


Empowerment in Chinese primary caregivers of post-stroke patients with disability

A cross-sectional study

Youhua Liu, MD^{a,b}, Hong Guo, MD^{a,*} 

Abstract

To investigate the status quo of empowerment ability of primary caregivers in post-stroke patients with disability and its influencing factors.

A cross-sectional design and a convenience sample were used. Participants (N = 189) from 3 hospital in Beijing were recruited from October 2018 to June 2019. The following measurement tools were used in this study: Barthel index, Main Caregiver Empowerment Measurement, General Self-Efficacy Scale, Simplified Coping Style Questionnaire and Social Support Rating Scale. Multiple linear stepwise regression analysis was used to statistically infer the influencing factors of empowerment ability of primary caregivers.

The total score of main caregivers' empowerment measurement among the participants was 161.03 ± 14.678 , the median (interquartile range) score was 162.00 (150.00–171.50). The average scores of each dimension ranged from high to low: relationship with the person being cared for, goodwill care, expectation for care outcomes, subjectivity of caregiver, faith in care, understanding of care role, knowledge and skills of care, scruples about the surroundings, personal resources. The single factor analysis showed that the patient's payment method for medical expenses, whether the patient accompanied by other chronic diseases and the gender of the caregiver had an effect on the empowerment ability of primary caregivers, and the positive coping style, negative coping style, self-efficacy and subjective support of primary caregivers were positively correlated with their empowerment ability ($P < .05$). Multiple linear stepwise regression analysis showed that the type of payment for treatment of patients ($b = 7.449, P < .01$), and gender of caregivers ($b = 5.039, P < .05$), subjective support of caregivers ($b = 0.439, P < .05$), positive coping style of caregivers ($b = 0.585, P < .01$), self-efficacy of caregivers ($b = 6.456, P < .01$) were the main influencing factors of empowerment ability of primary caregivers.

The empowerment ability of the primary caregivers of post-stroke patients with disability in China is at the upper middle level. However, there are more scruples about the surrounding and less personal resources, which deserve attention. Furthermore, the identification of the factors related to empowerment lays a foundation for clinical nursing practitioners to further develop targeted interventions on empowerment of caregivers.

Abbreviations: BI = Barthel index, GSES = general self-efficacy scale, MCEM = main caregivers' empowerment measurement, SCSQ = simplified coping style questionnaire, SSRS = social support rating scale.

Keywords: activities of daily life, caregiver, disability, empowerment ability, influencing factors, rehabilitation, stroke

Editor: Chiedu Eseadi.

This article was supported by Key Projects for Basic Scientific Research Operating Expenses of Central Universities; Award ID: 2020-JYB-ZDGG-074; Recipient: Hong Guo.

The funding organization did not contribute to the design or conduct of this study, preparation, review, approval, or decision to submit this manuscript for publication.

All the researchers involved performed this study in the context of their research.

The authors have no conflicts of interest to disclose.

All data generated or analyzed during this study are included in this published article [and its supplementary information files].

^a School of Nursing, Beijing University of Traditional Chinese Medicine, Beijing, Shantou Health School, Shantou, China.

* Correspondence: Hong Guo, School of Nursing, Beijing University of Traditional Chinese Medicine, Beisanhuan-dong 11, Chaoyang, Beijing 100013, China (e-mail: guohong700423@126.com).

Copyright © 2021 the Author(s). Published by Wolters Kluwer Health, Inc. This is an open access article distributed under the terms of the Creative Commons Attribution-Non Commercial License 4.0 (CCBY-NC), where it is permissible to download, share, remix, transform, and buildup the work provided it is properly cited. The work cannot be used commercially without permission from the journal.

How to cite this article: Liu Y, Guo H. Empowerment in Chinese primary caregivers of post-stroke patients with disability: a cross-sectional study. *Medicine* 2021;100:5(e23774).

Received: 6 July 2020 / Received in final form: 14 October 2020 / Accepted: 16 November 2020

<http://dx.doi.org/10.1097/MD.00000000000023774>

1. Introduction

Stroke is the second cause of death and the leading cause of disability in the world, while it is the leading cause of death and disability among Chinese population.^[1] According to the Global Burden of Disease data, the prevalence of ischemic stroke in China in 2016 was 1762.77/100,000, and the prevalence of hemorrhagic stroke was 406.16/100,000.^[2] With the progress of modern medical approaches and extension of understanding towards disease pathogenesis, the survival rate of stroke has been gradually improved. But the disability rate is still high, most stroke patients will leave hemiplegia, dysphagia, depression, and other sequelae. Stroke has become 1 of the 3 major causes of disability-adjusted life year. According to the “Report on Stroke Prevention and Treatment in China, 2018” issued by the National Health Commission, the disability-adjusted life of stroke in China had risen sharply from 10.1610/100000 in 2005 to 11.8622/100000 in 2016.^[3] According to the “China Cardiovascular Disease Report, 2017”, the number of new stroke cases in China is nearly 2.5 million per year, while the number of remaining dysfunction among survivors is as high as 75%.^[4] Based on this, most post-stroke patients need long-term care. Under the influence of the current imperfect medical care system and the traditional concept of filial piety, about 80% of post-stroke patients will eventually choose to return to the

family,^[5] and the primary family caregivers will take care of their daily life and help them to complete the stroke rehabilitation.^[6,7]

However, studies have shown that the primary caregivers of disabled patients in China generally pay too much attention to the physical disability of patients, and lead to the phenomenon of over-care.^[8,9] While providing meticulous care services for disabled patients, the primary caregivers ignore the potential of disabled patients themselves, thus accelerating the loss of self-care ability of disabled patients.^[10,11] In addition, the disability often makes the patients lose control and confidence in lives,^[12] and the disabled patients will feel the depression caused by the loss of empowered.^[13] Therefore, the empowerment ability of primary caregivers, that is, the ability to capture and activate the potential power of disabled patients and create self-support opportunities for them, is particularly important.

