

# The mediating effect of caregiver burden on the caregivers' quality of life

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**Abstract.** [Purpose] Quality of life (QoL) can be closely related to caregiver burden, which may be a potential mediating effect on the relationships among stroke patient caregivers. This study investigated the predictors of caregiver's QoL based on patient and caregiver characteristics, with caregiver burden as a mediator. [Methods] This study was conducted using surveys, a literature review, and interviews. Survey data were collected from 238 subjects, who were diagnosed with stroke, and their family caregivers from October 2013 to April 2014. [Results] Caregiver health status, income, spouses caring for patients, and duration of hospitalization were identified as significant predictors of caregivers' QoL with a mediating effect of caregiver burden. The time spent on caregiving per day and patient education level were the only direct predictors of caregivers' QoL. [Conclusion] The responsibility of caring for patients with stroke, in particular for a spouse, must be administered by means of a holistic family-centered rehabilitation program. In addition, financial support and availability of various health and social service programs must be comprehensively provided in order to maintain caregivers' well-being.

**Key words:** Caregivers, Stroke, Quality of life

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## INTRODUCTION

Caregivers who provide care to a chronically ill family member at home or in an institution are potentially at risk of caregiver burden, as well as declining physical and mental health due to the significant amount of time and energy, sometimes over the course of months or years, required to perform caregiving tasks. Such tasks can be physically, emotionally, socially, or financially demanding<sup>1)</sup>. For the majority of stroke patients, this care is mainly provided by family members<sup>2)</sup>.

Recently, there has been an increasing awareness of the role of caregivers in the long-term management of stroke patients, and there is a growing body of literature concerning caregiving burden, poor caregiver outcomes, and lack of caregiver support, which can eventually lower a caregiver's QoL<sup>3-5)</sup>.

Several studies have investigated the association between the characteristics of both patients and caregivers, as well as the caregiver's QoL that includes the caregiver burden, which has been shown to be either a strong determinant

of caregiver QoL<sup>6, 7)</sup>, or an outcome instead of a predictor, and are more or less similar to QoL predictors<sup>7)</sup>. As such, caregiver burden and QoL may be closely related, implying that the caregiver burden could be a potential mediating effect between the characteristics of both the patient's and caregiver's QoL. Therefore, investigations of the determinants of both patient and caregiver characteristics in terms of caregiver's QoL are needed, and results from these investigations could help to mediate the caregiver burden of stroke patient caregivers.

## SUBJECTS AND METHODS

This study collected data from 238 subjects, who were diagnosed with stroke, and their family caregiver. The stroke patients were receiving rehabilitation therapy at university and rehabilitation hospitals located in Seoul and Gyeonggi-Do province from October 2013 to April 2014. Subjects who had no family caregiver, a history of mental disorders, or difficulties in communication were excluded from the study. All research subjects were limited to those who agreed to participate in the study and data were collected via the survey method. The participation rate of stroke patient caregivers meeting the inclusion criteria was 100%. The present study was supported by the Catholic University and approved by the Catholic University Institutional Review Board (Approval: MC 13QASI0017).

Caregiver burden was measured using the Zarit Burden Interview (ZBI) developed by Zarit<sup>8)</sup>, which is the most

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widely used reference scale<sup>9</sup>). The survey has 22 questions, each of which are answered on a 4 point Likert scale, with higher scores denoting higher caregiver burden. In this study only the total score was used. The internal consistency of the ZBI ranges from 0.70 to 0.87, and it has good reliability and validity for stroke patients and caregivers<sup>10</sup>). Our analysis yielded a Cronbach alpha score of 0.91.

Quality of life (QoL) was measured with the psychometrically and clinically validated Korean version of the World Health Organization Quality of Life-BREF (WHO-QoL-BREF), an abbreviated version of WHOQoL<sup>11</sup>). This questionnaire has 26 questions, each of are answered on 5 point Likert scale, with higher scores signifying greater QoL. The raw score for each domain of the WHOQoL-BREF was transformed to a scale of 0–20 with higher scores indicating better QoL. The internal consistency of the WHOQoL-BREF is 0.90, and it has good reliability and validity in the Korean population<sup>11</sup>). The Cronbach alpha score for this aspect of the study was 0.92.

