# <u>Original Research</u>

# The Status Quo and Influencing Factors of Care Activities and Support Behaviors of the Main Caregivers of Stroke Patients During the Transition Period from Discharge

Yilu Li, BM; Yajun Zhou, MM; Chenxi Ren, MM; Jiguo Yao, MM; Yingying Ke, MM; Yingzi He, BM

### ABSTRACT

**Objective** • This study investigated stroke patients and their primary caregivers, examining the impact of stroke events on caregivers and families, identifying factors affecting burden levels, and proposing measures to improve caregivers' quality of life and reduce family burden.

**Methods** • This study adopted a questionnaire method, which includes a general information questionnaire, a patient self-care ability evaluation scale (Barthel index), a caregiver needs evaluation scale, and a social support evaluation scale (SSRS).

**Results** • A total of 163 primary caregivers, mostly spouses or children of the patients, participated with an

Yilu Li, BM; Chenxi Ren, MM; Yingying Ke, MM; Yingzi He, BM, Department of Geriatrics, Shanghai Sixth People's Hospital, Shanghai, China. Yajun Zhou, MM,; Jiguo Yao, MM; Department of Neurology, Shanghai Sixth People's Hospital, Shanghai, China.

Corresponding author: Yingzi He, BM E-mail: yingZI88lu@126.com

### INTRODUCTION

"Cerebralstroke", also known as "stroke" or "cerebrovascular accident", is an acute cerebrovascular disease. It is a group of diseases that cause brain tissue damage due to sudden rupture of brain blood vessels or blood vessel blockage that has a high mortality and disability rate. It is mainly divided into ischemic stroke (cerebral infarction, cerebral thrombosis) and hemorrhagic stroke (cerebral hemorrhage or subarachnoid hemorrhage). Cerebral infarction is the most common.<sup>1,2</sup> However, stroke, listed as the first chronic disease, has become a global health problem due to its high incidence rate, mortality, associated disability rate, and recurrence rate.<sup>3</sup> Literature shows that the absolute number of ischemic stroke and hemorrhagic stroke increased by 37% and 47% respectively from 1990 to 2010, and the number of deaths increased by 20% and 21% respectively. At present, there are about 50 million average age of  $55.99 \pm 11.92$  years. A significant portion (36.81%) provided care alone for an average of 6.06 years. Social support received by caregivers was generally low, with only 1.84% reporting high support. 90.13% of caregivers experienced varying levels of burden, with 61.35% experiencing mild burden, 25.15% moderate burden, and 3.68% severe burden.

**Conclusion** • The study concluded that China's nursing system for stroke patients is inadequate, relying heavily on family members for rehabilitation. (*Altern Ther Health Med.* 2023;29(7):302-315).

stroke patients in the world, and the number of new stroke patients in the United States alone is about 795000 each year.4,5 It is pointed out that at present, there are about 2 million new cerebrovascular disease patients in China every year, and about 1.3 million patients die of cerebrovascular disease every year. Almost one person is reported to have stroke every 12 seconds, and one person dies of stroke every 21 seconds. This is not only much higher than the global average but also shows a trend of continuous increase every year.<sup>6,7</sup> The report also points out that China is the youngest country with high incidences of stroke. While the age of stroke in Western countries is about 73-75 years, the average age of onset in China is 63-65 years. The increasing number of people suffering from the disease and the trend of decreasing age of onset have become a huge burden hindering China's social progress and economic development.<sup>6</sup> With the improvement of medical treatment and care, timely treatment, and effective rehabilitation measures, the global mortality rate of stroke has decreased, but its disability rate is still high, which has become a critical challenge for medical workers.7 It is reported that about 80% of patients surviving stroke will have different degrees of cognitive, physical, physical activity, language, and other dysfunction, which seriously affect their ability to live and require long-term or even permanent care, and 30% of patients will have permanent neurological damage, which is more dependent on caregivers. In the United States, United

Kingdom, Australia, Canada, and other developed countries, stroke patients often receive continuous care from professional rehabilitation institutions after discharge. However, for some families unable to afford the high cost of care services, most of the care responsibilities lie with the family members.8 At present, there are two main ways of long-term care in China, namely, institutional care and home-based care. Institutional care has many defects in management, economy, and service, and is subject to dual restrictions of the current medical system and medical expenses. About 80% of patients choose to return to home-based care after initial treatment and rehabilitation in a hospital. Family members, as primary caregivers, play a crucial role in providing daily care for stroke patients. In addition to addressing the patients' daily living needs, family members also contribute to the patient's long-term rehabilitation by assisting with rehabilitation exercises, thus taking care of the issue of medical expenses. Some caregivers also need to deal with cognitive disorders, depression, and personality changes associated with patients.9 When caregivers are faced with various problems related to health and care that cannot be solved, they will be eager to get professional help.<sup>10</sup> The higher the degree of satisfaction the caregivers need, the faster will the caregivers grow in response to negative events of family stroke. On the contrary, the lower the degree of satisfaction the caregivers need, the heavier will be their care burden. Many studies at home and abroad have confirmed that long-term, high-intensity, and high-pressure care work has a huge burden on caregivers, making them feel tired, prone to depression, anxiety, hostility, and other negative emotions, which not only affects the physical and mental health of the caregivers but also affects the quality of care provided by the caregivers.11

Influenced by many factors, China has not yet formed a complete management system for caregivers of stroke patients, and the nursing needs of patients and caregivers have not been fully met.<sup>12</sup> In addition, although domestic scholars have recognized the importance of family caregivers in rehabilitation of stroke patients, and the relevant research has increased year by year, the current domestic research on care needs of caregivers of stroke patients mainly focuses on the overall needs survey or cross-sectional survey of specific stage of preparation before discharge, and the attention to different stages of the complete care process is lacking.13 Rehabilitation of stroke patients is a long-term process. At different stages of the disease, patient's condition, degree of rehabilitation, and subjective experience will change. The needs of main caregivers will also need to change with the change in patient's state. An overall study or a single crosssectional study cannot comprehensively and objectively reflect the dynamic feelings of the caregivers.<sup>14</sup> Only by understanding the specific needs of caregivers at each stage can we provide the targeted interventions to reduce their care burden and improve their care quality.<sup>15</sup> Therefore, it is necessary to use a special scale to measure the needs of stroke caregivers and explore the correlation between specific needs and social support of family caregivers of stroke patients at different stages in a longitudinal study, so as to provide a basis for clinical intervention measures.

### DATA AND METHODS Research object

We selected stroke patients who were hospitalized in geriatric ward and neurology department of Shanghai Sixth People's Hospital from January 2015 to December 2021 and their main family caregivers.

#### Standards for inclusion, exclusion, and removal of samples

**Inclusion criteria.** (1) The caregiver is at least 18 years old, has clear consciousness, clear speech, and has primary school education or above. (2) The relationship between the caregiver and patient is family: including patient's parents, spouse, children or siblings, or grandchildren. (3) The patients they care for meet the following conditions: a) meet diagnostic criteria of fourth national cerebrovascular disease in 1995, and are diagnosed by skull CT or MRI, and TIA is excluded; b) hospitalization due to stroke; c) ability of daily living (ADL) score <60; d) choose home-based care after discharge; (4) The patients and caregivers are informed and are willing to cooperate with the investigation. (5) The caregiver owns and can use mobile communication devices such as mobile phones.

**Exclusion criteria.** The patient has (1) severe cardiac, hepatic and renal insufficiency, or malignant tumor; (2) nurses, nursing workers, and other caregivers as main caregivers who need to be paid; (3) the caregiver has no mobile phone or cannot use mobile phone, and cannot guarantee the quality of follow-up.

