# Factors Influencing Caregiver Burden During Rehabilitation of Stroke Patients

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# 뇌졸중 환자 재활 시 간병인 부담에 영향을 미치는 요인

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**Abstract** In this study, we aimed to determine which medical conditions of the stroke patients admitted for rehabilitation more than four weeks after onset affect caregiver burden. Participants diagnosed with stroke and their respective primary caregivers were enrolled and assessed after an 8-week follow-up period. The areas of evaluation for stroke patients included neurologic state, cognition, performance in daily life movements, gait, and balance, and caregivers were evaluated in the area of burden. The evaluation was conducted at the start of the rehabilitation course and eight weeks later. Patient caregivers were found to be under mild to moderate burden while providing care throughout the hospitalization period. The patient's neurologic state and cognition were correlated with caregiver burden. In the all patient and the subacute stroke patient group, multiple regression analysis confirmed that the neurologic state and balance stability were factors that influenced caregiver burden. Hence, we suggest that improvement in the patient's balance stability be emphasized during the course of rehabilitation to mitigate caregiver burden.

Key Words : Stroke, Rehabilitation, Caregiver burden, Balance stability, Neurologic state

**요 약** 본 연구에서는 뇌졸중 환자의 어떤 의학적 요인이 간병인 부담에 영향을 미치는지 알아보기 위해 8주간의 치료 전후 환자의 신경학적 상태, 인지, 일상생활수행능력, 보행, 균형 지표와 간병인의 부담감을 측정하여 그 변화를 비교하였습니다. 간병인은 8주간의 재활 치료 기간 동안 경도-중등도의 부담감을 느끼고 있었으며, 환자의 신경학적 상태, 인지 상태가 간병인 부담과 연관이 있었습니다. 전체 환자군 및 아급성기 뇌졸중 환자군의 의학적 지표와 간병인의 부담감을 다중회귀분석 하였 을 때, 신경학적 상태와 균형 능력이 보호자 부담감에 영향을 주는 요소로 나타났습니다. 이에 입원한 뇌졸중 환자의 재활 치 료 시 간병인 부담 경감을 위해 환자의 균형 능력 향상에 중점을 둘 것을 제안합니다.

키워드 : 뇌졸중, 재활, 간병인 부담, 균형 능력, 신경학적 상태

## 1. Introduction

Stroke leaves sequela of both physical and cognitive disabilities for affected patients [1,2]. In many cases, such consequences gravely reduce their quality of life by limiting their performance in daily activities and social participation [3–6]. Moreover, this decrease in functionality also places heavy psycho-

\*Corresponding Author : Yong-Soon Yoon(gvcdr@daum.net) Received July 19, 2022 Accepted November 20, 2022 logical and economic burdens on their caregivers [7,8]. The caregiver plays a critical role throughout the patient's rehabilitation, and caregiver burden affects the patient's long-term prognosis [9,10]. Thus, simultaneous interventions are essential in addressing caregiver burden during the ultimate rehabilitative treatment course of stroke patients. Caregivers are generally divided into two distinct

Revised August 29, 2022 Published November 28, 2022 groups: family caregivers and professional caregivers. In the article, we use the word "caregiver" to describe the people who physically take care of patients.

In previous studies regarding caregiver burden in the management of stroke patients, social support [11], health status [12], economic status, age, resilience, and duration period of patient care [13] were reported as critical variables that influenced caregiver burden. However, these factors cannot be managed by the hospital or clinician for the benefit of the patients. Thus, the purpose of this study is to determine the specific medical conditions in stroke patients that directly affect caregiver burden during hospitalization.