Data were also obtained for other variables that, according to the literature, influence caregiver burden and/or QoL including: gender of stroke patients and their family caregiver, age, marital status, education, and occupation. The duration of symptoms after stroke onset and hospitalization time were also recorded. Information concerning family income, co-habiting, duration of caregiving (months), time spent on caregiving per day (h/d) and the relationship with the patient were also considered. Furthermore, a one question survey tool that was scored on a scale of 4 points, with “very healthy” yielding 4 points and “very unhealthy” yielding 1 point, and a higher score implying better health conditions, was utilized to assess the health status of the caregivers of stroke patients<sup>12</sup>).

The subject characteristics are presented as frequencies and percentages. Patients’ and caregivers’ variables were found to be normally distributed by the Kolmogorov-Smirnov test ( $p > 0.05$ ). The t-test or analysis of variance (ANOVA) was used to analyze categorical independent variables, and *Pearson* correlation coefficients were calculated for continuous variables to examine the relationship between the characteristics of both patients and their caregivers, and the caregivers’ QoL. Variables determined as significant by univariate analyses were entered into multiple stepwise regression analyses to identify predictors associated with caregivers’ QoL and burden, and to evaluate the mediating effect of caregiver burden using the bootstrapping method of SPSS. Statistical analyses were performed using SPSS ver. 17.0.

## RESULTS

As shown in Tables 1 and 2, the caregivers’ QoL and burden, based on caregiver and patient characteristics, were positively associated with caregiver’s income and health status, and negatively associated with duration of caregiving, time spent on caregiving per day, duration of hospitalization and caregiver burden. Caregivers’ burden was positively associated with caregiver’s age, spouses caring for patients, duration of caregiving, time spent on caregiving per day, time since onset, and duration of hospitalization, and negatively

**Table 1.** Bivariate correlations among study variables

	QoL	CBS
Caregiver characteristics		
Age (years)	−0.065	0.178**
Income	0.305***	−0.234***
Health status	0.386***	−0.329***
Caregiving duration (month)	−0.182**	0.134*
Time spent on caregiving per day (h/d)	−0.296***	0.190**
CBS	−0.619***	1
QoL	1	−0.619***
Patient characteristics		
Age (years)	0.098	−0.064
Time since onset (month)	−0.024	0.138*
Duration of hospitalization (month)	−0.213***	0.205**

CBS: Caregiver Burden Scale; QoL: quality of life

\*\*\* $p < 0.001$ , \*\* $p < 0.01$ , \* $p < 0.05$

associated with caregiver’s income, health status, and QoL.

A multiple stepwise regression analysis with caregiver burden as the mediator is shown in Table 3. Caregiver health status ( $z = 3.86$ ), income ( $z = 2.70$ ), spouses caring for patients ( $z = 2.31$ ), and duration of hospitalization ( $z = -2.83$ ) were identified as significant predictors of caregivers’ QoL with a mediating effect of caregiver burden. The time spent on caregiving per day and patients’ education level were the only direct predictors of caregivers’ QoL.

## DISCUSSION

This study revealed that caregiver burden has a mediating effect on caregivers’ QoL with caregiver health status, income, relationship with patient, and duration of hospitalization identified as predictors with a direct effect on QoL. In addition, the time spent on caregiving per day and patient education were the only direct predictors of a caregivers’ QoL.

The caregiver burden with a mediating effect was substantial for the caregivers’ QoL, a result which is consistent with several earlier studies<sup>6, 13</sup>). To the best of our knowledge this is the first study to address the issue of which caregiver and patient characteristics are most likely to affect caregivers’ QoL with caregiver burden having a mediating effect.

