet and eating concerns, mobilizing, falls for three times, medication concerns, and should pain. Mobilizing Eating and meals. Fatigue for PSP health care concerns.

Stroke-related disability

The Barthel index showed stable over time, but completely dependence upon family members after discharge home.

Care issues

Mrs. J also had two kinds of chronic diseases (coronary heart disease and hypertension). There were 95% free medical care coverage for Mr. J, but extremely difficult in access to health care service due to severe limitation of functional status. Some feelings expressed by the couples, such as worry and fear (death preparation).

Coping resources

Responses to illness by Mr. I and I's wife: holding a Buddhist Belief, acting as a Confucian Scholar, holding a sense of humor, improvising therapeutic measures, such as vinegar (massage, and magnetic therapy), and upholding the Communist ideology.

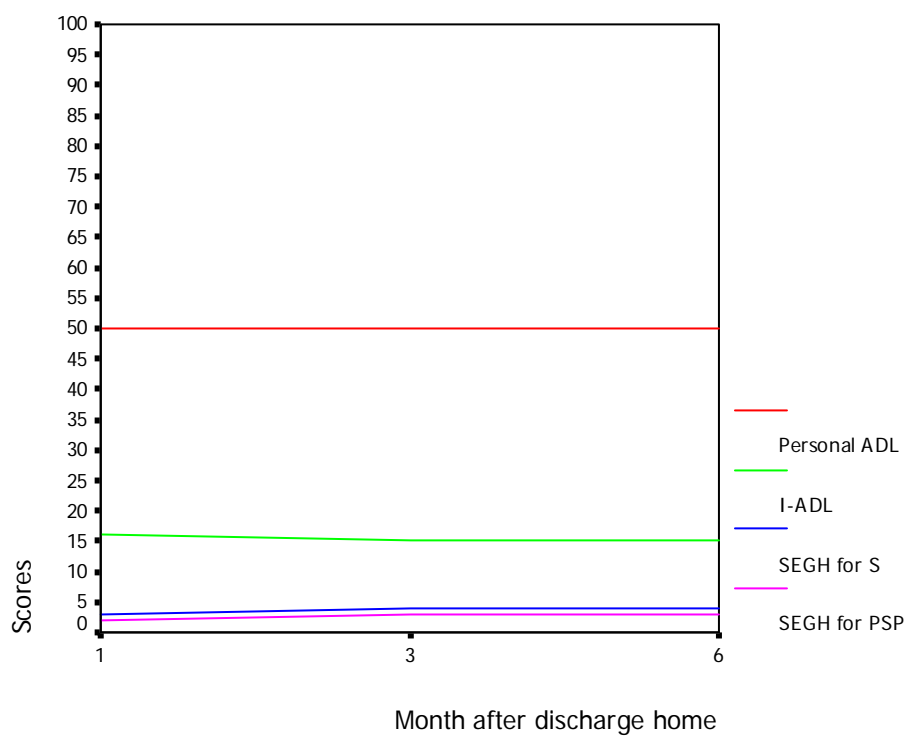
Organization of caring work

They understood each other well and manage multiple care issues such as multiple chronic illness and medication without any complaints over time after discharge home.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family from T2-T4 for Mr. J



Mrs. K's Family

Stroke survivor characteristics

Mrs. K, 65 years. Being hospitalized on July, 20, 2001. Because of right side of face and limbs numbness, weakness, not getting progressively serious, right limb lame when walking, with headache, intermittent dull pain in both temporal region.

PE: 140/80mmHg, consciousness, both pupils equal size, round, light reflex exists, musculus tonus normal, pathological sign (-).

CT scan: Lacunar infarction of left basal nodule region.

Past history: no particular past history..

Diagnosis: Lacunar infarction of left basal nodule region (first-ever stroke), diabetes.

Length of hospital stay: 19 days, 6000 Yuan for hospitalization fare. No free medical care coverage enjoyed. Only 500yuan paid, financial burden heavy

Observation: she was cared by her elder son, lying in bed, able to perform self care. When discharge, he could walk by himself, when going on stairs, he had to hold the bars.

Educational level: high school, retired wage 400 Yuan.

Primary caregiver and family

K's husband, 65 years, high school, retired worker. His retired wage 400 Yuan. He was suffered from stroke infarction in 1995 and admitted to the hospital. Left limb mild lame, BP highest being 180/100, took hypotensive drug intermittently, after stroke his eye sight was subtle, listening ability poor..

The couple lived at the 6th floor with two flats, had 3 sons and 2 daughters living nearby. The parents lived with the 2nd son's family (4 members including two granddaughters, 6 and 9 years old), For safety consideration there was a barrier between the 5th and 6th floor. Mrs. K, after retirement shared the housework with daughter-in-laws. Besides, the old couple would go shopping and prepared meals for the whole family, the relationship between the family members were harmonious. The wage of he old couple was 800 Yuan in total.

Heath care service utilization

After discharge they went to OPD once a month to check blood sugar and got medicine, the 6-month payment was 3000 Yuan (around 500 Yuan a month). She was not satisfied with the service of the hospital after discharge: high payment and poor effect, especially the unhappy conflicts with some medical workers made the whole family unpleasant.

They finally agreed to set up an co-operative activity, every member offered 30 Yuan to the Labor Organization, in case one suffers from some illness, this money can be used.

Qualitative content analysis

Care issues

Activities of daily living

Mrs. K described her contribution to the family with smiling:

She smiled and said: “Every morning we went together shopping, this is very good exercise, can promote strength and lasting ability”

一家人大锅饭 is considered to build family harmony and union., But regarding risk factors associated with diets that are high in fats and salty food. For example, they need education regarding the use of less salty fish and meat which increase the risk of hypertension spicy food regarding stomach ulcer.

Observation: Some leftover was on the dining table, it seemed very salty and hot (chilly), typical Hubei's feature.

Health problems: medication issues

“At present it is not the question of no strength to work, but the feeling is that no motivation to do anything. When at home, I do nothing”.

Mrs. K described her discomforts: “Last night I had tooth pain the whole night, this, see, swollen, they said there's ‘fire’.....My eyes also in trouble, they said it was caused by ‘fire’.” Lead to sleeping disturbance and high blood pressure.

Observation: The need of guidance for diabetes diet: Their view about medicine: a) economic, b) forget c) poisonous. She was reluctant to take drug because of the high price, when not of absolute necessity, she'd not take medicine. So the attitude toward medicine: poisonous and expensive. Only when the feeling of uncomfortable occurs, then taking medicine. That is what their philosophy of taking medicine. The other view point was that: to choose the right medicine, to use cheaper medicine to cure illness, and to take proper medicine to certain disease.

Coping resources

Cognitive

Mrs. K “Me, just like this, everything just letting nature taking its course. for example tooth pain, terribly pain, just neglect it, if it drops off, just let it go....”

When talking about the poor profit of her factory, the uncertainty of her wage, she'd sigh, but she'd treat such situation carelessly, just calmly made this hard nut pass away from normal heart, she said:” Money, more, OK, less, all right, enough for us. What is the definition of ‘enough’? If going to “five-star” to spend money, impossible, what I need is just a quiet and peaceful life!” She thought she was a luck person among the unlucky ones.”

Affective

Mrs. K expressed her worry: “Unhealthy is boring, be ill, all right, but never paralysis, once paralysis, finished!

This would cause burden to my children, because it will need money to cure, need people to help, where on earth can I get money? Yes, I have difficulty, unhappy, but still I think I am lucky!”

Organization of caring work

Life style modification, Less cooking, regular go to market for whole family's life, shopping.

Usually she went to take a walk after 3pm, to do exercises. Since Mrs. K fell ill, two daughter-in-laws cooked in turn. But for a long time, the whole family all got accustomed with Mrs. K's cooking, that was a trouble. From this week, Mrs. K began shopping again and also cooking, but, when cooking it was not easy for her. The old couple paid great attention to every meal, K's husband, though disabled too, walked with difficulty, but every time when going shopping, he was very energetic:” We will cook for more then 10 people, at least 5-10 KG vegetable and 2 KG meat. Because we are laborers for the whole life, offer love to our children gives us very great satisfaction and happiness. ” “he continued: about taking medicine, this person said this drug good, OK, that said that drug good. OK.....we have five children, they are all very kind, if one offers a little respect to us, then I will be too busy to accept their love, and everyday I'll have much love to enjoy”.

