



Exploring Caregiving Burden and Family Resilience Among Caregivers of Young and Middle-Aged Stroke Survivors in China

Bei Zhu ¹, Mohamed Saifulaman Mohamed Said ^{1*}, Beng Geok Tan ²

Abstract

Background: Stroke, characterized by high morbidity, disability, and mortality, has increasingly affected younger populations. In China, the proportion of strokes among individuals aged 40-64 has risen significantly. This study explored the caregiving burden and family resilience among caregivers of young and middle-aged first-stroke survivors, comparing caregivers of those with good versus poor functional outcomes. **Methods:** A cross-sectional survey was conducted from January to June 2024, involving 119 family caregivers of stroke survivors from two tertiary hospitals in Yancheng City, Jiangsu Province, China. Data were collected using the Modified Rankin Scale (mRS), Zarit Burden Interview (ZBI), and the Family Resilience Assessment Scale (FRAS-C). Independent t-tests and Pearson's correlation analysis were performed to examine differences in care burden and family resilience between caregiver groups. **Results:** Caregivers had an average ZBI score of 28.32 ± 20.66 , with 39.5% reporting no or minimal burden, 29.4% light burden, and 25.2% moderate burden. Caregivers of patients with mRS 0-2 had significantly lower care burdens (23.84 vs. 37.17, $p < 0.01$) and higher family resilience (98.22 vs. 93.00, $p < 0.05$) compared to those with mRS 3-5. Care burden was

negatively correlated with family resilience ($r = -0.243$, $p = 0.008$). **Conclusion:** Caregivers of young and middle-aged stroke survivors generally experienced mild to moderate care burden, while family resilience was moderate. Caregivers of survivors with better functional outcomes had lower care burdens and higher family resilience. These findings highlight the need for targeted interventions to support caregivers of survivors with poorer functional outcomes to enhance family resilience and reduce care burden.

Keywords: Caregiving burden, Family resilience, Stroke survivors, Young adults, China.

Introduction

Stroke, an acute cerebrovascular disease that encompasses both ischemic and hemorrhagic subtypes, is characterized by high rates of morbidity, disability, and mortality. It poses a significant public health challenge worldwide, ranking as the second leading cause of death and the third leading cause of death and disability combined. According to the Global Burden of Disease (GBD) Study 2019, stroke continues to be a major cause of mortality globally. In China, it is the leading cause of both death and disability among adults. Recent data reveal an alarming trend—stroke is increasingly affecting younger populations. The Global Stroke Report indicates that the incidence of stroke among young and middle-aged individuals has risen to 40%, reflecting a concerning shift in the age distribution of stroke patients. In China, the situation is particularly worrisome. The China Stroke Prevention and Control Report notes that more than 66.6% of first-time stroke cases occur in individuals aged 40-64. This highlights a growing

Significance | Understanding caregiving dynamics might help identify support strategies for families of stroke survivors, which in turn promotes resilience and enhances their overall well-being.

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issue: younger people, traditionally considered at lower risk, are now becoming more susceptible to stroke. Moreover, the proportion of stroke patients under 70 years of age continues to rise, and young and middle-aged individuals now account for 31% of all stroke cases in China. This shift toward younger stroke patients is concerning because these individuals are often the primary earners and caregivers in their families, playing a central role in both their households and the economy. The sudden onset of stroke not only damages their physical and mental health but also disrupts family dynamics, placing a significant burden on the entire family system. This burden is multi-faceted, involving emotional, financial, and caregiving challenges that profoundly impact both the patient and their family.

The long-term impact of stroke is staggering. The American Heart Association estimates that nearly 75% of stroke survivors live with some form of disability, with 15-30% experiencing severe disabilities that affect their ability to function independently. Disability-adjusted life years (DALYs), a measure that combines the loss of healthy life due to death and disability, serves as a critical indicator of the overall burden of stroke. Globally, stroke accounts for 143 million DALYs, making it a major contributor to the global disease burden. In China, despite a slight decline in DALYs for ischemic stroke between 2010 and 2019, the overall trend remains weak, and the stroke-related DALYs in China are still significantly higher than in countries such as the United Kingdom, the United States, and Japan. This high burden underscores the severity of stroke in China, where a substantial proportion of survivors experience long-term disabilities that require ongoing care.

