# Assessing Caregiver Burden and Relationship between Caregiver Burden and Basic Activities of Daily Living in Stroke Patients with Spasticity

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**Objective:** To evaluate caregiver burden of stroke patients with spasticity and to study the relationship between the caregiver burden and the ability to perform basic activities of daily living (bADL) of these patients.

Material and Method: The study design was a cross-sectional descriptive research. The demographic data of 52 stroke patients with spasticity and their caregivers at Songklanagarind Hospital in Thailand were recorded. The Zarit Burden Interview (ZBI) in the Thai version measured the caregiver burdens. The modified Barthel Index (BI) evaluated the bADL of the patients. The correlation between the ZBI and modified BI were calculated by The Spearman's rank correlation coefficient (r) with p < 0.05 considered as a significant level.

**Results:** The caregivers were mainly female (80.8%) who felt no burden (57%). The ZBI score did not significantly relate to the modified BI in either the activity or total score. However, the ZBI score was significantly associated to the caring hours per day (median 14 hours/day,  $r_* = 0.37$ , p = 0.007) and left hemiparesis (p = 0.03).

**Conclusion:** Most caregivers realized that stroke survivors with spasticity were not a burden. There was no relationship between the caregiver burden and the bADL of the patients, but the burden was related to daily caregiving hours and stroke that affected the left side of the body.

Keywords: Stroke, Spasticity, Caregiver burden, Activities of daily living

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Stroke is a major global disease as it is mainly the leading cause of long term disability in the elderly population<sup>(1)</sup>. Thai Public Health statistics showed that the incidence of stroke is increasing every year and it was the third leading cause of death at a mortality rate of 31.4 per 100,000 population in 2010<sup>(2)</sup>. The risk factors of stroke included male, hypertension, diabetes mellitus, and dyslipidemia<sup>(3)</sup>.

Spasticity commonly occurs in disorders of the central nervous system that affect the upper motor neurons in stroke. It is defined as velocity-dependent resistance to stretch, where a lack of inhibition results in excessive contraction of the muscles, eventually leading to hyperreflexia<sup>(4)</sup>. It is found in about 19 to 42.6% of all stroke patients during recovery<sup>(5-7)</sup>. Spasticity causes increased physical disability, limb deformities, and pain. It also limits the ability to perform basic activities of daily living such as hygiene

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workload that occurs from the adaptation to care for the patient. Caregiver burden is divided into two types. Objective burden is the physical burden required to assist patients, and subjective burden is the impact on the mental, emotional, and social burden of caregivers(11). The incidence of caregiver burden in stroke globally was reported as 25 to 54%(12). There were relationships among stroke patients with spasticity and higher caregiver burdens and costs<sup>(13)</sup>. A study by Doan et al in the United States found that stroke patients with spasticity of the arm needed the number of caring hours per week that were proportional to the severity of the disability, especially for patients who had difficulties in hygiene care and dressing<sup>(14)</sup>. However, there has never been any study of caregiver burden in Thai stroke patients with spasticity. The objectives of the present study were to

evaluate the caregiver burden in stroke with spasticity,

and to study the relationship between the caregiver

care and mobility; therefore, caregivers play an

a burden on the caregiver. The burden refers to the

Caring for a patient with a disability places

important role in these patients<sup>(8-10)</sup>.

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burden and the ability to perform basic activities of daily living.

# Material and Method Study participants

The study population was composed of patients and their caregivers in a rehabilitation clinic and physical therapy unit at Songklanagarind Hospital in Thailand. The inclusion criteria were patients who were diagnosed as first episode of stroke by imaging procedures, age more than 18 years old, developed spasticity of the arm, leg or both, clinical features, and were evaluated by the Modified Asthworth Scale. Patients who were diagnosed as other brain diseases such as Alzheimer disease or Parkinson disease or admitted to inpatient care were excluded. Primary caregivers who played the key role in caring, age more than 18 years old and able to answer questionnaire were screened. Caregivers who were hired, had psychiatric diseases, or were admitted to the hospital were excluded from the study.

The present study was approved by the Ethics Committee of the Faculty of Medicine, Prince of Songkla University.

