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A survey of caregiver burden for stroke survivors in non-teaching hospitals in Western China

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Abstract

The social factors that moderate stroke caregiver burden have been found to be culture- and gender-specific. We examined the factors that influence the social support and self-efficacy of caregivers of stroke survivors and the burden of caregiving in China. To determine the caregiver burden of stroke survivors, their social support, and their self-efficacy. A total of 328 stroke survivors and their caregivers were recruited from 4 tertiary medical centers to participate in this cross-sectional study. The sociodemographic and stroke-related characteristics of the participants were obtained. Perceived social support and self-efficacy were assessed using the Social Support Rating Scale and General Self-efficacy Scale, respectively. Caregiver burden was assessed using the Zarit Burden Interview Scale. Relationships between the variables were assessed using Pearson's correlation, the chi-square test, and a paired *t* test. A total of 27.4% of the caregivers reported receiving adequate social support, while 20.7% reported high levels of self-efficacy. A total of 67.1% of the caregivers experienced varying degrees of care burden, while the remaining 32.9% felt no burden. Participants' sociodemographic characteristics (age, daily care time, self-rated health, and financial situation) were significantly related to caregiver burden, social support, and self-efficacy ($P < .001$). The findings indicate an inverse relationship between caregiver burden, social support and self-efficacy. Adequate social support and self-efficacy can reduce stroke caregivers' burden. Hospital departments should provide assistance to stroke caregivers through educational programs and group training to increase their social support and self-efficacy, thereby alleviating their burden.

Abbreviations: BI = Barthel Index, GCS = Glasgow coma scale, GSES = General Self-efficacy Scale, mRS = modified Rankin Scale, SSRS = Social Support Rating Scale, ZBI = Zarit Burden Interview Scale.

Keywords: caregiver, caregiver burden, self-efficacy, social support, stroke

1. Introduction

Stroke is caused by a sudden rupture of cerebral blood vessels or a disturbance of blood circulation caused by vascular occlusion. It has a high mortality and disability rate. According to the 2016 Global Burden of Disease study, the global lifetime risk of stroke after age 25 is 24.9%, with regional and inter-country differences.[1,2] The report shows that among 195 countries, people over the age of 25 in China have the highest risk of stroke (close to 40%), which means that in China about 2 in 5 people over the age of 25 suffer from stroke during their lifetime.[3] In China, the number of stroke cases among residents over 40 years old is 13.18 million,[3] and more than 1.9 million people die from stroke every year. China has the highest stroke mortality rate, a rate higher than that of cancer and other diseases, accounting for more than 40% of deaths caused by diseases.[4] According to a report by Hu et al,[4] hospitalization expenditure for stroke in 2016 totaled 14.254 billion US dollars. High disability rates mean that most stroke survivors live with enduring impairments of physical and neurological function, necessitating intensive long-term care.

In China, the principal caregivers of stroke survivors are generally family members who typically do not possess professional nursing skills.[5] Caregivers of stroke survivors not only have to undertake most of the survivors' daily care work and assist in functional exercises, but also bear tremendous psychological, social, and financial pressure. Heavy care work places an immense burden on family caregivers, causing depression,[6] anxiety,[7] fatigue, a decline in quality of life,[8] social isolation,[9] and financial problems.[10] Several factors that influence caregiver burden in this population have been

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identified in the literature. The most frequently studied factors include the stroke survivors' functional status[11] and depressive symptoms,[6] the time spent by caregivers on care,[12] and their everyday social support.[13] In addition, some sociodemographic characteristics of stroke survivors and their caregivers, such as gender,[10,14,15] educational level,[15,16] and socioeconomic status,[10,15] are also related to caregivers' burden. Findings on the aforementioned factors have been inconsistent, and it seems that the factors influencing caregiver burden vary. For example, survivors' cognitive status can predict caregiver burden in most developed countries, such as Canada.[17] However, survivors' cognitive status has not been found to affect caregiver burden in certain developing countries, such as Brazil.[8] Similarly, there is no consensus in the literature on whether survivors' age, gender, physical function, mental health, and their relationship with caregivers are correlated with increased caregiver burden.

Few studies have focused on predictors of caregiver burden in China. In past studies, the determinants of caregiver burden included stroke survivors' physical function and depression and caregivers' age, self-rated burden, daily care time, depressive symptoms, and social support.[5,18] However, we believe that the above findings do not fully explain all determinants of caregiver burden. The caregiver burden of stroke survivors in China could differ from that of other cultures. Therefore, cultural differences are excluded from the scope of this study. This study sought to assess caregiver burden for stroke patients in a Chinese cultural context, and the determinants of said burden.