Stroke patients often rely on family members for care and support, especially in the years following the event. This caregiving responsibility, while essential, comes with significant challenges. Caregivers face a range of difficulties, including financial strain, physical exhaustion, and emotional distress. The continuous nature of caregiving tasks can lead to burnout, social isolation, and a decline in the caregiver's own health and well-being. In China, studies have shown that 68.4% of caregivers for stroke patients experience a significant burden, which negatively affects their physical and mental health, as well as their quality of life. Caregivers are often forced to make personal sacrifices, including reducing their participation in social and economic activities, which further compounds the strain they experience.

However, not all families struggle equally when faced with the adversity of caring for a stroke survivor. Some families demonstrate a remarkable capacity to adapt and recover, a concept known as family resilience. Family resilience refers to the ability of a family to withstand and recover from crises, setbacks, and challenges. It involves the integration and utilization of both internal and external resources to maintain stable family functioning and foster positive growth, even in the face of adversity. Research has shown that **strong family resilience can accelerate both the physical and**

psychological recovery of stroke patients. It also enhances the family's ability to cope with stress, promotes positive perceptions of challenges, and facilitates the reintegration of stroke survivors into society.

Given the profound impact of stroke on both patients and their caregivers, there is a pressing need to better understand the factors that influence caregiving burden and family resilience. This study aims to explore these dynamics by focusing on caregivers of young and middle-aged stroke survivors, a population increasingly affected by stroke. Specifically, the research seeks to answer several key questions. First, it investigates the caregiving burden experienced by family caregivers of young and middle-aged first-stroke survivors. Next, it examines the level of family resilience among these caregiving families. Additionally, the study explores how caregiving burden and family resilience differ between caregivers of patients with good functional outcomes compared to those with poor functional outcomes. Finally, it seeks to determine the relationship between caregiving burden and family resilience. By addressing these questions, this study aims to provide insights into the challenges faced by caregivers of young and middle-aged stroke survivors, as well as the factors that may help mitigate these challenges through enhanced family resilience. Understanding these dynamics is crucial for developing targeted interventions that support both caregivers and patients in their recovery journey.

2. Methodology

2.1. Participants and Procedures

This study employed a non-experimental, quantitative, descriptive, cross-sectional survey design. The primary goal was to systematically examine the caregiving burden and family resilience of caregivers of young and middle-aged first-time stroke survivors, comparing those with good and poor functional outcomes. Data were collected from 119 family caregivers of stroke survivors within six months of hospital discharge. The participants were recruited from two tertiary hospitals in Yancheng City, Jiangsu Province, China, between January and June 2024.

The first six months following hospital discharge were chosen as the study period because this phase is widely recognized as the "critical" transition period for stroke survivors. During this time, caregivers often assume a significant burden of care, making this a vital period for assessing their experiences and resilience (Hodson et al., 2019). The study's inclusion criteria required participants to be the primary caregivers of stroke survivors who met the diagnostic criteria outlined in the Chinese Medical Association's 2010 Clinical Guidelines for Neurology, confirmed by CT or MRI scans. If a stroke survivor had multiple caregivers, the one who provided the most hours of care per day was selected to participate, as caregiving burden increases with the time spent in caregiving activities. Caregivers needed to be at least 18 years old, fluent in the local language, and capable of understanding the questionnaire. They

had to voluntarily agree to participate in the study. Exclusion criteria included caregivers who had experienced a major life event (such as divorce, widowhood, unemployment, or a traumatic event) within the past two weeks or those who were professional, paid caregivers.

A convenience sampling method was used to select participants. Caregivers were informed about the study before data collection and provided consent to participate. The data were collected through an electronic questionnaire distributed to caregivers. Each participant provided informed consent before completing the survey.

2.2. Data Collection and Analysis

2.2.1. Measures

2.2.1.1. Socio-Demographic Characteristics

A self-designed questionnaire was developed to collect basic demographic information about the stroke survivors and their primary caregivers. This included the age and gender of the stroke survivors, stroke type (as confirmed through a review of medical records), payment method for medical care, and time since hospital discharge. For caregivers, data such as age, gender, marital status, education level, caregiver-patient relationship, current employment status, and household income were also collected. Most of the demographic information was gathered through caregiver self-reports and confirmed through medical records where applicable.

2.2.1.2. Modified Rankin Scale (mRS)

The Modified Rankin Scale (mRS) is a widely used tool to measure the degree of disability or dependence in daily activities following a stroke. The mRS categorizes patients on a scale from 0 to 6, with 0 indicating no symptoms and 6 indicating death. For this study, stroke survivors were grouped into two categories: those with good functional outcomes (scores 0-2) and those with poor functional outcomes (scores 3-6). The mRS assessment was completed by the primary caregiver as a proxy for the stroke survivor, using face-to-face interviews, telephone, or questionnaires.

