CHAPTER 4

FINDINGS AND DISCUSSION

A correlational descriptive study was conducted to describe social support and burden of stroke patient caregivers. The chapter presents demographic data of the subjects, findings and discussion relevant to the research questions and the hypothesis.

Demographic data of the subjects

The sample of the study was composed of 50 Chinese stroke patient caregivers aged 36 to 80 years old with mean age of 59.62, and S.D. of 8.54. More than half (56%) of the caregivers aged 60 years and older, and 22% of the caregivers were at least 70 years of age. Most of the caregivers (72%) were female, and married (98%). The predominant education level was primary school or junior school. Thirty-eight percent of caregivers were workers, while only 4% were health care personnel. Majority of the subjects (58%) had family per capita income of equal or less than 500 yuans (See Table 1).

Table 1

Caregiver's Characteristics (N=50)

Variables	**N(%)**
Sex	
Male	14(28)
Female	36(72)
Age (years)	
35-49	9(18)
50-59	13(26)
60-69	17(34)
≥70	11(22)
Marital status	
Married	49(98)
Divorced	1(2)
Education level	
Primary school	18(36)
Junior school	10(20)
Senior school	9(18)
College or above	8(16)
Other	5(10)
Occupation	
Teacher	8(16)
Office staff	11(22)
Worker	19(38)
House keeper	1(2)
Business person	1(2)
Farmer	3(6)
Health personnel	2(4)
Other	5(10)
Monthly income (Yuan/person)	
100-250	6(12)
251-500	23(46)
501-750	6(12)
>750	15(30)

In present study, almost all of caregivers (94%) resided with the stroke patients. The majority of them (82%) were spouse. Caregivers reported spending 8 to 24 hours (Mean = 19.90, SD = 5.71) per day giving care to the patients and had been doing this for 1.5 months to 35 years (Mean = 46.16 months, SD = 69.59), and 66% of subjects reported that they gave care to the patients for more than 17 hours per day. Majority of the subjects (58%) mentioned that they had been providing care for more than one year. Thirty four percent of caregivers reported caring for the stroke patient by themselves without any assistants. The average number of assistant per primary caregiver was 1.04 (SD = 1.19)(See Table 2).

Table 2

Characteristics of Caregivers and Caregiving (N=50)

Variables	**N(%)**
Living arrangement	
Shared	47(94)
Unshared	3(6)
Relationship with patient	
Son	3(6)
Daughter	5(10)
Daughter in law	1(2)
Husband or wife	41(82)

Table 2

haracteristics of Caregivers and Caregiving (N=50) (Continue)

Variables	**N(%)**
Length of caregiving (months)	
1-12	21(42)
13-24	8(16)
25-36	4(8)
>36	22(44)
Hours of care (/day)	
1- 8	1(2)
9-16	16(32)
17-24	33(66)
Caregiving assistant (Number)	
0	17(34)
1	23(46)
≥2	10(20)

In this study, nearly half of the stroke patients (56%) had a diagnosis of cerebral hemorrhage, while the remaining (54%) of patients had cerebral embolism and cerebral thrombosis. The patients had experienced stroke over an average period of 48.52 months (SD of 70.07) with a range from 1.5 to 420 months. Most of the patients (66%) could partially reimburse for medical payment. Majority of the stroke patients (72%) had other chronic diseases including hypertension (44%), cardiac disease (18%), diabetes mellitus (6%), chronic bronchitis (6%), and others.

Sixty two percent of the patients had mild or moderate ADL impairment (ADL = 60-41), 26% had severe impairment (ADL = 40-21), and 12% had total impairment (ADL > 20) (See Table 3).

Table 3

Characteristics of Patients (N=50)

Variables	**N(%)**
Type of medical diagnosis	
Cerebral hemorrhage	23(46)
Cerebral thrombosis	15(30)
Cerebral embolism	7(14)
Cerebral hemorrhage and Cerebral thrombosis	5(10)
Duration of stroke (Months)	
1-12	20(40)
13-24	8(16)
25-36	4(8)
>36	18(36)
ADL score	
≤20	6(12)
21-40	13(26)
41-60	31(62)
Medical payment	
Total reimbursement	8(16)
Partial reimbursement	33(66)
Total self paid	9(18)
Having other disease	
Yes	36(72)
No	14(28)
Disease reported *	
Hypertension	22(44)
Cardiac disease	9(18)
Chronic bronchitis	3(6)
Diabetes mellitus	3(6)
Others	6(12)

Note: * Seven (14%) stroke patients had two kinds of other chronic diseases

Social support of stroke patient caregivers

Social support score of the subjects ranged from 65 to 116 with a mean of 88.98 and SD of 10.64. The total social support score were categorized into low, moderate, and high level. The findings showed that the caregivers perceived social support ranged from moderate to high level. Majority of the subjects (60%) perceived social support at moderate level (See Table 4).

