Caregiver Burdens and Perceived Self-Efficacy of Family Caregivers of Stroke Survivors During the COVID-19 Pandemic in Chengdu, the People's Republic of China*

ภาระของผู้ดูแลและการรับรู้สมรรถนะแห่งตนของผู้ดูแลในครอบครัวของผู้รอดชีวิตจากโรคหลอดเลือดสมองในช่วงการระบาดของโรคโควิด 19 ในเฉิงตู สาธารณรัฐประชาชนจีน*

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Abstract

Caregiver burden is common among family caregivers of stroke survivors, especially during the COVID-19 pandemic. A strong sense of self-efficacy for family caregivers might reduce this burden. The purposes of this correlational research were to explore caregiver burdens and self-efficacy, as well as the relationship between self-efficacy and caregiver burdens among family caregivers of stroke survivors during the COVID-19 pandemic in Chengdu, Sichuan Province, the People's Republic of China. One-hundred and two participants from two tertiary hospitals in Chengdu, China were recruited by purposive sampling. The research instruments included a demographic data form, the Chinese version of the Caregiver Burden Inventory for measuring caregiver burden, and the Chinese version of the Caregiver Inventory for measuring perceived self-efficacy. The internal consistency of the two questionnaires were .96 and .91, respectively. Data were analyzed using descriptive statistics and Spearman's rank-order correlation analysis.

This study showed that the mean score for caregiver burden was 34.39 (SD = 14.50) while the mean score for perceived self-efficacy was 22.09 (SD = 3.25). The mean score was moderate for caregiver burden and high for self-efficacy. There was a negative correlation between perceived self-efficacy and caregiver burden among family caregivers of stroke survivors during the COVID-19 pandemic (r_s = -.30, $p < .01$).

The findings could be used as basic information for developing programs to promote self-efficacy in family caregivers of stroke survivors during public health emergencies in China.

Keywords: Caregiver burden; Perceived self-efficacy; Family caregivers; Stroke; COVID-19

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บทคัดย่อ

ภาระของผู้ดูแล เป็นสิ่งที่พบได้ในผู้ดูแลในครอบครัวของผู้รอดชีวิตจากโรคหลอดเลือดสมอง โดยเฉพาะในช่วงการระบาดของโรคโควิด 19 การรับรู้สมรรถนะแห่งตนในระดับสูงของผู้ดูแลในครอบครัวอาจลดภาระของผู้ดูแลได้ การศึกษาเชิงพรรณนาหาความสัมพันธ์ครั้งนี้ มีวัตถุประสงค์เพื่อศึกษาภาระของผู้ดูแลและการรับรู้สมรรถนะแห่งตน และความสัมพันธ์ระหว่างภาระของผู้ดูแลและการรับรู้สมรรถนะแห่งตนของผู้ดูแลในครอบครัวของผู้รอดชีวิตจากโรคหลอดเลือดสมองในช่วงการระบาดของโรคโควิด 19 ในเฉิงตู มณฑลเสฉวน สาธารณรัฐประชาชนจีน ใช้วิธีการสุ่มแบบเจาะจงเพื่อคัดเลือกกลุ่มตัวอย่างจำนวน 102 ราย จาก 2 โรงพยาบาลตติยภูมิ ในเฉิงตู สาธารณรัฐประชาชนจีน เครื่องมือที่ใช้ในการวิจัยประกอบด้วย แบบฟอร์มข้อมูลส่วนบุคคล แบบประเมินภาระของผู้ดูแลฉบับภาษาจีน และแบบประเมินการรับรู้สมรรถนะแห่งตนฉบับภาษาจีน ค่าสัมประสิทธิ์ความสอดคล้องภายในของแบบประเมินภาระของผู้ดูแล และการรับรู้สมรรถนะแห่งตนเท่ากับ .91 และ .96 ตามลำดับ วิเคราะห์ข้อมูลโดยใช้สถิติเชิงพรรณนา และสถิติ Spearman's rank-order correlation analysis