2.2.1.3. Zarit Burden Interview (ZBI)

The Zarit Burden Interview (ZBI) is a standard instrument used to assess the caregiving burden. Originally developed by Zarit et al. (1986), the ZBI has since been widely adopted and adapted for various cultures, including China (Wang et al., 2006). The ZBI used in this study contains 22 items scored on a 5-point Likert scale, with responses ranging from "never" to "always." The ZBI consists of two subscales: personal burden (12 items) and responsibility burden (6 items), with four additional independent items. The total ZBI score ranges from 0 to 88, with higher scores indicating greater caregiving burden. Scores are categorized as follows: 0-19 indicates no or minimal burden, 20-39 indicates mild burden, 40-59 indicates moderate burden, and scores above 60 indicate a heavy burden. In this study, the ZBI had a Cronbach's alpha reliability coefficient of 0.963, indicating high internal consistency.

2.2.1.4. Shortened Chinese Version of the Family Resilience Assessment Scale (FRAS-C)

The Family Resilience Assessment Scale (FRAS), developed by Sixbey (2005), is a tool designed to measure family resilience. The FRAS was adapted into a shortened Chinese version (FRAS-C) by Yuli Li, following cross-disciplinary translation guidelines. The FRAS-C includes 32 items across three dimensions: family communication and problem-solving, utilizing social resources, and maintaining a positive outlook. The items are scored on a 4-point Likert scale, with values ranging from 1 (strongly disagree) to 4 (strongly agree), and total scores range from 32 to 128. Higher scores reflect greater family resilience. In this study, the Cronbach's alpha for the FRAS-C was 0.985, indicating excellent reliability.

2.2.2. Main Analyses

Data were analyzed using the SPSS 26 statistical package. Descriptive statistics were used to summarize the socio-demographic characteristics of the caregivers and stroke survivors. Independent t-tests were performed to determine differences in caregiving burden and family resilience between caregivers of stroke survivors with good versus poor functional outcomes (mRS 0-2 versus mRS 3-6). Additionally, Pearson's product-moment correlation was used to assess the relationship between caregiving burden (as measured by the ZBI) and family resilience (as measured by the FRAS-C).

Results were considered statistically significant at $p < 0.05$. The use of both t-tests and Pearson's correlation allowed the study to examine both the differences between groups and the relationships between variables, providing a comprehensive understanding of the caregiving burden and family resilience in this population.

3. Results

3.1. Care Burden and Family Resilience Status

Among the 119 caregivers of young and middle-aged first-time stroke survivors, the overall caregiving burden score averaged 28.32 ± 20.66 . The burden was further broken down into two dimensions: personal burden, with a mean score of 16.08 ± 10.88 , and responsibility burden, with a mean score of 7.47 ± 6.15 . Based on the established criteria for the Zarit Burden Interview (ZBI), 47 caregivers (39.50%) experienced no or very little burden, 35 caregivers (29.41%) reported a light burden, 30 caregivers (25.21%) experienced moderate burden, and 7 caregivers (5.88%) reported a severe burden.

In terms of family resilience, measured by the Family Resilience Assessment Scale (FRAS-C), the average total score was 96.46 ± 15.33 . The scores for the three key dimensions were as follows: family communication and problem-solving averaged 69.24 ± 11.19 , utilization of social resources averaged 8.88 ± 1.47 , and maintaining a positive outlook averaged 18.34 ± 3.01 .

3.2. Socio-Demographic Characteristics of the Two Groups

The sample was divided into two subgroups based on the Modified Rankin Scale (mRS) scores of the stroke survivors. Of the 119 caregivers, 79 cared for survivors with good functional outcomes (mRS 0-2), while 40 cared for survivors with poor functional outcomes (mRS 3-5). The socio-demographic data of both groups are detailed in Table 1. These two groups differed in various socio-demographic characteristics, providing the basis for further analysis of their caregiving experiences and family resilience.

3.3. ZBI and FRAS-C Scale Scores of the Two Groups

An independent t-test was conducted to compare the scores on the ZBI (caregiving burden) and FRAS-C (family resilience) scales between caregivers of stroke survivors with good (mRS 0-2) and poor (mRS 3-5) functional outcomes. The results are summarized in Table 2.