**Standard of falling off.** (1) The patient died during study period; (2) caregivers failed to complete research task due to various reasons.

#### Estimation of sample size

The formula and algorithm provided below are used to calculate the sample size in a descriptive study. In this study, the sample size is determined using the empirical formula: sample size =  $[(sum of dimensions) * (10-20)] * (1+45\%).^{16}$ 

In the questionnaire utilized for this study, there are four dimensions in the caregiver needs evaluation scale and three dimensions in the social support scale. The required sample size for this survey is estimated to be between 100 and 200, with a minimum of 100 cases.

By applying the formula, the minimum sample size can be calculated as follows: Minimum sample size = (4 + 3) \* 10 \*  $(1+0.45) \approx 100$  cases.

This approach considers the sum of dimensions in the scales, multiplies it by a range between 10 and 20, and adjusts it by adding 45% to account for potential non-response or attrition rates.

It is important to note that this specific formula and algorithm might be tailored for this study or research group and may not be widely referenced in recent English literature. It is advisable to refer to the original research paper or methodology section for a detailed understanding of the rationale and context behind the chosen formula.

#### Sampling method

This study adopts a convenience sampling method.

#### Survey time node

1-2 days after admission, 1 day before discharge, 1 month after discharge, 3 months after discharge, and 6 months after discharge.

#### **Research tools**

This study adopts questionnaire method, which includes general information questionnaire, patient self-care ability evaluation scale (Barthel index), caregiver needs evaluation scale, and social support evaluation scale (SSRS).

#### General data questionnaire of stroke patients

The researchers themselves designed questionnaire based on general data of similar research, including demographic data questionnaire and disease-related situation questionnaire. Demographic data include: age, sex, education level, marital status, per capita monthly income of family, payment method of medical expenses, etc. Disease related information includes: disease type, state of consciousness, activity, language disorder, and other chronic diseases.

# General information questionnaire for main caregivers of stroke

The researcher himself designed questionnaire based on general data of similar research, which mainly includes caregiver's gender, age, marital status, education, occupation, family income, relationship with patients, chronic diseases, care data, etc.

#### Assessment of self-care ability of patients (Barthel index)

The Barthel index of ADL was designed by Mahoney and Barthel of the United States in 1965 and applied to clinical practice.17 There are 10 evaluation items: eating, transferring, decorating, using toilet, bathing, walking on flat, going up and down stairs, dressing, and stool control. Each item is divided into four grades: 0, 5, 10, and 15 according to the need for help and degree of help, with a total score of 100 points. Those with more than 60 points are slightly disabled and basically take care of themselves; 60 points to 40 points are moderately disabled, with dysfunction, and need help in life; those with 40-20 scores are severely disabled and dependent on life; and, those who score less than 20 are completely disabled and completely dependent on life. The scale is simple to use, and its reliability and validity have been widely confirmed. Its double-sided reliability reached 0.89, inter-raiser reliability is greater than 0.95, has high sensitivity, and is one of most widely used and studied ADL evaluation methods in clinical practice.

#### Caregiver needs satisfaction evaluation scale

The scale was developed by Xu et al<sup>12</sup> with 24 items in total and composed of four dimensions: medical service needs, care-related information needs, emotional needs, and human support needs. The score ranges from 1 to 4 points, 1 point implies complete dissatisfaction, and 4 points implies complete satisfaction; the higher the score, the better is the degree of satisfaction of needs. The scale has good reliability and validity. Cronbach's  $\alpha$  coefficient is 0.87 and the retest reliability is 0.80. Since demand satisfaction scale is to continue to answer satisfaction degree only when there is a need, and answer of "no need" in demand indicates that the main caregiver has no need or demand to be met, so the caregiver's answer of "no need" is deemed that the demand has been "fully met". This scale was used by Lu Jue and others in 2013 to measure the satisfaction of needs of main caregivers of stroke patients, and Cronbach's value in his study was 0.92.<sup>18</sup>

#### Social Support Rating Scale (SSRS)

The level of social support is evaluated from the quantity and utilization of social support. The amount of social support refers to the amount of social support an individual receives from others or groups. Generally, the level of social activity or social contact can be used to objectively assess an individual's social loneliness or social interaction. The utilization of social support refers to the degree to which social networks are mobilized and others' support and help are utilized. The social support assessment scale was designed by Xiao Shui Yuan in 1986 and revised in 1990.19 It has 10 items in total, including three dimensions, namely objective support (3 items), subjective support (4), and utilization of support (3). The higher the score, the higher the social support. The scale is reasonable in design, easy to understand, and has good reliability and validity. Since 1986, the scale has been used in more than 20 studies of healthy people and cancer patients.

#### Investigation method

The survey was completed in the form of questionnaires, in which the survey of occurrence/diagnosis period and preparation period was completed in the geriatric department and neurology department of the hospital. Considering the actual situation of onset/diagnosis period, investigation at this stage was completed by guiding family members of patients to review their needs within 1-2 days after the patients completed their hospitalization procedures and were properly settled. The preparation period ranges from the time the doctor issues the discharge order until the time before discharge. The investigator will distribute questionnaire to main caregivers, explaining filling requirements and precautions. If there are any problems during filling process, the researcher will give a detailed explanation. When questionnaire is retrieved, it will be checked one by one, and any missing items will be filled in at that time. At the same time, the respondent will be informed that surveys will be conducted again at 2 weeks, 1 month, 3 months, and 6 months after the discharge of the patient. The survey method was completed by distributing questionnaires on-site during an outpatient review. If the patient failed to come to the hospital in time, the researchers could make an appointment by telephone and obtain the consent of the main caregiver.

#### Data collection methods and steps

Before conducting this study, the permission of the hospital leader and support of director of implementation department and head nurse was obtained; A questionnairebased survey was conducted among 20 subjects, and the preliminary reliability and the validity of the measurement tool were measured in study population. At the same time, the researcher attempted to understand whether the text is easy to understand by the survey respondents and conforms to their expression habits. The researcher explained significance, purpose, method, and confidentiality of survey to the primary caregiver, obtained informed consent of primary caregiver, and signed informed consent form. Inpatient survey: completed in inpatient ward, and informed of survey time nodes and contents that need follow-up cooperation. Investigation at different time nodes after discharge: researchers could make an appointment with patients or family members for outpatient review in advance through telephone communication or WeChat group, and complete the questionnaire at the outpatient site. If the questionnaire was not completed on time at outpatient site, respondent would be interviewed by telephone, and researcher would ask items of questionnaire one by one and record after reconfirmation.

#### Data analysis method

SPSS17.0 software package was used to enter data, and recheck completeness and rationality of data during entry process. The accuracy of input data was checked by software after being entered by two personnel respectively, and SPSS 17.0 software package was used for statistical analysis. The average and standard deviation, frequency and percentage were used to make descriptive statistics on general data and activities of daily living of stroke patients, as well as general data and discharge needs of main caregivers. The repeated measurement analysis of variance was used to make inferential statistics on the needs of main caregivers at different time points. Correlation analysis was used to analyze the correlation between care needs of main caregivers of stroke patients and social support.

#### Ethical review

Before survey, all respondents were informed that patients who did not wish to participate in study, their treatment would remain unaffected and the information obtained from the study would only be used for academic research. During survey, principles of anonymity, confidentiality, and voluntary participation were strictly followed.

