

ARTICLE



# Caregiver burden according to ageing and type of care activity in caregivers of individuals with spinal cord injury

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**OBJECTIVE:** To describe caregiver burden according to the caregivers' general characteristics, especially with ageing, and type of care activities provided by caregivers of individuals with spinal cord injury.

**DESIGN:** A cross-sectional study was conducted utilizing a structured questionnaire that included general characteristics, health conditions, and caregiver burden.

**SETTING:** A single center study in Seoul, Korea.

**SUBJECTS:** Participants were recruited from 87 individuals with spinal cord injuries and 87 caregivers.

**METHODS:** The Caregiver Burden Inventory was used to assess caregiver burden.

**RESULTS:** Caregiver burden was significantly different by age ( $p = 0.001$ ), relationship ( $p = 0.025$ ), sleep hours ( $p = <0.001$ ), underlying disease ( $p = 0.018$ ), pain ( $p = <0.001$ ), and daily activities of individuals with spinal cord injury ( $p = 0.001$ ). Caregiver's age ( $B = 0.339$ ,  $p = 0.049$ ), sleep duration ( $B = -2.896$ ,  $p = 0.012$ ) and pain ( $B = 2.558$ ,  $p < 0.001$ ) predicted caregiver burden. Toileting assistance was the most challenging and time-consuming for caregivers, while patient transfer was associated with the greatest concerns for body injury.

**CONCLUSION:** Caregiver education should be targeted according to caregiver's age and type of assistance. Social policies need to be developed to distribute devices and care-robots to reduce caregiver burden and thereby assist caregivers.

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## INTRODUCTION

Spinal cord injury (SCI) is characterized by motor, sensory, and autonomic nerve injuries; depending on the level of injury, individuals may have difficulty with ambulation and independent activities of daily living (ADL) [1]. This impacts patients and their families' mental, physical, emotional and social aspects [2–4]. In many cases, family members (including spouses) become caregivers of individuals with SCI, and they undergo an equivalent level of physical, psychosocial, and emotional stress as that experienced by individuals with SCI [5–7].

A caregiver is an individual who cares for a person with having limitations due to disease or injury. In Korea, older men who receive care for a chronic illness from a family member may exert a considerable amount of family caregiver burden on women [8]. According to Korean health care system, this caregiver burden starts from the inpatient rehabilitation except for the period in the intensive care unit. This caregiver burden continues after discharge, when living at home due to societal support restrictions, such as day care centers and the economic burden to hire a paid caregiver. In addition, the burden of caregiving influences caregiver's quality of life, and causes health problems [9].

The mean age at SCI increased due to incidence of ageing population [10] and ageing in spinal cord injured patients. The mean age traumatic spinal cord injury (TSCI) in Korea also steadily increased over the last 30 years, from 32.4 years in the 1990s to 47.1 years in the 2010s [11]. The mean age of family caregivers

also increased. According to a previous study, older caregivers had more difficulty caring for patients due to health problems and physical limitations [12].

The amount of support provided from partners of persons with SCI was related to their perceived burden of care and life satisfaction [13]. Although the general characteristics and health conditions of caregivers and individuals with SCI affect the level of caregiver burden. Type of care is also affected.

This study aimed to describe factors affecting caregiver burden of caregivers of individuals with SCI according to general and health-related characteristics, especially with ageing, and type of care activities provided. The study highlights the need for measures to reduce Korean caregiver burden and to prioritize appropriate nursing rehabilitation, attuned to caregiver burden.

## METHODS

### Design

A cross-sectional study aimed at identifying the predictors of caregiver burden in caregivers of individuals with SCI, using a structured questionnaire was adopted.