The analysis revealed that caregivers of stroke survivors with good functional outcomes (mRS 0-2) experienced significantly lower caregiving burden compared to those caring for survivors with poor outcomes (mRS 3-5). Specifically, the total ZBI caregiving burden score was significantly lower in the mRS 0-2 group (23.84 vs. 37.17, $p < 0.001$). The personal burden score was also lower in the mRS 0-2 group (13.86 vs. 20.48, $p < 0.001$), as was the responsibility burden score (6.15 vs. 10.07, $p < 0.001$). These differences were statistically significant.

In terms of family resilience, caregivers of stroke survivors with good functional outcomes (mRS 0-2) demonstrated significantly higher overall resilience than those in the poor outcome group (98.22 vs. 93.00, $p = 0.029$). In the dimension of family communication and problem-solving, caregivers of mRS 0-2 patients scored higher (70.49 vs. 66.78, $p = 0.033$), indicating stronger problem-solving abilities and communication within the family. Additionally, the dimension of maintaining a positive outlook also yielded significantly higher scores for caregivers in the mRS 0-2 group (18.68 vs. 17.65, $p = 0.027$). However, no statistically significant difference was found between the two groups in the utilization of social resources dimension ($p > 0.05$).

3.4. Correlation Between Caregiving Burden and Family Resilience

A Pearson product-moment correlation analysis was conducted to examine the relationship between caregiving burden and family resilience. The results showed a significant negative correlation between caregiving burden and family resilience ($r = -0.243$, $p = 0.008$). This indicates that as the caregiving burden increases, family resilience tends to decrease, and vice versa.

Caregivers of stroke survivors with good functional outcomes experienced lower caregiving burden and higher family resilience compared to those caring for survivors with poor functional outcomes. Additionally, the study found that higher caregiving burden was associated with lower family resilience across the sample. These findings underscore the importance of targeted interventions to alleviate caregiving burden and bolster family

resilience, particularly for caregivers of patients with poorer functional outcomes.

4. Discussion

This study revealed that 60.50% of young and middle-aged family caregivers of stroke survivors experienced varying degrees of caregiving burden, with most caregivers reporting mild to moderate levels of burden. This finding aligns with the results of Azar Kazemi et al. and Rajesh Kumar et al. (2015), who found that approximately 63% of stroke caregivers experienced similar levels of burden. Caregiving, especially for stroke patients, is known to be physically and emotionally taxing, often leading to stress and burnout among caregivers. As caregivers take on continuous, demanding responsibilities, their physical, mental, and emotional health can deteriorate, exacerbating their caregiving burden (Achilike et al., 2020).

Stroke caregivers face unique challenges that amplify their burden. Stroke survivors often require assistance with daily tasks, medical care, and rehabilitation, which demands time, energy, and emotional investment from caregivers. As these responsibilities accumulate, caregivers are likely to experience burnout and negative emotional, social, and health-related consequences. Therefore, it is crucial to address caregiver burden through targeted interventions, providing caregivers with the support, resources, and education they need to manage their role more effectively.

The study also found that family resilience among caregivers of young and middle-aged stroke survivors was at a moderate level, which was higher than that reported by Qian Li et al. (2024). This discrepancy may be due to the dynamic nature of family resilience, which tends to be stimulated during sudden, stressful events like a stroke (Maurović et al., 2020). When faced with such challenges, families often come together, strengthening their bonds and working collaboratively to overcome difficulties. This increased closeness and problem-solving ability can foster resilience, enabling families to manage the caregiving burden more effectively. Additionally, the higher level of family resilience observed in this study may be attributed to the fact that most caregivers were the immediate family members of stroke survivors, such as children, parents, or spouses, who are typically more invested in the patient's recovery and well-being.

Moreover, 66.39% of stroke survivors in this study had good functional outcomes (mRS ≤ 2), which likely contributed to the higher family resilience observed. Patients with better functional outcomes tend to have fewer physical and cognitive limitations, allowing families to adapt more easily to the caregiving role. Additionally, young and middle-aged stroke survivors often undergo positive psychological changes during their recovery process, developing a new perspective on life and fostering stronger family relationships. This shared experience of overcoming

Table 1. Descriptive statistics of demographic characteristics of mRS subgroups 0-2 and 3-5