The empowerment of caregivers is a “enabling” process, which helps disabled patients to find themselves again and enables them to gain a sense of competence in the process of interaction with the environment.^[13] It advocates getting out of the misunderstanding of pathology and opposes putting disabled patients in problematic care situations. It emphasizes the need to discard discriminatory labels in the care process; to create opportunities for connecting family, institutional and community resources; to keep disabled patients away from their thinking patterns; and to convince them of their dreams.^[14] Several studies have shown that the empowerment ability of primary caregivers during care is closely related to the health outcomes and quality of life of disabled patients.^[14–16] The effective empowerment of caregivers creates opportunities for disabled patients to support themselves and promotes them to actively participate in the rehabilitation process. It is conducive to the enhancement of the disabled patients’ self-consciousness of disease and self-care ability. For disabled families, it also greatly improves family function and promotes family well-being.^[17,18] Focusing on the empowerment of primary caregivers may provide a new perspective for optimizing chronic disease management and addressing long-term care dilemmas.

In recent years, scholars at home and abroad have tried to explore the factors affecting the empowerment of primary caregivers of chronic patients. Studies have pointed out that demographic sociological factors such as the age,^[19] gender,^[20] education level,^[21] physical health condition,^[22] and number of caregivers^[23] affect the empowerment of primary caregivers. Gordon et al^[24], Zheng^[23] have shown that the empowerment of primary caregivers is related to their coping style, and that primary caregivers who take an evasive approach tend to have a lower level of empowerment. Wakimizu et al^[19], Wu et al^[14] and Li et al^[16] revealed that self-efficacy is a positive influence factor on the empowerment of primary caregivers.

However, the literature review found that although there have been many previous studies on the health management of patients with chronic diseases and their caregivers from the concept of empowerment, little attention has been paid to the special group of primary caregivers of post-stroke patients with disability. Only 1 study^[23] in China analyzed empowerment as an aspect to explore the burden of primary caregivers in post-stroke patients with disability and did not explore it in depth. Therefore, there is not sufficient knowledge about the empowerment of the primary caregivers of post-stroke patients with disability. In view of this, this study investigated the current status and influencing factors of the empowerment ability of the primary caregivers of post-stroke patients with

disability in Beijing. The aim was to help medical staffs understand the empowerment status of the primary caregivers of post-stroke patients with disability, and to provide evidence for the empowerment-related interventions for the primary caregivers of stroke patients.

2. Method

2.1. Study design

A cross-sectional descriptive design and convenience sampling were used from October 2018 to June 2019 at the stroke ward of 3 teaching hospitals in Beijing, China. A total of 189 patients with post-stroke disability and their main caregivers admitted to the stroke ward of the Third Affiliated Hospital of Beijing University of Chinese Medicine, Dongzhimen Hospital of Beijing University of Chinese Medicine, and Dongdong Hospital of Beijing University of Chinese Medicine were selected as the study subjects. Multiple linear regression analysis was used to analyze the influencing factors of caregivers’ empowerment ability in post-stroke patients. According to the sample size requirement of multiple linear regression analysis model, the sample size should be 5 to 10 times of the number of independent variables.^[25] This study involved 24 independent variables with a theoretical sample size of 120 to 240. Considering the response rate and the limitations of manpower, time and cases, and for the accuracy and stability of the analysis results, the final sample size was 200. This study was approved by the Beijing University of Chinese Medicine Ethics Committee (Approval No.2015BZHYLL0143). All participants provided a written informed consent, which described the goal and method of the data collection, how the data would be handled and also an assurance of confidentiality.

2.2. Inclusion criteria

The inclusion criteria for post-stroke patients with disability were:

- (1) diagnosed with stroke by cranial computed tomography or magnetic resonance imaging;
- (2) still unable to fully self-care after being discharged home.

The inclusion criteria for primary caregivers of post-stroke patients with disability were:

- (1) undertook the major care tasks for selected post-stroke patients with disability, each caregiver was selected for each patient;
- (2) family members aged ≥ 18 years old, with kinship or legal relationship;
- (3) with care time ≥ 1 month, ≥ 4 hours per day; (4) with clear consciousness, informed consent and were willing to cooperate with the investigator.

2.3. Exclusion criteria

The exclusion criteria for post-stroke patients with disability were:

- (1) with other acute and critical illnesses;
- (2) admitted to hospital for the first time due to an acute attack of stroke.

The exclusion criteria for primary caregivers of post-stroke patients with disability were:

- (1) with previous or current mental disorders;
- (2) recently experienced significantly negative life events.

2.4. Study instruments

2.4.1. General information. General information questionnaire was designed by the researchers, including post-stroke patients with disability and their primary caregivers 2 parts. Sociodemographic data such as gender, age, religious belief, marital status, family monthly income per capita, and payment method of medical expenses were collected. Disease-related data such as types of disease, course of stroke, stroke frequency, and number of chronic diseases combined were collected. Care information such as long-term care time and average daily care time were collected.