2. Methods

2.1. Study settings and participants

This study adopted an observational and cross-sectional design. It was approved by the Ethical Subcommittees of Mianyang Centre Hospital, Sichuan Science City Hospital, Sichuan Mianyang 404 Hospital, and The Third Hospital of Mianyang. Informed consent was obtained from all participants (ethics approval number: S-2020-049).

This study was conducted at four public tertiary-level hospitals in Sichuan, China. On average, each of the 4 hospitals had 1500 to 2000 hospital beds. Approximately 1.8 million outpatient visits and 80,000 inpatient visits are typically accepted for hospitalization each year. The study participants, who were stroke survivors and their informal caregivers, were selected from stroke wards at the four hospitals. The inclusion criteria were that patients be diagnosed, for the first time, with acute ischemic or hemorrhagic stroke with dysfunction (Barthel Index [BI] score < 100). Diagnoses were made by a qualified doctor according to the International Classification of Diseases, Tenth Revision.[19] Those with serious diseases (e.g., heart disease, renal failure, and tumors) were excluded. The inclusion criteria for informal caregivers were: age > 18 years, clear consciousness, and understanding of the study and the study tools. The caregivers could be the survivor's parents, spouse, children, or other relatives who were largely responsible for providing all types of care needed by the patient and provided support upon the patient's discharge from the hospital. Caregivers who were paid to provide care were excluded.[10] Stroke survivors with caregivers who met the inclusion criteria were included in this study. After obtaining informed consent from the participants, face-to-face interviews with caregivers were conducted by the principal investigator. Caregiving burden, as measured in this study, is caregiving burden during stroke hospitalization. The questionnaires were completed by each caregiver, and the researcher assisted participants who had difficulties completing the surveys. The questionnaires took 20 to 25 minutes for each caregiver to complete. Data were collected between May and October 2020. We distributed 329 questionnaires, and 328 caregivers completed them, with one caregiver (0.3%) completing <50% of the questions. Incomplete questionnaires were excluded from the analysis. The data of the stroke survivors were collected by a trained researcher based on a case or site assessment. For conscious stroke survivors, data were provided by the survivors. For unconscious stroke survivors, data were provided by their caregivers.

2.2. Outcome measures

Caregiver burden was assessed using the Zarit Burden Interview (ZBI) scale,[20] which was designed by Zarit in the 1980s and adapted into Chinese by Wang in 2006.[21] The ZBI scale measures caregiver burden in the following two dimensions: personal burden (e.g., the patient being cared for demands too much care); and responsibility burden (e.g., caring for the patient reduces the caregiver's time for other responsibilities). The scale consists of 22 items assessed on a 5-point Likert scale. A score of 0 represents no, and 4 represents always. Each question's score was added, with the possible total score ranging from 0 to 88. The level of burden was classified as mild or no care (<21), moderate care (21–39), or severe care (>40). The reliability coefficient (Cronbach's α) of the ZBI scale (Chinese version) is 0.87.[22]

2.3. Caregiver and patient characteristics

The baseline data included caregivers' demographic characteristics (e.g., gender, age, educational level, marital status, and daily care time), relationship with the stroke survivor, financial status, ZBI questionnaire score, and self-rated health (excellent, good, fair, poor, and very poor). The self-rated health score assigns higher scores to better states of health. Stroke survivors' baseline information, in addition to their demographic characteristics, included the type of stroke they suffered (ischemic or hemorrhagic) and their stroke outcome measurements (modified Rankin Scale [mRS][23] BI,[24] and Glasgow coma scale [GCS][25]), as assessed by the researchers. BI and mRS scores are commonly used to measure disability in stroke survivors.[25] Swallowing dysfunction was assessed by a professional physician using the Water Swallow Test, and it was recorded in the patient's medical record, where Grade I means no swallowing dysfunction.[26] The BI score can be used to assess stroke survivors' physical function. Stroke survivors with BI ≤ 60 were considered to be physically dysfunctional.[24] The mRS score was used to determine stroke survivors' degree of disability, with 0 to 2 indicating mild disability, 3 to 4 indicating moderate disability, and 5 indicating severe disability.[23] The Social Support Rating Scale (SSRS)[27] was used to assess the social support received by caregivers of stroke survivors. Social support refers to the psychological and material support received by individuals. Social support is an important factor that affects people's social lives, and in this study, it encompasses objective support, subjective support, and support utilization.[28] The SSRS contains 10 items divided into three dimensions: objective support (items 2, 6, and 7), subjective support (items 1, 3, 4, and 5), and utilization of social support (items 8, 9, and 10). The total possible score ranges from 12 to 66 points. Higher scores indicate higher social support. A total score of <33 indicates a low level of social support, a score of 33 to 45 indicates an average level of social support, and a score >45 indicates a high level of social support. The SSRS is widely used in China and has good reliability and validity. Cronbach's alpha was 0.768. Self-efficacy was measured using the 10-item General Self-Efficacy Scale (GSES).[29] The GSES has a possible range of 10 to 40, with higher scores indicating higher self-efficacy, and >30 points indicating high self-efficacy.[29] Cronbach's alpha was 0.927.

