

Factors Influencing Caregiver Burden among Family Caregivers of Post-Stroke Persons in Wenzhou, China

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ABSTRACT

Providing care to post-stroke persons who are dependent at home may lead to the burden for the family caregivers and there are various factors influencing the burden. This predictive correlational study aimed to examine the caregiver burden at three months after providing care for post-stroke persons and examine whether caregiver health status, caregiver amount of caregiving activities, and caregiver mutuality can predict caregiver burden at three months after providing care for the post-stroke persons in Wenzhou, China. A simple random sampling was used to recruit 101 family caregivers who took the patients to follow-up at the outpatient department of the First Affiliated Hospital of Wenzhou Medical University in China. Data were collected using questionnaires including the demographic questionnaire, The SF-12 Health Survey Version 2, The Caregiving Activities Scale, The Mutuality Scale, and the 12-item Zarit Burden Interview. Data were analyzed using descriptive statistics and standard multiple regression. The results showed that the family caregiver burden was at a mild to moderate level with a mean score of 18.29 (SD=4.9). Standard multiple regression revealed health status ($\beta=-0.30$, $p<0.001$), caregiver amount of caregiving activities ($\beta=0.24$, $p<0.001$), and caregiver mutuality ($\beta=-0.38$, $p<0.001$) as the predictor of caregiver burden. The findings provided information for developing an appropriate nursing intervention to prevent progressive caregiver burden, and, in turn, will enable post-stroke persons to receive effective care by targeting caregiver health status, caregiver amount of caregiving activities, and caregiver mutuality.

Keywords: stroke; caregiver burden; influencing factor; China

INTRODUCTION

Stroke has become a serious public health issue devastating millions of lives across the world and China (Faridah, Noor Istiqomah, Kurnianto, & Khovifah, 2022). It is defined as an interruption of blood flow to the brain, damaging neurological function, and it has a large global impact and is the major cause of long-term disability in the world (Helen, Evilianti, & Juita, 2021). Stroke causes movement disorders in sufferers due to decreased muscle function (Abdillah et al., 2022). Worldwide approximately 15 million people have a stroke annually, and one-third suffer permanent physical, cognitive, and emotional impairment. In China, there are more than 2.4 million new stroke victims each year, approximately 70-80% lose their ability to work to some extent, 40% have moderate dysfunction, and 15-30% have severe disabilities (Lu et al., 2019). In Wenzhou, there are more than 20,000 new cases every year and 60% of persons are stroke survivals and have disability as high as 80% (Wang, 2021).

With the consistent improvement in the quality of stroke care, outcomes for post-stroke persons have gradually improved recently, which enables more post-stroke persons to survive (Tsao, et al. 2022). After the treatment at the acute period has been completed, the post-stroke persons will suffer from disease transitions and start their rehabilitation. After a stroke, post-stroke persons probably have some physical changes in how they move, speak, or see (Ferro and Santos, 2020). These physical impacts make post-stroke persons have the limitation and need helping or care from the family caregivers (Zhang and Lee, 2019). In Chinese culture, including in Wenzhou, after a stroke person discharged from hospital, most of them stay with family members, need caring from families in their daily living (Lu et al., 2019).

Caregivers' burden remains a serious problem in the first six months (Han et al., 2017). Many studies show the golden period of the stroke is during the first six months, and this is the first period that they need more assistance with daily activities from family caregivers (Zhang and Lee, 2019). Family caregivers are in transitions because this is first

time they take the caregiver role. In this first period, family caregivers have to deal with difficulty caused by helping the post-stroke persons with their daily living activities, taking the post-stroke persons to see the doctors, encouraging rehabilitation, preventing accidents, and constantly observing for signs and symptoms (Muhrodji et al., 2021). However, if they cannot take in their role and feel more impacts, including physical, mental, emotional, and social well-being aspects, these may cause family caregivers to feel more burden (Han et al., 2017; Zhang and Lee, 2019). It is an increasing hazard, which enables post-stroke persons to receive effective care.