Field notes

Exploring the reason why it was so difficult when I visited their home, full of doubt and suspicion?

Observation: they talked short and little, just question and answer, full of suspicion. They tried to make clear the visitor's identity and purpose. After repeated explanation, they still repeatedly asked. When asking for the date of next visit, they tried to avoid and made excuse { we are very busy, we can not accept you.....} It was also because they were deeply impressed by the poor service in the hospital (forcing them to shorten finger nails and charge them unfairly, changing bed sheets by asking to pay, dropping down the infusion bottle...they thought: "why, in hospital such bad service, why suddenly come to my home and show such a kindness, just incredible!"

The last reason was that they were too afraid of the salesmen, they thought the visitor might force them to buy sphygmomanometer or drugs. After several visits they made clear of the purpose of my visits. They told me the above thoughts and asked to understand their situation and their suspicions.

Statistical analysis and time-series analysis for Mrs. K's family

Category	Scales	T1 *	T2*	T3*	T4*	Others
Mrs. K						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	100	100	100	100	--
4	I-ADL	--	0	0	0	--
5	SEGH	5	6	4	6	--
K's husband						
1	CES-D	0	0	0	0	--
2	SEGH	5	5	5	6	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. K, 65, medical condition was stable, besides infarction, she had hypertension, and diabetes.

Family background

They were extended family: the couple was living with two daughters, and one son's family. There were no free medical care coverage, and financial burden for medical care was heavy

Health care service utilization

Only OPD used after discharge home for prescribed medication. Issues included Diet and nutrition, Mobility and exercises (feeling fatigue while walking), sleeping disturbance due to toothache, and medication concerns. Fatigue, Toothache and eye swollen, Medication concerns

Stroke-related disability

Barthel index showed improvement over time, independent living at home and in the community.

Care issues

Meal and eating preparation, teeth ache, medication concerns.

Coping resources

Thinking dominated by the couple were very positive.

- a) Children's acting as their prescribed role: filial piety,
- b) Letting nature taking its course
- c) On the other hand, some feelings expressed by them as worry for stroke recurrence

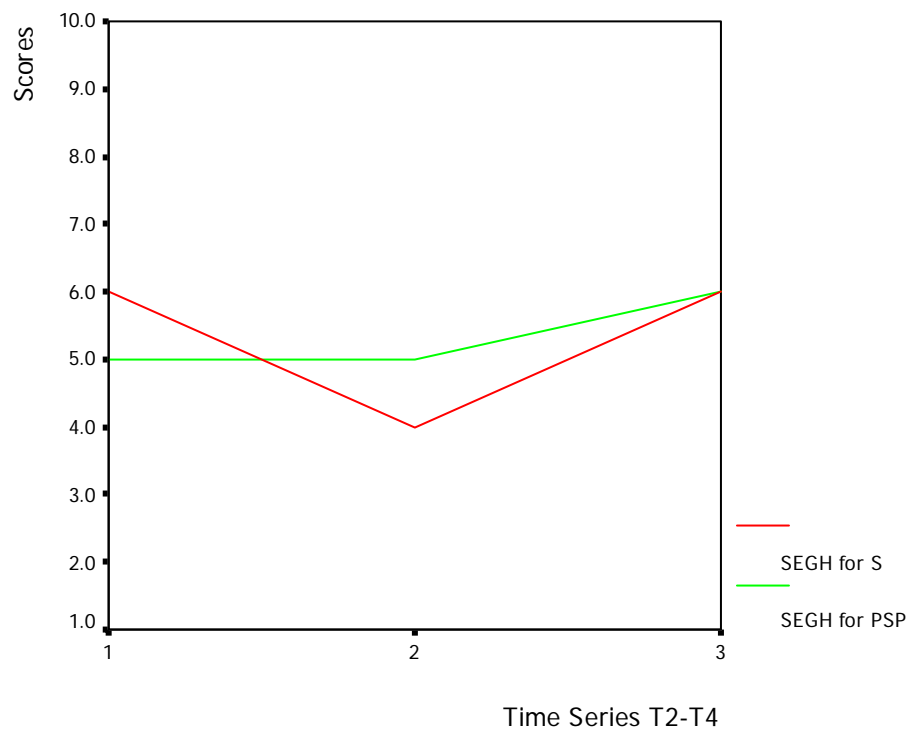
Organization of caring work

Ordinary and common life is real life. Wife sings after husband, the elderly kindness and the younger respect (the younger behave after the example of the elderly). Sons and grandsons forming a sweet home, being a happy-go-lucky elderly.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mrs. K



Mr. L's Family

Stroke survivor characteristics

Mr. L: 55 years. Being hospitalized on July 16, 2001. Because of 5 days ago, sudden attack of right limb numbness, unable to walk, with headache (frontal and temporal region), nausea, vomiting, sweating. No unconsciousness, no cough when drinking, no aphasia, convulsion, incontinence and motion limitation.

PE: BP150/80 mmHg, consciousness, neck soft, both pupils equal size and round, heart and lungs normal, heart beat regular, abdomen soft. Musculus tonus of left limbs: upper limb grade V, lower limb V. Tongue extension, pointed left, both knee reflex mild weakened, left Babinski (+). No edema in lower limbs. ECG: Axis normal, low voltage, myo-ischemia.

CT scan: lacunar infarction in both basal nodular and parietal deep white substance region.

Past history: Schistomiasis cured, hypertension for 3 years, no hypotensive drug taken, "migraine" for more than 10 years (not treated).

Diagnosis: stroke infarction (first-ever).

Length of hospital stay: 11 days. 4000 Yuan for hospitalization fare, 80% free medical care fare.

Educational level: college, retired carder, and retired wage was about 600 Yuan. He was just retired this year.

Primary caregiver and family

L's wife, 55 years-old, high school, retired wage 600 Yuan, family monthly income 1200 Yuan. They had two daughters and two grandsons.

They lived in fifth floor, the younger daughter's family lived together with them.

Health care service utilization

In the first week, The internal medicine department of the NO 3 Hospital gave him the last "blood dilution treatment", 400 Yuan for 1 time, 1200 Yuan in total. In the first month after discharge, the medical fare was within 10 Yuan. In the 6th month paid 1000 Yuan to the Traditional medical department of the Community OPD. The total fare within 6 months 3210 Yuan (1200+10+1000=3210).

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

While walking, feel fatigue.

Multiple health problems

After discharge he consulted the OPD doctor in hospital, the doctor told him, at least 200 Yuan of medicine was needed, he said:” medical fare is a heavy burden to me”. He had much medicine at home, sometimes he took medicine blindly. Some were cheap, some, expensive. “Somebody said, for hypertension, at first, good medicine should be taken. Now, the doctor of his factory asked him to take cheaper medicine. Oh, I absolutely have no idea about what medicine to be taken.”

Coping resources

Cognitive

Mr. L was born in 1949, and was built up from the Party school, factory, he was a “middle-level cadre”. On the background of such a history, he has never thought of after retirement, when falling ill, he even was not afford to pay for his treatment, this was absolutely unacceptable. But after repeatedly thinking and learning, he, at last found his proper position, more important was that he has mastered the way of how to adjust himself and solve the problem in the present reality so as to happily and peacefully shared his late life with his beloved family.

He got a way of cooking “vinegar egg” from the newspaper, it was said this way could soften the blood vessel, he described the way of cooking in details(with honey, put in vinegar for 1 week, crack down the shell of the egg...)After eating and drinking this vinegar-egg, he would go to do exercises and sent a bottle to his daughter.

Affective

What I need most? How about my illness, to what extent is my disease going to be? How about the recovery? What treatment do I need? Generally speaking, patient has to follow what the doctor says, then which doctor shall I trust? The No 3 Hospital’s, or our factory’s clinics’, or who else???