Earlier studies showed that caregiver health is an important factor in determining caregivers’ QoL<sup>14, 15</sup>), which is similar to the findings of our present study. Caregivers traditionally accompany stroke survivors to physical therapy and are taught to conduct and assist stroke survivors with exercises, which may leave caregivers feeling isolated and exhausted. A previous study also reported negative effects on the physical aspects of caregiving on caregivers’ well-being<sup>16</sup>).

Economic status was also associated with caregivers’ QoL<sup>15</sup>), a result which is supported by our present findings. In particular, there is a tendency to lose purchasing power due to the reduction in work-derived incomes, as well as the expenses arising from the specific care requirements of the dependent person<sup>17</sup>).

**Table 2.** The characteristics of patients and caregivers related to the caregiver's CBS and QoL

Independent		N	QoL	CBS
			Mean $\pm$ SD	Mean $\pm$ SD
Hospital type	General or university	201	10.83 $\pm$ 2.40	2.20 $\pm$ 0.72
	Rehabilitation	37	10.23 $\pm$ 2.65	2.26 $\pm$ 0.61
	T		1.37	-0.48
Caregiver characteristics				
Gender	Male	73	11.16 $\pm$ 2.50	2.18 $\pm$ 0.67
	Female	165	10.54 $\pm$ 2.40	2.22 $\pm$ 0.71
	T		1.81	-0.44
Education	Below high school	149	10.41 $\pm$ 2.30	2.29 $\pm$ 0.68
	Above high school	89	11.27 $\pm$ 2.59	2.06 $\pm$ 0.71
	T		-2.63**	2.51*
Marriage	Single	30	10.95 $\pm$ 2.55	1.99 $\pm$ 0.88
	Marriage or co-habiting	202	10.67 $\pm$ 2.42	2.24 $\pm$ 0.66
	Divorce or by death	6	11.67 $\pm$ 3.17	2.18 $\pm$ 1.03
	F		0.61	1.72
Occupation	Yes	105	11.49 $\pm$ 2.36	2.11 $\pm$ 0.68
	No	132	10.13 $\pm$ 2.37	2.29 $\pm$ 0.71
	T		4.40***	-1.98*
Relationship	Spouse	144	10.29 $\pm$ 2.25	2.30 $\pm$ 0.65
	Children	52	11.67 $\pm$ 2.73	2.03 $\pm$ 0.80
	Daughter-in-law	6	12.00 $\pm$ 2.52	2.32 $\pm$ 0.70
	Brothers or sisters	16	11.85 $\pm$ 2.49	1.89 $\pm$ 0.76
	Patients	20	10.20 $\pm$ 2.06	2.22 $\pm$ 0.76
	F		4.86**	2.36
Patient characteristics				
Gender	Male	148	10.56 $\pm$ 2.50	2.22 $\pm$ 0.70
	Female	90	11.02 $\pm$ 2.35	2.18 $\pm$ 0.71
	T		-1.40	0.47
Education	Below high school	169	10.57 $\pm$ 2.48	2.18 $\pm$ 0.73
	Above high school	69	11.14 $\pm$ 2.32	2.26 $\pm$ 0.63
	T		-1.66	-0.78
Marriage	Single	29	10.58 $\pm$ 2.58	2.18 $\pm$ 0.72
	Marriage or co-habiting	188	10.67 $\pm$ 2.39	2.22 $\pm$ 0.67
	Divorce or by death	21	11.55 $\pm$ 2.71	2.09 $\pm$ 0.94
	F		1.29	0.35
Occupation	Yes	59	11.57 $\pm$ 2.19	2.11 $\pm$ 0.69
	No	179	10.46 $\pm$ 2.47	2.24 $\pm$ 0.70
	T		3.10**	-1.24

CBS: Caregiver Burden Scale; QoL: quality of life

\*\*\*p &lt; 0.001, \*\*p &lt; 0.01, \*p &lt; 0.05

Moreover, most informal care for stroke patients is usually provided by spouses, who may suffer high levels of burden and poor family relationships<sup>3, 6</sup>. In another Korean study<sup>18</sup>, however, daughters-in-law acting as caregiver were associated with caregiver burden, a finding that was inconsistent with our results. The differences in these outcomes may be related to the recruited patients because the caregivers of the inpatients in our study may have incurred greater expenses than those of outpatients. Therefore, the spouse caregivers may have experienced greater financial burdens, with negative effects on their well-being.