ผลการศึกษาพบว่า ค่าคะแนนเฉลี่ยภาระของผู้ดูแลเท่ากับ 34.39 (SD = 14.50) และค่าคะแนนเฉลี่ยการรับรู้สมรรถนะแห่งตนเท่ากับ 22.09 (SD = 3.25) โดยภาระของผู้ดูแลอยู่ในระดับปานกลาง และการรับรู้สมรรถนะแห่งตนอยู่ในระดับสูง ภาระของผู้ดูแลมีความสัมพันธ์ทางลบกับการรับรู้สมรรถนะแห่งตนของผู้ดูแลในครอบครัวของผู้รอดชีวิตจากโรคหลอดเลือดสมองในช่วงการระบาดของโรคโควิด 19 อย่างมีนัยสำคัญทางสถิติ (r_s = -.30, $p < .01$)

ผลการศึกษานี้สามารถใช้เป็นข้อมูลพื้นฐานสำหรับพัฒนาโปรแกรมเพื่อส่งเสริมการรับรู้สมรรถนะแห่งตนในครอบครัวของผู้รอดชีวิตจากโรคหลอดเลือดสมองในช่วงภาวะฉุกเฉินด้านสุขภาพในประเทศจีน

คำสำคัญ: ภาระผู้ดูแล การรับรู้สมรรถนะแห่งตน ผู้ดูแลในครอบครัว โรคหลอดเลือดสมอง โรคโควิด-19

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Background and significance

Stroke has become one of the major diseases that endangers people's health around the world. In 2020, there were about 17.8 million stroke survivors in China (Wang et al., 2021), and more than 80% of these received care at home from family members after discharge (Gao et al., 2020).

Family caregivers refer to the unpaid spouse, adult children, relatives, friends, or neighbors who take care of someone with physical, psychological, or cognitive impairments (Schulz et al., 2020). In addition to routine caregiving tasks, family caregivers had to undertake more caregiving tasks during the COVID-19 pandemic, such as taking up the role of rehabilitation therapist at home to maintain functional abilities (Lee et al., 2021) and preventing COVID-19 infection (Bakas & Commiskey, 2021).

Caregiver burdens refer to the adverse effects or costs to the family caregiver resulting from caregiving to an impaired family member and include five aspects: time-dependence, developmental, physical, social, and emotional caregiver burdens (Novak & Guest, 1989). There is a burden on family caregivers of stroke survivors regardless of the level of a country's development (Chafjiri et al., 2017; Tsai & Pai, 2016). Caregiver burdens not only have an influence on caregivers but also have an impact on stroke survivors and the healthcare system (Chou, 2000).

In the previous literature, perceived self-efficacy is often reported as one of the factors associated with the caregiver burden. According to Bandura (1977), self-efficacy is a family caregiver's degree of confidence in performing activities and tasks specific to caregiving. Even though various studies have demonstrated that perceived self-efficacy has a negative relationship with caregiver burden among family caregivers of stroke survivors (Boonsin et al., 2021; Gao et al., 2020; Kruithof et al., 2016), it is still necessary to study caregiver burdens and perceived self-efficacy among family caregivers of stroke survivors in China for two reasons.

Firstly, most previous studies do not distinguish between severity or stages of disease, but only identify inpatients or community stroke survivors (Gao et al., 2020; Zhang et al., 2023), and use the general self-efficacy scale to measure self-efficacy (Jia et al., 2021) which does not reflect the specific efficacy of stroke survivors living in China.

Secondly, the COVID-19 outbreak has caused many changes in the healthcare system, including difficulty in accessing hospitals, changes in diagnosis and treatment methods (Shen et al., 2020), and limitations of medical resources (Lee et al., 2021; Zhao et al., 2020). Difficulty in accessing the entrance to a hospital was because of "no visitor" policies (Sutter-Leve et al., 2021) which resulted in family caregivers missing out on learning opportunities from doctors, nurses, or therapists to provide care to their relatives; therefore, they could not assess the abilities of their relatives and, subsequently, would require assistance when returning home (Sutter-Leve et al., 2021). Additionally, "no visitor" policies had a great impact on the family caregivers of stroke survivors including their care competency, patients' uncertain progress, and feelings of unpreparedness for discharge (Sutter-Leve et al., 2021). With limited medical resources, family

caregivers and stroke survivors had relatively reduced access to health service resources which could result in an increase in unmet needs. Moreover, access to health care service also became more procedural. All of these changes can increase the caregiving burdens of family caregivers.