Organization of caring work

Establishing a better relationship with daughter and wife: “Now I am paying back the debt I owed them, because when I were young I didn’t take good care of them!”

Mr. L was a person who was good at thinking and had independent view point. Although he was unsatisfied and had much contradicting thinking, he often could release the pressure and maintained a optimistic mood. He said:” I think, taking medicine might not cause much side effect, economically no loss, no great pain in my spirit, so I have no burden.”

Mr. L could actively arrange his time, made life colorful, he loved football, he always take a walk to the football ground, and also went to the kindergarten to send and meet his grandson, enjoyed sunshine, found pleasure in reading novel. At weekends, with his friends, he went fishing in the suburbs, he thought his life was very enjoyable.

Statistical analysis and time-series analysis for Mr. L’s family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. L						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	100	100	100	100	--
4	I-ADL	--	0	0	0	--
5	SEGH	5	6	4	6	--
L’s wife						
1	CES-D	0	0	0	0	--
2	SEGH	5	6	6	6	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. L, 55, medical conditions were severe, the blood pressure was high (180/90mmHg); besides infarction, she had coronary heart disease, hypertension, several times of stroke recurrence, asthma, diabetes. Mrs. L was the primary caregiver.

Family background

The couple was living together, their second daughter's family lived with them. They were extended family. Mr. L took care of grandson. There were 80-90% free medical care coverage, but financial burden was still very high; they were extended family.

Health care service utilization

A number of health care services had been used.

Stroke-related disability

Barthel index showed improvement over time, but completely dependence upon family members after discharge home. After one month, he had depression. Meanwhile, her self evaluation of general health was remained low (2), and his wife gave the scores of his evaluation of general health as 4 over time.

Care issues

Care issues including constipation, mobilizing (walking), sleeping disturbance due to fear of death, physical discomforts (leg pain and numbness, swollen and skin rash) and medication concerns.

Coping resources

Mr. L was very positive. He used to deal with hassles:

- a) Improvising therapeutic measures
- b) Upholding the communist ideology
- c) Fulfilling family obligation (spousal responsibility)
- d) upholding the principle of self-reliance
- e) He also expressed uncertainty for future, particularly fear of stroke recurrence.

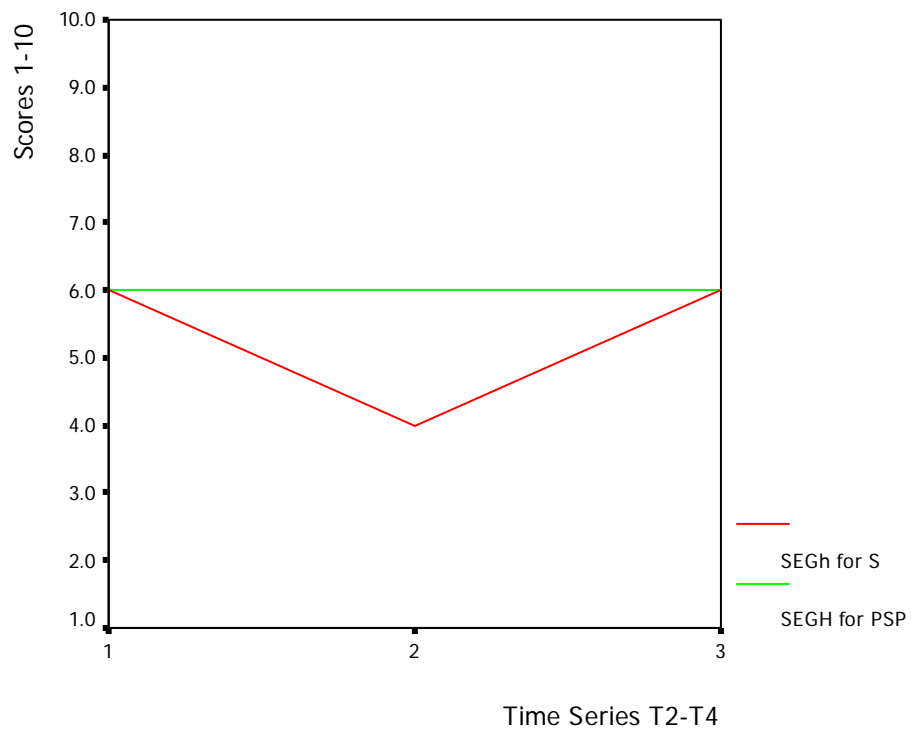
Organization of caring work

Wife sings after husband, self-adjustment, children's filial piety, raising grandchildren.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mr. L



Mr. M's Family

Stroke survivor characteristics

Mr. M, 65 years. Came to emergency department and being hospitalized on June 12, 2001. Because of a sudden attack of left-limb weakness, unstable and fell down, his left hand had difficulty in holding things, with dizziness and temporary aphasia, no headache, palpitation, chest distress, tremor, incontinence and limb numbness.

PE: BP195/120mmHg; Consciousness, both pupils 2.5mm, light reflex sensitive. Superficial sensation of left limb decreased, muscular tonus IV, pathological sign (+).

CT scan: Lacunar cerebral infarction.

Past history: "Cerebral infarction", "hypertension". "Coronary heart disease". Blood pressure usually 170-180/90 mmHg, the highest being 170/130mmHg, hypertensive drug has been used.

Diagnosis: Acute cerebral infarction, Hypertension(delayed type)III, coronary heart disease, chronic renal disorder, azotemia, benign renal vessel sclerosis.

Length of hospital stay: 37 days, 10,000 Yuan, enjoying free medical care coverage.

Observation: Restless, appetite all right, passing stool and urine normal, sleeping all right.

His educational level: high school, his monthly retired wage 600 Yuan.

Primary caregiver and family

Mrs. M, 65, no formal education received, monthly retired income 200 Yuan.

The couple had five children (four sons and one daughter), living in their own flat and with two sons. One was in the third floor and the other in the second floor.

Observation: Mrs. M. seemed never to be worried, always satisfied, used to be taken care of others, and being comfortable, and peaceful smiling. She was diligent, cooking around the stove, bending and working almost without rest. Besides caring her husband, she also cooked for the whole family, working hard and endure hardships, regardless of criticism.

The couple's Living surrounding was dark, poor equipped. They slept in a short double bed.

Health care service utilization

Prescribed medication fee in each month was about 650 Yuan (Mean) in OPD of a general hospital. Visiting hospital usually twice a month, 88% could be reimbursed by the working unit. He was unable to walk, her two sons carried him in turn on the way to hospital.

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

Mr. M described his fatigue while walking and standing. And only soft food can be taken due to false teeth and he was unable to bite. He said he did not put on the false teeth since it was uncomfortable.

Mrs. M Three days after discharge, while pouring boiled water, Mrs. M accidentally poured on her right leg, could not walk, it added hardship to the old couple. After that Mr. M has fallen down three times at home.

Health problems

Many kinds of medication, but he could administer by himself.

Mr. M frequently feeling short breath. He is out of breath, always like that, always. Previously also so, not feeling any difference. Constipation, 3-4 days once.

Coping resources

Cognitive

Mr. M had a full of wit and humor)

Humor 1: While asking him how about the effect of tonic? He immediately and thoughtlessly spoke out and imitated a sentence from the advertisement “Hao-wei-dao, hao-jing-shen-na! (“Tasty and in high spirits”)

Humor 2: When Mrs. M blamed him for not swearing off smoking in the past, and during hospitalization, he hid in a corner smoking. At this moment, Mr. M shouted and replied: “Oh, no more, scare of death, no more!”, his words aroused the laughter of his family and he himself was pleased too.

His son was accompanying him to the hospital follow-up; bathing him during summer. Mr. M:” My younger son driven for his boss, always touring. Others gave them much tonic as gifts, Hm-hm!” See, what a proud expression he showed. Mr. M faced with his illness peacefully.

Affective

Son expressed his concerns and worry: according to his present situation, if he insisted doing exercises, would he be able to walk by himself or walking independently?”