Caregiver burden refers to the feelings of the family caregiver about the effects of negative consequences of caring for post-stroke persons (Liu et al., 2020). As regards caregiver burden, caregiving such as the at first three months, studies showed many family caregivers experience caregiver burden as a result of taking on a new role (Gertrude et al., 2019; Han et al., 2017). Furthermore, in this period, family caregivers need a transition to take the role; transition and coping are needed to prevent caregiver burden (López-Espuela et al., 2018), which enables post-stroke persons to receive effective care. According to transitions theory, which was used as a theoretical guide, transition conditions are the factors influencing caregiver burden. The factors embedded in transition conditions, such as caregiver health status, caregiver amount of caregiving activities, and caregiver mutuality, were reported to influence caregiver burden among family caregivers at three months after providing care for post-stroke persons (Kes and Aydin Yildirim, 2020; Long et al., 2019; Wu et al., 2019a).

Some of the literature indicates strong negative correlations between caregiver burden and the health status of caregivers of stroke survivors. It is their first period of being family caregivers. Since family caregivers are taking on new caregiving roles, they need to do a lot of extra caregiving activities they haven't done before, which makes caregivers provide more time and energy, therefore can lead to adverse health effects of caregivers included sleep disturbance, fatigue, frequent headaches, and weight gain or loss and some health problems such as depression or social isolation for the caregiver (Lu et al., 2022). Empirical evidence demonstrated that there were strong negative correlations between caregiver burden and the health status of caregivers of stroke survivors ($r=-0.839$, $p<0.01$) (Long et al., 2019). Similarly, a study found that family caregivers' low health status was associated with a high caregiver burden (Caro et al., 2018).

Similarly, the caregiver's burden is also influenced by the caregiver's amount of caregiving activities. Caregiver amount of caregiving activities refers to a series of care activities that the family caregivers of post-stroke persons are helping their post-stroke persons. For the first period of stroke, most post-stroke persons cannot eat, cannot walk, and cannot take care of themselves; they need caregiver amount of caregiving activities as high. Wang et al. (2021) found that greater involvement in caregiving activities was related to high levels of caregiver burden. A similar study in China shows that caregiver amount of caregiving activities determinant of caregiving burden which explained 46.8% to 55.0% of the caregiver burden variance ($p<0.05$) (Han et al., 2017).

Caregiver mutuality refers to the perception of family caregivers of post-stroke persons about the positive quality of the relationship between family caregivers and post-stroke persons. In Chinese culture, after being discharged from the hospital, most of the strokes are living with the family, since family caregivers had a close relationship with sick relatives and the family caregiver is responsible for taking care of them (Zhang and Lee, 2019). Support from the family is very important in supporting the successful implementation of stroke management (Trisnadewi & Suniyadewi, 2022). Studies on mutuality between family caregivers of patients remained disabled show that, family caregivers who have high mutuality have lower levels of caregiver burden (Karlsted et al., 2020). Similarly, the study by Wu et al., (2019a) showed that the poor relationship ($OR=1.48$; $95\%CI=1.06-2.07$; $p=0.02$) increased odds of high caregiver burden.

In short, caregivers burden remains a serious problem in the first period of the caregiving. Factors such as caregiver general health status, caregiver amount of caregiving activities, and caregiver mutuality were shown to can predict caregiver burden of family caregivers at three months after providing care for post stroke person. However, studies which focus on the influence of the aforesaid predicting variables on caregiver burden among Chinese family caregivers of post-stroke persons, especially at three months after providing care for first six months of post-stroke persons in China is limited. In addition, since the way of life in China has unique culture and tradition, findings from other countries may not be generalization to its population. Therefore, it is essential to investigate and find out the factors predicting caregiver burden of family caregivers at three months after providing care for post stroke person.

METHOD

The design of this study is a predictive correlational research design. The population in this study were Chinese family caregivers who took the post-stroke persons to follow up on their health at the neurological outpatient department of the First Affiliated Hospital of Wenzhou Medical University. Moreover, the family caregivers provided continuous care for the post-stroke person for three months after discharge from the hospital. Data collection from July 21st, 2021, to September 30th, 2021. The sampling technique used was a simple random sampling method. A Sample of 101 family

caregivers was recruited. The research instrument used the Demographic Questionnaire, The Chinese version of SF-12 Health Survey Version 2, The Chinese Version Caregiving Activities Scale, The Chinese Version Mutuality scale, and The Chinese Version 12-Item Zarit Burden Interview. Data were analyzed using descriptive statistics and standard multiple regression.