#### Quality control measures

To ensure the quality of study, all questionnaires were tested for internal reliability and validity prior to their use. The questionnaire before discharge was distributed and retrieved on the spot. When retrieving the questionnaire, it was checked for any unanswered questions or omissions; if found, the response was completed in time to ensure the



integrity of data. The questionnaire after discharge was collected by the researcher in the outpatient department of hospital at the time of patient's return visit, and was retrieved on spot to timely check missing responses and complete the same. In case of a telephone interview, the researcher asked the questions one by one according to entries in the questionnaire, repeated the results of respondents, and recorded results after reconfirmation. Questionnaire screening: those who missed more than 15% of the questions, their questionnaire was rejected. In data entry stage, all data are entered separately by two persons, and the results were automatically checked by the computers. If case of any discrepancy, the original data was retrieved and the data entry was corrected to ensure the quality of the data.

#### Frame diagram

Figure 1 shows the pressure event framework diagram.

#### **Technical route**

The detailed technical route is shown in Figure 2.

#### RESULTS

Among 163 stroke patients investigated, 102 were male, accounting for 62.59% of the total. There were 61 female patients, accounting for 37.41% of total number of patients surveyed. Thus, the majority of the patients included in the study were male. The age of stroke in patients ranged from 49 to 93 years, with an average age of  $68.95 \pm 8.93$  years. Among them, patients aged 60 to 80 years accounted for about 67% of all patients.

134 cases had an education level of junior high school and below, accounting for 82.22% of the total survey; 28 cases with high school or technical secondary school education, accounting for 17.18% of the total survey; and, 1 case with junior college level of education or above, accounting for 0.61% of the total survey.

Among 163 stroke patients surveyed, 58 had a total family income of less than 10000 yuan, accounting for 35.59% of the total survey; 66 cases with a total annual income of 10000 yuan to 20000 yuan, accounting for 40.48% of the total survey; 30 cases with total annual household income ranging from 20000 yuan to 30000 yuan, accounting for 18.41% of the total survey; and, 9 cases where total annual income of families was more than 30000 yuan. It can be seen that the total annual income of most patients' families is less than 20000-yuan, accounting for about 76% of the total survey. The average number of family members living with stroke patients was  $3.87 \pm 1.61$ . Among the payment methods of medical expenses for stroke patients, 96 cases adopted social pooling method, accounting for 58.90% of the total survey and 58 cases were completely selffunded, accounting for 35.59% of the total survey. For the current treatment mode of patients, 91 patients were treated in outpatient service, accounting for 55.82% of total number of patients surveyed; 59 cases were treated with self-medication, accounting for 36.19% of the total survey; 4 cases were hospitalized, accounting for 2.46% of the total; and, 9 cases that were resolved without treatment, accounting for 5.53% of the total. It shows that in the majority of patients, treatment mode is mainly outpatient treatment and self-medication. For medical expenses in the past year, 42 cases were less than 1000 yuan, accounting for 25.78% of all patients; there were 37 cases with Renminbi (RMB) 1000 to 2500, accounting for 22.69% of all patients; there were 18 cases with RMB 2500 to 4000, accounting for 11.05% of all patients; 36 cases with RMB 4000 to 5500, accounting for 22.08% of all patients; and, there were 32 patients with medical expenses higher than 5500 yuan, accounting for 18.41% of all patients. The course of disease in stroke patients ranges from 1 to 15 years, with an average of  $4.55 \pm 2.78$  years. The course of the disease for most of them (80.00% of the total) is less than 6 years. The basic characteristics of 163 stroke patients are shown in Table 1 and Figure 3.

The widely used ADL was used to reflect the ability of daily living, quality of life, and medical care service needs of stroke patients. According to scoring method of the ADL scale, the average score of the scale is  $38.33 \pm 12.71$ , the average score of instrumental ability of daily living dimension is  $22.82 \pm 7.43$ , and the average score of physical ability of

#### Table 1. Basic Characteristics of 163 Stroke Patients

	Number	Composition
Characteristic variable	of cases	ratio (%)
Age (years)		
<60	30	17.80
60-	58	36.19
70-	59	35.59
80-	16	10.42
Gender		
Male	103	62.59
Female	60	37.41
Marital status		
Unmarried	2	0.62
Married or cohabiting	107	66.25
Divorce or separation	3	1.24
Bereavement	51	31.89
Degree of education		
Junior high school and below	135	82.22
High school and above	28	17.78
Annual household income (yuan)		
<1000	59	35.59
1000-	65	40.48
2000-	31	18.41
3000-	7	4.91
4000-	2	0.62
Payment method of medical expenses		
Fully self-funded	59	35.59
Not fully self-funded	104	40.48
Current treatment mode		
Hospitalization	5	2.46
Outpatient treatment	90	55.82
Self-medication	58	36.19
Untreated	10	5.53
Medical expenses in past year (yuan)		
<1000	42	22.78
1000-	38	22.69
2500-	19	11.05
4000-	35	22.08
5500-	31	18.41
Course of disease (year)		10.11
<3	37	22.10
3-	50	31.28
5-	44	26.39
7	32	20.33

Figure 3. Basic Characteristics of Patients



**Table 2.** Degree of ADL (ability of daily living) Loss Among

 Stroke Patients

	Number	Composition
ADL loss degree (score)	of cases	ratio (%)
Basically normal ( $\leq 20$ )	18	11.05
Mild disorders (21~30)	26	15.96
Moderate impairment (31~39)	42	25.78
Severe disorder ( $\geq 40$ )	77	47.25





self-care dimension is  $15.51 \pm 5.59$ . Among 163 stroke patients investigated, 18 patients had basically normal ADL scores, accounting for 11.05% of the total. There were 145 cases with different degrees of disorders, accounting for 88.96% of the total. Among them, were 26 cases with mild disorders, accounting for 15.96% of total number of investigations; 42 cases with moderate disorders, accounting for 25.78% of total number of investigations; and, 77 cases with severe disorders, accounting for 47.25% of total number of investigations. It shows that the outcome of stroke patients is relatively serious, and most survivors will lose part of their daily living ability and is associated with poor self-care ability, thus requiring more care. The degree of ADL loss in stroke patients is shown in Table 2 and Figure 4.

In this survey, 163 primary caregivers of stroke patients were investigated, including 63 male caregivers, accounting for 38.65% of the total; There are 100 female caregivers, accounting for 61.36% of the total survey. Most of them are women. The age of the caregivers ranged from 23 to 86 years, with an average age of  $55.99 \pm 11.92$  years. Most of the primary caregivers were over 40 years of age, accounting for 91.18% of all the caregivers, and nearly half of the caregivers were over 60 years of age (47.24%). Among caregivers, there were 87 cases with junior high school education or below, accounting for

Table	3.	Basic	Characteristics	of	Main	Caregivers	of	166
Patien	ts v	with St	roke					

	Number	Composition	
Characteristic variable	of cases	ratio (%)	
Age (years)			
<40	17	9.83	
40-	71	42.93	
60-	75	38.05	
Gender			
Male	62	38.64	
Female	101	61.36	
Marital status			
Unmarried	5	2.46	
Married or cohabiting	152	93.86	
Divorce or separation	2	0.62	
Bereavement	4	3.06	
Degree of education			
Junior high school and below	88	53.38	
High school and above	75	46.62	
Employment			
Full-time work	38	22.71	
Part-time work	9	6.12	
Not working	117	71.18	
Relationship with stroke patients			
Spouse	79	49.07	
Parent	2	0.62	
Children (including daughter-in-law	63	36.25	
and son-in-law)			
brothers and sisters	12	6.77	
Other	6	4.28	
Take care of patients alone			
Yes	61	36.82	
No	102	63.18	
Cognition of disease			
Do not understand	4	1.85	
Learn something	135	83.43	
Know a lot	25	14.73	