2.4.2. Activities of daily life of patients. The Barthel index (BI) scale compiled by Mahoney and Barthel^[26] was used to test the activities of daily life of the post-stroke patients with disability enrolled. The scale is rated by observers and contains 10 items, such as eating, dressing, bathing, moving, and walking. Evaluation score ≤ 40 points was rated as severe disability, 41 to 59 points as moderate disability, 60 to 99 points as mild disability and 100 points as completely self-reliant. The evaluation method is easy to understand, strong in operability, and has good reliability and validity.

2.4.3. Empowerment ability of primary caregivers. The Main Caregivers' Empowerment Measurement (MCEM) scale jointly compiled by Wu and Moriguchi^[27] was used to measure the empowerment ability of the primary caregivers of post-stroke patients with disability. The MCEM scale is an universal scale based on the Sino-Japanese cultural background, according to the characteristics of the caregiver population in China and Japan. It has been widely used in the research of the empowerment of disabled elderly caregivers in China. There are 51 items in the scale, which are divided into 9 dimensions, such as personal resources, subjectivity of caregivers, faith in care, knowledge and skills of care, scruples about the surroundings, relationship with the person being cared for, goodwill care, understanding of care role, expectation for care outcomes. Each item is assigned a score of 1 to 4 points in sequence. 1 point means "not at all", and 4 points means "usually". The total score is 51 to 204 points. Of the 51 items, 7 are negative scoring questions, which are 2, 25, 26, 27, 41, 42, 43 (points need to be converted for statistics). The higher the total score, the better the representative empowerment ability. The Cronbach's α coefficient of Chinese version MCEM is 0.89, showing high reliability.

2.4.4. Self-Efficacy of primary caregivers. The General Self-Efficacy Scale (GSES) compiled by Schwarzer^[28] was used to measure the self-efficacy of the primary caregivers of post-stroke patients with disability. GSES is a single-dimension scale with 10 items, and each item is assigned a score of 1 to 4 points in turn. 1 point means "completely incorrect" and 4 points means "completely correct". The higher the score, the better the self-efficacy. The average score of all items added up is the final score of the scale. Score < 2 points is rated as low self-efficacy, 2 to 3 points as medium self-efficacy and > 3 points as high self-efficacy.

2.4.5. Coping Style of primary caregivers. The Simplified Coping Style Questionnaire (SCSQ) compiled by Jie^[29] was used to measure the coping style of the selected primary caregivers of the post-stroke patients with disability. SCSQ contains 20 items, which are divided into 2 dimensions: negative response and positive response. Each item is assigned a score of 0 to 3 points in turn. The score of positive response dimension is 0 to 36 points and passive response dimension is 0 to 24 points. The Cronbach's α coefficient value of SCSQ is 0.90, with 0.89 and 0.78 in positive and negative dimension, respectively.

2.4.6. Social Support of primary caregivers. The Social Support Rating Scale (SSRS) compiled by Xiao^[30] was used to determine the social support of the primary caregivers of post-stroke patients with disability. The SSRS contains 10 items, which are divided into 3 dimensions: subjective support, objective support, and support utilization. The score range of 12 to 66 points. The higher the score, the higher the level of social support. The Cronbach's α coefficient of SSRS is 0.896, with 0.825 to 0.849 in each dimension, demonstrating good reliability, and validity.

2.5. Data collection

After the consent of the nursing departments and department directors of each hospital, a questionnaire survey was conducted in the wards. Investigator was self-introduced, and the content and significance of the survey was explained to patients and their primary caregivers. After obtaining their informed consent, the investigator issued questionnaires and asked them to fill out on the spot. General information questionnaire and BI scale for post-stroke patients with disability were filled out by the investigator. General information questionnaire, MCEM, GSES, SCSQ, and SSRS for primary caregivers were filled out by primary caregivers according to their own situation. For part of respondents who had difficulty in filling out the questionnaires, the researcher helped them by explaining the entries one by one, using a unified guidance language for question answering, and according to the true meaning of the respondents to fill in. All questionnaires were collected and reviewed on the spot, and the missing and repeated parts were corrected on the spot. The study actually distributed 200 questionnaires. 11 invalid questionnaires, such as missing key variables and large number of extreme responses, were excluded. Finally, 189 valid questionnaires were recovered, and the effective recovery rate was 94.50%.

2.6. Data analysis

SPSS ver. 20.0 (IBM SPSS Inc., Armonk, NY, USA) was used for data processing. The general information and scales' scores of post-stroke patients with disability and their primary caregivers were statistically described using mean, standard deviation, median, quartile, number, and constituent ratio. For measurement data consistent with normal distribution, mean \pm SD was used as the expression, and independent sample *t* test or analysis of variance (ANOVA) was used for comparison between groups. For measurement data that did not conform to normal distribution, median (interquartile range) was used as the expression, and the comparison between groups was performed by using Mann-Whitney *U* test or Kruskal-Wallis *H* test. When the independent variable was a continuous variable, the Spearman correlation was adopted for correlation analysis.

Table 1
Different dimensions of the empowerment of primary caregivers (N = 189).

Dimension	Number of items	Mean \pm SD
Personal resources	7	2.716 \pm 0.639
Caregiver subjectivity	6	3.308 \pm 0.488
Care beliefs	5	3.198 \pm 0.595
Care knowledge and skills	3	2.820 \pm 0.824
Scruples about the surroundings	6	2.932 \pm 0.773
Relationship with the person being cared for	6	3.685 \pm 0.409
Goodwill care	6	3.554 \pm 0.456
Understanding of care role	6	3.065 \pm 0.552
Expectation for care outcomes	6	3.495 \pm 0.652

And multiple linear stepwise regression analysis was used to statistically infer the influencing factors of the empowerment ability of the primary caregivers of post-stroke patients with disability. $P < .05$ was considered statistically significant.