RESULT

Table 1 shows that the family caregivers' ages ranged from 28 to 72 years, with a mean age of 48.76 (SD=10.42). Most of them were female (67.4 %). The majority of caregivers were wives (35.6%) and married (67.8%), with Buddhism (85.1 %), and 64.4% of them lived with 2 members in the same household. More than half (56.7%) were employed, and 50.5% of family caregivers earned a monthly family income of 2,000-4,500 Yuan/ month (\$314 - \$707). Most of them take care of post-stroke persons at the time of the patient's admission (87.5%), and 82.8% have a secondary caregiver. Before taking the caregiver role, 69.3% didn't receive stroke caregiving information, and 76.2 % didn't receive caregiving training from a health professional or others. For total hours per day for taking care of patients, family caregivers spent 8.11 hours per day (SD=2.55) taking care of post-stroke persons at home.

Table 1. Frequency, Percentage, Mean, and Standard Deviation of Demographic Characteristics of Family Caregivers (n=101)

Characteristics	Number	Percentage
Gender		
Female	68	67.4
Male	33	32.6
Age (years)		
28-40	19	18.9
41-60	67	66.7
61-72	15	14.4
(M=48.76, SD=10.42, min=28, max=72)		
Religion		
Buddhism	86	85.1
Christian	14	13.8
No religion	1	1.1
Relationship with stroke patient		
Wife	36	35.6
Daughter	28	27.8
Husband	8	7.9
Son	19	18.9
Others: mother, elder sister, younger sister	10	9.8
Marital status		
Single	11	11.1
Married	69	67.8
Divorced/ separated	13	13.3
Widowed	8	7.8
Occupation		
Employed	57	56.7
Unemployed	32	32.2
Retired	12	11.1
Family member		
1	18	17.8
2	65	64.4
≥3	18	17.8
Monthly income of family (Yuan/month)		
<2,000	9	8.9
2,000-4,500	51	50.5
4,500-6,000	19	18.8
6,000-8,000	13	13.1
>8,000	9	8.7

Cont...

Characteristics	Number	Percentage
Total hours per day for taking care patient (hours/day)		
1-5	11	11.1
6-10	72	71.1
11-15	16	15.6
16-20	2	2.2
(M=8.11, SD=2.55, min=4, max=16)		
Secondary caregiver		
Yes	84	82.8
No	17	17.2
Take care of post-stroke persons at admission period		
Yes	88	87.5
No	13	12.5
Source of information received before took caregiver role		
No	70	69.3
Yes*	31	30.7
Doctor	11	5.4
Nurse	12	5.6
Friend	19	9.4
Website	21	10.3
Source of care-giving skill training received before took caregiver role		
No	77	76.2
Yes*	24	23.8
Doctor	11	5.8
Nurse	15	8.0
Friend	19	10.0

*Each family caregiver can answer more than 1 items

Table 2 shows that post-stroke persons' age ranged from 38 to 90 years, with a mean of 65.06 years (SD=12.03). Most were male (63.4%), and 69.9% were married, with 87.2 % being Buddhist. Most payment sources were from medical insurance (88.9%). Considering the type of stroke, 86.1% had an ischemic stroke, whereas 11.9% had a hemorrhagic stroke. In addition, 80.6% of the post-stroke persons experienced co-morbidity; each post-stroke person may have more than one co-morbidity, the most frequently found of which were hypertension, heart disease, and diabetes mellitus.