53.38% of the total number of respondents; 61 cases with high school or technical secondary school education, accounting for 37.43% of the total survey; 15 cases with college education or above, accounting for 9.20% of total number of respondents. The majority of the respondents have education level below high school or technical secondary school. Among the main caregivers, 37 were full-time workers, 10 were part-time workers, and 116 were unemployed. Thus, majority of the respondents were unemployed. 153 respondents were married or cohabiting, accounting for 93.87% of total survey. Among 163 subjects surveyed, 80 were spouses of patients, accounting for about half of the total (49.07%), followed by patients' children, accounting for 36.25% of the total, and other were patients' siblings, parents and other relationships, accounting for 11.65% of the total. Among the caregivers surveyed, 60 caregivers said they were taking care of patients alone, accounting for 36.82% of the total; and, 103 caregivers said that there were other people to help them take care of patients, accounting for 63.18% of the total survey. This implies that about 1/3 of the caregivers independently took care of the patients. Of 163 subjects surveyed, 136 knew a little about disease, while 24 knew a lot, and only 3 did not. The average care time for main caregivers was  $6.06 \pm 4.08$  years. 27 patients took care for 1 to 2 years, accounting for 16.56% of the total



survey; 68 cases took care of for 2 to 5 years, accounting for 41.72% of the total number of investigations; 55 cases took care of for 5 to 10 years, accounting for 33.74% of the total survey; and, there were 13 cases with more than 10 years of care, accounting for 7.98% of the total survey. Thus, majority of the patients require care for 2 to 10 years. The basic characteristics of caregivers are listed in Table 3 and Figure 5.

The SSRS, prepared by Xiao Shui Yuan, which conforms to the characteristics of Chinese people and has been proved to have good reliability and validity by population tests, was used to evaluate objective support, subjective support, and support utilization of main caregivers of stroke patients. Among 163 caregivers surveyed, 79 had low social support, accounting for 48.46% of the total; 81 cases were generally supported, accounting for 49.68% of the total; and, there were 3 cases with high support, accounting for 1.85% of the total. It can be seen that the proportion of caregivers with high social support is very small, while proportion of caregivers with general and low social support is  $32.81 \pm 5.74$ , subjective support is  $17.62 \pm 3.27$ , objective support is  $8.62 \pm 2.01$ , and support utilization is  $6.57 \pm 1.81$ . See Table 4 and Figure 6 for social support.

The social support scores and support levels of caregivers with different characteristics are shown in Table 5 and Figure 7. There are differences in the total social support scores (t=-4.96, P<.01), objective support scores (t=-4.53, P<.01), subjective support scores (t=-2.25, P<.05) of caregivers with different education levels, The caregivers with high school education and above scored higher in total score of social support and all dimensions than caregivers with junior high school education and below. The score of each dimension with other people participating in care was higher than without other people participating in care. The

#### Table 4. Social Support of 163 Stroke Caregivers

Social support	Number of cases	Composition ratio (%)
Low support (<33)	79	48.46
General support (33-45)	81	49.68
High support (>45)	3	1.85



test found that the total score of social support (t=-3.03, P<.01), objective support (t=-4.35, P<.01), and subjective support (t=-2.17, P<.05) with other people participating in care were different from those without other people participating in care. The total score of social support (t=-2.13, P<.05) and subjective support score (t=-3.09, P<.01) of caregivers who are alone are different from those who are not alone.

The simple coping style questionnaire was used to evaluate coping style of main caregivers of stroke patients. The average score of positive coping style dimension of 163 caregivers was  $19.35 \pm 6.53$ , and average score of negative coping style dimension was  $10.34 \pm 3.93$ . It shows that among main caregivers of stroke patients in this survey, way to cope with difficulties is mainly positive. The scores of coping styles with different characteristics are shown in Table 6 and Figure 8. Among the caregivers, there is a difference in scores of positive coping styles between caregivers who are alone and caregivers who are not alone (P < .05). There were differences in total coping score, positive coping style score, and negative coping style score between caregivers with junior high school education or below and caregivers with senior high school education or above (P < .01, P < .05, P < .01). There were differences in total coping score, positive coping style score and negative coping style score among patients with different treatment methods (P < .01). Through pairwise comparison, it was found that scores of inpatients in total coping, positive coping style, and negative coping style were higher than corresponding to other treatment methods.

# Table 5. Basic Characteristics and Social Support of Caregivers

	Social support score $(\overline{x \pm s})$				Support	t level (compo	osition)
		Objective	Subjective	Support			
Characteristic	Total score	support	support	utilization	Low	Commonly	High
Gender of caregiver							
Male	32.96 ± 5.76	8.91 ± 1.87	17.68 ± 3.67	6.39 ± 1.50	44.5	54.1	1.7
Female	$32.73 \pm 5.76$	$8.45 \pm 2.09$	$17.60 \pm 3.02$	$6.70 \pm 1.98$	51.1	47.1	2.1
Age							
<40	$32.32 \pm 4.39$	8.70 ± 1.89	$17.20 \pm 3.12$	$6.45 \pm 1.55$	62.6	37.6	0.1
40-	$33.81 \pm 5.49$	$8.84 \pm 2.04$	$18.64 \pm 3.20$	$6.35 \pm 1.58$	38.7	60.1	1.5
60-	$32.02 \pm 6.12$	8.43 ± 2.02	$16.80 \pm 3.16$	$6.82 \pm 2.04$	54.6	43.0	2.7
Caregiver education							
Junior high school and below	$30.87 \pm 5.45$	$8.00 \pm 1.87$	$16.61 \pm 3.02$	$6.29 \pm 1.87$	63.3	36.9	0.1
High school and above	$35.05 \pm 5.27$	9.35 ± 1.94	$18.80 \pm 1.91$	$6.92 \pm 1.69$	31.7	64.6	4.0
Caregiver marriage certificate							
be on one's own	$29.11 \pm 4.68$	8.11 ± 1.91	$14.61 \pm 3.53$	$6.41 \pm 1.17$	70.1	30.1	0.1
Not alone	$33.06 \pm 5.73$	$8.66 \pm 2.02$	17.83 ± 3.17	$6.59 \pm 1.85$	47.2	51.1	2.1
Do you live together?				_			
Yes	32.91 ± 5.85	8.66 ± 2.05	17.70 ± 3.33	$6.57 \pm 1.80$	48.8	49.4	2.1
No	$31.78 \pm 4.38$	$8.24 \pm 1.74$	$16.86 \pm 2.58$	$6.70 \pm 2.02$	46.3	53.9	0.1
Caregiver's disease awareness							
Do not understand	$31.68 \pm 1.15$	8.34 ± 1.53	$16.68 \pm 1.53$	$6.68 \pm 0.58$	66.8	33.4	0.1
Learn something	$32.94 \pm 5.83$	$8.65 \pm 2.00$	17.77 ± 3.29	$6.54 \pm 1.80$	47.2	50.8	2.3
Know a lot	$32.26 \pm 5.65$	8.51 ± 2.19	$16.97 \pm 3.34$	$6.80 \pm 2.00$	54.3	45.9	0.1
Whether other people participate in care							
Nothing	$31.08 \pm 5.64$	7.78 ± 1.82	16.91 ± 3.05	$6.41 \pm 2.09$	65.1	33.4	1.8
Have	$33.84 \pm 5.58$	9.13 ± 1.96	$18.05 \pm 3.35$	$6.68 \pm 1.63$	38.9	59.3	2.0