# **Procedures**

The study design was a cross-sectional descriptive study. The stroke patients and caregivers who fulfilled the inclusion criteria were informed of the research project and signed the informed consent before joining the study. Then, the caregivers received the questionnaire regarding basic demographic data: age, gender, relation to patients, caregiving duration, number of caregiving hours per day, underlying disease, and occupation. Their burdens were evaluated using the Thai version of the Zarit Burden Interview (ZBI). The interviews of the caregivers were not conducted in the presence of the patients. Next, the data collected from the patients included age, gender, duration of stroke, type of stroke, affected body side, underlying diseases, and occupation. Finally, the ability to perform basic activities of daily living (bADL) in the patients was assessed by the modified Barthel Index (BI).

# Measures

The ZBI is a tool to evaluate caregiver burden in patients with chronic diseases developed by Zarit SH and Zarit JM<sup>(15)</sup>. It consists of 21 questions and the caregivers in the present study choose a score of zero to four for each question that match their

feelings (0: never, 1: rarely, 2: sometimes, 3: quite frequently, and 4: nearly always). The total scores are in the range of 0 to 84. More points mean a greater burden. In addition, the total ZBI score is categorized into four groups by burden severity (<21: no burden, 21-40: mild burden, 41-60: moderate burden, and 61-84: severe burden). This tool was translated into the Thai version and validated by Toonsiri et al in 2011<sup>(16)</sup>. The Cronbach alpha coefficient was 0.92. The score for each item correlated with the total score at a moderate to high level. The correlation coefficient varied from 0.39 to 0.73.

The modified BI is an ordinal scale used to assess the personal ability to do bADL<sup>(17)</sup>. It is comprised of 10 items including mobility, transfers, toilet use, grooming, bathing, dressing, defecation, urination, feeding, and climbing up and down stairs. The physician rated each item that most closely corresponded to the patient's current level of ability. The total score is in the range from 0 to 20. A low score means a high disability<sup>(18,19)</sup>.

# Statistical analysis

All data were analyzed by R software version 2.14.2. The Shapiro-Wilk test was used to access the normality of the findings. Descriptive data for continuous variables were presented as mean and standard deviation for parametric data, median and range for nonparametric data and discrete variables were presented as numbers and percentages. The Spearman's rank correlation coefficient (r<sub>a</sub>) was used to calculate correlation between the caregiver burden by ZBI, and the modified BI including the continuous demographic data. The Kruskal-Wallis rank sum test used to determine significant differences among three or more groups of the independent variables on the ZBI. The Wilcoxon rank sum test was applied when comparing two subgroups of the categorical demographic data. A p-value <0.05 was considered as a significant level.

#### Results

# Demographic data and correlation with caregiver burden

The data of 52 stroke patients with spasticity and their caregivers between October 2013 and April 2014 were collected. The mean ages of the caregivers and patients were 51.52 and 60.90 years, respectively (Table 1). The median number of months of post-stroke duration was 15. Fourteen hours per day was the median daily caregiving time. Most caregivers (80.8%)

**Table 1.** Continuous demographic data of the patients and their caregivers including the Spearman's rank correlation coefficient  $(r_s)$  between these data and the Zarit Burden Interview (ZBI)

| Continuous demographic data  | Caregivers (n = 52) |                | Patients (n = 52) |                |
|------------------------------|---------------------|----------------|-------------------|----------------|
|                              | Median (range)      | r <sub>s</sub> | Median (range)    | r <sub>s</sub> |
| Age (years) <sup>a</sup>     | 51.52 (13.24)       | -0.04          | 60.90 (13.46)     | -0.22          |
| Stroke duration (months)     | NA                  | NA             | 15 (95)           | -0.12          |
| Caregiving duration (months) | 15 (95)             | -0.13          | NA                | NA             |
| Daily caregiving (hours/day) | 14 (22)             | 0.37*          | NA                | NA             |

n = number; NA = not applicable

**Table 2.** Categorical demographic data of the patients and their caregivers and the median ZBI score classified as the subgroups

