

The Burden of Stroke on Caregivers at 1-year after Discharge: A Multicenter Study

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ภาระของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมอง 1 ปี หลังจำหน่ายออกจากโรงพยาบาล: การศึกษาสหสถาบัน

วิลัย คุปต์นิรัตัยกุล, พวงแก้ว อธิสกุลชัย, สุพิน สาริกา และ ศิริลักษณ์ แก้วนารี

ภาควิชาเวชศาสตร์ฟื้นฟู คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล กรุงเทพมหานคร

ABSTRACT

Objective: To investigate the burden of caregivers at the 1-year follow-up in stroke patients who had received inpatients post-stroke rehabilitation, and to identify factors associated with burden.

Study design: Cross-sectional study

Subjects and setting: One-hundred and sixty stroke patients who were discharged from the rehabilitation wards of nine tertiary care hospitals and their caregivers

Methods: The caregivers were asked to rate the degree of overall burden, and in physical, mental, social, and economic dimensions of burden. Degree of burden was categorized into no burden, slight burden, somewhat burden, moderate burden, and extreme burden. Factors associated with caregiver burden were analyzed using univariate and multivariate analysis.

Results: Mean \pm standard deviation age of caregivers was 44.6 ± 13.7 years and 76% were female. Regarding degree of caregiver burden, 30% rated burden of taking care as no burden, 20% slight, 30% somewhat, and 20% moderate to extreme burden. Responses of moderate to extreme burden in the physical and economic dimensions (19.4-20.0%) were more than those in the mental and social dimensions (12.5-16.9%). The only factor significantly associated with burden on caregiver was level of walking ability <10 meters, with an adjusted odds ratio of 3.30 (95% CI: 1.60, 6.83).

Conclusion: Twenty percent of caregivers rated themselves as being moderately to extremely physical and economic burden from taking care of stroke patients. Health policy strategies to effectively relieve caregiver burden should be developed in order to improve the post-stroke experience for both caregiver and patient.

Keywords: caregiver burden; stroke; multivariate; rehabilitation; geriatric

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บทคัดย่อ

วัตถุประสงค์: เพื่อศึกษาภาระของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองที่เคยได้รับการฟื้นฟูแบบผู้ป่วยใน ที่ 1 ปี หลังจำหน่ายออกจากโรงพยาบาล และเพื่อค้นหาปัจจัยที่มีความสัมพันธ์กับภาระดังกล่าว

รูปแบบการวิจัย: การศึกษาแบบตัดขวาง

กลุ่มประชากรและสถานที่ทำการวิจัย: ผู้ดูแลของผู้ป่วยโรคหลอดเลือดสมองที่ได้รับการจำหน่ายออกจากโรงพยาบาลระดับตติยภูมิ 9 แห่ง จำนวน 160 ราย

วิธีการศึกษา: ผู้ดูแลให้คะแนนภาระในการดูแลผู้ป่วยโดยรวม และภาระในด้านต่าง ๆ ได้แก่ ด้านกายภาพ จิตใจ สังคม และเศรษฐกิจ โดยแบ่งเป็นระดับต่าง ๆ ได้แก่ ไม่เป็นภาระเลย เป็นภาระเล็กน้อย เป็นภาระบ้าง เป็นภาระปานกลาง และเป็นภาระอย่างมาก จากนั้นวิเคราะห์หาปัจจัยที่มีความสัมพันธ์กับระดับภาระของผู้ดูแลโดยการวิเคราะห์โดยใช้สถิติแบบ univariate และ multivariate analysis

ผลการศึกษา: ผู้ดูแลมีอายุเฉลี่ย 44.6 ± 13.7 ปี และเป็นเพศหญิงร้อยละ 76 ผู้ดูแลให้คะแนนภาระในการดูแล ดังนี้ ไม่เป็นภาระเลย ร้อยละ 30 เป็นภาระเล็กน้อยร้อยละ 20 เป็นภาระบ้างร้อยละ 30 และเป็นภาระปานกลางถึงมากร้อยละ 20 โดยภาระปานกลางถึงมากในด้านกายภาพและเศรษฐกิจ (ร้อยละ 19.4-20.0) มากกว่าในด้านจิตใจและสังคม (ร้อยละ 12.5-16.9) ปัจจัยเดียวที่พบมีความสัมพันธ์อย่างมีนัยสำคัญทางสถิติกับภาระของผู้ดูแลคือความสามารถในการเดินของผู้ป่วยที่น้อยกว่า 10 เมตร (adjusted odds ratio=3.30; 95% CI: 1.60-6.83)