Table 4

Frequency and percentage of the subjects according to Level of Social Support of the Samples (N=50)

Level	**N(%)**
Moderate	30(60)
High	20(40)

Burden of the stroke patient caregivers

The potential score of objective burden measured by the Objective Burden Scale (OBS) was 9-45. The study demonstrated that the objective burden score of the subjects ranged from 24 to 43, with a mean of 36.96, and SD of 4.30. The possible range of score of subjective burden measured by the Subjective Burden Scale (SBS) was 13-65. The study showed that the subjective burden score of the caregivers ranged from 22 to 48 with a mean of 35.78, and SD of 6.29.

The objective burden score was categorized into low, moderate, and high level. It was showed that majority of the subjects (78%) reported objective burden at high level. The subjective burden was also divided into low, moderate, and high level. The study showed that the subjects' perceived subjective burden ranged from low to high level. Most subjects (80%) rated their subjective burden at moderate level, and 2% of subjects perceived high level of subjective burden (See Table 5).

Table 5

Frequency and percentage of subjects according to Level of Objective burden and Subjective burden of the samples (N=50)

	N(%)	
Level	**Objective**	**Subjective**
Low	—	9(18)
Moderate	11(22)	40(80)
High	39(78)	1(2)

Since the questions in Objective and Subjective Burden Scales seem to be independent from each other, score of each item was also analyzed. The possible score of each item was 1-5. The most frequently reported items of objective burden in the study was vacation activities and trips with a mean score of 4.92 and SD of .34, while the item of relationship with other family members had the lowest rating mean score of 3.10 and SD of .93. With respect to subjective burden, caregivers in the study most often reported that the feeling of relatives' expecting too much got the highest mean score of 4.10 and SD of .71. Many caregivers also felt afraid for what the future holds for the relatives with a second highest mean of 3.58 and SD of .99. Very few caregivers felt guilty over relationship with relative with the lowest mean score of 1.84 and SD of .89 (See Table 6).

Table 6

Means, Standard Deviations, and range for objective burden and subjective burden (N = 50)

Items	Possible score	Range	Mean	S.D.
Objective burden				
Vacation and trip	1-5	3-5	4.92	.34
Recreation and social activities	1-5	3-5	4.52	.68
Time for self	1-5	2-5	4.26	.90
Personal freedom	1-5	2-5	4.24	.92
Amount of privacy	1-5	3-5	4.24	.77
Amount of energy	1-5	2-5	4.10	.86
Your health	1-5	1-5	3.84	.93
Money available	1-5	2-5	3.74	.90
Relationship with other family	1-5	1-5	3.10	.71
Subjective burden				
Relative expectation	1-5	2-5	4.10	.71
Afraid of the future	1-5	1-5	3.58	.99
Painful to watch relative suffer	1-5	1-5	3.14	.99
Pleased with relationship with Relative	1-5	1-5	3.12	1.00
Strain relationship	1-5	1-5	3.00	1.21
Feeling of being manipulated	1-5	1-5	2.80	1.14
Nervous and depressed	1-5	1-5	2.76	1.13
Feeling of being unappreciated	1-5	1-5	2.74	1.08
Unreasonable requests	1-5	1-5	2.46	.99
Contributing to relatives' wellbeing	1-5	1-5	2.30	.84
Feeling of being useful	1-5	1-4	1.98	.59
Feeling of performance inadequate	1-5	1-5	1.96	.90
Feeling guilty over relationship With relatives	1-5	1-4	1.84	.89

Relationship between social support and burden of stroke patient caregivers

Pearson's correlation was undertaken to analyze the degree of association between social support and burden of stroke patient caregivers. Each dimension of burden was also analyzed separately for their relationship with social support. The results showed that social support was negatively related to total burden of stroke patient caregivers at moderate level ($r = -.365$, $p < .01$). It indicated that the stroke patient caregivers who perceived high level of social support would be more likely to have low level of burden. A significant negative relationship was also found between social support and subjective burden at moderate level ($r = -.421$, $p < .01$), but no statistically significant relationship between social support and caregivers' objective burden was demonstrated (See table 7).

Table 7

Pearson's correlation coefficient between Burden and Social support of the sample (N=50)

Type of burden	**Pearson's r**
Objective	-.162
Subjective	-.421**
Overall Burden	-.365**

Note: ** p < .01

Discussion

The discussion of this study is presented in three sections: discussion of the sample characteristics, discussion of the descriptive data related to social support and burden, and discussion of findings related to the relationship between the two variables.