### Participants

The National Rehabilitation Center (NRC) is the only rehabilitation hospital affiliated with the Ministry of Health and Welfare in Korea. The NRC

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provides in-patient and out-patient rehabilitation services to the greatest number of individuals with SCI in Korea. Volunteers were recruited from SCI patient-caregiver dyads admitted to the NRC as in-patients or out-patients between March 2020 and April 2021. G-power 3.1 software was used to determine the sample size. For F-test multiple regression with a medium effect size, significance level of 0.05, power of 0.80, and four predictor variables, the minimum sample size 85. The target sample size was set to 90 dyads, considering a 5% potential withdrawal rate.

The inclusion criteria were caregivers who one caregiver provided care to one patient with SCI rather than several, ability to understand and communicate in Korean, and individuals with SCI and their caregivers in the age range of 19–79 years. Participants who met all three criteria and voluntarily provided informed consent to participate in the study were enrolled. The exclusion criteria were patients having a disease other than SCI, caregivers providing 1:N care, inability to understand Korean or impaired cognitive function that hinders comprehension of the questionnaire, caregivers under 19 years of age or older than 79 years, or refusal to consent to study terms. Data from two dyads who withdrew their consent and one dyad who provided careless responses were excluded. The questionnaire was administered to 47 in-patient-caregiver dyads at the timing of discharge and 43 out-patient-caregiver dyads. Data from a total of 87 dyads, with 46 inpatient-caregiver dyads and 41 outpatient-caregiver dyads, were included in the analysis.

### Instruments

**Caregiver burden.** Caregiver burden was measured using the multi-dimensional caregiver burden inventory (CBI). The CBI was developed by Novak and Guest and each item is rated on a five-point Likert scale [14]. It comprises five dimensions: time-dependence burden (five items), developmental burden (four items), physical burden (four items), social burden (five items), and emotional burden (five items) [14]. The total score ranges from 25 to 125, with a higher score indicating greater caregiver burden. Cronbach's  $\alpha$  in this study was 0.947.

**Activities of Daily Living (ADL).** ADL was assessed using the Modified Barthel Index (MBI). Eleven items were rated on a scale of 0 to 5. The total score ranges from 0 to 100, where 0 indicates total dependence and 100 indicates independent ADL. Cronbach's  $\alpha$  in this study was 0.944.

**Pain.** Pain was assessed using the Numeric Rating Scale (NRS). The NRS is an 11-point rating scale used to assess pain intensity ranging from 0 (no pain) to 10 (extreme pain).

**Neurological classification.** Individuals with SCI were neurologically classified according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) including American Spinal Injury Association (ASIA) and Impairment Scale (AIS) [15]. This neurological exam data collected from discharge medical records. AIS is used to classify the degree of impairment from A to E. Grade A is classified as complete sensory and motor injury status, while grade E is normal sensory and motor injury status as tested with the ISNCSCI.

### Data collection

The Institutional Review Board of the NRC in Seoul approved this study (Approval No: NRC-2020-02-012). Prior to collecting data, inpatients and outpatients with SCI at the Center and their caregivers provided voluntary written informed consent, between May 2020 and April 2021.

The questionnaire took approximately 40–60 min to complete. Participants were informed that the questionnaire contained personal information and that they could withdraw from the study at any time without any disadvantages. To prevent errors in the responses by consenting participants, one researcher verbally administered the questionnaire and recorded the caregiver's responses in a place away from their patient. Information about individuals with SCI was obtained from the individuals themselves after obtaining their consent. Completed questionnaires were numerically coded after completion and placed in an individual envelope for storage.

### Statistical analysis

We used SPSS 20.0 software to analyze collected data. Caregivers' general characteristics, health status, type of care and general characteristics of individuals with SCI, disability-related characteristics, and health status were presented as real numbers with percentages, means, and standard deviations. The differences in caregiver burden according to the

characteristics of caregivers and individuals with SCI were analyzed using independent t-tests and ANOVA. Subsequently, Scheffe's test was used for post-hoc comparison. Types of caregiver burden were analyzed with mean, standard deviation, and ANOVA, followed by Scheffe's test for post-hoc comparison. Pearson's correlation coefficient was used to analyze the correlations among the factors associated with caregiver burden. We used multiple regression to analyze the relationship among the caregiver burden (dependent variable) and the gender, age, relationship, sleep duration, pain, ADL (independent variables).