3. Results

3.1. General information about post-stroke patients with disability and their primary caregivers

The average age of the 189 post-stroke patients with disability was 73.34 ± 10.179 years, and the average BI score was 47.70 ± 27.664 . The average age of 189 primary caregivers was 56.16 ± 11.402 years. Among all samples, 64% were female, 55.6% had daily care time more than 12 hours, 36.5% had to independently undertake all care tasks, 84.1% perceived caring pressure and 40% were conscious of general or poor health.

3.2. Scores on the empowerment ability of primary caregivers

The total score of MCEM among the participants was 161.03 ± 14.678 , the median (interquartile range) score was 162.00 (150.00–171.50). Scores on different dimensions are depicted as Table 1.

3.3. Influencing factors of the empowerment ability of primary caregivers

3.3.1. The single factor analysis. Independent sample *t* test, ANOVA and non-parametric method were used for comparison between groups. It was found that the patient's payment method for medical expenses, whether the patient accompanied by other chronic diseases and the gender of the caregiver had an effect on the empowerment ability of the primary caregivers, and the difference was statistically significant ($P < .05$) (Table 2). Correlation analysis showed that the positive coping style, negative coping style, self-efficacy, and subjective support of primary caregivers were positively correlated with their empowerment ability ($P < .05$) (Table 3).

3.3.2. The multi-factor analysis. The significant variables in single factor analysis were incorporated into the multivariate linear stepwise regression equation with empowerment ability as dependent variable (the introduction level was 0.05 and the removal level was 0.10). The independent variable assignment method is shown in Table 4. After removing the non-significant factors in turn, we found that the payment method of patient's

medical expenses and the gender, subjective support, positive coping style, self-efficacy of the caregivers are the main influencing factors of the empowerment ability of the primary caregivers (Table 5).

4. Discussion

4.1. Status quo of the empowerment of primary caregivers

In 1995, Anderson et al^[31] first introduced the concept of empowerment into the field of medical health to deal with the interaction between doctors and patients. Since then, empowerment has evolved in the area of health. In recent years, Japanese scholars Wu and Moriguchi^[27] have extended the concept of empowerment to the field of caregivers. The above 2 scholars have pointed out that caregivers are not only providers of care services, but also have the ability to explore and activate the potential ability of disabled patients, which significantly optimizes the patients' health outcome by generating opportunities for patients' self-support.^[32] The concept of empowerment advocates moving out of pathological misconceptions and opposing the placement of patients in problematic care situations. It believes that even if the disabled patients are reckoned as vulnerable group in urgent need of assistance, they also have their own potential for healthy development. And we should assist the patients to open a new chapter in their lives by stimulating their potential. It emphasizes that it is necessary to discard discriminatory labels in the care process; generate more opportunities for the connection of family, institutional and community resources; keep patients away from their own stereotyped thinking patterns; and convince patients of their dreams. With this definition, the importance of the role of caregiver in the iterative phase of aging, chronic illness, and dementia is highlighted. It also provides a new perspective for the management of chronic illness and the optimization of elderly care.^[33] In the iterative stage of the tide of aging, chronic illness and disability, this definition undoubtedly interprets the importance of the role of caregivers and provides a new perspective for the management of chronic diseases and the optimization of elderly care.

In this study, the total MCEM score of primary caregivers was 161.027 ± 14.678 , which was at an upper middle level compared with the median score of 102. Of the 9 dimensions, "personal resources" and "scruples about the surroundings" scored the lowest, similar to the results of Zheng^[23] and Liu et al^[34], indicating that these 2 aspects still need to be improved. In terms of personal resources, in the context of the current social transformation and low fertility rate, the situation, that sons, and daughters serving as the main supply of family care resources for stroke patients, is facing severe challenges. And the alternative resources of consanguinity available to the primary caregivers will be increasingly scarcity.^[35] In addition, the trend of spatial separation of family structure has ulteriorly weakened the family's care function. With regard to "scruples about the surroundings", under the influence of the traditional Confucian culture of "filial piety" and "no violation" in China, whether the caregivers can take care of the disabled family members has become a general standard for measuring their moral level.^[36] In this cultural context, caregivers, vulnerable to the influence of the surrounding public opinions and the Confucian concept of filial piety, are tend to take meticulous care of the lives of disabled post-stroke patients, and do what they can to assist or even