### 2. Participants and Method

#### 2.1 Participants and procedure

The selection criteria for study participants were as follows: 1) subacute or chronic phase stroke diagnosis confirmed by brain CT or MRI, 2) greater than four weeks since stroke onset, 3) age 18 years or older and 4) ability to verbalize, follow instructions and cooperate in the evaluation. The exclusion criteria were as follows: 1) difficulty understanding written instructions and commands due to illiteracy, 2) diminished visual acuity, 3) hearing loss, 4) evidence of a severe or unstable physical disease, 5) diagnosis of underlying mental health illness including schizophrenia, delusional disorder, and mood (affective) disorder, 6) history of encephalitis, 7) history of illicit drugs or alcohol use within the past 10 years, 8) history of cranial injuries that could cause loss of consciousness for more than one hour prior to stroke, or 9) history of metabolic encephalopathy prior to stoke onset. The selection criteria for caregivers were as follows: 1) family member or, 2) occupational caregivers with prior experience in caregiving and 3) ability to communicate, read, answer questionnaires, and agree to fully participate in the study.

The study was conducted for a total of 8±2

weeks, during which period patients underwent comprehensive rehabilitation. Patients and their caregivers were evaluated before the start of treatment and eight weeks following treatment. The patients were assessed in neurologic and cognitive functioning, daily life performance, and functionality, and the caregiver evaluated burden

#### 2.2 Measurements

The caregiver burden was evaluated using the Burden Interview (BI), which has been broadly used in recent articles [14,15]. The BI is evaluated with 22 questions. For each question, between 0 and 4 points were assigned by the subjects, and all scores were summed. Scores from 21 to 40 are classified as mild to moderate, from 41 to 60 as moderate to severe, and from 61 to 88 as severe [16]. Neurological evaluation of participants was accomplished using the Korean-National Institute of Health Stroke Scale (K-NIHSS). Cognitive function assessments were performed using the Wechsler Adult Intelligence Scale (Wechsler). The Korean Version of Modified Barthel Index (K-MBI) was used to evaluate daily life behavior, Functional Ambulation Categories (FAC) were used for gait evaluation, and the Berg Balance Scale (BBS) was used for balance evaluation.

#### 2.3 Data analysis

IBM SPSS Statistics (Version 24.0) was used for statistical analysis. The value for caregiver burden on the caregiver was calculated as the mean and standard deviation; the change in burden was analyzed by the Wilcoxon signed-rank test. To determine the correlation of survey items for stroke patients including the patient's neurologic state, cognition, daily life movement, and gait and balance state with caregiver burden, a correlation analysis was performed with the Shapiro-Wilk test, followed by a normality test. Multiple regression analysis was performed to determine the factors of stroke patients that influence caregiver burden, and the statistical significance level was set to  $p\langle 0.01$ 

#### 3. Results

#### 3.1 Participants

According to the selection criteria, 60 participants were recruited, 12 out of 60 dropped out for following reasons: one patient had a secondary infarction, four patients had medical complications, seven patients were discharged early. The remaining 48 patients were selected for participation in the study. The mean patient age was 60.4±14.9 years, with 29 (60.4%) males and 19 (39.6%) females. The mean duration of stroke was 12.23± 19.13 months. Cerebral infarction occurred in 23 patients (47.9%) and cerebral hemorrhage occurred in 25 patients (50.1%). The average age of the caregivers was 51.47±13.40 years old, with 14 (29.2%) males and 34 (70.8%) females. With regard to the caregiver's relationship to the patient, 21 caregivers were spouses (43.8%), 16 caregivers were children (33.3%), and 11 were professional caregivers (22.9%). The average care time was 76.3 hours per week (Table 1).

Table 1.	Characteristics of participants and	
	caregivers	

	Mean(SD)	Percent(%)	
Patient			
Age (years)	60.42(14.91)		
Male	29	60.40	
Female	19	39.60	
	Diagnosis		
Cerebral Infarction	23	47.91	
Intracranial hemorrhage	25	50.08	
Duration of stroke (months)	12.23(19.13)		
Caregiver participants (N=48)			
Age	51.47(13.50)		
Male	14	29.20	
Female	34	70.80	
F			
Family - Spouse	21	43.80	
Family - Sons & Daughters	16	33.30	
Professional Caregiver	11	22.90	
Caregiving time(hour/week)	76.25(49.45)		
Caregiving duration(month)	0.88(17.18)		

#### 3.2 Caregiver burden

The caregivers were found to bear a mild to moderate burden by the BI before and after eight weeks of treatment, and there was no significant difference before and after burden (Table 2).