2.4. Statistical analyses

Caregiver burden, mRS scores, BI scores, self-efficacy, level of social support, and sociodemographic and stroke-related data were described using means, standard deviations, and frequencies. We used the paired t test (e.g., age, GCS, mRS, BI, and ZBI) and chi-square test (e.g., gender, education, marital status, type of stroke, and physical dysfunction) to explore the relationships between variables. Pearson's inferential correlation statistics were computed to determine the relationships between caregiver burden and self-efficacy, as well as between caregiver burden and social support received by caregivers. The inspection level was set at α = 0.05, and the statistical significance was set at $P < .05$. The data were initially analyzed using SPSS version 24.0 (IBM Company, Armonk, NY).

3. Results

In this study, the mean age of stroke survivors was 64.9 ± 13.4 years, with men outnumbering women survivors. Most stroke survivors experienced an ischemic stroke (58.5%). Most stroke survivors had physical dysfunction (78%), and a small number of stroke survivors had swallowing dysfunction (28.7%). The mean BI of the participants was 53.4 ± 28.1. A total of 88 (26.8%) survivors had mild disability, and 240 (73.2%) had moderate to severe disability as per the mRS. The demographic information of stroke survivors is shown in Table 1.

The mean age of caregivers was 49.9 ± 12.6 years. A total of 42.1% of the caregivers were male, 81.1% were either married or cohabiting, 42.1% were spouses of the stroke survivors, 45.1% were their children, and 68.3% lived with stroke survivors; several caregivers (59.1%) had received junior high school or technical secondary education. Caregivers' outcomes were measured using the ZBI, SSRS, and GSES. The results suggest that a small proportion of the caregivers received an adequate level of social support (27.4%), while 20.7% had a relatively high level of self-efficacy. In this study, 32.8% of the caregivers indicated that they experienced a moderate to severe care burden. The demographic information on the primary caregivers of stroke survivors is shown in Table 2.

Table 1

Sociodemographic characteristics of the stroke survivors of this study.

Characteristics	(N = 328)
	Mean (SD)
Age (yr)	64.9 (13.4)
GCS (score)	13.8 (2.4)
BI (score)	53.4 (28.1)
	Frequency (%)
Gender	
Male	214 (65.2)
Female	114 (34.8)
mRS (score)	
0–2	88 (26.8)
3–4	176 (53.7)
5	64 (19.5)
Education	
Primary school and below	112 (34.1)
Junior high school/technical secondary school	170 (51.8)
College and above	46 (14)
Marital status	
Married/stable union	276 (84.1)
Divorced/widowed/single	52 (15.9)
Type of stroke	
Ischemic	192 (58.5)
Hemorrhagic	128 (39)
Both	8 (2.4)
Physical dysfunction	
Yes	256 (78)
No	72 (22)
Swallowing dysfunction	
Yes	94 (28.7)
No	234 (71.3)
Health insurance	
Public expense	2 (0.6)
Medical insurance for urban workers	162 (49.4)
Medical insurance for nonworking urban residents	159 (48.5)
Business insurance	2 (0.6)
Self pay	3 (0.9)

BI = Barthel Index, GCS = Glasgow coma scale, mRS = modified Rankin Scale.

Table 2

Sociodemographic characteristics of the caregivers of this study.