**Figure 7.** Social Support Score and Support Level of Caregivers with Different Characteristics

 Table 6. Coping Style of Stroke Caregivers



	Simple coping style score $(x \pm s)$						
	Total score	Positive	Negative				
Characteristic	(SCSQ)	coping style	coping style				
Gender of caregiver							
male	$28.55 \pm 10.78$	$18.34 \pm 6.71$	$10.22 \pm 4.81$				
female	$30.38 \pm 8.42$	$19.98 \pm 6.38$	$10.41 \pm 3.29$				
Caregiver's marital status							
Be on one's own	$24.21 \pm 9.90$	$15.3 \pm 5.73$	9.01 ± 4.57				
Not alone	$30.03 \pm 9.30$	$19.62 \pm 6.51$	$10.42 \pm 3.89$				
Caregiver education							
Junior high school and below	$27.54 \pm 9.55$	$18.16 \pm 6.59$	9.39 ± 3.98				
High school and above	$32.12 \pm 8.68$	$20.71 \pm 6.23$	$11.42 \pm 3.61$				
Age of caregiver (years)							
<40	$28.01 \pm 6.95$	$18.82 \pm 5.04$	$9.20 \pm 2.81$				
40-	$30.05 \pm 8.64$	$19.38 \pm 5.64$	$10.68 \pm 3.81$				
60-	$29.67 \pm 10.52$	$19.43 \pm 7.55$	$10.26 \pm 4.22$				
Whether to live together							
Yes	$29.68 \pm 9.41$	$19.34 \pm 6.50$	$10.35 \pm 3.98$				
No	29.55 ± 9.78	$18.84 \pm 6.64$	$10.16 \pm 3.48$				
Whether other people participa	ite in care						
Nothing	$30.94 \pm 8.96$	$20.21 \pm 6.31$	$10.74 \pm 4.01$				
Have	28.93 ± 9.63	$18.84 \pm 6.64$	$10.10 \pm 3.89$				
Patient course (year)							
<3	31.82 ± 8.93	$20.45 \pm 6.06$	$11.37 \pm 4.05$				
3-	30.66 ± 9.32	$20.28 \pm 6.67$	$10.38 \pm 3.54$				
5-	$29.29 \pm 10.33$	$19.41 \pm 7.26$	9.89 ± 4.19				
7-	26.31 ± 8.15	$16.62 \pm 5.17$	9.71 ± 4.49				
Caregiver's disease awareness							
Do not understand	$31.67 \pm 9.07$	$20.01 \pm 6.08$	11.68 ± 3.06				
Learn something	$30.14 \pm 8.95$	$19.59 \pm 6.30$	$10.56 \pm 3.81$				
Know a lot	$26.76 \pm 8.15$	$17.89 \pm 7.85$	$8.89 \pm 4.49$				
Treatment mode							
Hospitalization	$42.51 \pm 8.19$	$27.01 \pm 3.92$	$15.51 \pm 4.80$				
Outpatient treatment	$31.52 \pm 9.15$	$20.58 \pm 6.89$	$10.94 \pm 3.54$				
Self-medication	$26.11 \pm 8.44$	$17.04 \pm 5.22$	$9.08 \pm 4.01$				
Untreated	28 68 + 9 67	18 57 + 6 39	10.12 + 4.20				



**Table 7.** Scores of 163 Stroke Caregivers' Burden on the ZBIScale

Caregiver burden	Number of cases	Composition ratio (%)
No burden (≤ 19)	16	9.83
Light burden (20 -10)	100	61.34
Moderate burden (40 -5)	41	25.16
Heavy burden (60 -30)	6	3.67

The ZBI scale was used to evaluate care burden of the main caregivers of stroke patients. The average score of caregiver burden was  $33.92 \pm 12.91$ . Among 163 caregivers, there were 16 caregivers without burden, accounting for 9.83% of the total and 147 cases with care burden, accounting for 90.18% of the total number of investigations. Among those with burden, there were 100 cases with mild burden, accounting for 61.34% of the total; 41 cases were moderately burdened, accounting for 3.67% of the total. Thus, majority of the caregivers experienced light burden and moderate burden. The distribution of caregiver burden is shown in Table 7 and Figure 9.

See Table 8, Table 9, Figure 10 and Figure 11 for scores of the ZBI scale with different characteristics. As shown in Tables 8 and 9, burden of caregivers gradually increases with the age of caregivers. The care burden of male caregivers was  $31.95 \pm 12.52$  points, and that of female caregivers was  $35.18 \pm 13.06$  points. The burden of caregivers living with patients was different from that of caregivers not living with patients (t = -5.26, P < .01). It shows that the burden of caregivers living with caregivers is greater than caregivers not living together. There was a difference in the burden of care between caregiver who was spouse of the patient and caregiver who was in any other



 Table 8. Scores and Burden of Stroke Caregivers with

 Different Characteristics

	ZBI scale	Burden	degree (co	omposition	ratio)
Features	score $(\overline{x \pm s})$	Nothing	Light	Moderate	Severe
Age					
<40	$28.45 \pm 5.83$	2(6.3)	16(93.8)	1(0.0)	1(0.0)
40-	33.22 ± 13.05	10(12.9)	40(55.7)	20(27.1	4(4.3)
60-	35.71 ± 13.57	7(7.8)	47(59.8)	23(28.6)	4(3.9)
Gender					
Male	31.95 ± 12.52	11(15.9)	38(58.7)	17(25.4)	1(0.0)
Female	35.18 ± 13.06	7(6.0)	64(63.0)	26(25.0)	7(6.0)
Degree of education	on				
Junior high school and below	34.85 ± 11.52	10(10.3)	58(65.5)	20(21.8)	3(2.3)
High school and above	35.18 ± 13.06	7(9.2)	44(56.6)	23(29)	5(5.3)
Yes	34.76 ± 13.03	15(9.3)	90(59.3)	20(21.8)	7(4.0)
No	$24.39 \pm 5.98$	3(15.4)	44(56.6)	23(29)	1(0.0)
Whether other peo	ople participate i	n care			
Nothing	34.91 ± 11.65	5(6.7)	38(61.7)	18(28.3)	3(3.3)
Yes	33.36 ± 13.61	13(11.7)	64(61.2)	25(23.3)	5(3.9)
Cognition of disea	se				
Do not understand	22.1 ± 16.64	2(33.3)	3(66.7)	1(0.0)	1(0.0)
Learn something	3 ± 12.25	12(8.1)	85(61.8)	38(27.2)	5(2.9)
Know a lot	33.72 ± 15.83	5(16.7)	15(58.3)	5(16.7)	3(8.3)
For patient's spous	e				
No	31.35 ± 11.03	11(12.1)	56(66.3)	18(20.5)	2(1.2)
Yes	36.61 ± 14.19	7(7.5)	46(56.3)	25(23.3)	6(6.3)
For patients' child	ren				
No	35.22 ± 13.39	9(8.1)	61(60.6)	27(26.3)	6(5.1)
Yes	31.93 ± 11.97	9(12.5)	41(62.5)	16(23.4)	2(1.6)