Variables	Categories	mRS 0-2 Group	mRS 3-5 Group
		Number of Cases (Percentage, %)	Number of Cases (Percentage, %)
Stroke survivor’s age (years)	18-44	20(25.3)	13(32.5)
	45-59	59(74.7)	27(67.5)
Stroke survivor’s gender	male	48(60.8)	22()
	female	31(39.2)	18()
Stroke type	Ischemic	68(86.1)	27(67.5)
	Hemorrhagic	11(13.9)	13(32.5)
Payment methods for medical expenses	Self funded	2(2.5)	0(0)
	Medical insurance	57(72.2)	25(62.5)
	New rural cooperative medical system	20(25.3)	15(37.5)
Time after discharge	1 month	28(35.4)	19(47.5)
	2-3 months	19(24.1)	6(15.0)
	4-6 months	32(40.5)	15(37.5)
Age of caregivers (years)	18-44	16(20.3)	13(32.5)
	45-60	41(51.9)	15(37.5)
	>60	22(27.8)	12(30.0)
Gender of caregivers	male	31(39.2)	14(35.0)
	female	48(60.8)	26(65.0)
Marital status of caregivers	Unmarried	7(8.9)	1(2.5)
	Married	71(89.9)	37(92.5)
	Widowhood	1(1.2)	2(5.0)
Literacy level of caregivers	Primary school and below	18(22.8)	11(27.5)
	Junior high school	19(24.1)	8(20.0)
	High school	20(25.3)	13(32.5)
	College degree	20(25.3)	7(17.5)
	Post-graduate degree	2(2.5)	1(2.5)
caregiver-Stroke survivor relationships	Spouse	49(62.1)	27(67.5)
	Children	14(17.7)	10(25.0)
	Parent	11(13.9)	3(7.5)
	Brothers and sisters	5(6.3)	0(0)
Current work status	Unemployed	22(27.8)	13(32.5)
	Retired	19(24.1)	11(27.5)
	Be on the job	38(48.1)	16(40.0)
Monthly disposable household income(yuan)	1000	2(2.5)	5(12.5)
	1000~3000	20(25.3)	9(22.5)
	3000~5000	32(40.5)	11(27.5)
	5000~10000	20(25.3)	12(30.0)
	10000	5(6.4)	3(7.5)

Table 2. Statistical description and descriptive testing of differences in care burden and family resilience of mRS subgroups 0-2 and 3-5

Instrument	Item Group	n	Mean Score (SDa)	Sig. (2-tailed)	t	Mean dif.d	95% Cle Cohen's	
							Lower	Upper
ZBI	Personal Burden	mRS 0-2=79	13.86	.001	-3.257	-6.614	-10.636	-2.592
		mRS3-5=40	20.48					
	Responsibility Burden	mRS 0-2=79	6.15	.001	-3.432	-3.923	-6.187	-1.659
		mRS3-5=40	10.07					
	Total Score	mRS 0-2=79	23.84	.001	-3.481	-13.340	-20.928	-5.751
		mRS3-5=40	37.17					
FRAS-C	Family Communication and Problem-solving	mRS 0-2=79	70.49	.033	2.154	3.719	.299	7.139
		mRS3-5=40	66.78					
	Utilizing Social Resources	mRS 0-2=79	9.04	.069	1.837	.463	-.037	0.963
		mRS3-5=40	8.57					
	Maintaining a Positive Outlook	mRS 0-2=79	18.68	.027	2.239	1.034	.119	1.948
		mRS3-5=40	17.65					
	Total Score	mRS 0-2=79	98.22	.029	2.213	5.215	.547	9.883
		mRS3-5=40	93.00					

adversity can create a foundation for increased family resilience (Zhang et al., 2023).

Caregivers of stroke survivors with poor functional outcomes (mRS 3-5) reported higher caregiving burden compared to those caring for survivors with good functional outcomes (mRS 0-2). This finding aligns with previous studies, such as those by Adan Sardar et al. (2022) and Achilike et al. (2020), which found that caregivers of stroke survivors with greater dependence for daily living tasks experience higher levels of stress and burden. As stroke survivors with poor functional outcomes require more assistance with activities such as bathing, dressing, feeding, and medical care, caregivers must devote more time and energy to these tasks. In addition, these caregivers may need to acquire specialized knowledge and skills to provide adequate care, which can increase their learning burden and psychological stress.

The increased burden on caregivers of stroke survivors with poor functional outcomes can also lead to a decline in the quality of care provided. When caregivers are overwhelmed and underprepared for the demands of caregiving, they may experience feelings of helplessness and inadequacy. This can have a negative impact on both the caregiver's well-being and the patient's recovery. Therefore, it is crucial to provide caregivers with the necessary resources, education, and support to manage their role effectively. By doing so, caregivers can provide better care for stroke survivors while also maintaining their own health and well-being.