สรุป: ผู้ดูแลร้อยละ 20 รู้สึกว่าการดูแลผู้ป่วยโรคหลอดเลือดสมองเป็นภาระปานกลางถึงมากในด้านกายภาพและเศรษฐกิจ จึงควรมีการกำหนดนโยบายสาธารณสุขเพื่อช่วยแบ่งเบาภาระของผู้ดูแลเหล่านี้ และพัฒนาคุณภาพชีวิตของทั้งผู้ป่วยและผู้ดูแล

คำสำคัญ: ภาระของผู้ดูแล, โรคหลอดเลือดสมอง, การวิเคราะห์หลายตัวแปร, เวชศาสตร์ฟื้นฟู, ผู้สูงอายุ

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Introduction

Stroke is the leading cause of death and long-term disability worldwide. Stroke patient disability can adversely affect the quality of life (QoL) of their caregivers, including both caregiver physical and mental health.⁽¹⁾ In Thailand, the crude prevalence of stroke among people aged 65 years and older was 2.7% (95% CI: 2.28, 3.11). Differences were reported by geographic region, with Bangkok having the highest reported prevalence at 3.34%.⁽²⁾ After discharge from acute inpatient wards, most stroke patients return to their home and require direct care from their families.⁽³⁾ Much of the support given to stroke patients comes from unpaid caregivers⁽⁴⁾. The responsibilities associated with taking care of and assisting stroke patients with daily activities induced moderate to extreme adverse impact on caregivers.⁽⁵⁾ Moreover, the greater the unmet needs of stroke patients, the greater the burden on caregivers. It was reported that time spent providing care to a stroke patient could directly and negatively affect caregiver quality of life.⁽⁶⁾ Additionally, increased number of illnesses and older age of caregivers were both associated with lower physical health-related quality of life (HRQoL) among caregivers.⁽⁷⁾

Caregiver burden should be acknowledged and addressed, given the potential for direct improvement in patient quality of life and the continued well-being of the caregiver. Caregiver burden can lead to caregiver stress and an inability to provide continued care. This can result in unnecessary hospitalization of the patient, which results in huge costs to the health care system.⁽⁸⁾ Many studies have been conducted on the burdens of stroke patient caregivers. Ganapathy, et al. reported on how the burdens of taking care of stroke patients with spasticity-related problems had adverse societal and economic impact.⁽⁹⁾ Moreover, 44% of caregivers reported considerable burden from taking care of stroke patients at six months, and 30% at five years after stroke.⁽¹⁰⁾ Caregivers of stroke patients were also reported to have depressed mood (58%) and sleep problems (89.6%).⁽¹¹⁾ Another study revealed that 61% of caregivers rated their personal health as being only poor or fair.⁽³⁾ As Thai people had different culture and context from the western countries, the aim of this study was to investigate the burden of stroke on caregivers at the 1-year patient follow-up in stroke patients who had received post-stroke inpatient rehabilitation program, and to identify factors associated with patient care burden.

Methods

Participants

This study gathered and analyzed data from the Thai Stroke Rehabilitation Registry (TSRR), the first multicenter registry in Thailand.⁽¹²⁾ Stroke patients in this registry were admitted for rehabilitation with various objectives including intensive or less-intensive rehabilitation programs, treating complications and training caregivers. After discharge from rehabilitation wards, stroke patients were asked to visit their respective hospitals for a 1-year follow-up examination.⁽¹³⁾ The inclusion criteria were stroke patients who had caregiver and who received and recently completed one year of rehabilitation from any one of nine tertiary care hospitals and an expressed willingness of both caregivers and stroke patients to come to their respective study centers to participate in the 1-year follow-up examina-

tion and interview. The protocol for this study was approved by the Institutional Review Board of each center. This study was conducted in compliance with the provisions set forth in the Declaration of Helsinki and all of its subsequent amendments.