| Categorical demographic data | Caregivers (n = 52) |                               | Patients $(n = 52)$ |                               |
|------------------------------|---------------------|-------------------------------|---------------------|-------------------------------|
|                              | n (%)               | The ZBI score, median (range) | n (%)               | The ZBI score, median (range) |
| Gender                       |                     |                               |                     |                               |
| Male                         | 10 (19.2)           | 15 (42)                       | 36 (69.2)           | 16 (63)                       |
| Female                       | 42 (80.8)           | 15 (63)                       | 16 (30.8)           | 12 (44)                       |
| Marital status               |                     |                               |                     |                               |
| Single                       | 11 (21.2)           | 11 (43)                       | 4 (7.7)             | 11 (12)                       |
| Married                      | 40 (76.9)           | 15 (63)                       | 45 (86.5)           | 15 (63)                       |
| Divorced or widowed          | 1 (1.9)             | 28 (0)                        | 3 (5.8)             | 20 (36)                       |
| Relation to patient          |                     |                               |                     |                               |
| Spouse                       | 25 (48.1)           | 21 (59)                       | NA                  | NA                            |
| Child                        | 18 (34.6)           | 11 (42)                       |                     |                               |
| Sibling                      | 3 (5.8)             | 10 (38)                       |                     |                               |
| Others                       | 6 (11.5)            | 15 (19)                       |                     |                               |
| Underlying disease           |                     |                               |                     |                               |
| None                         | 23 (44.2)           | 13 (44)                       | 8 (15.4)            | 15 (41)                       |
| Hypertension                 | 11 (21.2)           | 17 (40)                       | 39 (75.0)           | 14 (56)                       |
| Diabetes mellitus            | 2 (3.8)             | 32.5 (49)                     | 9 (17.3)            | 21 (34)                       |
| Dyslipidemia                 | 5 (9.6)             | 20 (51)                       | 22 (42.3)           | 16 (33)                       |
| Obesity                      | 0                   | -                             | 2 (3.8)             | 26 (24)                       |
| Others                       | 16 (30.8)           | 15 (63)                       | 15 (28.8)           | 13 (63)                       |
| Occupation                   |                     |                               |                     |                               |
| Housewife                    | 12 (23.1)           | 18.5 (37)                     | 0                   | -                             |
| Business                     | 11 (21.2)           | 20 (40)                       | 9 (17.3)            | 20 (35)                       |
| Agriculturist                | 9 (17.3)            | 13 (62)                       | 7 (13.5)            | 13 (53)                       |
| Retired                      | 9 (17.3)            | 10 (44)                       | 10 (19.2)           | 14.5 (43)                     |
| Employee                     | 5 (9.6)             | 10 (24)                       | 7 (13.5)            | 21 (19)                       |
| Government officer           | 2 (3.8)             | 40 (24)                       | 12 (23.0)           | 16 (53)                       |
| Others                       | 4 (7.7)             | 22 (35)                       | 7 (13.5)            | 8 (34)                        |
| Type of stroke               |                     |                               |                     |                               |
| Infarction                   | NA                  | NA                            | 33 (63.5)           | 15 (63)                       |
| Hemorrhage                   |                     |                               | 18 (34.6)           | 16 (53)                       |
| Both types                   |                     |                               | 1 (1.9)             | 43 (0)                        |
| Affected body side           |                     |                               |                     |                               |
| Left                         | NA                  | NA                            | 24 (46.2)           | 21 (55)*                      |
| Right                        |                     |                               | 28 (53.8)           | 11 (63)                       |

n = number; NA = not applicable

<sup>\*</sup> Statistical significance, *p*<0.05

<sup>&</sup>lt;sup>a</sup> Mean (standard deviation)

<sup>\*</sup> Significant median ZBI score in the left side group compared with the right side group, p<0.05

were female, whereas 36 of the 52 patients (69.2%) were male (Table 2). The percentages of patients and caregivers who were married were 86.5% and 76.9%, respectively. Approximately half (48.1%) of the caregivers were spouses. Twenty-three caregivers (44.2%) had no underlying disease. Stroke patients had underlying hypertension (75%) and the related diseases were dyslipidemia (42.3%) and diabetes mellitus (17.3%). About 23% of the caregivers were housewives and 23% of the patients were government officers. According to the relationship between the continuous demographic data and the caregiver burden (Table 1), the ZBI was significantly correlated with the daily caregiving hours ( $r_s = 0.37, p = 0.007$ ). In addition, the caregivers of the stroke that affected the left side of the body had higher median ZBI score than the right side group (p = 0.03). There was no significance of the median ZBI score among the other categorical demographic data (Table 2).