Table 2**Comparison of the empowerment of primary caregivers (N = 189).**

Characteristics	n	mean ± SD/M(P25, P75)	F/t/Z	P
Patients				
Gender				
Male	107	161.51 ± 14.518	-0.521	.603
Female	82	160.39 ± 14.949		
Age				
≤ 69 yr old	81	163.00(147.00, 171.00)	0.503	.778
70–79 yr old	43	163.00 (156.00, 172.00)		
≥ 80 yr old	65	160.00 (153.00, 173.00)		
Payment method of medical expenses				
Fully self-paid expense	10	151.90 ± 19.513	5.356	.005
Medical insurance	151	160.36 ± 14.386		
Public medical	28	167.86 ± 11.906		
Stroke type				
Cerebral infarction	143	161.31 ± 14.760	-0.463	.644
Cerebral hemorrhage	46	160.15 ± 14.546		
Stroke number				
First time	98	162.15 ± 15.021	0.405	.749
2 times	64	159.88 ± 13.149		
3 times	21	159.91 ± 16.087		
4 times and above	6	158.83 ± 21.377		
Whether accompanied by other chronic diseases				
No	7	152.43 ± 22.634	2.675	.049
1 type	37	161.95 ± 12.981		
2 types	35	156.26 ± 14.716		
3 types and above	110	162.78 ± 14.309		
Self-care ability				
Mild disability	75	162.32 ± 14.005	0.551	.577
Moderate disability	34	159.38 ± 13.500		
Severe disability	80	160.51 ± 15.806		
Caregivers				
Gender				
Male	69	157.75 ± 14.763	2.352	.020
Female	120	162.91 ± 14.354		
Age				
≤ 49 yr old	56	160.00 (144.00, 170.50)	2.079	.556
50–59 yr old	55	163.00 (154.00, 173.00)		
60–69 yr old	60	165.50 (151.00, 171.00)		
≥ 70 yr old	18	161.00 (156.75, 170.50)		
Religious belief				
No	21	160.38 ± 14.908	1.735	.084
Yes	168	166.24 ± 11.717		
Marital status				
Married	175	166.00 (150.50, 175.75)	-0.688	.491
Unmarried and others	14	162.00 (150.00, 171.00)		
Household monthly income per capita				
1000–3999	43	159.02 ± 14.489	1.646	.180
4000–6999	68	160.79 ± 14.279		
7000–9999	45	159.69 ± 15.254		
≥ 10000	33	165.94 ± 14.506		
Relationship with the patient				
Spouse		165.00 (156.00, 171.50)	-1.382	.167
Children and others		160.50 (147.00, 171.75)		
Daily care time				
< 12 h	84	161.32 ± 13.960	-0.246	.806
≥ 12 h	105	160.79 ± 15.294		
Continuous care time				
≤ 1 year	111	162.08 ± 14.775	-0.525	.666
1 ~ 5 yr	37	159.08 ± 15.227		
5 ~ 10 yr	31	159.45 ± 13.591		
≥ 10 yr	10	161.40 ± 15.848		
Are there other people sharing the care tasks				
No	69	161.17 ± 14.252	-0.104	.917
Yes	120	160.94 ± 14.976		

(continued)

Table 2
(continued).

Characteristics	n	mean ± SD/M(P25, P75)	F/T/Z	P
Care pressure				
No	30	163.00 (151.25, 171.25)	2.312	.510
A little bit	75	162.00 (148.00, 176.00)		
Relatively large	60	162.50 (153.25, 171.75)		
Very large	24	159.50 (144.00, 167.00)		
Conscious health				
Very good	36	163.25 ± 16.065	1.232	.299
Good	76	162.21 ± 13.465		
Normal	61	159.49 ± 15.419		
Poor	16	156.25 ± 13.694		

replace the activities that patients can still engage in. In fact, this kind of care behaviors with loss of empowerment is not conducive to the stimulation of the potential of disabled patients and affects the recovery of their ability to live on their own. Therefore, enriching the source of personal resources and promoting the transformation of traditional care concepts are the key points to enhance the level of empowerment of caregivers.

4.2. Influencing factors of the empowerment ability of primary caregivers

4.2.1. Gender of caregivers. Compared with male caregivers, female caregivers have a higher level of empowerment, which is consistent with the results of Coutinho et al^[37]. Affected by the expectation of traditional gender roles and the unique resilience of women, female caregivers tend to pay more attention to the family, and they are also consistent with the traditional concept that women are the main caregivers. When patients can't take care of themselves, female family members, including spouses, daughters-in-law, and daughters, generally assume the task of caring for the patients.^[38] Correspondingly, influenced by the deep-rooted influence of traditional caregiver role, male caregivers often fail to autonomously and consciously assume the responsibility of caring for the patients. Coupled with the lack of family-related life experience, they cannot handle care work in a delicate and thoughtful way.^[39] Therefore, male caregivers should be given more attention, and encouraged to accept and blend in the caregivers' role that has been previously regarded as obligations of women in a calm and conscious manner. We can try to construct the mutual support network between male caregivers. Through the exchange of information and emotional confiding between male caregivers who with common experience, the self-identity and adaptation of male caregivers are strengthened, thereby improving their empowerment ability.^[36]

Table 3
Correlation analysis of the empowerment of primary caregivers (N = 189).

Variable	r	P
Self-efficacy	0.326	.000
Positive coping style	0.189	.000
Negative coping style	0.333	.009
Subjective support	0.272	.000
Objective support	0.061	.407
Support utilization	0.091	.211

4.2.2. Payment methods of patient's medical expenses. The payment methods of patient's medical expenses have a significant impact on the empowerment of primary caregivers. The level of empowerment of primary caregivers for publicly-funded medical patients is higher. Despite after 20 years of medical insurance reform, China has established a mixed medical insurance system composed of Basic Medical Insurance for Urban Employees, Basic Medical Insurance for Urban Residents, and the New Rural Cooperative Medical Scheme covering the vast majority of people, the level of security is still relatively limited.^[40] Compared with patients at public medical expense, patients at medical insurance are affected by the proportion and scope of reimbursement. Most of the post-rehabilitation costs can only be paid at their own expense, which is easy to cause expenditure-type economic poverty for the families of post-stroke patients with disability.^[41] The financial situation of stroke families is worrying facing the high cost of rehabilitation physiotherapy and the low medical security.^[42] As a result, the primary caregivers tend to be unable to do their best to cope with post-stroke disability.^[43] In order to alleviate the pressure of caregivers and improve the quality of life of post-stroke patients with disability, it is urgent to establish the long-term care insurance system that provides funds or services for the basic life of disabled patients. Japan has achieved outstanding progresses in the construction of the long-term care insurance system.^[44] It enjoys the same origin with Chinese culture, which may provide us an excellent reference for the construction of long-term insurance system in line with Chinese national conditions.