Table 2	. Changes o	f caregiver	burden	after	8 weeks
	of rehabilit	ation			

Variables	Baseline	8 weeks	p-value
BI(N=48)	30.33(17.66)	28.40(18.34)	0.196
	,		

Values are mean (SD), \*p(0.05, \*\*p(0.01, Wilcoxon signed rank test on difference. Burden Interview (BI), Mild to Moderate Burden Score(21-40), Moderate to Severe Burden Score(41-60), Severe Burden Score(61-88).

#### 3.3 Patient indices

When comparing the results of the initial evaluation with those after eight weeks of rehabilitation in stroke patients, the mean values for neurologic state (K-NIHSS), cognition (Wechsler), and functionality of daily life (K-MBI, FAC, BBS) showed significant improvement (Fig. 1). The K-NIHSS score significantly decreased after treatment (M= 12.81 ± 12.37) compared with before treatment (M=13.96  $\pm 13.93$ ; p=0.028 by the Friedman test). The Wechsler memory test score significantly increased after treatment (M=72.46±17.1) compared with before (M=76.94±21.10; p(0.001 by the Friedman test).. The K-MBI value increased after treatment  $(M=35.25\pm36.19)$  compared with before treatment (M=41.29±37.88; p<0.001 by the Friedman test). The FAC score was increased after treatment (M=2.60  $\pm 1.57$ ) compared with before (M=2.79 $\pm 1.71$ ; p=0.034 by the Friedman test). The BBS score increased after treatment (M=16.65±20.62) compared with before treatment (M= $20.67 \pm 22.2$ ; p=0.001 by the Friedman test).



Fig. 1. Changes of Participant's Parameters after 8 weeks of rehabilitation showed significant difference (p(0.01).

# 3.4 Relationship between changes in caregiver burden and changes in patient indices after eight weeks of rehabilitation

In this study, the change in each variable, which was determined by subtracting the initial value from the value after eight weeks of rehabilitation, was expressed by delta ( $\Delta$ ). When examining the relationship between caregiver burden and the patient variables, changes in the patient's neurologic state and cognition positively correlated with the change in caregiver burden (Table 3).

#### Table 3. Correlation between the changes in BI (∠BI) of the caregivers and changes in the patient indices after 8 weeks

Variables	Correlation coefficient	p-value
⊿K-NIHSS	0.262**	0.010
⊿K-Wecshler	0.212*	0.038
⊿K-MBI	-0.112	0.278
⊿FAC	0.069	0.503
⊿BBS	-0.039	0.706

\*p(0.05, \*\*p(0.01 in Spearman correlation analysis.

Multiple regression analysis was performed to analyze if changes in specific factors may have impacted changes in caregiver burden. The regression model yielded a power of 20.0% for the regression equation with the F statistic value ranging from  $p\langle 0.001$  to 12.252. Changes in the BBS (t=-3.882,  $p\langle 0.001 \rangle$  and K-NIHSS (t=3.015, p=0.003) scores had a significant effect on the change in the BI. Herein, the higher the BBS score, the lower the BI, and the lower K-NIHSS score, the lower the BI. Other variables had no significant effect on the BI (Table 4).