## RESULTS

### Characteristics of individuals with SCI and caregivers

79.3% of the caregivers were women. The mean age of primary caregivers was 57.2 years (SD 20.21). Relationships with patients were in the order of spouse (36.8%), employed caregiver (29.9%) and parents (25.3%).

In individuals with SCI, mean age was 51.7 years (SD 17.35) and most (69%) were male. Cervical level of injury was prevalent (51.7%), followed by thoracic level was most prevalent (37.9%), and lumbar level (10.3%). AIS grade were A in 44.8%, B in 25.3%, C in 12.6% and D in 17.2%. 51.7%. More than half of individuals with SCI (51.7%) had less than or equal to 24 score in MBI (Table 1).

### Caregiver burden according to caregivers' general characteristics

The mean CBI of caregivers was  $62.57 \pm 20.21$  out of 125 score. Caregiver burden was significantly higher among older caregivers ( $p = 0.001$ ), spouse, or parent caregivers, as opposed to child caregivers ( $p = 0.025$ ), those who slept for 8 hours or less ( $p < 0.001$ ), those who had an underlying disease ( $p = 0.018$ ), and those who experienced pain ( $p < 0.001$ ). Caregiver burden was higher among those with low-back pain, as opposed to pain in the upper body (shoulder or arm) or lower body (leg or ankle;  $p < 0.023$ ). However, caregiver burden was not associated with gender, marital status, education level, duration of caregiving, place of caregiving, and daily duration of caregiving (Table 1).

### Caregiver burden according to general characteristics of individuals with SCI and health status

Caregiving burden significantly differed between caregivers of individuals with SCI with an MBI score of 24 or lower than those with 75 or higher ( $p = 0.001$ ). However, it did not differ according to the gender, age, BMI, level of injury, severity of injury, time from injury, fall, pressure injury, respiratory problem, voiding method, or defecation method of the individuals with SCI (Table 1).

### Type of caregiver burden by caregiver age group

The most severe type of caregiver burden was time-dependence burden, followed by physical burden, developmental burden, and financial burden. In terms of age group, caregivers aged 70 or older had significantly greater caregiver burden than other age groups ( $p < 0.001$ ). All types of caregiver burden, namely time-dependence burden, developmental burden, physical burden, emotional burden, social burden, and financial burden were the highest in those aged 70 or older ( $p = 0.001$ ; Fig. 1).

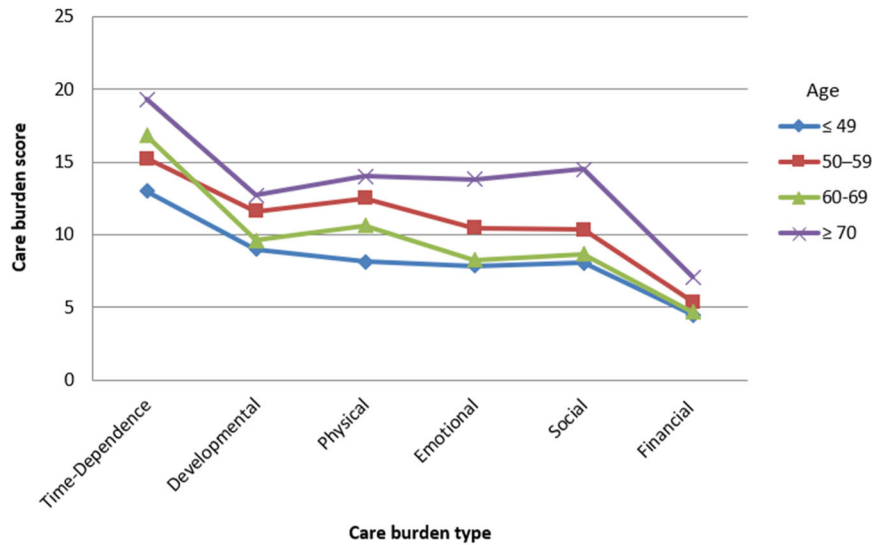
### Ranking of difficulty, time spent, and physical injury risk associated with care activities