	ZBI scale	e Burden degree (composition ratio)				
Features	score $(x \pm s)$	Nothing	Light	Moderate	Severe	
Age						
<60	$31.56\pm9.11$	2(3.5)	26(86.2)	3(6.9)	2(3.5)	
60-70	$34.09 \pm 13.48$	8(11.9)	34(55.9)	18(28.8)	3(3.4)	
70-80	$36.35 \pm 14.09$	5(6.9)	33(55.3)	20(32.8)	4(5.2)	
80-90	$29.12 \pm 10.98$	5(23.5)	11(58.8)	11(58.8)	1(0.0)	
Gender						
Male	$34.78 \pm 11.60$	11(9.8)	61(58.8)	27(25.5)	7(5.9)	
Female	$32.50 \pm 11.84$	7(9.8)	41(65.6)	16(24.6)	1(0.0)	
Degree of education	on					
Junior high	32.66 ± 11.60	15(10.5)	90(66.4)	30(21.6)	3(1.5)	
school and						
below						
High school	$39.80 \pm 16.79$	3(6.9)	12(37.9)	13(41.4)	5(13.8)	
and above						
Number of family	members (pers	on)				
1-3	$33.65 \pm 12.76$	5(8.9)	30(64.4)	11(22.2)	3(4.4)	
3-5	$32.62 \pm 10.02$	5(7.0)	41(70.2)	13(21.1)	2(1.8)	
5-7	$35.73 \pm 15.27$	9(13.1)	32(50.8)	20(31.2)	4(4.9)	
Course of disease	(year)					
<3	$35.73 \pm 4.01$	3(5.6)	22(58.3)	12(30.6)	3(5.6)	
3-5	$34.83 \pm .73$	2(2.0)	38(72.6)	14(25.5)	1(0.0)	
5-7	$31.13 \pm 12.98$	8(16.3)	26(58.1)	11(23.3)	2(2.3)	
7-9	$34.22 \pm 15.65$	7(18.2)	18(51.5)	8(21.2)	4(9.1)	
Cognition of disea	ise					
Do not	$33.16 \pm 11.52$	2(7.7)	10(69.2)	4(23.1)	1(0.0)	
understand						
Learn	$34.15 \pm 12.93$	14(9.9)	92(62.8)	36(24.1)	7(4.1)	
something						
Know a lot	$29.41 \pm 17.56$	3(40.0)	1(0.0)	4(60.0)	1(0.0)	
Treatment mode						
Hospitalization	$28.26\pm7.50$	1(0.0)	5(100.0)	1(0.0)	1(0.0)	
Outpatient	$36.30 \pm 12.21$	7(6.6)	53(57.1)	30(31.9)	5(4.4)	
treatment						
Self-	$31.89 \pm 12.14$	8(11.9)	41(67.8)	11(17.0)	3(3.4)	
medication						
Untreated	$25.90 \pm 11.89$	4(33.3)	5(44.4)	3(22.2)	1(0.0)	
Payment method	of medical expe	nses				
Not fully self-	$35.80 \pm 14.82$	14(12.4)	52(48.6)	52(48.6)	7(5.7	
funded						
Fully self-	$30.54\pm7.40$	4(5.2)	52(48.6)	7(10.3)	1(0.0)	
funded						

 
 Table 9. Relationship Between Stroke Patient Characteristics
 and Caregiver Scores on the ZBI Scale

status (t=-2.64, P<.01). It shows that care burden of spouse is greater than other caregivers. Among different education levels of patients, burden of caregivers with junior high school education and below was 32.66 ± 11.60 points, and burden of caregivers with senior high school education and above was 39.80  $\pm$  16.79 points. The difference was (t = 2.76, P < .01 or P = .01). It shows that the burden of patients with high school and higher education is greater than junior high school and below. Among different treatment methods, caregiver burden of inpatient patients was  $28.26 \pm 7.50$  points, caregiver burden of outpatient patients was 36.30 ± 13.21 points, caregiver burden of self-medication patients was 31.89 ± 12.14 points, and caregiver burden of untreated patients was  $25.90 \pm 11.89$ points. The difference was significant (F = 3.04, P < .05 or P = .05). The caregiver burden of outpatient treatment was highest.





Figure 11. The Relationship Between Characteristics of Stroke Patients and Scores of Caregivers on the ZBI Scale



The burden outcome (i.e. response variable "Y") of main caregivers of 163 stroke patients was divided into four orderly grades of "no burden, mild burden, moderate burden, and severe burden", which were respectively assigned to following values for quantification: Y = 1: no burden; Y = 2: light burden; Y = 3: moderate burden; and, Y = 4: heavy burden. For analysis, binary variables were directly quantified with 0 and 1 values; For unordered multi-classified variables,

Factor	Parameter estimate	Wald Chi-square	P value	OR	OR (95% CI)
Constant term 1	2.3416	2.8624	.0908		
Constant term 2	6.8206	20.5573	<.0002		
Constant term 3	9.0040	32.2405	<.0002		
Patient education					
High school and above	1.1866	7 1 2 2 0	0077	2 277	1 272 7 929
Junior high school and below	1.0001	7.1239	.0077	3.277	1.3/2-7.828
Others participate in care					
Have	-0.9274	6 4271	0112	0.207	0 104 0 911
No	1.0001	0.43/1	.0115	0.397	0.194-0.811
Self-paid medical expenses	1.2722	8.93%	.0029	3.569	1.550-8.221
Patient's daily living ability	0.0402	6.8385	.0090	1.042	1.011-1.074
Negative coping styles of caregivers	0.2458	23.9012	<.002	1.280	1.159-1.412

Table 10. Multi-Factor Logistic Regression Analysis Results Affecting Burden Degree of the ZBI Scale

**Figure 12.** Multi-Factor Logistic Regression Analysis Results Affecting Burden of the ZBI Scale



**Figure 13.** Multi-factor Logistic Stepwise Regression Analysis Results Affecting Positive Reaction Rate of Each Dimension of the FBS Scale



they were divided into multiple dummy variables, and then assigned with 0 and 1 values for quantification. For ordered multi-classified variables, values "1, 2, 3, 4," were assigned to quantify according to their attributes from low to high. See Table 9 for the specific assignment of each variable. Twentyfour factors that may affect burden outcome of the ZBI scale, such as caregiver's gender, patient's education level, treatment method, self-paid medical expenses, payment method of medical expenses, degree of social support, evaluation of patient's ability of daily living, positive coping style, negative coping style, and patient's family income, were included in logistic stepwise regression analysis model of multiple ordered response variables for analysis. When screening indicators, discrimination level of inclusion and exclusion was kept at 0.05. See Table 10 and Figure 12 for specific assignment of each variable.

The family burden outcomes of 163 patients with stroke were divided into two types according to six dimensions of economic burden, daily life, recreational activities, family relationship, physical health, and mental health: "positive response and negative response". The following values were respectively assigned to quantify: Y = 1, answer is positive; Y =0, answer is negative. For analysis, binary variables were directly quantified with 0 and 1 values; and, for unordered multi-classified variables, they were divided into multiple dummy variables, and then assigned 0 and 1 values for quantification. For ordered multi-classified variables, values "1, 2, 3, 4," were used to quantify according to their attributes from low to high. The variables: patient's age, patient's sex, patient's educational level, number of family members of patient, treatment method, medical fee payment, and other factors that may affect outcome of burden were included in logistic stepwise regression analysis model of binary response variables for analysis. When screening indicators, discriminant level of variable selection and elimination was kept at 0.05, and regression results are shown in Table 11 and Figure 13.

**Table 11.** Multi-Factor Logistic Stepwise Regression Analysis Results Affecting Positive Response Rate of Each Dimension ofthe FBS Scale

		OR (95% CI)							
	financial	Daily			Physical health of	Mental health of			
Factor	burden	activities	Entertainment	Family relations	family members	family members			
Patient year		1.06(1.01-1.09)		1.05(1.01-1.09)		1.12(1.05-1.18)			
Patient sex	2.03(1.03-3.97)								
Patient education					3.89(1.44-10.5)				
Number of family members						0.73(0.53-0.98)			
Payment of medical expenses			1.17(1.03-1.32)	1.18(1.01-1.36)		1.23(1.04-1.43)			
Patient's family income			0.64(0.42-0.93)			2.66(1.46-4.81)			
ADL		1.07(1.03-1.09)	1.07(1.03-1.10)	1.16(1.10-1.21)	1.10(1.05-1.13)				

The results of logistic stepwise regression analysis showed that age of patients had an impact on the dimensions of daily activities, family relations and mental health of family members. The regression coefficient is positive, which indicates that with the increase in age of patients, the risk of positive responses in corresponding dimensions increased and the burden also increased. The ability of daily living of patients has an impact on dimensions of daily activities, recreational activities, family relations, and physical health of family members. The regression coefficient is positive, indicating that with the increase of score of ability of daily living, the risk of positive answers to family burden of corresponding dimensions increases. The family medicine payment mode of patients has an impact on the dimensions of entertainment activities, family relations, and mental health of family members. The regression coefficient is positive, indicating that patients who are completely selffunded have an increased risk of positive answers to burden of corresponding dimensions than those who are not completely self-funded. The number of family members has an impact on mental health dimension of family members, and regression coefficient is negative, indicating that with the increase in the number of family members, the risk of positive answers to mental health dimension of family members decreases. The regression coefficient of influence of patients' gender on economic burden is positive, indicating that male patients have a higher risk of positive answers to the family economic dimension than female patients. Patient's education level has an impact on the physical health dimension of the family members. With higher patient's education level, the risk of positive response of patient's family members' physical health increases.