During the COVID-19 pandemic, there has been no research exploring the correlation between caregiver burden and self-efficacy among family caregivers of stroke survivors. Therefore, this study aimed to explore the caregiver burdens and perceived self-efficacy among family caregivers of stroke survivors during the COVID-19 pandemic in China. The information gained could be used as the basis for the development of programs to improve self-efficacy during public health emergencies in China.

Objectives

1. To describe the caregiver burden and perceived self-efficacy among family caregivers of stroke survivors during the COVID-19 pandemic in Chengdu, Sichuan Province, China.

2. To examine the relationship between perceived self-efficacy and caregiver burden among family caregivers of stroke survivors during the COVID-19 pandemic in Chengdu, Sichuan Province, China.

Conceptual framework

The conceptual framework of this study is based on Novak and Guest's (1989) concept of caregiver burden and Bandura's (1977) concept of self-efficacy. Caregiver burden refers to adverse effects or costs to the family caregivers of stroke survivors resulting from their caregiving and includes five dimensions: 1) time-dependence burden, 2) developmental burden, 3) physical burden, 4) social burden, and 5) emotional burden. To reduce caregiver burdens, self-efficacy is needed (Leung et al., 2020). Self-efficacy is the belief of family caregivers of stroke survivors in their ability to carry out activities and tasks specific to caregiving. Caregivers' self-efficacy was divided into three dimensions: 1) care of stroke survivors, 2) management of medical information and self-care, and 3) management of emotional interaction with stroke survivors. Self-efficacy can affect caregiver burden by influencing the cognition process, the motivation process, affective proclivities, and the selection process (Bandura et al., 1999). That is, family caregivers with high self-efficacy are more likely to handle caregiving tasks as challenges, are proactive in self-care, are better able to control upsetting thoughts, are conducive to perceiving the positive aspects of the care experience, and are prone to facing caregiving roles with a positive attitude. Thus, family caregivers with high self-efficacy have lower caregiver burdens (Gao et al., 2020).

Methodology

This descriptive correlational study examined family caregivers who took care of stroke survivors for their first follow-up visit after discharge from the rehabilitation department in either the Affiliated Hospital of Chengdu University or Chengdu Fifth People's Hospital in Chengdu, Sichuan province, China.

Population and sample

The population in this study were family caregivers who took care of stroke survivors for their first follow-up visit after discharge.

Participants were recruited using the purposive sampling method. The inclusion criteria consisted of being a family caregiver of a patient first diagnosed with stroke or those with hemiplegia at first follow-up after stroke; being more than 18 years old; having the main responsibility as an unpaid caregiver; living with the stroke survivor and taking care of the stroke survivor for more than 14 days; having the ability to read, comprehend, and write in Chinese language; and being willing to participate in this study. The exclusion criteria were family caregivers who needed to care for more than one patient at a time; those with a psychiatric disease history; and those with other disabilities.

The sample size was calculated based on power analysis with a modest effect size of 0.3, power test of β of 0.8, and the level of α of 0.05, resulting in a sample size of 85. Considering for the possible loss of participants at 20% (Grove et al., 2012), the total number of the sample size was 102.

Research instruments

The research instruments in this study included three parts:

1. The demographic data form included general information about the stroke survivors and family caregivers.

2. Caregiver burden was measured using the Caregiver Burden Inventory (CBI) scale, developed by Novak and Guest (1989). It was translated by Yue (2006) and included 24 items with a 5-point Likert scale and five dimensions (time-dependence burden, development burden, physical burden, social burden, and emotional burden). The overall score on each subscale ranged from 0-20, except for physical burden, which ranged from 0-16. The overall possible score of the CBI ranged 0-96 with a higher score indicating a higher level of caregiver burden.