In terms of family resilience, caregivers of stroke survivors with good functional outcomes (mRS 0-2) exhibited higher levels of resilience compared to those caring for survivors with poor outcomes (mRS 3-5). This result is consistent with the findings of Panpan Cui et al. (2023) in families of advanced cancer patients. The poorer the functional status of the patient, the greater the impact on the daily lives of both the patient and the caregiver, leading to lower levels of family resilience. Stroke survivors with more severe impairments often have a greater symptom burden, which can strain family relationships and reduce the family's ability to cope with the caregiving challenges.

Within the three dimensions of family resilience, the study found significant differences between the two groups in family communication, problem-solving, and maintaining a positive outlook, but no significant difference in the use of social resources. Families of stroke survivors with better functional outcomes were more likely to have positive attitudes toward recovery, better communication, and stronger problem-solving abilities. This suggests that effective communication and a positive outlook are protective factors for family resilience, as they enable families to work together to overcome challenges (Park et al., 2022). In contrast, the lack of significant difference in social resource utilization suggests that both groups may have limited access to external support systems, such as community organizations or healthcare services. This highlights the need for increased attention

and support for families of stroke survivors, particularly those with poor functional outcomes, to help them build resilience and improve caregiving outcomes.

The study also found a significant negative correlation between caregiving burden and family resilience ($r = -0.243$, $p < 0.001$), indicating that as caregiving burden increases, family resilience decreases. This finding is consistent with previous research by Li et al. (2018), who reported that increased family resilience was associated with reduced caregiving burden in caregivers of breast cancer patients. When families possess higher levels of resilience, they are better able to adapt to the challenges of caregiving, utilize available resources, and maintain positive attitudes. This, in turn, can reduce the physical and emotional burden on caregivers, allowing them to provide more effective care without experiencing burnout.

Given the importance of family resilience in reducing caregiving burden, healthcare professionals should prioritize interventions that promote resilience among caregivers of stroke survivors. These interventions could include strategies to improve family communication, strengthen problem-solving abilities, and encourage positive coping mechanisms. By fostering a collaborative environment in which family members work together to manage the stroke survivor's illness, families can build resilience and reduce the stress associated with caregiving. Additionally, healthcare providers should educate caregivers on available resources, such as support groups and community services, to help them access external support and reduce their caregiving burden.

Caregivers of young and middle-aged first-stroke survivors generally experienced a mild level of caregiving burden, while their family resilience was at a moderate level. Caregivers of stroke survivors with mRS scores of 0-2 reported lower caregiving burdens compared to those caring for survivors with mRS scores of 3-5. Conversely, family resilience was higher among caregivers of survivors with better functional outcomes (mRS 0-2) than those with worse outcomes (mRS 3-5). Additionally, the study revealed a negative correlation between family resilience and caregiving burden, indicating that as family resilience increases, caregiving burden decreases.

These findings highlight the importance of focusing on families of stroke survivors with poor physical functioning, as they require enhanced support to fully utilize available resources, build on family strengths, and strengthen their resilience. By improving family resilience, caregivers' burdens can be reduced, leading to better care quality and enhanced overall family well-being.

5. Conclusion

In conclusion, this study highlights the significant caregiving burden experienced by young and middle-aged family caregivers of stroke survivors, as well as the critical role of family resilience in mitigating this burden. Caregivers of stroke survivors with poor

functional outcomes face greater challenges, experiencing higher caregiving burden and lower family resilience. Interventions that promote family resilience, improve communication, and provide caregivers with the necessary support and resources are essential for reducing caregiving burden and improving both patient and caregiver outcomes. By addressing these challenges, healthcare professionals can help caregivers provide better care for stroke survivors while also maintaining their own well-being.

Author contributions

B.Z, M.S.M.S, and B.G.T contributed to conceptualization, fieldwork, data analysis, drafting the original manuscript, editing, and manuscript review. M.S.M.S took the lead in research design, methodology validation, funding acquisition, and supervision, while B.Z and B.G.T were involved in data visualization and manuscript review. All authors have reviewed and approved the final version of the manuscript.

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Competing financial interests

The authors have no conflict of interest.