The most difficult caregiving task for individuals with SCI was toileting assistance-bowel, followed by transfer and going outside. The most time-consuming task was toileting assistance-bowel, followed by going outside and exercise assistance. The task with the greatest concern for physical injury was transfer, followed by toileting assistance-bowel and going outside (Fig. 2).

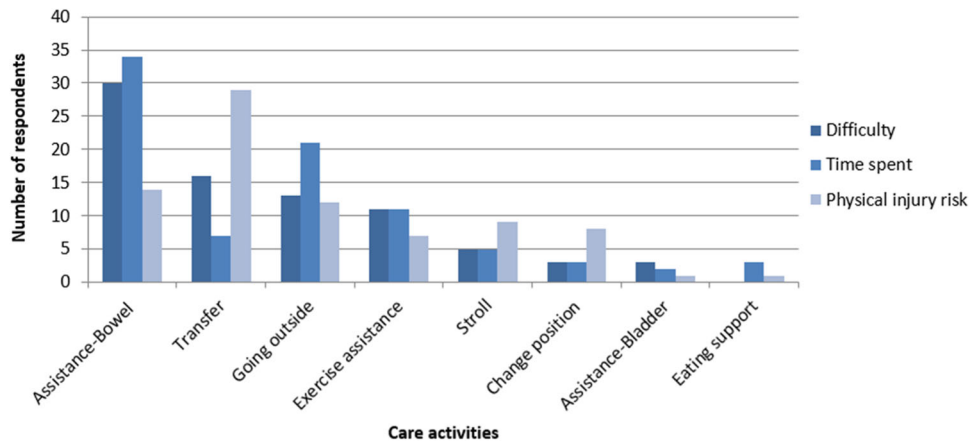
**Table 1.** Characteristics of caregivers and individuals with SCI and caregiver burden ( $N = 87$ ).