Sample characteristics

In this study, the mean age of the subjects was 59.62 years. This is similar to other studies in stroke patient caregivers in western country (Anderson et al, 1995; Scholle op reimer, Rijinders, & Van den bos, 1998). It may be that most of caregivers in these studies were couples of stroke patients who often aged 65 years and older. Most of the subjects (72%) were female and were married(98%). These characteristics of the sample are typical for caregivers all over the world which women-dominated care exists. Studies on burden of caregivers of noninstitutionalized follow up stroke patients did confirm this notion (Anderson et al, 1995; Scholle op reimer, Rijinders, & Van den bos, 1998). The demographic characteristics also fit with traditionally and culturally defined nuclear family type and family relationship in China which spouse is the major caregiver in the family. Majority of the subjects (56%) had junior school education or below. This was congruent with urban residents' educational background, in which 57.7% of Chinese had junior school education or below (China Health Ministry Statistics, 1998). This may be explained that according to the sample characteristics, only 6% of the caregivers were farmers, while most of them were teacher, office staff, worker or health personnel. Therefore, it can be estimated that majority of samples of this study were urban residents. In this study, most of the subjects (58%) had family per capita income of 500 yuans or below. In China, the mean of per capita income of urban resident was 362 yuans, while the mean of rural resident' per capita income was 151 yuans (China Health Ministry Statistics, 1998). Considering that majority of the subjects were urban residents, this finding suggested that most of the subjects were in average economic status.

In this study, 36% of the stroke patients had disease for more than 3 years, while the other studies (Anderson et al, 1995; Scholle op reimer, Rijinders, & Van den bos, 1998). on caregiver burden reported having longer periods of disease in stroke patients and longer periods of care among the caregivers. Sixty percent of the subjects reported that they had been providing care to the patients for 24 hour per day. This indicated that most of the subjects took care of the stroke patients at day and night. Majority of the patients (72%) had other chronic diseases including hypertension, cardiac disease, diabetes mellitus, and so on. This finding is supported by many authors (Plum & Posner, 1990; Sacco, 1995), who stated that these chronic diseases predispose and accompany with stroke. In present study, ADL of the stroke patient was assessed, the mean of ADL score of stroke patient was 42.92 and SD of 17.17. According to categories of Barthel index by Mahoney and Barthel (1965), the stroke patients were mildly and totally dependence. As discussed, the sample of the study seems to be good to represent the target population of this study.

Social support of stroke patient caregivers

The results of this study demonstrated that most subjects (60%) perceived social support at moderate level with a quite high mean score ($\bar{X}$ = 88.98) (Table 4). As literature reviewed, there are many factors affecting social support including age, gender, types and amount of support provided, support context. According to the sample characteristics in which majority of the subjects (98%) were married and were aged of around 59.62 years old, these caregivers might have high support from children or spouse. With this age, they could have more than one child from whom they might receive more support. Furthermore, in Chinese traditional culture, children have the responsibility to take care of parent when he/she is in illness. The children need to support their parents and make them feel better. This may support higher mean score of social support among caregivers. Another reason is that most of the subjects were female who was documented to perceive support received from the children as being the most positive (Lynch, 1998). Moreover, it may be explained that 66% of caregivers had one or more caregiving assistants who obviously gave instrumental support as aspect of social support to the primary caregivers. For those caregivers (18%) whose spouse did not experienced stroke, they might also receive social support from them, and those with stroke spouse might receive emotional and appraisal support from the stroke spouse as well. It was documented that spouse was one of the major resources of support for stroke patient caregivers

(Kenchaiwong, 1996).

This finding is similar to the study of Yan (1997) which found that Chinese COPD patients perceived a moderate level of social support. Since the samples were obviously from the same cultural background, they might have similar emotional, appraisal, and informational support from social resources and might have similar social support perception.

Burden of stroke patient caregivers

The results of the study found that most of subjects (78%) rated the objective burden at high level (Table 5) with a mean score of 36.96 and SD of 4.30. The study also showed that most of caregivers (80%) experienced moderate level of subjective burden. As reviewed in literature, dealing with stroke patients' physical and psychological problems was possibly associated with caregiving objective burden and subjective burden.

