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Burden Predictors for Long-Term Stroke Survivor Caregivers

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BACKGROUND

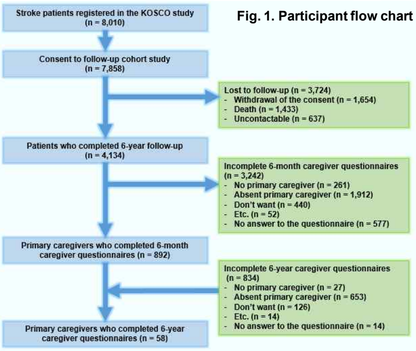
Determining long-term changes in caregiver burden is essential because post-stroke disability accumulates caregiver stress over a long duration. We assessed long-term changes in caregiver burden severity and its predictors.

METHODS

■ Study design and data collection

- **Korean Stroke Cohort for Functioning and Rehabilitation (KOSCO)**

① Inclusion criteria : ⓐ first-ever acute stroke, ⓑ age ≥ 19
ⓒ within 7 days from symptom onset
② Exclusion criteria : ⓐ transient ischemic attack, ⓑ stroke history
ⓒ traumatic intracerebral hemorrhage
ⓓ not Korean
③ Patient and caregiver survey data at 6 months and 6 years (Fig. 1)


Stroke patients registered in the KOSCO study (n = 8,010)
Consent to follow-up cohort study (n = 7,858)
Lost to follow-up (n = 3,724)
- Withdrawal of the consent (n = 1,654)
- Death (n = 1,433)
- Uncontactable (n = 637)

Patients who completed 6-year follow-up (n = 4,134)
Incomplete 6-month caregiver questionnaires (n = 3,242)
- No primary caregiver (n = 261)
- Absent primary caregiver (n = 1,912)
- Don't want (n = 440)
- Etc. (n = 52)
- No answer to the questionnaire (n = 577)

Primary caregivers who completed 6-month caregiver questionnaires (n = 892)
Incomplete 6-year caregiver questionnaires (n = 834)
- No primary caregiver (n = 27)
- Absent primary caregiver (n = 653)
- Don't want (n = 126)
- Etc. (n = 14)
- No answer to the questionnaire (n = 14)

Primary caregivers who completed 6-year caregiver questionnaires (n = 58)

Fig. 1. Participant flow chart

■ Variables and Measurement Tools

- **Dependent variable**
  - **Caregiver outcomes**

Caregiver burden : based on Korean version of Caregiver Burden Inventory (CBI)
cut-off score calculated based on total score > 36 (risk of "burning out" in CBI) ⟶ 36.6 points [(36 x 60/100) + 15 = 36.6]

- **Independent variable**
  - **Patient variables**

National Institute of Health Stroke Scale (NIHSS)
Charlson Comorbidity Index (CCI)
modified Rankin Scale (mRS), Korean Mini Mental State Examination (K-MMSE)
Fugl-Meyer Assessment (FMA), 9-Hole Peg board Test (9-HPT)
Korean Version of the Frenchay Aphasia Screening Test (K-FAST)
Functional Ambulatory Category (FAC)
American Speech-language Hearing Association National Outcome Measurement System Swallowing Scale (ASHA-NOMS)
Korean Modified Barthel Index (K-MBI)
Geriatric Depression Scale-Short Form (GDS-SF)
Quality of life : Euro Quality of life-five dimension (EQ-5D)

- **Caregiver variables**

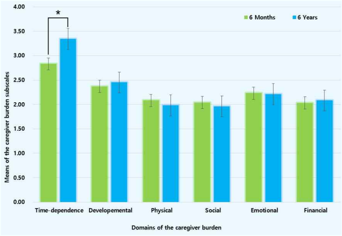
Age, Gender, Employment, Education level
Patient relationship, Relationship level
Patient cohabitation
Home care, Long-term care institution consignment, Hospitalization
Social support services use (home visit services, daycare center)
Alternative caregiver presence
Self-rated health, Self-rated stress
Stroke knowledge (symptoms, acute stage management)
Psychosocial stress : Psychosocial Wellbeing Index-Short Form (PWI-SF), EQ-5D

RESULTS

■ Caregiver burden change for 6 years after stroke

Fig. 2. Change in caregiver burden total score, proportion of high burden AND comparison of each domain score at 6 months and 6 years after stroke

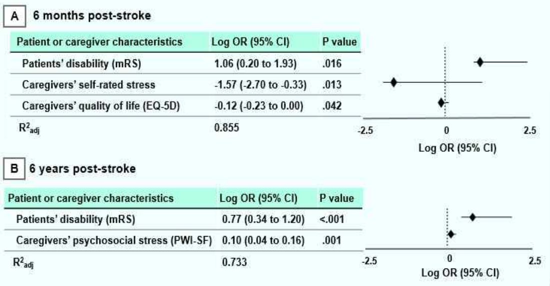
	6 Months	6 Years	P value
Caregiver burden total score, mean (SD)	33.62 (15.10)	34.38 (13.62)	.718
Time-dependence domain, mean (SD)	**2.83 (1.36)**	**3.34 (1.28)**	**.029**
Developmental domain, mean (SD)	2.37 (1.28)	2.45 (1.17)	.640
Physical domain, mean (SD)	2.08 (1.16)	1.98 (1.07)	.595
Social domain, mean (SD)	2.04 (0.91)	1.96 (0.90)	.542
Emotional domain, mean (SD)	2.23 (1.16)	2.21 (1.07)	.891
Financial domain, mean (SD)	2.03 (0.98)	2.08 (0.90)	.753
High caregiver burden, n (%)	**22 (37.9)**	**30 (51.7)**	**.077**



- Caregiver burden total score did **NOT** change
- Proportion of high caregiver burden did **NOT** change
- High caregiver burden, which represent the ***risk of burnout*** : **37.9% at 6 months** and **51.7% at 6 years**
- **Time-dependence domain, developmental domain** : consistently highest
- **Time-dependence domain** score increased ↑ over time

■ Caregiver burden predictors

Fig. 3. Predictors of high caregiver burden at 6 months, and 6 years after stroke



A 6 months post-stroke

Patient or caregiver characteristics	Log OR (95% CI)	P value
Patients' disability (mRS)	1.06 (0.20 to 1.93)	.016
Caregivers' self-rated stress	-1.57 (-2.70 to -0.33)	.013
Caregivers' quality of life (EQ-5D)	-0.12 (-0.23 to 0.00)	.042
R^2_{adj}	0.855	

B 6 years post-stroke

Patient or caregiver characteristics	Log OR (95% CI)	P value
Patients' disability (mRS)	0.77 (0.34 to 1.20)	<.001
Caregivers' psychosocial stress (PWI-SF)	0.10 (0.04 to 0.16)	.001
R^2_{adj}	0.733	

- **6 months post-stroke**
  - Patients' **disability (mRS)**
  - Caregivers' **self-rated stress**
  - Caregivers' **quality of life (EQ-5D)**
- **6 years post-stroke**
  - Patients' **disability (mRS)**
  - Caregivers' **psychosocial stress (PWI-SF)**

CONCLUSION

Nearly half of caregivers were at risk of burnout, which lasted until 6 years. **Patients' disability** and **caregivers' stress** were burden predictors in both subacute and chronic pahses of stroke. Findings can aid in developing Korean-specific interventions for alleviating the caregiver burden.

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