## DISCUSSION

Many scholars at home and abroad have confirmed that the satisfaction of supportive needs of main caregivers of stroke patients is relatively low.<sup>20</sup> A qualitative study was conducted to investigate the needs of main caregivers of 12 stroke survivors in Lima, Peru. It was found that the main caregivers received help and support of other family members in terms of money and sharing of care work and housework during the care process. Almost all participants said that they needed help of professional medical personnel in terms of improving mental health and care ability.<sup>21</sup> Caregiver Needs and Concerns Checklist (CNCC) assessment tool was used to investigate the most urgent care needs of main caregivers of stroke survivors at each stage after the discharge once a week via telephonic follow-up. It was considered that caregivers' needs were not effectively met, and it was suggested to provide timely and appropriate support to caregivers in a suitable way.<sup>22</sup> In qualitative interview with caregivers of stroke families, it was found that although caregivers had some basic rehabilitation knowledge, their rehabilitation skills were not consistent with the level of knowledge mastery. Therefore, it was suggested that main caregivers should also be involved in health education, and different health education plans should be formulated according to the individual needs of the main caregivers.<sup>23</sup> A self-designed caregiver needs questionnaire was used to study the needs of main home caregivers of stroke. It is confirmed that more than 55% of home-based caregivers have high needs in "methods to prevent common complications", "regular family visits", "professional telephone consultation", "methods to assist patients in rehabilitation and exercise", "basic knowledge of stroke disease", "patient diet guidance", and other aspects. Among the research on supportive needs of caregivers at different care stages of stroke patients, the most impactful is the results of research conducted by Cameron and his team, such as the framework of "timing theory" in which the care process of stroke patients is divided into five different stages: occurrence/diagnosis stage, stable stage, preparation stage, implementation stage, and adaptation stage. According to specific needs of each stage, targeted intervention measures were given, and good results were achieved. With deepening of research on main caregivers of stroke by foreign scholars, many domestic scholars have gradually realized importance of family caregivers in rehabilitation of stroke patients, and research on caregivers of stroke patients has increased year by year.<sup>19</sup> A self-designed questionnaire was used to investigate needs of main caregivers of stroke patients. The results showed that top five needs of home care for stroke patients were regular family visits, methods to assist patients in rehabilitation exercise, methods to prevent common complications, patient diet guidance, and professional telephone consultation services. It can be seen that caregivers urgently need professional help. How to correctly deal with problems in rehabilitation, take positive rehabilitation measures, and make their relatives get best rehabilitation as soon as possible is first consideration of caregivers. At the same time, study also

confirmed that with prolongation of course of stroke patients, the needs of their main caregivers change. It is suggested that the care and support for the main caregivers should be increased within 2 years of stroke rehabilitation to meet the needs of main caregivers, including education needs, human resources need, economic support need, and social support. When investigating the needs of primary caregivers in stroke patients' group,<sup>20</sup> it is proposed that the "discharge transition period" is the most chaotic and helpless period for primary caregivers, which often results in problems such as interruption of patient's nursing services and difficulty in meeting their health needs, and then affected rehabilitation of stroke patients. So, in their study, "Caregiver Discharge Needs Assessment Questionnaire" was used to investigate the current situation of needs of main caregivers of stroke patients during the discharge transition period. The discharge needs were measured at three time points, namely, before discharge, 1 week after discharge, and 4 weeks after discharge. The results showed that caregivers before discharge had high needs in medical services, carerelated information, emotional support, and human support, while in 1 week and 4 weeks after discharge, these mentioned needs are all reduced. It is to be pointed out that the discharge transition period is a stage where main caregivers have most needs and strongest learning motivation, and also the stage where the main caregivers have relatively weak care ability. This stage is an important time to give health education or to implement intervention measures. It is suggested that caregivers' needs must be included in nursing evaluation, which will help caregivers express their needs and enhance their learning motivation. Medical staff can also formulate appropriate health education content.21 A self-designed caregiver demand scale was used to investigate care needs of main family caregivers of patients with stroke sequelae. It was found that main family caregivers of patients with stroke sequelae have high needs for rehabilitation training and disease management. Medical staff should strengthen guidance and education in relevant aspects, and promote development of continuous care, to ensure that patients with stroke sequelae and their main family caregivers can receive continuous individualized nursing guidance and health education in hospitals or families. As a social system with multiple levels and functions, social support is an external resource available to individuals. Social support can not only directly improve quality of life of patients by providing economic and material support, but also provide protection for individuals under stress through buffering, so as to relieve stress and reduce psychological tension of individuals on life events, and it is also of great significance for individuals to maintain good emotional experience.<sup>22</sup> The care burden of main caregivers of stroke patients is negatively correlated with social support. This implies that with an increase in personal resources, the care burden of caregivers decreases. At present, some interventions for main caregivers of stroke survivors are based on social support research, and the purpose of intervention is to help caregivers with different aspects of social support.23 It is found that the best effect can be achieved only when social support provided is closely combined with the needs of caregivers at that time. It is suggested that when providing social support to caregivers, needs at that time should be evaluated so as to give appropriate types of intervention. Therefore, it is of great significance to study the needs of caregivers of stroke patients and their own health maintenance, promote rehabilitation process of stroke patients, optimize medical resources, and save economic costs.

The main caregivers of 163 patients with stroke in this survey are women, accounting for 61.35% of the total. Nearly 1/2 of caregivers are elderly over 60 years of age, and majority of caregivers are spouse or children of patients. This situation indirectly reflects that China's nursing system has not been established and improved, and rehabilitation nursing work of stroke patients is mostly completed by patients' families.<sup>24</sup> Among 163 main caregivers, 1/3 of them independently take care of patients, with an average care time of 6.06 years. Long-term care work is bound to have a negative impact on physical, mental, and social life. 163 caregivers were assessed by ZBI scale, and more than 90% of caregivers reported different levels of burden, indicating that the main caregivers of stroke patients generally felt pressure. At same time, evaluation results of Disease Family Burden Scale (FBS) showed that family system of patients was also affected. The positive response rate of family economic burden, family daily life, and family recreational activities of stroke patients is higher than 50%, which indicates that family economy, family daily activities and family recreational activities of patients are affected by the disease. This survey found that caregivers' understanding of disease has nothing to do with their reported burden level. Only 3 people thought they did not know about stroke, and they reported lowest burden level. The remaining 160 caregivers knew a little or a lot about disease and reported a high burden level. However, the difference between them is not significant. Since sample size of this study is small, whether higher level of understanding of disease will increase the burden of caregivers needs further discussion.<sup>25</sup> There is no relevant report on the relationship between caregivers' understanding of disease and the level of care burden in China. This survey found that caregivers with high school education and above reported a higher burden level on ZBI scale than those with junior high school education and below. This implies that, lower the education level of patient, lower is the burden on main caregiver, and higher the education level of patient, higher is the burden score on the ZBI scale of the main caregiver. One possible explanation is that patients with higher level of education have a higher requirement on their own quality of life. However, the influence of patients' different education levels on family burden was not significant. Increase in influence of control ON the caregiver increases the care needs of the caregiver to a certain extent, thus increasing the care burden of the main caregiver. The above results suggest that main caregiver burden and family burden of stroke patients are affected by both patients and caregivers. It is not only determined by the disease itself but also affected by patients,

as well as by the caregiver's own coping style, social support, and other factors. It is a complex result of physiological and social interaction. To effectively control the burden of patients' main caregivers, it is necessary to analyze various possible influencing factors, confirm their significance, and implement corresponding countermeasures.