4.2.3. Subjective support of caregivers. Our result showed that subjective support has a significant impact on the level of empowerment of primary caregivers, which is similar to that of Che et al^[45]. In fact, under the busy domestic care, the primary caregivers have little time to arrange their own social activities. Therefore they are apt to feel lonely and lost, and then fall into depression and inferiority. As a kind of exogenous resource, emotional support from all aspects of society, such as family, friends and units, can provide spiritual supports to the primary caregivers, helping to weaken the mental burden and fatigue they perceive during the care process. It can also imperceptibly help caregivers build a sense of value and ability, and promote their confidence of continuous care for stroke patients.^[46] In view of this, it is recommended to strengthen the emotional comfort for primary caregivers by mobilizing relatives, friends, communities, work units, and other social aspects. At the same time, regularly online or offline activities organized by organizations such as the

Table 4**Independent variables assignment method.**

Variables	Assignment method
Patient	
Payment method of medical expenses	Fully self-paid = 1; medical insurance = 2; public medical = 3
Whether accompanied by other chronic diseases	No = 1; 1 type = 2; 2 types = 3; 3 types and above = 4
Caregiver	
Gender	Male = 0; Female = 1
Self-efficacy	Original value substitution
Positive response	Original value substitution
Negative coping style	Original value substitution
Subjective support	Original value substitution

Table 5**Multiple regression analysis on the factors associated with empowerment.**

Variables	B	SE	β	t	P	F	P	VIF
Constant term	94.826	8.199		11.565	.000	10.637	.000	
Patient								
Payment method of medical expenses	7.449	2.104	0.223	3.541	.001			1.013
Whether accompanied by other chronic diseases	-0.025	1.039	-0.002	-0.024	.981			1.065
Caregiver								
Gender	5.039	1.934	0.166	2.605	.010			1.034
Self-efficacy	6.456	1.927	0.229	3.350	.001			1.194
Positive response	0.585	0.179	0.223	3.278	.001			1.181
Negative coping style	0.342	0.177	0.124	1.934	.055			1.041
Subjective support	0.439	0.199	0.144	2.200	.029			1.099

Stroke Caregivers Association are helpful to the caregiver's emotional release, as well as physical and mental stress relief.

4.2.4. Positive coping style of caregivers. Positive coping style is a positive influencing factor on the empowerment ability of primary caregivers. Primary caregivers who tend to adopt positive coping styles have relatively better empowerment ability. Gordon and Perrone^[24] on the role structure of young spousal caregivers also corroborates this result. The coping style, as an individual's behavioral tendency when facing the adversity of life, is closely related to the empowerment ability of primary caregivers. The primary caregivers with positive coping style tend to have sufficient confidence to continuously take care of patients, and often take the initiative to undertake care work with the expectation of coping with the disease together with the patients to improve their self-care ability, as well as actively seek social resources to improve the quality of life of patients.^[14] Therefore, the impact of positive coping styles on the caregiver's empowerment ability should be emphasized. We should pay attention to the caregivers with relatively negative attitude in emotion, cognition and behavior, strengthen their emotional communication, and guide them to carry out self-emotional regulation and the correct method of stress coping.^[47] From the perspective of positive psychology, we can help the primary caregivers grasp the meaning of their roles, and guide them to respond to difficult situations encountered in the care process in a more positive and optimistic attitude, gradually making them shape positive emotional, cognitive, and behavioral responses.^[48]

4.2.5. Self-Efficacy of caregivers. Self-efficacy has a positive effect on the empowerment ability of primary caregivers, which

has been corroborated by Wakimizu et al^[49] and Wu et al^[14]. The primary caregivers with high self-efficacy levels believe that they have sufficient capacity to care for stroke patients, demonstrating greater confidence and control in performing specific care tasks and dealing with potentially difficult situations in the care process.^[50] While they also have a stronger motivation to master the knowledge and skills of caregivers in care. Their choice of care methods is generally based on their own independent thinking and judgment, which is not susceptible to outside public opinions.^[49] The formation of self-efficacy is influenced by alternative experience, social evaluation, emotion, and physiological state. In view of this, in terms of the alternative experience, the primary caregivers with low self-efficacy can be encouraged to take the initiative to strengthen some simple and necessary learning of medical knowledge and caring skills via the "Internet +" medical information platform, such as medication precautions, rehabilitation training skills, oral care, skin care, blood pressure, and blood glucose monitoring.^[51] It can make primary caregivers' care more professional and efficient, and avoid discouraging their enthusiasm to participate in care. In terms of social evaluation, through the power of mass media and the public education, the community should be encouraged to further recognize and respect the social values of primary caregivers.^[52] In terms of emotion, neighborhood volunteer services can be introduced to provide support such as caring companionship and case counseling to help primary caregivers express negative feelings.^[53]

5. Conclusions

This study describes the characteristics of the primary caregivers of post-stroke patients, and provides the status quo and related

factors of the empowerment of them. In clinical practice, this study is helpful for clinical nurses to better understand the situation of the primary caregivers of post-stroke patients, to further carry out targeted intervention, to update the concept of health care, and to enhance the empowerment of the primary caregivers of post-stroke patients. In nursing research, given that the few reports on applying the concept of empowerment to the caregiver population in China, this study also enriches the connotation of empowerment and the research content in the field of nursing to a certain extent. In policy, this study will render the government, WHO and society begin to pay attention to the weak position of post-stroke disabled patients and their caregivers. However, this study only selected post-stroke patients with disability and their primary caregivers in the stroke ward of 3 Grade 3A hospitals in Beijing. And the sample size is small. Therefore, the representative of the samples was limited, and the results could not be extended to the primary caregivers of post-stroke patients with disability in China. It is necessary to expand the regional scope of sample selection and enrich the sample size for enhancing the extensibility of the research results.