Study design

This study was a prospective cross-sectional multicenter study. Demographic and experiential data of caregivers that were collected included age, gender, educational level, prior course in how to care for stroke patients, prior experience in taking care of stroke patients, duration and time spent in taking care of stroke patients, and caregiver relation to patients. Demographic and clinical data of stroke patients that were collected included age, gender, functional score, anxiety and depression at discharge, complications at discharge, quality of life (QoL), discharge destination, and level of walking ability. Those complications comprised of musculoskeletal pain, bowel/bladder dysfunction, anxiety and depression, pneumonia, spasticity and pressure ulcer.⁽¹⁴⁾

Modified Barthel Index (BI), Hospital Anxiety and Depression Score (HADS), and WHOQOL-BREF were used to assess functions, anxiety and depression, and QoL, respectively. Modified BI score ranged from 0-20, with a higher score indicating better function.⁽¹⁵⁾ HADS is composed of 14 items in two dimensions (anxiety and depression), each of which has a score that ranges from 0 to 21, with a score ≥ 11 regarded as indicating presence of clinical anxiety or depression.⁽¹⁶⁾ WHOQOL-BREF was used to assess QoL. QoL was classified to five grades, including very poor, poor, fair, good, and very good.⁽¹⁷⁾ All three of these evaluation questionnaires were previously tested and validated for their psychometric properties in Thai population.

Caregivers were asked to rate the degree of burden, the load or responsibility they perceived as a result of caring for a stroke patients. Specifically, caregivers were asked to answer the question, "Would you please rate the degree of burden you perceive as a result of taking care of your stroke patient in the past six months?" for each of the physical, mental, social, and economic dimensions. Burden for each dimension would be classified as no burden, slight, somewhat, moderate, and extreme. Factors associated with caregiver burden were then analyzed relative to demographic and experiential data of caregivers and demographic and clinical data of patients using univariate and multivariate analysis. Burden was grouped into two groups: low burden (included no and slight burden) and high burden (included somewhat, moderate, and extreme burden).

Statistical analysis

Demographic data of caregivers and stroke patients are presented as mean \pm standard deviation (SD) or median and range for continuous data, and number and percentage for categorical data. Factors associated with caregiver burden were tested by chi-square test or Fisher's exact test in univariate analysis. Any factors that presented with $p < 0.2$ were introduced in multivariate analysis. The multivariate analysis was performed using multiple logistic regression to assess the confounding effect of factors on caregiver burden. Strength of association was measured using odds ratio (OR) and adjusted odds ratio with 95% confidence interval (95% CI). A p-value less than 0.05 was considered statistically significant. All data

analyses were performed using SPSS Statistics version 18.0 (SPSS, Inc., Chicago, IL, USA).

Results

One-hundred and sixty stroke patients were recruited from the TSRR. Demographic and experiential characteristics of caregivers are shown in Table 1. Mean± standard deviation age of caregivers was 44.6±13.7 years and 76% were female. Most caregivers had more than a primary school education (65.6%), never took a course in how to care for stroke patients (64.4%), and had no experience in taking care of stroke patients (68.7%). Most caregivers were family relatives (83.1%) that took care of stroke patients on a part-time basis (65.0%).

Regarding stroke patients, mean age was 62.4±12.0 years and approximately 60% were male. Mean functional score (BI) at discharge was 13.3±4.5. The percentage of patients who had anxiety and depression at discharge was 5.9% and 17.8%, respectively. The number (%) of patients who developed at least one complication at discharge was 126 (78.8%). Most patients (60.7%) had poor to fair QoL. The vast majority of patients were discharged to their home (96.9%). Regarding walking ability, 57.0% could walk more than or equal to 10 meters. Demographic and clinical characteristics of stroke patients are given in Table 2.

An overall evaluation of caregiver burden is given in Figure 1. Thirty percent of caregivers rated taking care of stroke patients as not being a burden. Only 20% rated stroke care as being either a moderate or extreme burden. Physical, mental, social, and economic data relative to caregiver burden are presented in Figure 2. The data from these four dimensions shows a similar pattern from dimension to dimension. Those were no burden (25.0-36.3%), slight burden (14.4-26.3%), somewhat burden (28.8-30.6%), and moderate to extreme burden (12.5-20.0%). The four dimensions of caregiver burden specific to respondents who described moderate to extreme burden are shown in Figure 3. Among caregivers who rated their burden as moderate to extreme, all dimensions ranged from 12.5% to 20%. Among this same group of caregivers, the burdens associated with taking care of stroke patients in the physical and economic dimensions (19.4%-20.0%) were higher than the burdens associated with the mental and social dimensions (12.5%-16.9%).