# Modified BI and correlation with the caregiver burden by ZBI

The median total modified BI of the stroke patients was 11.5 of 20 (range 0-19). The median ZBI score of the caregivers was 15 of 84 (range 1-64). The results were also classified by the degree of burden: no burden (57.7%), mild (32.7%), moderate (7.7%), and severe burden (1.9%). The  $r_s$  between the total modified BI and the ZBI scores was 0.10 and p = 0.50 (Table 3). In each domain of the modified BI, there were the negative correlations between bathing, bladder control

**Table 3.** Relationship between each domain including total score of the modified Barthel index and the Zarit Burden Interview by the Spearman's rank correlation coefficient (r<sub>o</sub>)

| Domain of modified Barthel index | Median score (range) | r <sub>s</sub> |
|----------------------------------|----------------------|----------------|
| Feeding                          | 2 (2)                | 0.18           |
| Bathing                          | 0(1)                 | -0.04          |
| Grooming                         | 1(1)                 | 0.13           |
| Dressing                         | 1 (2)                | 0.28           |
| Bowel                            | 2 (2)                | 0.11           |
| Bladder                          | 2 (2)                | -0.04          |
| Toilet use                       | 1 (2)                | 0.12           |
| Transfer                         | 2 (3)                | 0.07           |
| Mobility                         | 0(3)                 | -0.03          |
| Stairs                           | 0(2)                 | 0.09           |
| Total score                      | 11.5 (19)            | 0.10           |

and mobility, and the ZBI scores; however, it was not statistically significant. The positive correlations between the other domains of the modified BI and the ZBI were revealed without statistical significance.

#### **Discussion**

Numerous global studies described caregiver burden in the stroke population. However, there were few studies that evaluated caregiver burden in stroke patients with spasticity, which is a common problem of stroke and probably resulted in many unsatisfactory outcomes in both patients and caregivers. This is the first study that reported caregiver burden of the subgroup of stroke patients in Thailand. The assessment of caregiver burden in the present research used the Thai version of the ZBI with a high internal consistency and it predominantly appeared that the caregivers felt no burden. According to a review of recent studies, caregiver burden in stroke patients with spastic sequelae was not the primary outcome; however, some clinical therapeutic trials measuring caregiver burden in these specific patients as a secondary outcome could present useful data. First, a randomized controlled trial by Bhakta et al<sup>(20)</sup> studied the botulinum toxin type A (BoNT-A) effect on spastic reduction in 40 stroke patients with arm spasticity. They reported a median caregiver burden score at baseline that consisted of four items and rated each item by a 5-point Likert scale. The scores of each item were summed and divided by four to give a summary score from 0 = none to4 = maximum caregiver burden. The score in the placebo group was 1.3 and the score in the BoNT-A group was 2, which indicated a mild to moderate burden<sup>(20)</sup>. Another study by McCrory et al<sup>(21)</sup> also revealed a caregiver burden score as the second endpoint in spastic treatment of 96 stroke survivors with upper limb spasticity. The pretreatment caregiver burden scores of the placebo and BoNT-A groups were 1.9 and 1.5, respectively, that were categorized into mild to moderate burden as well<sup>(21)</sup>. The regional culture and personality probably explained why the present study presented a lower caregiver burden than both of the previous studies. As reported by Janthayanont et al<sup>(22)</sup>, who explored the attitude of 122 caregivers of stroke patients in Phra Nakhon Si Ayutthaya Province in Thailand, the majority of caregivers would not like to care for the patients but it was their duty and had no idea that it was a burden. In addition, there were statistically significant relationships between some mental attitudes such as great sympathy, belief in returning the favor, and religious considerations of sin

and good of the caregiver group<sup>(22)</sup>. There were some differences between the stroke subjects with spasticity in the present study and the Janthayanont's study that included stroke patients with and without spasticity. However, a religious conviction could be presumed in most of the Thai population in both studies.

The hypothesis was that the ability in doing bADL by the modified BI negatively correlated with the caregiver burden (i.e., as the ability increased then the burden decreased) in stroke patients with spasticity. The present study revealed that there was no relationship between the modified BI for each item and the total scores and caregiver burden assessed by the ZBI. This finding probably resulted from a positive attitude of Thai people<sup>(22)</sup>. The other reason was likely the tool to assess caregiver burden, which has multidimensional aspects. The ZBI used in the present study consisted of personal and role strain factors that referred to direct stress from care and social role limitations of caregiving(15). Since the items had more mental components than physical components, these items possibly played a key role in caregiver burden in this specific stroke population. Future studies should consider this issue.

In spite of no correlation between the bADL ability and caregiver burden, the present study revealed that the caregiver burden was significantly related to daily caring hours. The median number of caring hours per day was 14 hours, which is approximately two-thirds of a day. Many published papers in general stroke patients also reported a similar relationship<sup>(12)</sup>. The clinical implication was to reduce the duration of caregiving and train the patients to be independent as much as possible, which might decrease the caregiver responsibilities. Furthermore, interventions to relief the caregiving burden based on numerous studies should also be established<sup>(23-26)</sup>.