Organization of caring work

During the first visit, Mrs. M was busy with housework in the kitchen, bending, and her face was full of wrinkles, and her tooth was almost all dropped off. But she looked kind and happy while greeting me, and hurried to serve me a cup of drink. She said, “It is hot, take it, this is not bought by me, it is my son bringing back from outside”. Mr. M was lying down on bed, quiet but peaceful.

At the second time, Mrs. M was accidentally burned by hot water. The burned area was wrapped by thick white gauze, she looked sad. The couple was lying in bed.

At the third month, Mrs. M was able to walk smoothly, and again busy in and out. She bought a bottle of soft drink for me on purpose.

At the sixth month, there were more people at home. They were daughter-in-law, the second son, the youngest daughter and her newborn baby, Mr. M. was also sitting in front of the door, with 3 to 4 neighbors to chat with each other. While Mrs. M was washing clothes, she was talking to me delightfully.

Statistical analysis and time-series analysis for Mr. M's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. M						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	45	45	55	55	--
4	I-ADL	--	21	21	21	--
5	SEGH	2	3	3	3	--
M's wife						
1	CES-D	0	0	0	0	--
2	SEGH	4	3	4	4	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. M, 65, medical condition was table, besides infarction, he had coronary heart disease, hypertension.

Family background

The couple was living with two sons. They were extended family. And the big family (8 persons) came back home to have dinner every day. There was 90% free medical care coverage. They had an extended family.

Health care service utilization

Only OPD of general hospital service has been used after discharge home. Issues included constipation, mobilizing (walking), safety issues (i.e., Mr. M falls several times and Mrs. M was burned by boiling water); physical discomforts (wheeze, cough, dysphasia, fatigue) and medication concerns.

Stroke-related disability

Barthel index showed improvement over time, but completely dependent upon family members after discharge home. After one month, he had depression. Meanwhile, her self evaluation of general health remained low (2), and his wife gave the scores of his evaluation of general health as 4 over time.

Care issues

Eating and meal preparation, mobility, safety, caregiver's need.

Coping resources

Responses to illness by Mr. M:

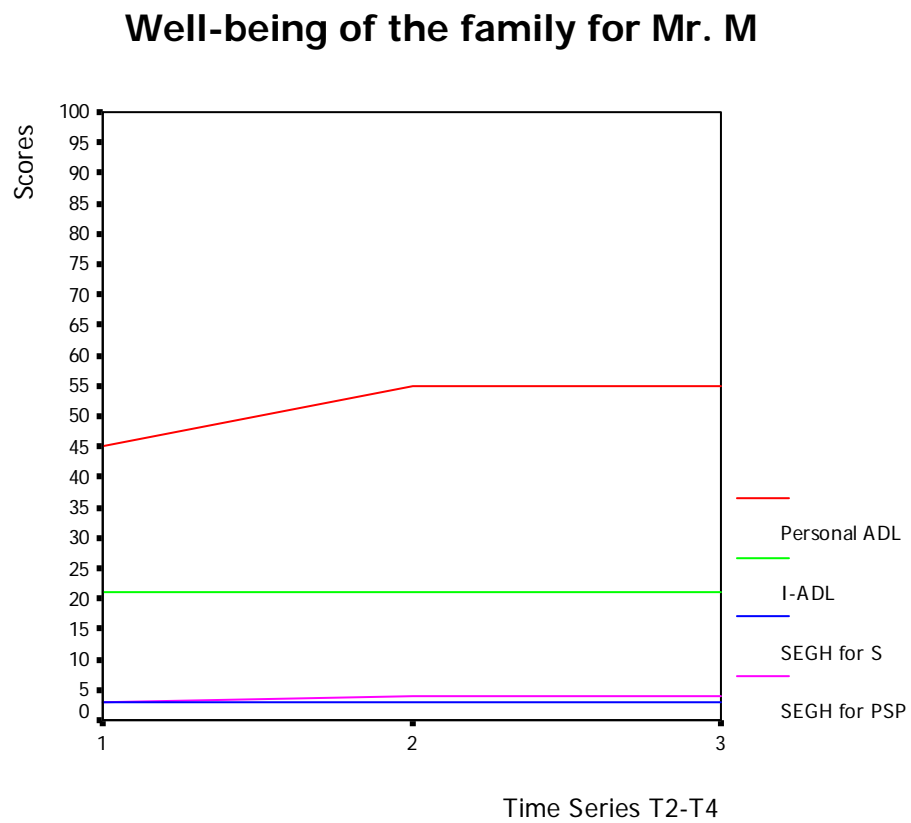
- having a sense of humor
- naturalist: complying with nature
- Sons acting as the prescribed role
- The couple also expressed anxiety, worry about re-hospitalization, fear of stroke recurrence.

Organization of caring work

A traditional Chinese woman, enduring hardships regardless of criticism, caring her husband is her responsibility.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Mrs. N's Family

Stroke survivor characteristics

Mrs. N, 69 Years. Being hospitalized on Dec. 11., 2001. Because of a sudden attack of asaphia for 3 hours, with weakness of right limb, right arm unable to hold things, right lower limb unable to stand, chest distress and pain in chest.

PE: BP150/90mmHg, consciousness, restless, with no headache. Left upper limb V, left lower limb IV. Right lower limb mild paralysis. Blood lipid LDL-Ch 2.07ml/L (3.1-3.6); ECG: Sinus rate, myo-ischemia.

CT scan: Multiple lacunar infarction, softened foci in left caudatus caput, mild cerebral vessel sclerosis, brain atrophy.

Past history: Hypertension for 20 years, (reached 180/120 mmHg) used hypotensive drug, BP controlled around 150/90mmHg. Two cerebralvascular accidents (1998, 2001), coronary heart disease for more than 10 years (angina pectoris type). Lumbar hypertrophy for 3 years.

Diagnosis: Multiple lacunar infarction, hypertension grade 3, high risk, coronary heart disease, angina pectoris.

Length of hospital stay: 9 days, 3000 Yuan.

Educational level: no formal education received, retired worker, monthly retired wage 400 Yuan.

Primary caregiver and family

N's husband: 70 years, no formal education received, retired worker, talkative.

The couple was living together, in the second floor. They had 4 sons, all married, living outside, they were busy, seldom came home. The old couple was accustomed with this type of quiet, careless and casual life. The house was assigned by the working unit. Mr. N had hypertension, the highest being 180/100 mmHg, used drug intermittently, sight subtle, prostata hypertrophy, frequent noturia causing uncomfortable.

Family monthly income 800 Yuan. They both had free-medical care.

Heath care service utilization

Only clinic affiliated to her working unit has been used after discharge home for prescribing simple medication and managing blood pressure. Difficult in walking, therefore difficult consulting medical service.

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

The couple expressed medical payment and effect of treatment, and leg pain and difficult in walking outside and downstairs.

Health problems

The couple could not recognize the words from the bottle of medications, sometimes confused by drugs. They distinguished the drugs according to color or shape of medications. Mr. N used to feel headache and difficult to pass urine. In this case, he said he had to lie on bed and did nothing.

Coping resources

Cognitive

Taking the nature to its own course, Tradition value but without asking for return, The couple relied on each other and helped each other in need, lived a peaceful and quiet life.

Affective

Worry: high medication fee, and Mr. N's health

Fear of further stroke recurrence.

Organization of caring work

Mrs. N was Very kind, slow motion, when visitor came, she would politely gave a stool, served water, then sat aside, listened to quietly, seldom spoke, mainly described by her husband, she only added a little or nod showing agreement.

At the sixth month after discharge, Mr. N said he has been admitted to the hospital for 10 days due to kidney problems. Now he has improved but he was still worried about the future deterioration of both of them.

Statistical analysis and time-series analysis for Mrs. N's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mrs. N						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	45	70	95	95	--
4	I-ADL	--	25	24	26	--
5	SEGH	2	3	3	4	--
N's husband						
1	CES-D	0	0	0	0	--
2	SEGH	5	5	5	4	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. N, 69, medical condition was stable, this was the second stroke (infarction). She also had coronary heart disease and hypertension, and hucklebone nerve pain. (sciatica). Mr. N, 70, had chronic kidney disease and hypertension.

Family background

The couple was living together, they had three sons, but lived separately. This was a nuclear family.