In univariate analysis, patient gender, patient age, and level walking ability <10 meters were significantly associated with caregiver burden, with crude odds ratios of 2.21 (95% CI 1.16, 4.22); 2.06 (95% CI 1.09, 3.92); and, 2.76 (95% CI 1.41, 5.39), respectively (Table 3). In multivariate analysis, the only factor that was found to significantly associate with caregiver burden was level walking ability <10 meters, with an adjusted odds ratio of 3.30 (95% CI 1.60, 6.83). A trend was observed that revealed male patients being more associated with burden than female patients, with an adjusted odds ratio of 2.11 (95% CI 0.99, 4.48) (Table 4).

Discussion

This study found that 70% of caregivers rated that taking care of stroke patients are burden with various degree. Compared to a study from Spain, our result was more than those reported by López-Espuela, et al. (70% vs. 31%).⁽¹¹⁾ In addition,

Table 1. Demographic and experiential characteristics of caregivers (n=160)

Characteristics	
Age (years) ¹	44.6 (13.7)
Gender ²	
- Male	38 (23.8)
- Female	122 (76.2)
Education ²	
- Primary school and lower	55 (34.4)
- Higher than primary school	105 (65.6)
Took course in how to care for stroke patients ²	
- Yes	57 (35.6)
- No	103 (64.4)
Experienced in taking care of stroke patients ²	
- Yes	50 (31.3)
- No	110 (68.7)
Duration of stroke patient care (years) ¹	1.38 (0.92)
- Median (range)	1.18 (0.05, 6.03)
Time spent taking care of stroke patient ²	
- Full-time	56 (35.0)
- Part-time	104 (65.0)
Relation to patient ²	
- Relative	133 (83.1)
- Non-relative	27 (16.9)

¹, mean (SD); ², number (%)

Table 2. Demographic and clinical characteristics of stroke patients (n=160)

Characteristics	Mean±SD or n (%)
Age (years) ¹	62.4 (12.0)
Gender ²	
- Male	94 (58.8)
- Female	66 (41.2)
Modified BI _{DC} ¹	13.3 (4.5)
Anxiety _{DC} ²	8/135 (5.9)
Depression _{DC} ²	24/135 (17.8)
Complication _{DC} ²	126 (78.8)
Quality of life _{DC} ²	
- Good to very good	59 (39.3)
- Very poor to fair	91 (60.7)
Discharge destination _{DC} ²	
- Home	155 (96.9)
- Home of relative	5 (3.1)
Level walking ability _{DC} ²	
- <10 meters	64 (43.0)
- ≥10 meters	85 (57.0)

¹, mean (SD); ², number (%); DC, at discharge

prevalence of stroke caregiver burden reported by Jaracz, et al. was 44% evaluated at the 6-month and 30% at the 5-year periods.⁽¹⁰⁾ When considered in a group of moderate to extreme level of burden, this study found only 20% compared to a study by Jaracz, et al. in 2014 who studied 150 pairs of stroke patients and caregivers and found that 47% of caregivers reported moderate or severe burden.⁽¹⁸⁾ Differences in prevalence between our study and others may be attributable to differences in questionnaires. Another possible reason may be cultural. In Thai culture, it is considered an honor to have the opportunity to