3. Perceived self-efficacy was measured using the Caregiver Inventory (CGI) scale, developed by Merluzzi et al. (2011). The Chinese version of the CGI adapted by Leung et al. (2017) included 18 items with a 9-point Likert scale and three domains (care of the care recipient, managing information and self-care, and managing emotional interactions with the care recipient). The score of each subscale was the sum of each item divided by the number of items, ranging from 1 to 9. The overall score ranged from 3 to 27. High scores indicated a high level of caregiving self-efficacy.

With permission from the original developers and translaters, the Chinese version's reliabilities (CBI and CGI) were .91 and .96, respectively, based on 10 participants sharing similar characteristics to those in the main study.

Ethical considerations

This study was approved by the Institutional Review Board (IRB) of the Faculty of Nursing, Chiang Mai University, Thailand (2021-EXP026). Permission to collect data was obtained from the

directors of nursing of the Affiliated Hospital of Chengdu University and the Chengdu Fifth People's Hospital. The consent form, in a Chinese version, was signed before the beginning of data collection. The completed questionnaire and the consent form were collected separately to ensure anonymity and confidentiality.

Data collection

In this study, the researcher explained the purpose and benefits of the study to all eligible participants and emphasized the confidentiality and anonymity of their personal responses. Those who agreed to participate in this study were asked to sign an informed consent form before responding to the self-report questionnaires. The questionnaires were distributed to participants while they waited to meet with a doctor. The researcher provided a quiet and private room for participants to fill out the questionnaires which took approximately 15-25 minutes per participant.

Data analysis

Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 25.0 provided by Chiang Mai University. The demographic data were analyzed using frequency and percentage to describe distributions. The scores from the CBI and CGI were analyzed using mean, standard deviation, and range to describe averages and dispersion. The Kolmogorov-Smirnov test was used to examine the type of data distribution. The results showed that the CBI and CGI scores were not normally distributed. Therefore, Spearman's rank-order correlation was used to examine the relationship between self-efficacy and caregiver burden among family caregivers of stroke survivors.

Results

In this study, all stroke survivors were diagnosed with hemiplegia. Most of them (n = 82; 80.39%) were married. The ages ranged from 23 to 78 years with a mean age of 49.19 years. Slightly over a third of them (37.25%) had a college degree or above. Forty family caregivers (n = 40; 39.21%) were either spouses or an adult child of the stroke survivor (Table 1).

The results showed that the mean CBI score was 34.39 ± 14.50. The mean score of time-dependence burden was highest when compared to other subscales (Table 2). To give equal weight to each dimension, the physical burden score was multiplied by 1.25; therefore, the mean score of physical burden was 7.76. In other words, the top three caregiver burden scores were time-dependence burden, development burden, and physical burden. The mean CGI score was 22.09 ± 3.25. Among the three dimensions of the CGI scale, participants had the highest score on care of the care recipient dimension, with a mean score of 7.77 ± 1.20, and had the lowest self-efficacy on the managing information and self-care dimension, with a mean score of 6.75 ± 1.27 (Table 3).

The correlation analysis demonstrated a weak negative relationship between the total score of self-efficacy and caregiver burdens among family caregivers of stroke survivors during the COVID-19 pandemic in China (r_s = -0.30, $p < .01$); between managing information and self-care

and the total score of caregiver burdens (r_s = -0.34, p < .01); and between managing emotional interaction with the care recipient and the total score of caregiver burdens (r_s = -0.27, p < .01). There was no relationship between care of the care recipient and the total score of caregiver burdens. In addition, there were no relationships between the self-efficacy subscales and time-dependence burden (Table 4).

Table 1 Demographic characteristics of stroke survivors and family caregivers (n = 102)

Demographic characteristics	Frequency (n)	Percentage (%)
Stroke survivors diagnosed with hemiplegia		
Gender		
Female	42	41.18
Male	60	58.82
Age (Years) (Mean = 60.71, SD = 16.37, Range = 23.00-100.00)		
20-40 years old	14	13.72
41-60 years old	40	39.22
61-70 years old	15	14.71
>70 years old	33	32.35
Marital status		
Single	5	4.90
Married	82	80.39
Divorce	3	2.94
Widow	12	11.77
Employment status		
Not employed	39	38.24
Self-employed	11	10.78
Privately employed	6	5.88
Government-employed	7	6.86
Retired	39	38.24
Educational level		
Senior high school or below	70	68.63
Associate's degree	23	22.55
Bachelor's degree	9	8.82
Family caregivers		
Gender		
Female	72	70.59
Male	30	29.41
Age (Years) (Mean = 49.19, SD = 12.54, Range = 23.00-78.00)		
20-40 years old	26	25.49
41-60 years old	64	62.75
61-70 years old	10	9.80
>70 years old	2	1.96