Health care service utilization

Only clinic was used after discharge home for prescribed medication to manage hypertension.

Stroke-related disability

Barthel index showed improvement over time, but completely dependent upon family members after discharge home.

Care issues

Care issues included mobilizing (walking), physical discomforts (leg pain and numbness) and medication concerns.

Coping resources

- a) Self-reliance
- b) Taking its nature to its course
- c) But also expressed worried about financial stress, and fear of stroke recurrence.

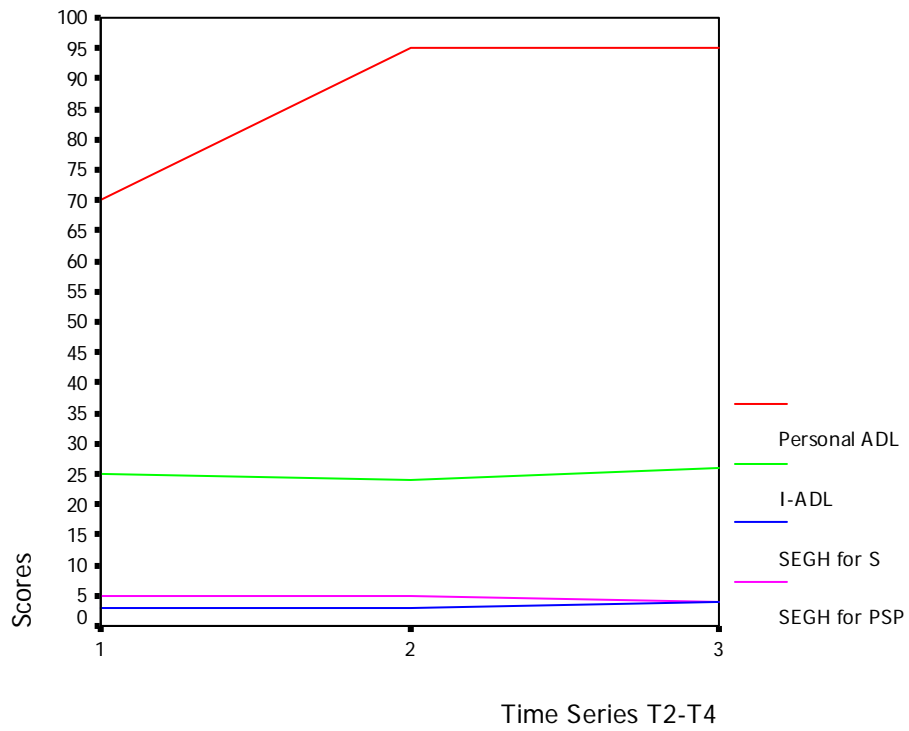
Organization of caring work

They help and support each other intimately over time.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mrs. N



Mrs. O's Family

Stroke survivor characteristics

Mrs. 76 years. Being hospitalized on Oct. 28, 2001. Because of dizziness, headache for one week, with subtle sight and weakness of right limb for 6 hours.

PE: Bp190/100mmHg, Consciousness, both pupils equal size, 2mm, light reflex sensitive, asaphia, whistles in both lungs. Musculus tonus: right limb IV, left limb, V.

CT scan: Lacunar infarction in left radiation crown region, left thalamus and left cerebellum.

Past history: Diabetes for more than 10 years, no special treatment. Hypertension, length and treatment unknown. Cough, sputum and asthma: length and treatment unknown.

Diagnosis: Multiple lacunar infarction, chronic asthmatic bronchitis, hypertension, diabetes Type II.

Length of hospital stay: 13 days, hospital payment, 6000 Yuan.

Observation: Four daughters took care in turn, mainly the second daughter, the 3rd sending meals, the oldest and youngest at night in turn. Rescued in emergency room for 1 week, urinary catheter was on, painful expression, moaned and groaned with pain.

Her educational level: no formal education received, no fixed job (housewife).

Primary caregiver and family

O's second daughter, 37 years, high school, laid-off worker. She owns a house, has one 4 years old son.

O's husband, 76 years, no formal work and education.

The couple was living with the second daughter's family. Four daughters provide financial support for their parents. They were extended family.

Health care service utilization

- a) using drug store regularly
- b) occasional OPD selective use;

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

The daughter said her mother did wash her face, take bath, even walk besides the bed.

Health problems

Mrs. O felt uncomfortable and said her abdomen was extremely distension. The daughter used to urge her mother to take medication (for diabetes), but Mrs. O said after taking medications, she felt mouth dry bad. Then they had to give up.

Coping resources

Cognitive

Mrs. O felt guilty for the family due to spending so much money for her hospitalization and a big burden on her daughters. She used to say she would prefer dying rather than alive. Thus money could be saved.

Affective

During the stay in the hospital, Mrs. O fear of staying heavily. She used to say she had seen a dead man while falling asleep. She insisted on leaving for home at once.

The daughter expressed her worries and fear of her mother's condition when she refused to eat and just lied on bed without communication at all.

Mrs. O frequently expressed her guilty for her nephew's death that was she should die instead of his. She said: "I would like to die and save his life's back, I want to die..."

Organization of caring work

Mrs. O is a 76-year-old housewife. Illiterate and jobless, she and her husband depend on their daughters for a living. They have 4 daughters and always regret being unable to bear a son to continue the family line. To fulfill their wish, they fostered their nephew as their stepson. Poverty-stricken, Mrs. O has been in poor health and suffering from various chronic diseases. Then, her health began to deteriorate and had to be hospitalized. While she was in the hospital, her nephew was involved in a street fight and was stabbed to death. The sad news completely carried her away and worsened her illness. She had lost all hopes of life and buried herself deep in desperate despair. Moreover, she had somehow developed the strange thought that it was she that in some way caused her nephew's death, she felt guilty, and she should die for him. The guilty notion only added to her worsening health and threw her into the bitter valley of self-accusation. As a result, she refused remarkably to be looked after, and said: "let me die, don't waste money and treat me anymore, I don't want to live in this world any longer". At the Time 4 interview, under the careful tending of her daughters, Mrs. O bit by bit regained confidence, recovered from her illness and lit up once again the flame of life. She has finally realized that in modern times son or daughter makes no difference and what matters is that they should have a loving heart. The daughter said: 'she is my Mum, she has devoted all her life to take care of us, four daughters, taking good care of her is my responsibility and I will never give up!'

Statistical analysis and time-series analysis for Mrs. O's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mrs. O						
1	SPMSQ	0	--	--	--	--
2.	CES-D	27	13	15	0	--
3	ADLs	45	60	65	85	--
4	I-ADL	--	25	24	26	--
5	SEGH	2	3	3	4	--
O's daughter						
1	CES-D	0	0	0	0	--
2	SEGH	5	5	5	5	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mrs. O: 76 years old, medical condition was severe, the blood pressure was high (180/90mmHg); besides infarction, she had hypertension and diabetes.

Family background

The couple was living with their second daughter's family. There was no free medical care coverage, financial burden was still very high; they have an extended family.

Health care service utilization

No any health care service has been used after discharge home.

Stroke-related disability

Barthel index showed improvement over time, but completely dependent upon family members after discharge home. After immediately discharge home, she had depression. Meanwhile, her self evaluation of general health remained low (2). After three months discharge home, her depression was improved and scores of SEGH was improved (4). And her daughter gave the scores of her evaluation of general health as 4 over time.

Care issues

Care issues included constipation, mobilizing (walking), sleeping disturbance due to fear of death, physical discomforts (distention) and medication concerns.

Coping resources

Thinking dominated by her was perceived unbearable burden of illness and being treated unfairly by heaven. Negative affects (emotional disturbance) overwhelmed by guilty, and fear to death.