References

Achilike, S., Beauchamp, J. E. S., Cron, S. G., Okpala, M., Payen, S. S., Baldrige, L., Okpala, N., Montiel, T. C., Varughese, T., Love, M., Fagundes, C., Savitz, S., & Sharief, A. (2020). Caregiver Burden and Associated Factors Among Informal Caregivers of Stroke Survivors. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*, 52(6), 277-283. doi:10.1097/jnn.0000000000000552

Chen, C. M., Du, B. F., Ho, C. L., Ou, W. J., Chang, Y. C., & Chen, W. C. (2018). Perceived Stress, Parent-Adolescent/Young Adult Communication, and Family Resilience Among Adolescents/Young Adults Who Have a Parent With Cancer in Taiwan: A Longitudinal Study. *Cancer Nurs*, 41(2), 100-108. doi:10.1097/ncc.0000000000000488

Collaborators, G. S. (2021). Global, regional, and national burden of stroke and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol*, 20(10), 795-820. doi:10.1016/s1474-4422(21)00252-0

Cui, P., Shi, J., Li, S., Getu, M. A., Wang, R., & Chen, C. (2023). Family resilience and its influencing factors among advanced cancer patients and their family caregivers: a multilevel modeling analysis. *BMC Cancer*, 23(1), 623. doi:10.1186/s12885-023-11101-z

Fang, L., Dong, M., Fang, W., & Zheng, J. (2022). Relationships between care burden, resilience, and depressive symptoms among the main family caregivers of stroke patients: A cross-sectional study. *Front Psychiatry*, 13, 960830. doi:10.3389/fpsy.2022.960830

Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., Dai, S., Ford, E. S., Fox, C. S., Franco, S., Fullerton, H. J., Gillespie, C., Hailpern, S. M., Heit, J. A., Howard, V. I., Huffman, M. D., Judd, S. E., Kissela, B. M., Kittner, S. J.,

Lackland, D. T., Lichtman, J. H., Lisabeth, L. D., Mackey, R. H., Magid, D. J., Marcus, G. M., Marelli, A., Matchar, D. B., McGuire, D. K., Mohler, E. R., 3rd, Moy, C. S., Mussolino, M. E., Neumar, R. W., Nichol, G., Pandey, D. K., Paynter, N. P., Reeves, M. J., Sorlie, P. D., Stein, J., Towfighi, A., Turan, T. N., Virani, S. S., Wong, N. D., Woo, D., & Turner, M. B. (2014). Heart disease and stroke statistics--2014 update: a report from the American Heart Association. *Circulation*, 129(3), e28-e292. doi:10.1161/01.cir.0000441139.02102.80

Group., R. o. s. p. a. t. i. C. W., & Wang, L. D. (2020). Brief report on stroke prevention and treatment in China, 2019. *Chinese Journal of cerebrovascular diseases*, 17, 272-281. doi:10.3969/j.issn.1672-5921.2020.05.008 in chinese]

Hodson, T., Gustafsson, L., & Cornwell, P. (2019). Unveiling the complexities of mild stroke: An interpretative phenomenological analysis of the mild stroke experience. *Aust Occup Ther J*, 66(5), 656-664. doi:10.1111/1440-1630.12607

Hu, P., Yang, Q., Kong, L., Hu, L., & Zeng, L. (2018). Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients. *Medicine (Baltimore)*, 97(40), e12638. doi:10.1097/md.00000000000012638

Kumar, R., Kaur, S., & Reddemma, K. (2015). Burden and coping strategies in caregivers of stroke survivors. *J Neurol Neurosci*, 6(5), 1-5. doi:10.21767/2171-6625.S10005

L, W., XS, Y., Z, H., & QL, F. (2006). Application and evaluation of the Chinese version of the caregiver burden scale. *Chinese Journal of Public Health*, 22(8), 970-972. doi:1001-0580(2006)08-0970-03 in chinese]

Li, Q., Luo, C., Ye, J., Bian, Z., Sun, W., Zhou, M., & Rong, M. (2024). Relationship Between Illness Uncertainty and Family Resilience Among Caregivers of Stroke Patients in Chinese Nuclear Families: The Mediating Role of Perceived Stress. *Patient Prefer Adherence*, 18, 1095-1105. doi:10.2147/ppa.S463562

Li, X., & Li, H. (2021). Reliability and validity of the Chinese version of the Revised Walsh family resilience questionnaire. *Ann Palliat Med*, 10(8), 8709-8717. doi:10.21037/apm-21-1152

Li, Y., Wang, K., Yin, Y., Li, Y., & Li, S. (2018). Relationships between family resilience, breast cancer survivors' individual resilience, and caregiver burden: A cross-sectional study. *International journal of nursing studies*, 88, 79-84. doi:10.1016/j.ijnurstu.2018.08.011