Table 2. Frequency, Percentage, Mean, and Standard Deviation of Demographic Characteristics of Post-Stroke Persons (n=101)

Characteristics	Number	Percentage
Gender		
Female	37	36.6
Male	64	63.4
Age (years)		
38-40 (Adult)	1	1.1
41-60 (Middle age)	36	35.5
≥60 (Elderly)	64	63.4
(M=65.06, SD=12.03, min=38, max=90)		
Religion		
Buddhism	88	87.2
Christian	12	11.7
No Religion	1	1.1
Marital status		
Single	2	2.2
Married	71	69.9
Divorced/separated	16	15.6
Widowed	12	12.3

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	Characteristics	Number	Percentage
Stroke type			
	Ischemic stroke	87	86.1
	Hemorrhagic stroke	12	11.9
	Ischemic & Hemorrhagic stroke	2	2.0
Source of payment			
	Self-paid	11	11.1
	Medical insurance	90	88.9
Co-morbidity			
	No	20	19.4
	Yes**	81	80.6
	Hypertension	52	39.9
	Diabetes mellitus	21	15.7
	Heart disease	15	11.2
	Allergy	4	3.0
	Kidney	3	2.2
	COPD	3	2.2
	Skin diseases	3	2.2
	Dementia	2	1.4
	Hyperlipidemia	2	1.4
	Gout	2	1.4

**Each post-stroke persons have more than 1 co-morbidity

Table 3 shows family caregivers had a burden with a mean score of 18.29 (SD=4.9), indicating family caregivers had mild to moderate burden.

Table 3. Range, Mean, and Standard Deviation of Caregiver Burden among the Participants (n=101)

	Range		M	SD	Meaning
	Possible score	Actual score			
Caregiver burden	0-48	7-26	18.29	4.9	mild to moderate

Table 4 shows the mean score of the caregiver health status was 43.5 (SD=12.0), indicating poor health status. The mean score of caregiver amount of caregiving activities was 50.9 (SD=10.3) indicating they provide care activity for their stroke persons at moderate to a high level. The mean score of caregiver mutuality was 47.5 (SD=6.1), the finding indicated that participants in the study perceived high mutuality with stroke persons.

Table 4. Possible Score, Actual Score, Mean, Standard Deviation, and Meaning of Variables

	Range		M	SD	Meaning
	Possible score	Actual score			
Caregiver health status	0-100	23.38-81.25	43.5	12.0	poor
Caregiver amount of caregiving activities	0-87	34-73	50.9	10.3	moderate to high
Caregiver mutuality	0-60	34-59	47.5	6.1	high

Table 5 shows correlation of the studied variables. From the correlation matrix, caregiver burden was significantly positive correlated with caregiver amount of caregiving activities ($r=0.62$, $p<0.01$), and was significantly negative correlated with caregiver mutuality ($r=-0.68$, $p<0.01$), caregiver health status ($r=-0.65$, $p<0.01$).

Table 5. Correlation Matrix among the Variables (n=101)

	Caregiver health status	Caregiver amount of caregiving activities	Caregiver mutuality	Caregiver burden
Caregiver health status	1			
Caregiver amount of caregiving activities	-0.53**	1		
Caregiver mutuality	0.56**	-0.56**	1	
Caregiver burden	-0.65**	0.62**	-0.68**	1

*p<0.05, **p<0.01, ***p<0.001

To determine the predictors of caregiver burden, standard multiple regression was performed. Table 6 shows caregiver health status, caregiver amount of caregiving activities, and caregiver mutuality explained 59% of the variance in caregiver burden among family caregivers of post-stroke persons (F=49.24, p<0.001). Among the three factors, caregiver mutuality (β =-0.38, p<0.001) was the best predictor, followed by caregiver health status (β =-0.30, p<0.001) and caregiver amount of caregiving activities (β =0.24, p<0.001).

Table 6. Influencing Factors of Caregiver Burden among the Participants (n=101)

Predicting variables	B	SE	β	t	p-value
Caregiver health status	-0.12	0.033	-0.30	-3.37	<0.001
Caregiver amount of caregiving activities	0.11	0.039	0.24	2.97	<0.001
Caregiver mutuality	-0.30	0.06	-0.38	-4.52	<0.001

Constant=32.32, p<0.001, R²=0.60, R²(adj)=0.59, F=49.2

DISCUSSION

The findings of the study revealed that caregiver burden among family caregivers at three months after providing care for the post-stroke person was predicted by caregiver health status (β =-0.30, p<0.001), caregiver amount of caregiving activities (β =0.24, p<0.001), and caregiver mutuality (β =-0.38, p<0.001), which is in line with the objective of the study. All the variables explained 49% of the variance in caregiver burden (SD=4.9). The reasons for these findings can be enumerated in terms of the demographic characteristics of the family caregivers, post-stroke persons, and Chinese culture.