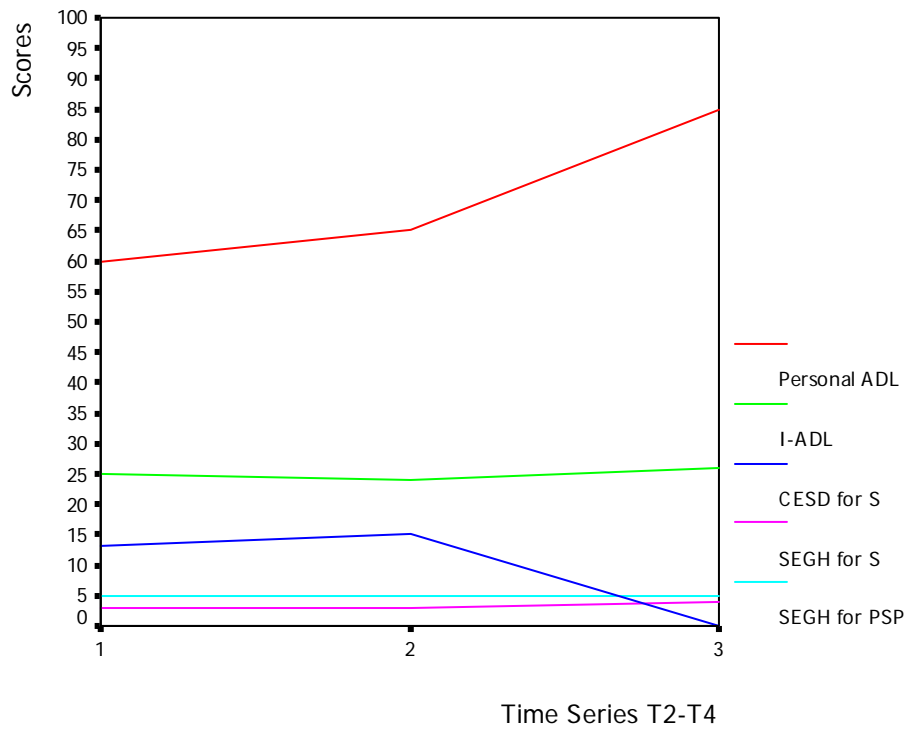
Organization of caring work

Her daughters took the whole responsibilities to take care of the mother, finally Mrs. O was moved by her daughters' filial piety.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mrs. O



Mr. P's Family

Stroke survivor characteristics

Mr. P, 66 years old. Being hospitalized on Dec. 4, 2001. Because of headache, with weakness of limbs for 5 hours. Nausea, vomiting 4 times (stomach content), unable to stand, sweating. No unconsciousness, no incontinence. Consulting emergency department '120' admitted to the hospital.

PE: conscious and clear, in low spirit, both pupils equal size, diameter:3mm, light reflex sensitive, BP 150/90mmHg, speaking clear. Muscular tonus of left limbs IV, right limbs V. Mild paralysis test (+), pathological sign (-). Lab exam: LDC 1.8mmol/L (3.1-3.6), lipid-carrier protein 0.96g/L (1.010-1.6), HDC 0.23mmol/L (0.34-0.7), ECG: sinus rhythm, left ventricle hypertrophy and damage.

CT scan: 1) Multiple lacunar infarction of right basal nodule region and parietal lobe, and 2) Soften foci in right external capsule.

Past history: hypertension for more than 10 years, the highest reached 240/120mmHg, oral reserpine and NI-fuda (hypotensive drug), BP usually being 140/90mmHg. Cerebral hemorrhage (1991.4), 10 years (right thalamus hemorrhage), cerebral infarction (2000.6), 1 year (right side), right limbs mild paralysis, able to walk and manage daily activity. Diabetes for more than 10 years, oral melbinum etc.

Diagnosis: Recurrent cerebral infarction, hypertension, grade II, extremely high risk, diabetes grade II, old cerebral infarction, coronary heart disease.

Length of hospital stay: 21 days, 3000 Yuan for hospitalization fare, 90% free medical coverage.

Observation: he was cared by his sister-in-law during day time. His son came at night. His wife and daughter paid regular visit during hospital stay.

Educational background: Senior high school, senior technician (piano).

Primary caregiver and family

P's wife, 66 years. She was graduated from Music Academy in the 1960s. the couple lived at ground floor, they had one son (piano technician too), one daughter (newspaper correspondent), both lived nearby.

The old couple lived with their grandson (8 years old). Because the son was very busy, so the grandparents took over the overall responsibility of raising their grandson, such as: meals, sending him to school. The son and daughter came back for lunch everyday for lunch, the whole family cared each other and were living harmoniously.

Health service utilization

Drug store was frequently used. They expressed the reason why not being hospitalized was that they didn't have enough money, only very limited salary, and free medical care coverage also very limited.

Qualitative content analysis

Care issues

Activities of daily living

Mr. P was reluctant to use stick in the initial time after discharge home, his wife encouraged him to use it since the stick would help him to prevent from falling while he was alone going outside. Mrs. P said “Oh, look, Shun Zhong Shang (Previous President of China, a famous leader) had used to stick in taking a picture, well, how handsome he was, try it!”

Health problems

Mr. P was very cautious to his diet since he had a long time experience of diabetes, Mrs. P described his meal while using a small bowl of rice, “it is a pity for him to control everything he takes”. Mr. P added: “I am hungry sometimes, then I will take salty biscuit with sodium or have a cup of soya bean milk with no sugar”.

The couple used to prepare various kinds of medications in advance from the drug store by themselves. They thought it would be cheaper than those obtained from the hospital.

Coping resources

Cognitive

The couple was very proud of their self help approach to control Mr. P’s multiple chronic illness for over ten years. They used to prescribe medications and therapeutic regime by themselves, like monitoring physical changes through electronic blood pressure thermometer, and blood sugar by using sugar check machine. They had their own diet and drug regime everyday and record the alternation in the notebook. In addition, they also promoted their views and shared with neighbors when the person has same problems like hypertension and diabetes. They guided people living around and provide help and support to those in need.

Affective

Worry about financial strain.

Organization of caring work

Mr. P has experienced hospitalization for 6 times. For every experience, he could remember clearly. The couple had a special notebook to record the history and medication used, as well as the result from Lab examination were well recorded and kept at hand. The history and the illness process were written as following:

- a) April 20, 1991, cerebral hemorrhage, the first attack;
- b) August 28, 1996, stayed in hospital for 34 days, coronary heart disease;
- c) September 30- November 9, 41 days, hypertension and coronary heart disease
- d) July 2-August 15, small-scaled infarction (exhausted during decoration of housing), 44 days.
- e) October 29-November 28,2001, Insulin treatment, 30 days, (diabetes, coronary heart disease)

Field notes

The couple expressed their dissatisfaction with medical staff and nursing professionals when answering their questions. A nurse once said: “You have pain today, it will be all right tomorrow” another doctor said when they discussed about their conditions whether it would be necessary to give blood transfusion. He said “If blood transfusion is needed, well, we, doctors have no way to help!”. They thought medical professionals did not pay enough attention to their concerns while providing care during hospital stay.

Statistical analysis and time-series analysis for Mr. P's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. P						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	90	95	100	100	--
4	I-ADL	0	5	5	5	--
5	SEGH	3	4	4	5	--
P's wife						
1	CES-D	0	0	0	0	--
2	SEGH	5	5	5	5	--
* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.						

Summary of the case

Prognosis

Mr. P, 66, medical condition was stable, blood sugar was high, monitored by himself. Besides infarction, he also had coronary heart disease, hypertension, several times of stroke recurrence and diabetes.

Family background

The couple was living with their grandson, having lunch with son and daughter. They were modified nuclear family.

Health care service utilization

Drug store was used frequently after discharge home.

Stroke-related disability

Barthel index showed improvement over time, and became independent upon family members after discharge home. Emotional status was stable and remained normal.

Care issues

Care issues included mobilizing (fatigue), diet and meal, physical discomforts (leg pain and numbness) and medication concerns.

Coping resources

Responses to illness: Thinking dominated by the family:

- a) Acting as a folk healer
- b) Letting nature as its nature
- c) Having a sense of humor
- d) Improvising therapeutic measures
- e) Upholding the principle of self-reliance
- f) They also expressed worry about financial strain.