Table 1 Demographic characteristics of stroke survivors and family caregivers (n = 102) (continue)

Demographic characteristics	Frequency (n)	Percentage (%)
Employment status		
Not employed	45	44.12
Self-employed	12	11.76
Privately employed	14	13.73
Government-employed	8	7.84
Retired	23	22.55
Educational level		
Senior high school or below	64	62.75
Associate's degree	28	27.45
Bachelor's degree	9	8.82
Master's degree or above	1	0.98
Relationship with stroke survivors		
Spouse	40	39.21
Adult child	28	27.45
Parents	16	15.69
Other relatives	18	17.65
Hours of caregiving per day		
2 hours/day < Time ≤ 5 hours/day	6	5.88
5 hours/day < Time ≤ 8 hours/day	8	7.84
8 hours/day < Time ≤ 13 hours/day	12	11.77
Above 13 hours/day	76	74.51
Caregiving duration		
Below 1 month	25	24.51
1 month < Duration ≤ 3 months	41	40.20
3 months < Duration ≤ 6 months	10	9.80
6 months < Duration ≤ 12 months	2	1.96
Above 12 months	24	23.53

Table 2 The scores of caregiver burden and the five sub-scales (n = 102)

Scale/sub-scale	Possible range	Range	Mean	SD
Total CBI score	0-96	12-85	34.39	14.50
Time-dependence burden	0-20	5-20	14.42	4.08
Development burden	0-20	0-20	8.45	5.15
Physical burden	0-16	0-16	6.21	3.75
Social burden	0-20	0-20	3.92	4.31
Emotional burden	0-20	0-14	1.39	2.89

Table 3 The scores for self-efficacy among family caregivers and the three sub-scales (n = 102)

Scale/sub-scale	Possible	Range	Mean	SD
Total CGI score	3-27	11.89-27.00	22.09	3.25
Care of the care recipient	1-9	3.14-9.00	7.77	1.20
Managing information and self-care	1-9	3.71-9.00	6.75	1.27
Managing emotional interaction	1-9	3.75-9.00	7.57	1.27

Table 4 The relationship between self-efficacy and caregiver burden among family caregivers of stroke survivors (n = 102)

Caregiver Burden	Perceived Self-efficacy			
	Total score	Care of the care	Managing information and self-care	Managing emotional interaction with care recipient
Total score	-.30**	-.17	-.34**	-.27**
Time-dependence burden	0.98	-.00	.16	.09
Development	-.35**	-.21*	-.38**	-.29**
Physical burden	-.24*	-.13	-.29**	-.23*
Social burden	-.37**	-.16	-.45**	-.38**
Emotional burden	-.31**	-.18	-.36**	-.24**

** p < .01. * p < .05.

Discussion

Additional challenges for family caregivers are presented against the changes in the caregiving context caused by COVID-19 (Lee et al., 2021), for example, increased caregiving tasks, such as the series of measures for preventing COVID-19 infection. However, in this study, the overall mean caregiver burden score was lower compared to another study of stroke survivors prior to the pandemic in China (Tsai & Pai, 2016), which is consistent with the results of Liu and colleagues (Liu et al., 2022). This might be related to the management of home isolation during the COVID-19 pandemic which allowed caregivers more free time to accompany and care for stroke survivors, as well as reduce family role conflicts. In addition, Liu and colleagues reported high satisfaction with family support during COVID-19 which would reduce family caregivers' burden (Liu et al., 2022). The relatively lower burden might also be attributed to the higher educational level of family caregivers and the shorter care duration (Unsar et al., 2021).