Characteristics	(N = 328)
	Mean (SD)
Age (yr)	49.9 (12.6)
ZBI (score)	27.2 (13.8)
GSES (score)	25.6 (6.1)
	Frequency (%)
Gender	
Male	138 (42.1)
Female	190 (57.9)
SSRS (score)	
<33	57 (17.4)
33–45	181 (55.2)
>45	90 (27.4)
Education level	
Primary school and below	60 (18.3)
Junior high school/technical secondary school	194 (59.1)
College and above	74 (22.6)
Marital status	
Married/stable union	266 (81.1)
Divorced/widowed/single	62 (18.9)
Relationship to stroke survivors	
Husband/wife	138 (42.1)
Son/daughter	148 (45.1)
Relatives	10 (3)
Friends/son-in-law/daughter-in-law	32 (9.8)
Living together	
Yes	224 (68.3)
No	104 (31.7)
Daily care time	
≤4 h/d	60 (18.3)
5–8 h/d	74 (22.6)
9–12 h/d	98 (29.9)
>13 yr/d	96 (29.3)
Self-rated health	
Very poor	4 (1.2)
Poor	16 (4.9)
Fair	119 (36.3)
Good	145 (44.2)
Excellent	44 (13.4)
Economic situation	
Low	136 (41.5)
Medium	92 (28)
High	100 (30.5)
Living area	
Urban areas	239 (72.9)
Rural areas	89 (27.1)
Underlying disease	
Yes	28 (8.5)
No	300 (91.5)

GSES = General Self-efficacy Scale, SSRS = Social Support Rating Scale, ZBI = Zarit Burden Interview Scale.

3.1. Correlation analysis

Table 3 shows that the daily care time, self-rated health, and the financial situation of caregivers were significantly related to caregiver burden, social support, and the GSES ($P < .05$).

Table 4 shows that social support had a significantly negative relationship with caregiver burden ($r = -0.427$, $P < .001$). This suggests that caregivers with high levels of social support had low levels of caregiver burden. A negative correlation was observed between caregivers' self-efficacy and burden ($r = -0.433$, $P < .001$). The higher a caregiver's sense of self-efficacy, the lighter their care burden felt.

4. Discussion

We present the findings of this study that examine the level of caregiver burden, social support, and general self-efficacy of caregivers of stroke survivors in China.

We found that most participants (67.1%) had different levels of care burden. Among them, only 27.4% of caregivers received adequate social support, while only 20.7% of caregivers had high levels of self-efficacy. Caregiver burden is a multidimensional and complex concept that is affected by many factors and is an important part of caregiver research. As we assumed, marital status, relationship with the patient, daily care time, self-rated health, financial situation, social support, and self-efficacy of caregivers were important predictors of caregiver burden. In China, taking care of a sick family member is considered a familial responsibility, likely stemming from thousands of years of Confucian traditions and filial piety. Chinese people uphold collectivist values and advocate collective interests over individual interests, which may lead to higher tolerance and lower care burden for caregivers. In hospitals, doctors are responsible for the treatment of a disease, nurses provide medical advice, and the patient's family members assist in the daily life activities of the patient. Family members with sufficient financial means can afford to hire nursing staff to help manage patient care. As a result, caregivers with sufficient financial means tend to bear a lighter burden, a finding that is similar to those of previous studies.[10,15,30] Gender was not a predictor of caregiver burden, in contrast to the findings of previous studies.[31] This may be because we did not obtain separate statistics on whether the female caregivers were spouses or children. We also investigated the relationship between the physical function of stroke survivors and caregiver burden. The BI score was shown to be an important predictor of caregiver burden, in accordance with previous studies.[5,11,32,33] This may be because stroke survivors with poor physical functioning require more help from their caregivers, especially more physical care. Many daily activities

(such as eating, going to the bathroom, and getting dressed) are required, irrespective of the time of day. Caregivers' assistance with these activities can affect the amount of time they get to rest. In addition, since stroke survivors cannot perform simple activities, caregivers inevitably worry about the future of the survivors, which in turn increases their psychological burden. Therefore, caregivers with better self-rated health tend to feel a lower care burden. The severity of a stroke survivor's condition (mRS) can also affect the caregivers' burden. The more severe the condition, the heavier the caregiver burden. Strokes always lead to an financial burden as well, as the costs of daily treatment and care are high. In addition, we found that the type of health insurance has no impact on reducing the burden of caregivers ($F = 2.054$, $P = .087$). We believe that this may be due to the low proportion of insurance reimbursement and the limited content of reimbursement, which has a limited impact on reducing the burden of caregivers.