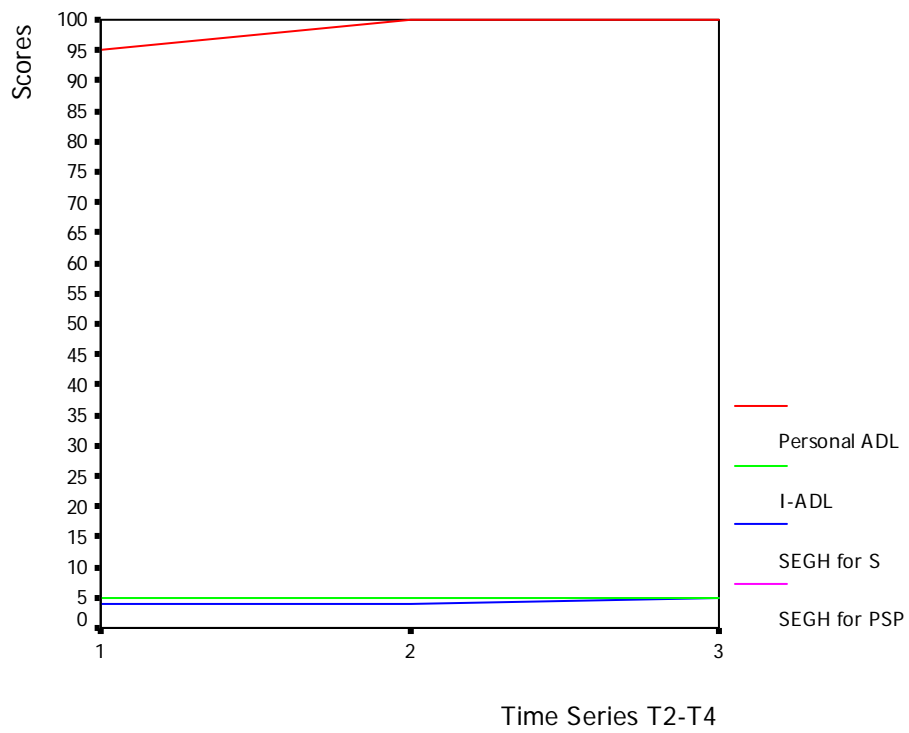
Organization of caring work

The wife sang after the husband, living harmoniously.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mr. P



Mr. Q's Family

Stroke survivor characteristics

Mr. Q: 82-year-old. Being hospitalized on Jan. 2, 2002, because of Headache, sense of nausea and vomiting 2 days before admission.

PE: BP 150/100mmHg, clear, both pupils equal size, D=3mm. Light reflex sensitive, speaking clear,; muscular tonus of left side grade V, left upper limbs grade V; Babinski's sign (-), ECG: sinus rhythm, change of T wave.

CT scan: Right lateral ventricle with low-density foci, the cause might be the absorption of original brain bleeding and softening. Possible infarction of the posterior branch of internal capsula and the left caudate nodule. Brain atrophy.

Past history: hypertension for many years, usually oral hypotensive drugs were taken, blood pressure was basically under control. Stroke history, "brain bleeding" in 1998, no obvious paralysis left. No coronary heart disease and diabetes history.

Diagnosis: Cerebral infarction, hypertension 3rd stage.

Length of hospital stay: 18 days, 10,000 Yuan. Enjoying 100% free medical coverage.

Observation: he was cared by his relatives.

His education level: no formal school attended, (illiteracy). Monthly retired wage was 1400 Yuan.

Before retirement he was the chairman of the Workers' Federation of the Match Factory, in the 1930s (anti-japanese war) he was an old soldier, therefore he enjoyed special treatment after retirement, he was healthy before stroke, poor sight, listening ability all right.

Primary caregiver and family

The couple lived at 3rd floor, had two sons. In order to maintain the balance between two sons' families, the couple decided to live with two sons' in turn (every six months the couple would move from one son's family to the other). Two sons were laid-off, they shared a taxi. The family members were living harmoniously.

The old couple had retired wage, every month they gave the one son's family a certain amount of money while living together (700 yuan/month). Mrs. Q obeyed the arrangement of the husband.

Mrs. Q: 80 years old. No formal school attended, a retired worker, her health status was poor, caught cold easily, heart disease. Both of the old couple had no religious belief.

Health care service utilization

OPD in the hospital for prescribed medication to manage hypertension. Once a month.

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

Mr. Q would go downstairs everyday for walking and communicating with neighbors.

Health problems

Mr. Q's son would help him bring medications back each month from OPD. Mr. Q administered his medications regular, but used to ask questions about how to properly use them since he had a long time to take medications and concerned with side effects since discharge home.

Coping resources

Cognitive

Mr. Q was a red Army when he was 16 years old. The long period of hardship furnace, he was very satisfied with current life and situation, and be proud of leadership of community party.

Affective

Fear of stroke recurrence.

Organization of caring work

The couple was very easy going and friendly. They were living with two sons' family alternatively (six months in younger son's family, another six months in older son's family, in order to be fair (offer financial support to two sons since both of them were laid-off workers, and shared a taxi to drive by them. For example, one was on duty during the day time, and the other on night shift.

Statistical analysis and time-series analysis for Mr. Q's family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. Q						
1	SPMSQ	0	--	--	--	--
2.	CES-D	0	0	0	0	--
3	ADLs	100	100	100	100	--
4	I-ADL	--	13	12	11	--
5	SEGH	4	4	4	4	--
Q's wife						
1	CES-D	0	0	0	0	--
2	SEGH	3	4	4	4	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. Q, 82, medical conditions were stable, this was the second stroke (infarction).

Family background

The couple was living with sons' families alternatively. They were extended family.

Health care service utilization

Only OPD used after discharge home

Stroke-related disability

Barthel index showed improvement over time, but completely dependent upon family members after discharge home. After one month, he had depression. Meanwhile, her self-evaluation of general health remained low (2), and his wife gave the scores of his evaluation of general health as 4 over time.

Care issues

Care issues included mobilizing (walking), physical discomforts (leg numbness) and medication concerns.

Coping resources

Thinking dominated by the family

- a) Upholding the Communist ideology:
- b) Improvising therapeutic measures, such as vinegar with beans and garlic
- c) Fulfilling family obligation: Prescribed father and sons, and husband as well as wife, very kind, wife sang after husband, had the spirit of self-sacrifice.
- d) The couple also expressed fear of stroke recurrence

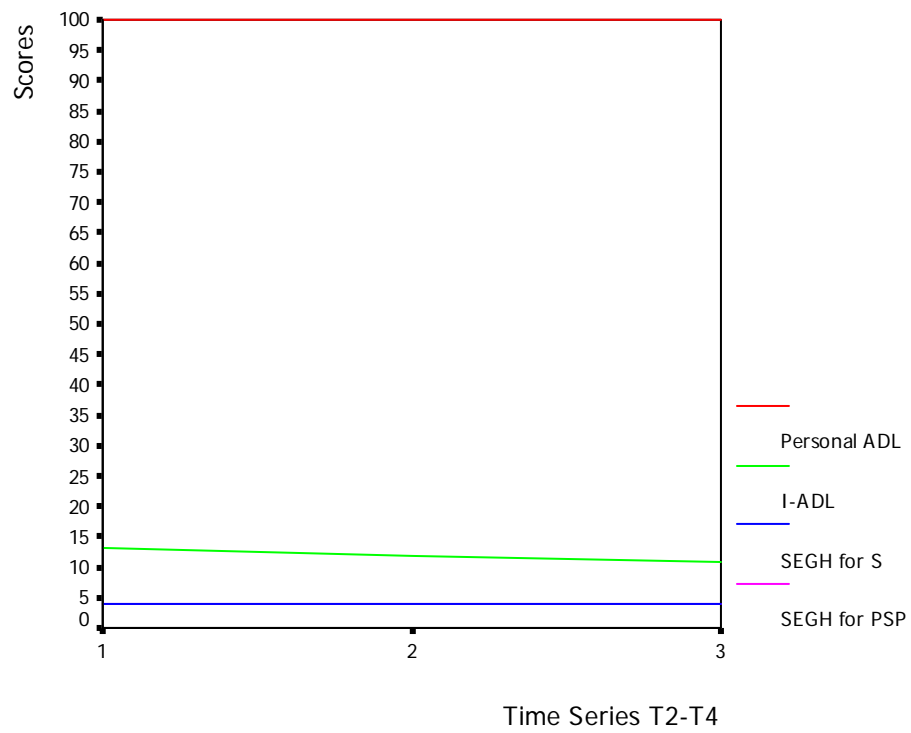
Organization of caring work

Q's wife sang after husband, family members living harmoniously, sons' behaved according to the traditional filial piety.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mr. Q



Mr. R's Family

Stroke survivor characteristics

Mr. R, 44 years, being hospitalized on Dec. 27, 2001, because of sudden headache and falling down with chest distress, palpitation and lose consciousness at once. He was sent to No 1 Municipal Hospital by emergency ambulance "120". BP 190/120mmHg, hypotensive drug and nitro-glycerine were given, no obvious improvement, still headache, aphasia, cough while drinking. Finally he was transferred to No. 3 hospital due to family's request.