Acknowledgments

The authors would like to thank all the post-stroke disabled patients and their primary caregivers for their willingness to complete the questionnaires.

Author contributions

Conceptualization: Liu Youhua.

Data curation: Liu Youhua, Guo Hong.

Formal analysis: Liu Youhua, Guo Hong.

Investigation: Hong Guo, Liu Youhua.

Methodology: Hong Guo.

Project administration: Liu Youhua, Guo Hong.

Resources: Hong Guo.

Software: Hong Guo.

Supervision: Guo Hong, Youhua Liu.

Validation: Youhua Liu.

Visualization: Youhua Liu.

Writing – original draft: Youhua Liu.

Writing – review & editing: Liu Youhua, Guo Hong.

References

- [1] Wang W, Jiang B, Sun H, et al. Prevalence, incidence, and mortality of stroke in China: results from a nationwide population-based survey of 480 687 adults. *Circulation* 2017;135:759–71.
- [2] GBD 2016 Lifetime Risk of Stroke Collaborators. Global, regional, and country-specific lifetime risks of stroke, 1990 and 2016. *N Engl J Med* 2018;379:2429–37.
- [3] Editorial team of Stroke Prevention and Treatment Report 2018 in China. The prevention and treatment of stroke in China is still facing great challenges — summary of China stroke prevention and control report 2018. *Chin J Circ* 2019;34:105–19.
- [4] Chinese Cardiovascular Disease Report writing Group. Summary of China cardiovascular disease report 2017. *Chin Circ J* 2018;33:1–8.
- [5] Lin BL. Analysis on the Status and Influencing Factors of Functional Exercise Compliance in Community Stroke Patients. Zhengzhou, China: Zhengzhou University; 2012.
- [6] Li X, Xia X, Wang P, et al. Needs and rights awareness of stroke survivors and caregivers: a cross-sectional, single-centre questionnaire survey. *BMJ Open* 2017;7:e013210.
- [7] Fang YF, Fang DP, Jiang ZF, et al. Study on the care needs and health status of major caregivers in stroke. *J Nurs* 2013;20:37–9.
- [8] Shen S, Chen Z, Xue M, et al. How to relieve stress in adult child caregivers of the older adults with disabilities: a survey study from the city of Nanjing, China. *Soc Work Health Care* 2019;58:291–303.
- [9] Chen S, Zheng J, Chen C, et al. Unmet needs of activities of daily living among a community-based sample of disabled elderly people in eastern China: a cross-sectional study. *BMC Geriatr* 2018;18:160.
- [10] Chen S, Zheng J, Chen C, et al. Relevance of unmet needs for daily life activities and caregivers' capacity to care for disabled people at home. *Chin J Gerontol* 2019;39:1482–6.
- [11] Zhu H. Unmet needs in long-term care and their associated factors among the oldest old in China. *BMC Geriatr* 2015;15:46.
- [12] Horne J, Lincoln NB, Preston J, et al. What does confidence mean to people who have had a stroke? A qualitative interview study. *Clin Rehabil* 2014;28:1125–35.
- [13] Nowotny M, Dachenhausen A, Stastny P, et al. Empowerment, quality of life and participation in neurological rehabilitation. empirical study with stroke patients and their relatives. *Wien Med Wochenschr* 2004;154:577–83.
- [14] Wu XY, Hu XY, Hu H, et al. A survey on the empowerment and self-efficacy of the disabled elderly in China and Japan. *Chin J Mod Nurs* 2015;21:3114–8.
- [15] Sit JW, Chair SY, Choi KC, et al. Do empowered stroke patients perform better at self-management and functional recovery after a stroke? A randomized controlled trial. *Clin Interv Aging* 2016;11:1441–50.
- [16] Li XF, Chen CJ, Liu XY, et al. A correlative study on empowerment of main caregivers and activity daily living of the community disabled elderly. *Nurs J Chin PLA* 2017;34:29–32+76.
- [17] Deyhou IN, Vasli P, Rohani C, et al. The effect of family-centered empowerment program on the family caregiver burden and the activities of daily living of Iranian patients with stroke: a randomized controlled trial study. *Aging Clin Exp Res* 2020;32:1343–52.
- [18] Francescato D, Pezzuti L, Mebane M, et al. Dispositional characteristics, relational well-being and perceived life satisfaction and empowerment of elders. *Aging Ment Health* 2017;21:1052–7.
- [19] Wakimizu R, Fujioka H, Yoneyama A, et al. Factors associated with the empowerment of Japanese families raising a child with developmental disorders. *Res Dev Disabil* 2011;32:1030–7.
- [20] Warren CM, Gupta RS, Sohn MW, et al. Differences in empowerment and quality of life among parents of children with food allergy. *Ann Allergy Asthma Immunol* 2015;114:117–25.
- [21] Feng HY. A survey of parental enabling psychological nursing in children with congenital heart disease. *Contemp Nurse* 2015;9:29–30.
- [22] Liu YN. Development and Clinical Empirical Study of Enabled Psychological Nursing Scale for Critical Patients and their Families. Fuzhou, China: Fujian Medical University; 2012.
- [23] Zheng J. A Study on Care Burden and Empowerment of Major Carers in Elderly Stroke Patients. Zhengzhou, China: Henan University; 2016.
- [24] Gordon PA, Perrone KM. When spouses become caregivers: counseling implications for younger couples. *J Rehabil* 2004;70:27–32.
- [25] Fang JQ, Hao YT. Design and implementation of quality of life research. *Chin Oncol* 2001;10:69–71.
- [26] Mahoney FI, Barthel D. Functional evaluation: the Barthel index. *Md State Med J* 1965;14:56–61.
- [27] Wu XY, Moriguchi Y. Pre-experiment on the self-potential activation process of primary care. *Chin J Pract Nurs* 2009;25:38–42.
- [28] Schwarzer R, Aristi B, Iwawaki S, et al. The assessment of optimistic self beliefs: comparison of the Chinese, Indonesian, Japanese, and Korean versions of the general self efficacy scale. *Psychologia* 1997;40:1–13.
- [29] Yaning X. Reliability and validity of the simplified coping style questionnaire. *Chin J Clin Psychol* 1998;6:114–5.
- [30] Xiao SY. The theoretical basis and application of social support rating scale. *J Clin Psychiatry* 1994;4:98–100.
- [31] Anderson RM, Funnell MM, Barr PA, et al. Learning to empower patients. Results of professional education program for diabetes educators. *Diabetes Care* 1991;14:584–90.
- [32] Zhang Y. Construction of a theoretical framework for empowerment of elderly chronic patients. Shanghai, China: Second Military Medical University; 2012.
- [33] Kayser L, Karnoe A, Duminski E, et al. A new understanding of health related empowerment in the context of an active and healthy ageing. *BMC Health Serv Res* 2019;19:242.
- [34] Liu W, Guo AM. An analysis of the current situation and influencing factors of the empowerment ability of elderly caregivers with home disability. *Chin J Mod Nurs* 2017;23:2619–23.