Table 4. Multiple regression analysis of the changes of patients' parameters predicting the changes of caregivers' burden

Variables	β	p-value	Adjusted R <sup>2</sup>
⊿K-NIHSS	0.284*	0.003	
⊿Wechsler	-0.020	0.837	
⊿K-MBI	0.089	0.478	0.200
⊿FAC	0.122	0.254	
⊿BBS	-0.366**	(0.01	

\*p(0.05, \*\*p(0.01, in multiple regression analysis (Adjusted R<sup>2</sup>=0.20)

## 3.5 Subgroup analysis of patients

Stroke patients were divided into two groups ac-

cording to onset duration based on 6 months: subacute and chronic. The relationship between the changes in caregiver burden and the patient variables after rehabilitation were analyzed using correlation analysis and multiple regression. In the subacute group, improvement in the patient's K-NIHSS and BBS score was significantly correlated with a decreased burden index (Table 5). As in the previous regression analysis (Table 4), changes in the K-NIHSS (t=5.001, p(0.001) and BBS scores (t=-5.046, p(0.001) were significant factors affecting changes in caregiver burden in the subacute group. The regression model in the subacute group yielded a power of 49.8% for the regression equation with an F statistic value ranging from p(0.001 to 22.834)(Table 6). In the regression analysis performed on all patients, the standardized beta coefficients of the K-NIHSS and BBS scores were 0.284 and -0.366 respectively, and the standardized beta coefficients in the subacute regression analysis were 0.537 and -0.542, respectively. Comparing the absolute values of these two values, both were greater in the subacute model than in all patients. Thus, changes in the K-NIHSS and BBS score had a greater effect on the change in the BI in the subacute group than in all patients.

#### Table 5. Correlation between the changes in BI (∠BI) of the caregivers and changes in the subacute (Within 6 months of onset) patients' indices after 8 weeks

Variables	Correlation coefficient	p-value
⊿K-NIHSS	0.411**	0.003
⊿K-Wecshler	-0.201	0.161
⊿K-MBI	-0.141	0.327
⊿FAC	0.065	0.655
⊿BBS	-0.297*	0.012

\*p(0.05, \*\*p(0.01 in Spearman correlation analysis.

#### Table 6. Multiple regression analysis of changes of subacute patients' parameters predicting changes of caregivers' burden

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Variables	β	p-value	Adjusted R <sup>2</sup>
⊿K-NIHSS	.537**	<.001	
⊿Wechsler	.004	.973	
⊿K-MBI	184	.334	.498
⊿FAC	.106	.339	
⊿BBS	542**	<.001	

\*p(0.05, \*\*p(0.01, in multiple regression analysis (Adjusted R<sup>2</sup>=0.498)

In the chronic group, there were no particularly correlated variables (Table 7), and an explainable regression model was not produced.

## Table 7. Correlation between changes in BI of the caregivers and changes in the chronic patient indices after 8 weeks

Variables	Correlation coefficient	p-value
⊿K-NIHSS	0.155	0.302
⊿K-Wecshler	-0.131	0.387
⊿K-MBI	-0.019	0.898
⊿FAC	-0.024	0.874
⊿BBS	-0.159	0.292

\*p(0.05, \*\*p(0.01 in Spearman correlation analysis.

## 3.6 Subgroup analysis of caregivers

Another analysis was attempted by classifying the subgroups of caregivers into professional caregivers and family members, men and women, and age older and younger than 65 years, but there were no statistically significant difference. Changes in the BI according to caregiving time and caregiving duration did not show statistically significant results.

#### 4. Discussion

The purpose of this study was to determine which specific medical conditions among patients admitted to rehabilitation more than four weeks after the onset of stroke directly affect caregiver burden during hospitalization. We observed that caregivers of stroke patients undergoing an inpatient rehabilitation course had a mild to moderate burden, and there were no significant changes at baseline or eight weeks later. Patient indices after eight weeks of rehabilitation showed significant changes, and comprehensive improved the patient's neurologic state, cognition, and functionality.