PE: BP 160/80mmHg, aphasia, both pupils equal size and round, left naso-labial sulcus shallowed, tongue extension pointed left, HR 120/min, arrhythmia, limb tonus grade V, right side reflex sensitive, ECG: sinus rhythm, electric axis inclined to left.

CT scan: Multiple infarction in both external capsules and parietal lobe.

Past history: Hypertension for more than 10 years, hypotensive drug was taken, cerebral infarction happened in 1992 and 11996. He smoke each package a day and love to drink white alcohol frequently.

Diagnosis: Multiple infarction, hypertension III stage (Length of hospital stay: 18 days, 4000 Yuan for hospitalization fare, no free medical coverage enjoyed).

Observation: Since the occurrence of this attack, mental, appetite, strength and sleeping were all right, passing urine and stool normal.

Educational level: high school, working in the factory as a driver. His monthly income 400 Yuan.

Primary caregiver and family

R's wife, 44 years old. She used to be an accountant in the factory, now laid off at home. Her education level: high school. Her monthly income 400 Yuan. They had a 16-year old daughter, now in high school.

The couple lived with their daughter, at third floor. They had a lovely white dog at home. This pet dog loved its masters, nobody was allowed to contact its master.

Health care service utilization

Only drug store was used frequently after discharge home.

*CT scan: computerized tomography scan.

Qualitative content analysis

Care issues

Activities of daily living

R's wife always complained about Mr. R's reluctance of moving around. She said: "He was so lazy to walk, always sitting and lying on bed to watch TV.....even though he passed stool, he did not attend to the toilet, he used the basin in his room and waited for me to deal with it when I came back home.

Health problems

The first time visits, it seemed that too much sputum was in his throat. His wife said: "His sputum looked very sticky, not clear, he had Brown mixture..... What's more, he just smokes, too long a history of smoking, he just can't give up, even he coughed seriously. Sometimes, it is very difficult to let the sputum out. OK, you say your heart is still red, not being smoked to black. It's lucky that this stroke attack stops his smoking. He has smoked too much.

Patient: "Well, when somebody who smokes come to visit me, I still wish to smoke. Now, I don't want to smoke any more, sometimes, when I cough, it hurts, hard to get rid of sputum.. As for red or black, nonsense, how can my heart be smoked to black?"

Coping resources

Cognitive

He was neither a person who has experienced much hardship, nor has he struggled hard to win a self-reliance life, he was born in a cadre family, from his childhood, he enjoyed high position and lived in comfort, he had a feeling of superiority complex. With the change of the society, what he once owned has diminished forever. Now he was a laid-off worker with 400 Yuan, still he was living a happy-go lucky life: drinking alcohol and raising pigeons for fun. Then, suddenly, in one night, he was pushed to the dark edge of death, as he passed the death-line at last, he was deep in frightening, uncertainty, reminding his happy past and wondering for his uncertain future....

He expressed his experience on the day of stroke attack, following as he described. At that day, he was drinking with friends, all of a sudden, he fell down, lost consciousness, aphasia, transferring to emergency department. During the first visit, he was in bed, speaking not clearly, sticky sputum in his throat, coughing, but sputum could not come out, a painful expression...Thinking of he 'd not be long in this world, and had not a cent left for his wife and child, he groaned, sighed, wept hopelessly. Can I recover quicker? If not, what a life they would live?

Talking about the friends who drank together happily in the past, but now, they just turn a blind eye to me. Oh, how cool is the relation between people!"

Furthermore, now his working unit has been transferred to others, he could no more do his favorite job: driving car, no income, the sudden attack was really unacceptable for him. Every time, when talking about the escape from the death-line, he was deadly scared, " You just can't imagine because you haven't experienced it, see, no matter how strong you are!

Remember the other day in hospital, I asked you to turn to my side, you said: "Why should I ? I look at that side, there are pretty nurses, why should I turn to see your "old vegetable face?", I said: "Me, old vegetable face? Look at your own face, like 'old tree bark' (hahaha), we said that for fun, otherwise we will have nothing to enjoy. You also made joke with doctors and nurses, right?"

Affective

He expressed his dissatisfaction with attitudes of his working unit treating him after the consequence of stroke, he said: "Don't believe what Communist has done. You have made too much

propaganda for Communist, all not true.... You see, when I am sick nobody comes to see me...they have eaten a lot, drunk a lot, sold the factory... I have been the model of the Worker's Federation for 5 years...Just so so. I didn't know the truth before, I was cheated..."

Organization of caring work

The first time when I met the couple, his wife, tears in her eyes, gently stroking his head and comforted him, and tried to make joke with him:" Nothing to worry about, we still have half of our house to sell, (tears flowing). Don't worry about our life. Furthermore, we can move to my mother's house to live with them (weeping), please don't worry, don't worry.

In their room, there was a lovely white pet dog, always sticking around its master's legs, it brought great pleasure and comfort to him. He said:" This dog is my loyal friend, with it beside me, I am very

happy. See, It eats what I eat.”

Then he changed the topic talking about his pet pigeons: “ A series of description, species, Chinese species, foreign species, their eyes...there is lots of knowledge and interest in raising them.”

The last time I saw him, he was standing beside the terrace, with newspaper in his hands, enjoying sunshine, chatting with neighbors, and again, very talkative, chatting about what he was interested in: dog, pigeons, eating meat, he looked very much satisfied with his life, he seemed to say, you thought I were dead, but, what, I am still alive and living happily.

Statistical analysis and time-series analysis for Mr. R’s family

Category	Scales	T1*	T2*	T3*	T4*	Others
Mr. R						
1	SPMSQ	0	--	--	--	--
2.	CES-D	35	17	16	15	--
3	ADLs	35	60	70	80	--
4	I-ADL	--	25	24	26	--
5	SEGH	2	3	4	4	--
R’s wife						
1	CES-D	0	0	0	0	--
2	SEGH	4	4	5	5	--

* T1: discharge from the hospital; T2: discharge home after one week; T3: discharge home after one month; T4: discharge home after 3 months; T5: discharge home after 6 months.

Summary of the case

Prognosis

Mr. R, 44 years old, medical conditions were severe, the blood pressure was high (190/120mmHg); besides infarction, he had coronary heart disease, hypertension, and stroke infarction history.

Family background

The couple was living with their young daughter (high school). They were nuclear family. The working unit is broken, they had no medical coverage and paid medical care by himself. The financial burden was high.

Health care service utilization

OPD was used occasionally, drug store was used more frequently.

Stroke-related disability

Barthel index showed improvement over time, but completely dependence upon family members after discharge home. After one month, he had depression. Meanwhile, her self evaluation of general health was remained low (2), and his wife gave the scores of his evaluation of general health as 4 over time.

Care issues

Care issues included elimination, mobilizing (walking), sleeping disturbance complained by his wife, and medication concerns.

Coping resources

- a) Sense of humor
- b) The couple also expressed guilty, worry and fear (death, high BP and stroke recurrence).

Organization of caring work

Mutually support after discharge home.

Determination of the type of family well-being and a change of family well-being over time

Type of family well-being	From optimal to optimal
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Well-being of the family for Mr. R