In consistent with the hypothesis of the study, caregiver health status significantly predicted caregiver burden among family caregivers at three months after providing care for post-stroke person. According to Transitions Theory, caregiver health status is considered as transition condition factors affecting on transition outcome of family caregivers. Possession of good health status is reported to positively facilitate successful transitioning. When poor health status may be an inhibitor, it will lead to unhealthy and ineffective transitions, and may result in negative outcomes, including caregiver burden (Caro et al., 2018).

With regard to this result, family caregivers at three months after providing care for post stroke person did not have good health status with the mean score of 43.5 (SD=12.0) and lead them to a greater feeling of perceived burden. This was because the stressful task of taking care may lead caregivers cannot cope with the new transition situation by themselves, which may make them more stressed and therefore affect their health status and bring the caregiver burden (Lu et al., 2019).

The finding of our study is in congruence with those of the previous studies. A study demonstrated that higher caregiver health status was associated with the lower burden score (Long et al., 2019). Additionally, Mamta et al. (2017) stated there was a significant negative correlation between quality of life and burden scores of caregivers.

It is consistent with our research hypothesis; caregiver amount of caregiving activities is another factor that significantly predicted caregiver burden in the current study. According to Transitions Theory, caregiver amount of caregiving activities is also considered as transitions condition factors affecting on transition outcome of family caregiver.

This study showed caregiver amount of caregiving activities was at moderate to a high level. When providing care, if caregiver amount of caregiving activities spends more time and energy, it will be reduced family caregivers' personal daily activities for themselves. Caregivers' life may be affected more when they had to spend more daily activities providing care, which inhibits the family caregiver's ability to successfully transition, and this could lead them to increase perceived caregiver burden.

This finding was consistent with previous studies. A study demonstrates that the burden is more on family caregivers for the post-stroke persons providing more caregiving activities (Khanittanuphong and Leelasamran, 2016; Wang et al., 2021). Moreover, the level of caregiver burden is influenced by the number of caregiving activities the family caregivers perform for their post-stroke persons; the more caregiver amount of caregiving activities performed, the more caregiver burden of those family caregivers of post-stroke persons feels (Chen et al., 2020; Kavga et al., 2021).

Likewise, caregiver mutuality is a factor reported as a potent predictor of caregiver burden in previous studies. According to Wu et al. (2019a), it is assumed that family caregivers with high mutuality have lower levels of caregiver burden. Caregiver mutuality was high among the participants in this study and significantly predicted the caregiver burden of family caregivers three months after providing care for post-stroke persons in Wenzhou, China. In Chinese culture, after being discharged from the hospital, most of the strokes are with the family since family caregivers had a close relationship with sick relatives, and the family caregiver is responsible for taking care of them (Lu et al., 2022). Family caregivers try to make the best of their abilities in providing care and positively cope with the new transition. This factor may facilitate successful transitioning and lead to healthy and effective transitions, leading them to perceive a mild to moderate caregiver burden.

This finding is consistent with our research hypothesis and previous literature. The previous study showed that family caregivers with high mutuality have lower levels of caregiver burden (Mei et al., 2020). Likewise, another study showed that a lower relationship was associated with a higher caregiver burden (Wu et al., 2019a). Additionally, the study by Tough et al. (2017) found that Caregiving partners who rated their relationship quality as high encountered less caregiver burden ($\beta=-1.10$; 95% CI=-1.47 to -0.72; $p<0.001$).

CONCLUSION

The study revealed that the caregiver burden of family caregivers at three months after providing care for post stroke persons in Wenzhou, China was at a mild to moderate level. Additionally, caregiver health status, caregiver amount of caregiving activities, and caregiver mutuality can predict caregiver burden of family caregivers at three months after providing care for post stroke persons in Wenzhou, China.

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