General self-efficacy refers to the degree of self-confidence that an individual possesses to use their own skills to accomplish a task.[34] In our study, a univariate analysis showed that caregivers' self-efficacy was related to stroke survivors' mRS score, caregivers' educational level, their relationship with stroke survivors, average time spent on daily care, self-rated health status, and financial situation. Similar findings were observed in previous studies[35]; however, there were some differences.[36] It is unclear whether a caregiver's age affects their self-efficacy. People with a high sense of self-efficacy are typically positive and optimistic, enjoy doing high-achieving and challenging work, and tend to be more comfortable in the role of caregiver. In contrast, people with low self-efficacy are more prone to pessimism and self-denial and tend to resign themselves to doing simple things in a step-by-step manner; difficult and challenging things make them feel uncomfortable and exhibit evasive behaviors. They are often unable to perform the stressful and anxiety-inducing tasks of caring for patients. Some studies[35,36] have shown that caregivers' self-efficacy can be improved through training, thus reducing their care burden.

The results of this study show that caregivers' social support is related to age, educational level, marital status, daily care time, self-rated health status, and financial status. The older the caregiver, the higher their educational level, the better their financial status, the healthier their self-evaluation, and the more social support they receive from friends, relatives, and other sources. Although similar observations have been made in previous studies,[11,22,37] our results differed in notable ways. There were no obvious differences in social support based on the gender of caregivers.[9] This may be because the sample size of this study was relatively small, or

Table 3

Relationship between sociodemographic characteristics, caregiver burden, social support and general self-efficacy.

Sociodemographic	Caregiver burden		Social support		General self-efficacy	
	r*	P	r*	P	r*	P
Stroke survivor						
GCS	−0.150	**.007**	0.076	.177	0.011	.839
mRS	0.273	**<.001**	−0.103	.064	−0.126	**.023**
BI	−0.283	**<.001**	0.095	.086	0.063	.258
Caregiver						
Age	0.162	**.003**	0.178	**.001**	−0.107	.054
Education level	−0.077	.165	0.129	**.020**	0.154	**.005**
Daily care time	0.324	**<.001**	−0.127	**.022**	−0.133	**.016**
Self-rated health	−0.149	**<.001**	0.119	**.031**	0.186	**.001**
Economic situation	−0.254	**<.001**	0.237	**<.001**	0.233	**<.001**

The significance of bold values is a P value of <.05.

BI = Barthel Index, GCS = Glasgow coma scale, mRS = modified Rankin Scale.

*r, correlation coefficients and P values were estimated using Pearson correlation coefficient.

Table 4

Relationship between caregiver burden social support and general self-efficacy.

	Caregiver burden	
Variable	r*	P
Social support	−0.427	**<.001**
General Self-efficacy Scale	−0.433	**<.001**

The significance of bold values is a P value of <.05.

*r, correlation coefficients and P values were estimated using Pearson correlation coefficient.

because of other unaccounted factors that may have affected the role of gender in social support. In this study, only 27.4% of the caregivers received adequate social support. Possibly, some of the caregivers who did not receive adequate social support were older, had narrower social networks, and more restrained personalities than those who did receive adequate social support, and were unwilling to trouble others (including doctors and nurses) with their difficulties. Our findings show that caregivers with higher levels of social support had lower levels of caregiver burden. This result may also be attributed to the positive effect of social support, which increases caregivers' confidence and hope and reduces their mental and physical burden. Previous studies have shown that regular caregiver participation and communication in stroke support groups can enhance their perceived social support.[38] Therefore, caregivers should participate in such activities to strengthen the social support they receive and thereby reduce their care burden.

4.1. Study limitations

This study has some limitations. First, stroke survivors and caregivers who participated in this study were limited to Sichuan Province, China. Second, the study data did not include the total number of caregivers a patient had; primary caregivers may have reported a higher caregiving burden than non-primary caregivers. Third, a cross-sectional design was used to measure the care burden for stroke patients during hospitalization; thus, the results of this study may not apply to other contexts.

5. Conclusion

Most caregivers of stroke survivors experienced a mild-to-moderate caregiving burden and did not receive adequate social support. Caregiver burden is inversely related to self-efficacy and social support, meaning that the lower the caregivers' self-efficacy level and the lower the social support they receive, the higher their care burden.

Our analysis, in conjunction with previous studies, suggests that mental health experts could provide group training for caregivers of stroke survivors based on the caregivers' self-efficacy and social support to improve their self-efficacy and mobilize the community to help them through difficult times. Furthermore, health insurance reimbursement policies in developing countries should be designed to reduce the financial burden on stroke survivors and their families. Such policies should also include facilities and training programs that support the families of stroke survivors and persons living with other chronic diseases.

Acknowledgments

Author contributions

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