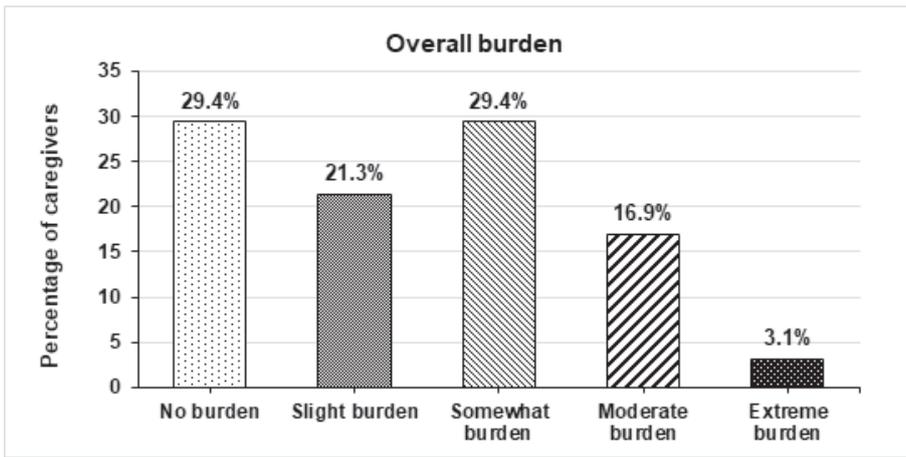


Figure 1. Overall evaluation of burden on caregivers

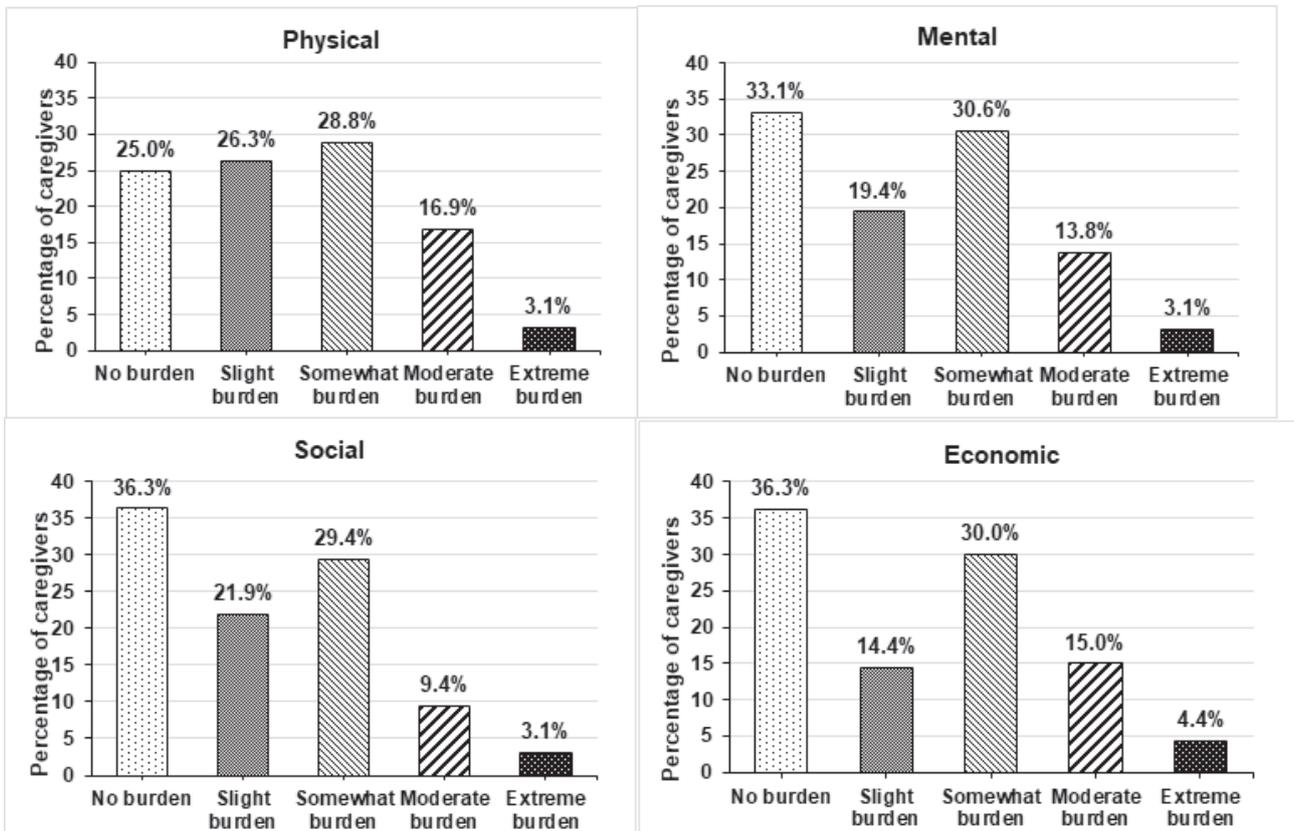


Figure 2. Overall evaluation of burden on caregivers

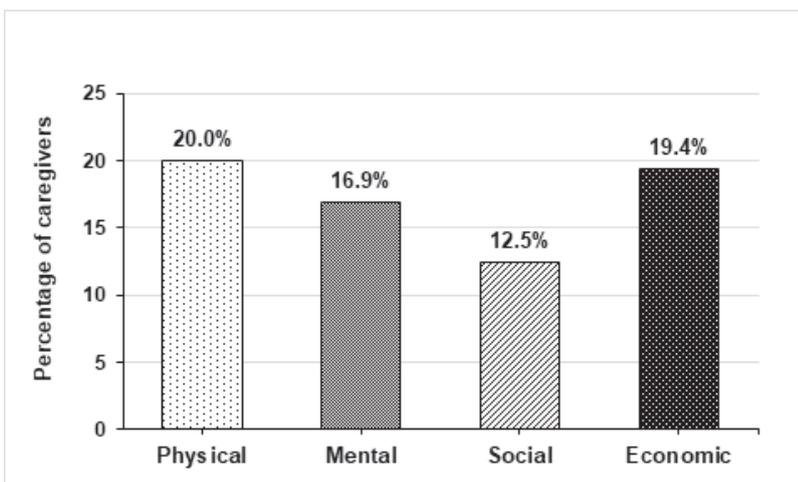


Figure 3. Proportions of patients that are considered to represent either moderate or extreme caregiver burden for each of the 4 dimensions

Table 3. Factors related to burden on caregivers from univariate analysis (n=160)

Factors	High burden ^A (n=79)	Low burden ^B (n=81)	Odds ratio (95% CI)	p-value [#]
Caregiver factors				
Gender				0.406
- Female	58 (47.5)	64 (52.5)	1.00	
- Male	21 (55.3)	17 (44.7)	1.37 (0.66, 2.86)	
Age				0.189
- ≥60 years	8 (36.4)	14 (63.6)	1.00	
- <60 years	71 (51.4)	67 (48.6)	1.85 (0.73, 4.70)	
Education				0.344
- Higher than primary school	49 (46.7)	56 (53.3)	1.00	
- Primary school and lower	30 (54.5)	25 (45.5)	1.37 (0.71, 2.63)	
Took course in how to care for stroke patients				0.479
- Yes	26 (45.6)	31 (54.4)	1.00	
- No	53 (51.5)	50 (48.5)	1.26 (0.66, 2.42)	
Experienced in taking care of stroke patients				0.565
- Yes	23 (46.0)	27 (54.0)	1.00	
- No	56 (50.9)	54 (49.1)	1.22 (0.62, 2.38)	
Duration of stroke patient care				0.783
- >1.0 years	56 (48.7)	59 (51.3)	1.00	
- ≤1.0 year	23 (51.1)	22 (48.9)	1.10 (0.55, 2.17)	
Time spent in taking care of stroke patient				0.226