#### DATA AVAILABILITY

The experimental data used to support the findings of this study are available from the corresponding author upon request.

#### AUTHOR DISCLOSURE STATEMENT

The authors declare that they have no conflicts of interest regarding this work.

#### ACKNOWLEDGEMENT

This study was supported by the longitudinal study of supportive care needs of primary caregivers of stroke patients based on timing theory, X in-hospital-2221

#### REFERENCE

- Benjamin EJ, Muntner P, Alonso A, et al. Heart disease and stroke statistics-2019 update: a report 1. from the American Heart Association. Circulation. 2019;139(10):e56-e528. doi: 10.1161/ CIR.00000000000659
- Roth GA, Abate D, Abate KH, et al. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980-2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet, 2018; 392(10159):1736-1788. doi: 10.1016/ S0140-6736(18)32203-7
- Campbell BC, Khatri P, Stroke GBD, et al. (2020). Stroke. In Disease Control Priorities. World 3. Bank, 2020;7:261-274.
- GBD 2016 Stroke Collaborators. (2019). Global, regional, and national burden of stroke, 1990-4. 2016: a systematic analysis for the Global Burden of Disease Study 2016. Lancet Neurol. 18(5), 439-458, doi: 10.1016/S1474-4422(19)30034-1
- Feigin VL, Vos T, Nichols E, et al. Global, regional, and country-specific lifetime risks of stroke, 5. 1990 and 2016. N Engl J Med. 2017;379(25), 2429-2437. doi: 10.1056/NEJMoa1804492
- 6. Fereydooni S, Lorenz K, Gamboa R, Ganesh A, Giannitrapani K. Empowering families to take on a primary caregiver role for patients with cancer in india: promising strategies, persistent challenges, and tradeoffs (sci928). Journal of Pain and Symptom Management, 2021;61(3):684. doi: 10.1016/j.jpainsymman.2021.01.089
- Thrift AG, Thayabaranathan T, Howard G et al. Global stroke statistics. Int J Stroke. 2017;12(1):13-7. 32. doi: 10.1177/1747493016676285
- 8 Cameron, J. I., Tsoi, C., Marsella, A. et al. (2020). A feasibility randomized controlled trial of optimal timing of specialized stroke family caregiver training. Archives of Physical Medicine and Rehabilitation. 2020;101(4):634-642.
- Makai P, Looman W, Adang E, Melis R, Stolk E, Fabbricotti I. Cost-effectiveness of integrated care in frail elderly using the ICECAP-O and EQ-5D: does choice of instrument matter? Eur J Health Econ. 2015;16(4):437-450. doi: 10.1007/s10198-014-0583-7
- Moyle W, Borbasi S, Wallis M, Raghavendra P, Griffiths S. Acute care nurses' needs for education 10. and support when caring for patients with dementia and delirium: a systematic review. J Clin Nurs. 2018;27(1-2):e11-e24.
- 11. Kim H, Chang M, Rose K, Kim S. Predictors of caregiver burden in caregivers of individuals with dementia. J Adv Nurs. 2019;75(3):639-650. doi: 10.1111/j.1365-2648.2011.05787.x
- Xu X, Zhang Y, Wang L, Wang X. Needs and preferences of stroke caregivers: A systematic 12. review. Patient Prefer Adherence. 2020;14:2489-2500.
- Yang F, Grimmer K, Hyun KK. Family caregivers of stroke survivors: A scoping review of challenges and interventions. *Disability and Rehabilitation*. 2021;1-16. 13.
- 14. Chung MC, McKee KJ, Austin CA, Peternelj-Taylor C. Dynamic changes in caregiving needs and health among family caregivers of stroke survivors: A growth curve analysis. Rehabilitation Psychology. 2019;64(4):393-406.
- van Eenennaam R, Hoogland J, van der Zee CH, Schans CP, de Jong BA. Unmet care needs of 15. stroke survivors and their informal caregivers: A systematic review of qualitative and quantitative studies. Disability and Rehabilitation. 2020;42(1):1-14.
- 16. Stapleton LM. The incorporation of sample weights into multilevel structural equation models[J]. Structural Equation Modeling. 2002;9(4):475-502. doi: 10.1207/S15328007SEM0904\_2 Shah S, Cooper B, Maas F. The Barthel Index and modified Rankin Scale as outcome measures 17.
- in stroke research: A systematic review and meta-analysis. Brain Injury. 2020;34(3):273-282.
- Jeong YG, Kim MJ, Yoon SJ. Predictors of caregiver burden in caregivers of individuals with stroke: A path analysis. J Clin Nurs. 2018;27(1-2):262-272. 18. Xiao S, Li J, Wang Y, Yuan Y. Social support assessment scale: Development, reliability and 19.
- validity. Chinese Journal of Mental Health. 2008;22(2):90-94. Huang YC, Sousa VD, Martin A. The role of social support on caregiver burden. J Appl Gerontol. 20.
- 2018:37(8):1014-1036 21.
- Huang YC, Sousa VD, Martin A. Caregiver burden, family support, and poststroke depression in patients with stroke: A cross-sectional study. J Neurosci Nurs. 2020;52(5):274-280.
- 22. Loh, A. Z., Tan, J. S., Zhang, M. W., & Ho, R. C. (2017). The global prevalence of anxiety and depressive symptoms among caregivers of stroke survivors. Journal of the American Medical Directors Association, 18(2), 111-116.
- Hekmatpou, D., Mohammad Baghban, E., & Mardanian Dehkordi, L. (2019). The effect of 23. patient care education on burden of care and the quality of life of caregivers of stroke patients. Journal of Multidisciplinary Healthcare, 211-217.
- Sennfält, S., & Ullberg, T. (2020). Informal caregivers in stroke: Life impact, support, and 24. psychological well-being-A Swedish Stroke Register (Riksstroke) study. International Journal of Stroke, 15(2), 197-205.
- Mandizvidza V, London L, Bryer A. Shortfall in stroke care: a study of ischaemic stroke care 25. practices in a South African metropole. South African medical journal. 2021;111(3):215-219. doi: 10.7196/SAMJ.2021.v111i3.15104
- Heiberger CJ, Busch C, Chandler J, et al. Caregiver's recall of stroke discharge education exceeds patients and is associated with greater satisfaction. J Patient Exp. 2019;7(5):796-800. doi: 10.1177/2374373519893201 26.

- Filho P, Gonalves LB, Koetz NF, et al. Long-term follow-up of patients undergoing decompressive 27. hemicraniectomy for malignant stroke: quality of life and caregiver's burden in a real-world setting. *Clin Neurol Neurosurg.* 2020;197:106168. doi: 10.1016/j.clineuro.2020.106168 Han B, Yan Z, Cong B et al. Effect of mirror therapy combined with functional electrical
- 28. stimulation on lower limb function in stroke patients. Basic Clin Pharmacol Toxicol. 2019;S1:124.