A previous study showed that the duration of patient hospitalization was inversely associated with caregivers' QoL and caregiver burden<sup>15</sup>, which is similar to the results of our present study. The ability of caregivers to cope with their role during the initial period after the stroke has been identified<sup>19</sup>. It has been reported that as caregiving time increases, financial support often decreases, leaving primary caregivers with the sole responsibility of providing informal care, which can lead to poor health status and reduced time for participation in social activities<sup>20</sup>.

Educational level was associated with caregivers' QoL in

**Table 3.** The mediator effects of caregiver burden between the caregivers' or patients' characteristics and the caregivers' QoL

Step	Independent	Dependent variable	B	SE	$\beta$
1 step	Caregiver health status	Quality of life	0.862***	0.143	0.330
	Caregiving time		-0.972**	0.282	-0.191
	Caregiver income		0.002**	0.001	0.170
	Children of patients relations (vs. spouse)		1.241**	0.317	0.213
	Patients occupation (vs. yes)		-0.686*	0.321	-0.123
	Duration of hospitalization		-0.235*	0.092	-0.140
	Education level of patients (vs. university)		0.696*	0.306	0.131
2 step	Caregiver income	Caregiver burden	-0.001**	0.000	-0.172
	Caregiver health status		-0.191***	0.044	-0.262
	Children of patients relations (vs. spouse)		-0.234*	0.097	-0.143
	Duration of hospitalization		0.083**	0.028	0.178
3 step	Caregiver burden	Quality of life	-1.683***	0.193	-0.469
	Caregiver health status		0.512***	0.135	0.196
	Caregiver income		0.002**	0.001	0.155
	Children of patients relations (vs. spouse)		0.683*	0.288	0.117
	Duration of hospitalization		-0.166*	0.083	-0.099

$F=39.066^{***}$ ,  $R^2(\text{adj-}R^2)=0.459(0.447)$

\*\*\* $p<0.001$ , \*\* $p<0.01$ , \* $p<0.05$

our present study. Several studies have reported that a high education level of the caregiver is a significant contributor to the QoL of caregivers providing care to patients with stroke or other neurological diseases<sup>9, 15</sup>). Although the educational level of patients was only a direct predictor of caregivers' QoL in our present study, higher education has been reported to provide a better understanding of stroke-related disability and its various consequences<sup>21</sup>), resulting in caregiver's adaptation to their new role and better coping strategies<sup>22</sup>). Consequently, educating caregivers about stroke and teaching caregiver coping skills could be an effective way of improving caregivers' QoL.

This study had a number of limitations. First, it was a cross-sectional, clinically based investigation that included mainly patients with moderate or severe stroke because it enrolled only hospital inpatients. Thus, these results cannot be generalized to a wider population of stroke patients. Furthermore, this study explored the causality between the caregivers' QoL and the characteristics of patients and caregivers. Second, our study did not consider physical disabilities, social support networks, and personal attributes of stroke patients. However, several studies have found that the burden of stroke caregivers is independent of functional dependency or stroke severity<sup>23</sup>). Third, although the general health status of the caregivers was examined, we did not specifically examine the effect of comorbidities of patients or caregivers, such as degenerative arthritis or heart disease, on caregivers' QoL<sup>24</sup>). Finally, the assessment of caregivers' QoL and burden was performed only once, and serial follow-up studies are needed to understand the changing pattern of caregivers' QoL relative to caregiver burden.

The present study found that caregivers' health status, income, spouses caring for patients, and duration of hospitalization are important factors that influence caregivers' QoL through the mediating effect of caregiver burden. To mini-

mize negative effects on caregivers' QoL, the responsibility of caring for patients with stroke, in particular for spouses, must involve a holistic family-centered rehabilitation program. In addition, financial support and various health and social service programs must be comprehensively provided in order to maintain the well-being of caregivers.

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