- Full-time	24 (42.9)	32 (57.1)	1.00	
- Part-time	55 (52.9)	49 (47.1)	1.50 (0.74, 3.04)	
Relation to patients				0.067
- Non-relative	9 (33.3)	18 (66.7)	1.00	
- Relative	70 (52.6)	63 (47.4)	2.22 (0.93, 5.30)	
Patient factors				
Gender				0.015*
- Female	25 (37.9)	41 (62.1)	1.00	
- Male	54 (57.4)	40 (42.6)	2.21 (1.16, 4.22)	
Age				0.026*
- ≥60 years	40 (42.1)	55 (57.9)	1.00	
- <60 years	39 (60.0)	26 (40.0)	2.06 (1.09, 3.92)	
BI _{DC}				0.256
- ≥15	31 (44.3)	39 (55.7)	1.00	
- <15	48 (53.3)	42 (46.7)	1.43 (0.77, 2.70)	
Anxiety _{DC}				0.493
- No	62 (48.8)	65 (51.2)	1.00	
- Yes	5 (62.5)	3 (37.5)	1.75 (0.40, 7.62)	
Depression _{DC}				0.624
- No	54 (48.6)	57 (51.4)	1.00	
- Yes	13 (54.2)	11 (45.8)	1.25 (0.52, 3.02)	
Complications _{DC}				0.639
- No	18 (52.9)	16 (47.1)	1.00	
- Yes	61 (48.4)	65 (51.6)	0.83 (0.39, 1.78)	
Quality of life _{DC}				0.299
- Good to very good	26 (44.1)	33 (55.9)	1.00	
- Very poor to fair	48 (52.7)	43 (47.3)	1.42 (0.73, 2.74)	
Level walking ability				0.003*
- ≥10 meters	32 (37.6)	53 (62.4)	1.00	
- <10 meters	40 (62.5)	24 (37.5)	2.76 (1.41, 5.39)	

Number (%); DC, at discharge; *, p-value<0.05 indicates statistical significance; #, Chi-square test or Fisher's exact test; A, High burden included somewhat, moderate and extreme burden; B, Low burden included no burden and slight burden.