Factors affecting burden from literature review being mentioned included patients' cognitive incapacity, physical disability, ADL impairment, disrupture behaviors, social support, as well as caregivers' physical health, functional ability, educational status, caregiver behaviors, high income and social network can influence caregiver burden. Many explanations can be given to explain high level of objective burden and moderate level of subjective burden according to the sample characteristics. Firstly, all patients in the present study suffered from stroke with ADL score equal or less than 60, and 12% of patient had ADL score of 20 or below. This meant that the patients' self-care ability was partially or totally impaired. These patients, therefore, had to depend on caregivers to meet the essential daily life demands resulting in burden of caregiving. Secondly, 58% of subjects had over one year caregiving experience, and 64% of caregivers provided care to the patients for 24 hours. These findings certainly showed a great impact of caregiving on caregiver's life. Most of their time was spent on caregiving, thereby causing objective burden. Thirdly, 34% of caregivers did not have any assistance from others. These caregivers, therefore, have to take all responsibilities in helping the patients to meet physical, psychological, and social demands. The objective and perception of subjective burden might be high. Lastly, since 56% of caregivers were aged 60 years or older, it was not surprising that many physical illnesses were also presented in the caregivers themselves at the time of patient's stroke. However, the physical aspects of caregiving might be interfered with management of their caregivers' own illness, such as hypertension or cardiac disease. The caregivers might feel exhaustion, overload, and obviously, the health status of caregivers would be affected. Jones (1996) noted that for burden as related to caregiver behaviors, objective burden is systemically higher than subjective burden. However, for burden related to client disrupture behavior, there are more equal intensity between objective burden and subjective burden, whereas, the disrupture behaviors occurred less frequently. Jones' study (1996) supported the level of objective burden was much higher than subjective burden level in this study.

It was not surprising that the mean score of the subjects' burden in this study was much higher than what reported in Foxall's study (1996) in 24 bone marrow transplant patients in USA using the same instrument. In Foxall's study (1996), the mean score of objective burden was 32.9 (SD = 5.5), that of subjective burden was 22.8 and SD of 5.5. The disparity between the two studies results can be explained by difference of the patients. In present study, all of the patients' ADL dependence, caregivers' long-term care experience, and long duration of care of caregivers per day certainly influenced objective burden and subjective burden. Therefore, objective burden and perceived subjective burden of this study were much higher than those of Foxall's (1996)study.

With respect to objective burden, vacation activities and trips ($\bar{X}$ = 4.92), recreational and social activities ($\bar{X}$ = 4.52) were the areas most affected by caregiving for stroke patients. These might be explained that these primary caregivers may be anxious about leaving the patients unattended for all day because of fear that the patients might fall, experience another stroke, or other problems such as bowel and bladder elimination might not be handled well. These often meant these caregivers had to curtail their vacation activities and trips, and limited recreational and social activities at home. However, the caregivers might withdraw due to anxiety about the own vulnerability and if depressed, blame others (Reisberg & Ferris, 1982 cited in Brandstater & Brasmajian, 1987), the recreational and social activities were not compensated by an increase in social contact at home. This finding supported those of others who reported that limitation in social and personal activities was the most frequently mentioned objective burden by caregivers (Anderson, 1992; Anderson et al, 1995; Foxall, 1996).

Caregivers in this study concerned that the least affected area of the own life was the relationship with other family members ($\overline{X}$ = 3.10). This finding is consistent with Foxall's (1996) study in bone marrow transplant patients' caregivers. In China, family members will help each other in both physiopsychological and financial aspects when one of the family members had the disease, therefore, the relationship among family member is not affected. In

Anderson and colleagues' study (1995) among 84 caregivers of stroke patients, 35% of caregivers reported adverse effects on family relationship measured by different instrument, Social Behavior Heath Questionnaire. Also they did not look at the level of burden of the subjects. So, the two study results can not be compared. Surprisingly, although most of the caregivers' (58%) family per capita income were 500 or below, 84% patients' medical payment were partially or totally paid by themselves in this study, money available was the second least objective burden being reported with a mean of 3.74 and SD of .90. The financial aids from relatives, friends or colleagues were most likely to interpret this result.

With respect to subjective burden, it was interesting to note that although most of subjects (66%) received additional assistance from others, the issue that patient's expectation was rated as the highest mean score ($\bar{X}$ = 4.10) in subjective burden by the caregivers. This finding could be due to the dominant role in caregiving of the subjects in this study, so the patients might depend mainly on the subjects. This finding is not consistent with other studies. In Foxall's study (1996) of bone marrow transplant patient caregivers, painful to watch relative suffer got the highest mean score ($\bar{X}$ = 3.9). However, worry about the future was frequently reported area of subjective burden in Reinhard's (1994) study of caregivers of mental illness patients. This disparity might be explained by the difference in the subjects. In the present study, caregiver tasks were much more than other studies because all patients were ADL dependence and 34% of caregivers did not have any assistance. The caregiving tasks might be exceed the caregiver's capacity to perform the tasks, therefore, the feeling of high expectation from the patients might occur. Another reason is that the cultural difference existed between the previous study and the present one might cause different perception of subjective burden. In China, the patients hold the opinion that they should be taken care by their family members, especially their couples. Besides, Chinese patients often feel shame at expressing privacy and psychological needs from other people. These may make the patients excessively depend on primary caregiver on both physical and psychological aspects.