In addition to the relationship between the caregiver burden and caregiving hours per day, we discovered that the burden was associated to weakness of the left side, which resulted from a right hemispheric lesion. The specific and co-occurrence of cognitive impairments of right hemispheric damage were neglect syndrome and anosognosia that were probably the causes of the caregiver burden. Many published studies reported the impact of neglect syndrome on stroke patients such as negative predictor for recovery, association with disability in basic as well as instrumental ADL and predictable family caregiver burden by neglect severity<sup>(27-30)</sup>. Additionally, anosognosia significantly affected the recovery process and daily

life functioning in stroke patients<sup>(31,32)</sup>. However, these factors were not assessed in the present study. For further research, the relationship between neglect syndrome including anosognosia and caregiver burden in this specific stroke population should be explored.

The limitations of the present study were the small sample size and no control group of stroke patients without spasticity.

In conclusion, the majority of caregivers felt that stroke survivors with spasticity were not a burden. There was no relationship between the caregiver burden and the ability to perform the bADL of the patients but the burden was related to daily caregiving hours and left hemiparesis.

# What is already known on this topic?

The relationship between caregiver burden and numerous possible influences in stroke survivors were widely studied; however, there are few research reports that specified stroke patients with spasticity. According to previous evidence in the United States, Doan et al<sup>(14)</sup> found that stroke patients with spasticity of the arm needed the number of caring hours per week that were proportional to the severity of the disability, especially for patients who had difficulties in hygiene care and dressing. To the extent of our knowledge, there has never been a study of caregiver burden and associated factors as well as the ability to perform basic activities of daily living in Thai stroke patients with spasticity.

# What this study adds?

The authors revealed that most caregivers of stroke survivors with spasticity felt no burden. In addition, the caregiver burden did not correlate with the ability to perform basic activities of daily living by using the modified BI. On the contrary, the burden was related to daily caregiving hours and left hemiparesis. The implication was that the caring time should be decreased so the caregiver burden might diminish.

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#### **Potential conflicts of interest**

None.

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การประเมินภาระของผู้ดูแลและความสัมพันธ์ระหว่างภาระของผู้ดูแลและความสามารถในการทำกิจวัตรพื้นฐานของผู้ป่วย โรคหลอดเลือดสมองที่มีอาการเกร็ง

# พิชามญชุ์ คณิตานุพงษ์, วิภาวรรณ ลีลาสำราญ

วัตถุประสงค์: เพื่อประเมินภาระของผู้ดูแลผู้ป่วยโรคหลอดเลือดสมองที่มีอาการเกร็งและศึกษาความสัมพันธ์ระหว่างภาระของผู้ดูแล กับข้อมูลพื้นฐานและความสามารถในการทำกิจวัตรพื้นฐานของผู้ป่วยเหล่านี้

วัสดุและวิธีการ: รูปแบบการศึกษาเป็นการศึกษาเชิงพรรรณนาแบบตัดขวาง โดยข้อมูลพื้นฐานของผู้ป่วยโรคหลอดเลือดที่มีอาการ เกร็งและผู้ดูแลที่โรงพยาบาลสงขลานครินทร์ ประเทศไทย จำนวน 52 คู่ ถูกบันทึก ภาระของผู้ดูแลประเมินด้วยแบบสอบถาม Zarit Burden Interview (ZBI) ฉบับภาษาไทย และความสามารถในการทำกิจวัตรพื้นฐานของผู้ป่วยประเมินด้วย modified Barthel Index (BI) วิเคราะห์ความสัมพันธ์ ระหว่าง ZBI กับข้อมูลพื้นฐานแบบต่อเนื่องและ modified BI โดยใช้ Spearman's rank correlation coefficient (r) โดย p<0.5 มีนัยสำคัญทางสถิติ

สรุป: ผู้ดูแลส่วนใหญ่รู้สึกว่าการดูแลผู้ป่วยโรคหลอดเลือดสมองที่มีอาการเกร็งไม่เป็นภาระ ไม่มีความสัมพันธ์ระหว่างภาระของผู้ดูแล ผู้ป่วยกับความสามารถในการทำกิจวัตรพื้นฐานของผู้ป่วยกลุ่มนี้ แต่มีความสัมพันธ์กับจำนวนชั่วโมงที่ใช้ในการดูแลผู้ป่วยต่อวัน และผู้ป่วยที่มีซีกซ้ายอ่อนแรง