Lu, Y. (2024). Independent predictors of family resilience in patients with ischemic stroke: A cross-sectional survey. *Heliyon*, 10(3), e25062. doi:10.1016/j.heliyon.2024.e25062

Ma, Q., Li, R., Wang, L., Yin, P., Wang, Y., Yan, C., Ren, Y., Qian, Z., Vaughn, M. G., McMillin, S. E., Hay, S. I., Naghavi, M., Cai, M., Wang, C., Zhang, Z., Zhou, M., Lin, H., & Yang, Y. (2021). Temporal trend and attributable risk factors of stroke burden in China, 1990-2019: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*, 6(12), e897-e906. doi:10.1016/s2468-2667(21)00228-0

Maurović, I., Liebenberg, L., & Feric, M. (2020). A review of family resilience: Understanding the concept and operationalization challenges to inform research and practice. *Child Care in Practice*, 26(4), 337-357. doi:10.1080/13575279.2020.1792838

Ning, X., Sun, J., Jiang, R., Lu, H., Bai, L., Shi, M., Tu, J., Wu, Y., Wang, J., & Zhang, J. (2017). Increased Stroke Burdens Among the Low-Income Young and Middle Aged in Rural China. *Stroke*, 48(1), 77-83. doi:10.1161/strokeaha.116.014897

- Park, M., Choi, E. K., Lyu, C. J., Han, J. W., & Hahn, S. M. (2022). Family resilience factors affecting family adaptation of children with cancer: A cross-sectional study. *Eur J Oncol Nurs*, 56, 102078. doi:10.1016/j.ejon.2021.102078
- Sardar, A., Shahzad, K., Arshad, A. R., Shabbir, K., & Raza, S. H. (2022). Correlation Of Caregivers' Strain With Patients' Disability In Stroke. *J Ayub Med Coll Abbottabad*, 34(2), 326-330. doi:10.55519/jamc-02-9488
- Shamoun, C., & Harris, M. A. (2022). Impact of Stroke Survivors' Physical Disability on the Presence of Caregiver Burden: A Systematic Review. *The Journal of neuroscience nursing : journal of the American Association of Neuroscience Nurses*, 54(4), 146-150. doi:10.1097/jnn.0000000000000651
- Sixbey, M. T. (2005). Development of the family resilience assessment scale to identify family resilience constructs: University of Florida.
- Tu, W. J., & Wang, L. D. (2023). China stroke surveillance report 2021. *Mil Med Res*, 10(1), 33. doi:10.1186/s40779-023-00463-x
- Ugur, H. G., & Erci, B. (2019). The Effect of Home Care for Stroke Patients and Education of Caregivers on the Caregiver Burden and Quality of Life. *Acta Clin Croat*, 58(2), 321-332. doi:10.20471/acc.2019.58.02.16
- Walsh, F. (1996). The concept of family resilience: crisis and challenge. *Fam Process*, 35(3), 261-281. doi:10.1111/j.1545-5300.1996.00261.x
- Yuda, T. K., & Munir, M. (2023). Social insecurity and varieties of family resilience strategies during the COVID-19 pandemic. *International Journal of Sociology Social Policy*, 43(7/8), 756-776. doi:10.1108/IJSSP-08-2022-0201
- Yuliana, S., Yu, E., Rias, Y. A., Atikah, N., Chang, H. J., & Tsai, H. T. (2023). Associations among disability, depression, anxiety, stress, and quality of life between stroke survivors and their family caregivers: An Actor-Partner Interdependence Model. *J Adv Nurs*, 79(1), 135-148. doi:10.1111/jan.15465
- Zarit, S. H., Todd, P. A., & Zarit, J. M. J. T. G. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. 26(3), 260-266.
- Zhang, W., Feng, X., Zhang, H., & Sun, J. (2023). Family resilience experience of young and middle-aged stroke patients: a qualitative study. *Chinese nursing research*, 37(4), 717-721. doi:10.12102/i.issn.1009-6493.2023.04.029 [in chinese]
- Zhang, W., Zhou, W., Ye, M., Gao, Y., & Zhou, L. (2022). Family resilience of stroke survivors within 6 months after a first-episode stroke: A longitudinal study. *Front Psychiatry*, 13, 968933. doi:10.3389/fpsy.2022.968933
- Zhou, J., He, B., He, Y., Huang, W., Zhu, H., Zhang, M., & Wang, Y. (2020). Measurement properties of family resilience assessment questionnaires: a systematic review. *Family Practice*, 37(5), 581-591.