In this study, many caregivers were also worried about the future of the patients ($\bar{X}$ = 3.58) and felt painful to watch their relative's suffer ($\bar{X}$ = 3.14), even though the score were less than other aspects. The results confirmed other studies' findings of subjective burden of the caregivers (Reinhard, 1994; Foxall, 1996). In contrast, the caregivers rated the item of guilt over relationship with their relatives at lowest mean score ($\bar{X}$ = 1.84). The finding is consistent with Foxall's finding (1996) in which felt guilty over relationship with relatives got the lowest mean score ($\bar{X} = 1.2$). No studies were available to compare the data related to subjective burden with the same subjects.

Relationship between social support and burden of stroke patient caregivers

A significant moderate negative relationship was found between social support and burden of the subjects ($r = -.365$, $p < .01$). It indicated that stroke patient caregivers who perceived high level of social support rated low level of burden. Moreover, further analysis indicated social support was moderately associated with subjective burden of the stroke patient caregivers ($r = -.421$, $p < .01$). However, the results failed to confirm the relationship between perceived social support and objective burden of the subjects. Social support seems to be a buffer when individual encounter problems (Cobb, 1976). Social network provides individuals with moral support as well as aid in time of trouble (Kahn & Antonucci, 1980 cited in Braithwaite, 1990). Social support which moderated the burden-symptom relationship could prove advantageous, buffering burden caregivers (Braithwaite, 1990). Burden caregivers may be supported from others by being told that they are doing well, have made the correct decision, or to be given effective advice. In time of difficulties, caregivers may also seek assistance that is always available, therefore, caregivers' perceived subjective burden might be reduced.

As previously discussed, high patient's expectation was the most burdensome feeling of caregivers in this study. Even though instrumental support was available for the caregivers, the stroke patients' physical and emotional demands were mainly expressed to family caregivers, especially spouse and primary caregivers. This is most likely to explain why the relationship between social support and caregivers' objective burden was not statistically significant.

The negative relationship between overall social support and caregiver's burden was consistent with Beigel and associates' (1994) study among lower socioeconomic status caregivers of chronic mental illness patients. In Beigel et al's study, caregivers' social support was measured by Interpersonal Support Evaluation List developed by Cohen and associates (1985). It was found that caregivers with low social support reported high levels of burden. This study's finding was also in accordance with the study of Reinhard (1994) among mental illness patient caregivers in which social support from professional negatively related to burden. However, the other studies previously mentioned used different tools for measurement of social support and burden. The negative relationship between the social support and burden of stroke patient caregivers is clinically relevant for nurse and other professionals and warrants further study.

A noteworthy finding that was rarely addressed was significantly negative relationship between social support and subjective burden of the stroke patient caregivers (r = -.421, p <.01). Most of studies of stroke patient caregivers restricted the study to burden of the subjects, but did not test the relationship between these two variables. Only one exceptional study (Kenchaiwong, 1996) in which investigator explicitly examined the relationship between the two variables, but no statistically significant relationship between social support and caregivers' subjective burden was demonstrated. The explanation for the difference of the present study resulted from Kenchaiwong's might be the different data collection methods. In Kenchaiwong study, interview methods was used, while in the present study, self-administered method was used to collect the data. Since both perceived social support and subjective burden are personal perceptions or feelings, there might be some different results using different data collection methods.

Considering of the relationship between social support and objective burden of the subjects, the finding of this study was inconsistent with the study of stroke patient caregivers by Kenchaiwong (1996). That study showed that there was statistically negative relationship between social support and caregivers' objective burden ($p < .001$) using the same instruments.

With regard to the conceptual framework of his study, the concepts of social support derived from Weinert and Brandt (1987) and burden from Montgomery, Gonyea and Hooyman (1985) were used. According to the conceptual framework, the more the social support, the possibly less the burden of caregivers. The findings of this study showed a moderate negative relationship between social support and subjective burden of stroke patient caregivers, but no significant relationship between social support and caregivers' objective burden was demonstrated. The only one part of hypothesis was support. Therefore, the result of this study is partially consistent the conceptual framework. It suggested that the nursing intervention for enhancing stroke patient caregivers' social support would be beneficial to alleviate only the caregiver's subjective burden.