- [35] Su Z, Hu Z, Peng X. The impact of changes in China's family patterns on family pension functions. *Int J Health Plann Manage* 2017;32:351–62.
- [36] Liu J, Bern-Klug M. "I should be doing more for my parent:" Chinese adult children's worry about performance in providing care for their oldest-old parents. *Int Psychogeriatr* 2016;28:303–15.
- [37] Coutinho MT, Kopel SJ, Williams B, et al. Urban caregiver empowerment: Caregiver nativity, child-asthma symptoms, and emergency-department use. *Fam Syst Health* 2016;34:229–39.
- [38] Sakanashi S, Fujita K. Empowerment of family caregivers of adults and elderly persons: a concept analysis. *Int J Nurs Pract* 2017;23:e12573.
- [39] Pierce LL, Steiner V, Alamina F, et al. Male caregivers report problems in caring at home after spouses survive stroke. *Home Healthc Now* 2019;37:23–32.
- [40] Dou G, Wang Q, Ying X. Reducing the medical economic burden of health insurance in China: achievements and challenges. *Biosci Trends* 2018;12:215–9.
- [41] Xian W, Xu X, Li J, et al. Health care inequality under different medical insurance schemes in a socioeconomically underdeveloped region of China: a propensity score matching analysis. *BMC Public Health* 2019;19:1373.
- [42] Hu P, Yang Q, Kong L, et al. Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients. *Medicine (Baltimore)* 2018;97:e12638.
- [43] Gu H, Li Z, Zhao X, et al. Insurance status and 1-year outcomes of stroke and transient ischaemic attack: a registry-based cohort study in China. *China National Stroke Registries*. *BMJ Open* 2018;8:e021334.
- [44] Umegaki H, Yanagawa M, Nonogaki Z, et al. Burden reduction of caregivers for users of care services provided by the public long-term care insurance system in Japan. *Arch Gerontol Geriatr* 2014;58:130–3.
- [45] Che HL, Yeh ML, Wu SM. The self-empowerment process of primary caregivers: a study of caring for elderly with dementia. *J Nurs Res* 2006;14:209–18.
- [46] Cumming TB, Cadilhac DA, Rubin G, et al. Psychological distress and social support in informal caregivers of stroke survivors. *Brain Impair* 2008;9:152–60.
- [47] Barbabella F, Poli A, Andréasson F, et al. A web-based psychosocial intervention for family caregivers of older people: results from a mixed-methods study in three European countries. *JMIR Res Protoc* 2016;5:e196.
- [48] Sara A, Teixeira L, Azevedo MJ, et al. Effectiveness of a psychoeducational programme for informal caregivers of older adults. *Scand J Caring Sci* 2016;30:65–73.
- [49] Wakimizu R, Fujioka H, Nishigaki K, et al. Family empowerment and associated factors in Japanese families raising a child with severe motor and intellectual disabilities. *Int J Nurs Sci* 2018;5:370–6.
- [50] Jafari Y, Tehrani H, Esmaily H, et al. Family-centred empowerment program for health literacy and self-efficacy in family caregivers of patients with multiple sclerosis. *Scand J Caring Sci* 2020;34:956–63.
- [51] Ploeg J, Ali MU, Markle-Reid M, et al. Caregiver-focused, web-based interventions: systematic review and meta-analysis (part 2). *J Med Internet Res* 2018;20:e11247.
- [52] Dam AEH, Christie HL, Smeets CMJ, et al. Process evaluation of a social support platform 'inlife' for caregivers of people with dementia. *Internet Interv* 2018;15:18–27.
- [53] Guillamón N, Nieto R, Pousada M, et al. Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *J Clin Nurs* 2013;22:1579–90.