Previous studies have analyzed the relationship between caregiver burden and stroke patient variables at specific timepoints or focused on caregiver factors through longitudinal studies [21,29,30]. In this study, we used the change in each variable, which was determined by subtracting the initial value from the value after eight weeks of rehabilitation, including a time factor, and it was expressed by delta ( $\Delta$ ). The changes in the patient's neurologic state and cognition were positively correlated with the changes in caregiver burden. Among medical conditions, ability to balance and neurologic state were observed to be the factors that influenced the change in caregiver burden. Caregiver burden decreased with improved patient balance and neurologic state.

The K-NIHSS is a scale used to evaluate neurologic impairment in stroke patients and to assess the effectiveness of treatment. It consists of 11 items including consciousness, motor function, sensory, language, and ataxia, and the lower the score is, the better the function [23]. In 2017, Hong et al. showed that the higher the K-NIHSS score is, the higher the burden of caregivers of stroke patients [24]. In this study, the K-NIHSS score and BBS score affected the change in caregiver burden; thus, caregiver burden was found to increase as the patient's neurological condition deteriorated. The neurologic status of the stroke patients is a significant factor that influences caregiver burden, and comprehensive rehabilitation is needed to improve the patient's neurologic state.

The BBS is the most internationally used balance assessment tool developed for the purpose of assessing the risk of falls in the elderly and a strong predictor of falls in stroke patients [25, 26]. It consists of 14 rating categories including the ability to maintain the posture, the ability to control the voluntary motor, and reflexes to external factors, and the higher the score is, the better the performance. The BBS is used to easily evaluate the balance of stroke patients and predict independent gait [25, 27] and has higher reliability in the evaluation of early stroke patients [28]. Balance and gait instability are common clinical manifestations in stroke patients that lead to an increased risk of falls [17]. Moreover, patients have an even higher risk as they constantly move in rehabilitation programs [18,19]. Such falls can increase hospital stays, interventions, and treatment costs, adding to the burden on the already stressed patients, family, caregivers, and national economy [20]. This study highlighted that the increased risk of falling in stroke patients due to underlying problems with balance instability increases caregiver burden. The caregiver burden affects the patient and plays a critical role in the patient's rehabilitation and long-term prognosis [12,13]. Thus, it is highly advantageous to actively and simultaneously reduce caregiver burden throughout the rehabilitation course with emphasis placed upon patient stability in balance.

In a previous study, caregiver burden had a negative relationship with the cognition of stroke patients [31]. However, this study showed a positive correlation between the change in the patient's cognitive status and caregiver burden. This result suggests that improving the patient's cognitive ability can be a burden on the caregiver, and it can be inferred that caregiver burden may increase as the patient's requests increase.

We divided the subjects into subacute and chronic groups. When analyzing patients in the subacute group, similar to the previous analysis of the entire patient group, K-NIHSS and BBS scores were identified as factors affecting caregiver burden. Each factor had a greater influence on caregiver burden in the subacute patient group than in the entire patient group. Therefore, emphasizing balance training during inpatient rehabilitation to decrease caregiver burden and yield a better prognosis might be more effective in subacute stroke. In the chronic group, an analysis was impossible because a significant regression model was not created, which may have been due to the small number of patients included in the group.

There are several limitations in this study. First, there was only a small group of participants in this study. Second, the psychiatric scales of the patients were not included. Third, we used only the BI to investigate caregiver burden. In a further study, sufficient recruitment and various scales should be used for analysis.

## Conclusion

The balance stability and neurologic state of stroke patients during hospitalization influences caregiver burden; the better the balance ability and neurologic state of patients is, the lower the caregiver burden. Thus, rehabilitation of these stroke patients should involve not only comprehensive rehabilitation but also balance training early on in their course of treatment to decrease caregiver burden. If caregiver burden is expected to increase due to poor balance stability, active interventions to relieve the stress on the caregiver will be necessary. Further research in this area is warranted to substantiate generalizability across stroke management and rehabilitation centers.

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https://doi.org/10.1016/j.apmr.2004.09.013

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