To reasonably compare the burden of each dimension, the physical burden score was multiplied by 1.25, so that the top three caregiver burdens were time-dependence burden, followed by development burden and physical burden. Social burden and emotional burden received the lowest scores, which was consistent with a study conducted by Tsai and Pai (2016)

in China. The stroke patients in this study were all hemiplegic patients with varying degrees of limitations in their ability to provide self-care and needed help from their caregivers in daily life. At the same time, during COVID-19, due to home isolation, caregivers spent more time with stroke survivors (Lee et al., 2021), and due to the closure of rehabilitation facilities, they had to undertake the tasks of therapists (Lee et al., 2021), causing the time-dependence burden to be heavier.

According to the scoring of the CGI, there was a high level of self-efficacy among family caregivers in this study. The high self-efficacy of caregivers in caring of the care recipient might be related to the effects of quarantine policies, closure of rehabilitation facilities, and closure of day centers during the COVID-19 pandemic, with caregivers providing longer hours of caregiving and having more caregiving experience. On the other hand, in this study, all stroke survivors were classified as having hemiplegia with some degree of mobility restriction. Merluzzi and colleagues reported that high levels of restricted mobility were associated with moderately higher levels of self-efficacy in caring for the care recipient (Merluzzi et al., 2011). After all, the most effective technique to establish a strong sense of efficacy is via mastery experiences (Bandura et al., 1999). Self-efficacy in managing emotional interaction with the care recipient and managing information and self-care was lower than self-efficacy in caring of the care recipient because dealing with the negative emotions of the caregiving recipient can make caregiving tasks difficult (Merluzzi et al., 2011), and self-care is an area that is frequently overlooked (Adelman et al., 2014). Moreover, another reason for difficulty in managing emotional interactions with the care recipient may be that stroke survivors suffer from post-stroke depression (Dou et al., 2018).

The findings of this study revealed a weakly negative correlation between self-efficacy and caregiver burden among family caregivers of stroke survivors, which is consistent with research findings prior to the COVID-19 pandemic (Gao et al., 2020). These similar findings might involve the rapid development of the internet and the establishment of new models of health education during the COVID-19 pandemic, such as live broadcasting, WeChat public accounts (Zhao et al., 2020), and telemedicine technology. The average age of caregivers in this study was young, and all were educated; therefore, they were less affected by changes in the health care system. Through media channels and family caregivers, they could not only learn how to provide patients with better care on a regular basis but also be in contact with other family caregivers. Importantly, it was easier for family caregivers to consult with doctors. Tang and colleagues reported significant differences in the distribution of caregivers' self-efficacy scores at the doctor-patient communication level (Tang et al., 2019).

Managing information and self-care and managing emotional interaction with care recipient and caregiver burdens were negatively related, possibly due to the occurrence of media-based health education during the COVID-19 pandemic. Family caregivers shifted their focus from hospital visits to self-care, maintaining, promoting, and accomplishing optimal health and well-being for themselves (Martínez et al., 2021). There was a relationship between managing

emotional interaction with care recipients and caregiver burdens. This is because family caregivers with high self-efficacy tend to better control upsetting thoughts (Semiatin & O'Connor, 2012) and are more likely to be optimistic and cheerful, actively communicating with their loved ones and increasing the sense of effectiveness and satisfaction in their caregiving roles (Semiatin & O'Connor, 2012).

Conclusions and implications

Caregiver burden among family caregivers of stroke survivors in China during the COVID-19 pandemic was moderate, and self-efficacy of caregiving among family caregivers was relatively high. There was a weak negative relationship between self-efficacy and caregiver burdens among family caregivers of stroke survivors during the COVID-19 pandemic. The findings of this study provide basic knowledge for nurses to develop strategies to increase the self-efficacy of family caregivers, especially in managing information and self-care which may reduce the caregiver burdens of family caregivers of stroke survivors during public health emergencies.

Recommendations

The specific tools used in this study more clearly described the burden and self-efficacy of family caregivers. An interventional research design may be considered to improve self-efficacy in terms of managing information and self-care and managing emotional interactions with care recipients. However, many factors might affect the burden of family caregivers; therefore, other confounding factors should be explored in future research in order to better explore and be more realistic for individual stroke survivors.

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