Table 4. Factors related to burden on caregivers from multivariate analysis

Factors	Crude odds ratio (95% CI)	p-Value [#]	Adjusted odds ratio (95% CI)	p-Value ^{##}
Age of caregiver		0.189		0.109
- ≥60 years	1.00		1.00	
- <60 years	1.85 (0.73, 4.70)		2.29 (0.83, 6.28)	
Relation to patient		0.067		0.124
- Non-relative	1.00		1.00	
- Relative	2.22 (0.93, 5.30)		2.14 (0.81, 5.64)	
Patient gender		0.015*		0.051
- Female	1.00		1.00	
- Male	2.21 (1.16, 4.22)		2.11 (0.99, 4.48)	
Patient age		0.026*		0.072
- ≥60 years	1.00		1.00	
- <60 years	2.06 (1.09, 3.92)		1.96 (0.94, 4.09)	
Level walking ability		0.003*		0.001*
- ≥10 meters	1.00		1.00	
- <10 meters	2.76 (1.41, 5.39)		3.30 (1.60, 6.83)	

*p-value<0.05 indicates statistical significance; [#]Chi-square test or Fisher's exact test; ^{##}Multiple logistic

repay kindnesses to one's parents. Accordingly, Thai caregiver respondents may be less likely to choose a response that suggests a negative or burdensome experience.

Given the importance of caregivers to stroke patients, several interventions have been proposed, including increasing caregiver knowledge about the disease in order to improve competency and improving caregiver mental health to achieve an improved sense of well-being and emotional health for the caregiver.⁽⁴⁾ A study from Japan suggested the use of care services, reducing care time, and allowing caregivers some free time as ways to reduce caregiver burden.⁽¹⁹⁾ Jaracz, et al. suggested that the way to reduce stroke patient caregiver burden was to provide education to the caregiver regarding coping strategies and time management and to provide respite care so that primary caregivers could have some added time to themselves.⁽¹⁰⁾ These interventions were developed based on the expectation of decreasing the level of patient burden and increasing the level of caregiver quality of life.

Concerning burden-related factors, this study found 'walking ability less than 10 meters' to be the only factor significantly associated with burden, with an adjusted odds ratio of 3.30 (95% CI 1.60, 6.83). This indicates that the patient's mobility is associated with caregiver burden. As the patient with less mobility would require more caregiver's assistance. On the other hand, no association was found for Barthel Index. This may be because Barthel Index assesses both self-care and mobility ability, thus might not be specific and sensitive enough to show any association with burden on caregivers. To explore the association between patient's self-care ability and caregiver burden, some self-care functions that might require assistance, such as bathing, dressing, and transferring, should be explored independently.

Many studies have also reported on other factors related to burden on caregiver, including intimacy-related issues relative to stroke patients, fewer numbers of caregivers, longer duration of stroke, and more hours of caregiving in a day.⁽²⁰⁾ Caregiver burden also increased with informal caregiver support, patient age, low functional ability of patient, and low amount of social service support.⁽²¹⁾ In addition, burden was also related to

caregiver health, patient gender, time spent taking care of patient, and level of social support,⁽¹⁸⁾ as well as depressive symptoms and functional status.⁽²²⁾

This study has some mentionable limitations. First, given that our study was cross-sectional in design with a relatively small study group, we were only able to identify one factor that significantly correlated with burden on caregiver. Another potential limitation was that we did not use a standard questionnaire, such as the Zarit Burden Questionnaire;⁽²³⁾ so, it is difficult to compare our prevalence results directly with those of other studies. Thirdly, while many studies suggested that the caregiver's time spent in taking care of the patient can affect the level of burden perceived,^(18,20) in this study it was recorded as full-time or part-time only. This factor should be more accurately recorded in future studies. And finally, as this study collected and analyzed data from TSRR, we used Barthel Index at discharge period, which was assessed and recorded routinely in the rehabilitation ward, to measure the patients' functions. This may not truly represent their functions after discharge, and may not reflect the function as accurately as other indexes such as ICF or Modified Rankin Scale (mRS).

In conclusion, majority of the caregivers felt burden taking care of stroke patients and one-fifth rated their burden as moderate to extreme in physical and economic dimensions. The burden perceived significantly correlate with the patient's walking ability of less than 10 meters. Health policy strategies should be developed that effectively relieve caregiver burden, with the objective of improving the post-stroke experience for both caregiver and patient.

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Conflict of interest declaration

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