Category	Characteristics	Variable	Categories	<i>n</i> (%)	Mean care burden (SD)	<i>t</i> or <i>F</i>	<i>p</i>	
Caregiver	General	Gender	Male	18 (20.7)	61.89 (17.26)	0.161	0.873	
			Female	69 (79.3)	62.75 (21.02)			
			Mean (SD)		62.57 (20.21)			
		Age (years)	<50	13 (14.9)	50.54 (7.38) <sup>a</sup>	5.939	0.001	
			50–59	32 (36.8)	65.53 (21.49) <sup>a,b</sup>			
			60–69	32 (36.8)	58.62 (15.46) <sup>a</sup>			
			≥70	10 (11.5)	81.40 (19.89) <sup>b</sup>			
			Mean (SD)		57.29 (11.18)			
		Marital status	Single	6 (6.9)	47.83 (15.43)	1.879	0.064	
			Married	81 (93.1)	63.67 (20.16)			
		Relationship	Spouse	32 (36.8)	67.16 (20.90) <sup>b</sup>	3.284	0.025	
			Parents	22 (25.3)	67.00 (22.53) <sup>b</sup>			
			Employed caregiver	26 (29.9)	57.77 (15.89) <sup>a,b</sup>			
			Children	7 (8.0)	45.57 (12.15) <sup>a</sup>			
		Health	Hours of sleep	<8	70 (80.5)	66.67 (19.49)	4.19	<0.001
				≥8	17 (19.5)	45.71 (13.43)		
				Mean (SD)		7.31 (1.65)		
			Underlying disease	No	39 (44.8)	56.92 (18.34)	2.417	0.018
				Yes	48 (55.2)	67.17 (20.67)		
			Pain	No	18 (20.7)	48.11 (15.65)	3.645	<0.001
Yes	69 (79.3)			66.34 (19.63)				
pain site	Shoulder/Wrist		28 (32.2)	58.79 (15.81) <sup>a,b</sup>	3.967	0.023		
	Low back		26 (29.9)	71.62 (21.80) <sup>a</sup>				
	Knee/ankle		33 (37.9)	58.67 (20.50) <sup>b</sup>				
	Mean NRS (SD)			5.42 (2.28)				
Care type	Period of care (years)		<1	24 (27.6)	59.79 (18.43)	1.82	0.15	
		1~<5	34 (39.1)	67.35 (18.92)				
		5~<10	8 (9.2)	58.25 (31.95)				
		≥10	21 (24.1)	55.86 (17.58)				
		Mean (SD)		5.74 (7.64)				
	Place	Hospital	46 (52.9)	62.02 (18.98)	0.269	0.789		
		Home	41 (47.1)	63.20 (21.72)				
	Care time (hours)	≤12	46 (52.9)	57.05 (16.24)	1.495	0.139		
>12		41 (47.1)	64.45 (21.17)					
Mean (SD)			19.64 (7.32)					
Individuals with SCI	General	Gender	Male	60 (69.0)	60.75 (19.08)	1.260	0.211	
			Female	27 (31.0)	66.63 (22.35)			
		Age (years)	<50	60 (69.0)	60.66 ± 24.57	0.673	0.503	
			≥50	27 (31.0)	63.69 ± 17.33			
			Mean (SD)		51.70 (17.35)			
		BMI (kg/m <sup>2</sup> )	≤18.4	7 (8.0)	62.29 (20.32)	0.188	0.829	
			18.5–22.9	42 (48.3)	63.93 (17.51)			
			≥23.0	38 (43.7)	61.13 (23.20)			
			Mean (SD)		22.82 (3.33)			
		Disability	Level of injury	Cervical	45 (51.7)	66.51 (17.29)	2.058	0.134
				Thoracic	33 (37.9)	59.48 (22.94)		
				Lumbar	9 (10.3)	54.22 (20.86)		
			Severity of injury (AIS)	AIS A	39 (44.8)	59.87 (17.72)	0.889	0.45
				AIS B	22 (25.3)	67.45 (26.96)		
				AIS C	11 (12.6)	66.36 (13.58)		
				AIS D	15 (17.2)	59.67 (18.87)		
			ADL	≤24	45 (51.7)	69.53 (19.16) <sup>a</sup>	6.251	0.001
25–49	10 (11.5)			51.90 (7.91) <sup>a,b</sup>				
50–74	19 (21.8)			62.37 (21.00) <sup>a,b</sup>				
Post injury Period (years)	≥75	13 (14.9)	47.00 (18.24) <sup>b</sup>	0.175	0.84			
	Mean (SD)		35.49 (31.43)					
	<3	46 (52.9)	63.24 (16.78)					
	3~10	13 (14.9)	64.15 (27.11)					
	>10	28 (32.2)	60.75 (22.35)	7.51 (8.25)				
	Mean (SD)		7.51 (8.25)					

ADL Activities of daily living, AIS American Spinal Injury Association Impairment Scale, BMI Body Mass Index.  
<sup>a,b</sup>Scheffe test.



**Fig. 1 Type of caregiver burden by four groups ( $\leq 49$ , 50–59, 60–69,  $\geq 70$  years) ( $N = 87$ ).** Time dependence burden was most severe type among caregiver burdens. Eldest group (more than 70 years) had greater caregiver burden than other age group ( $<0.001$ ).



**Fig. 2 Ranking of difficulty, time spent, and physical injury of care activities ( $N = 87$ ).** Toileting assistance-bowel was the most difficult and time spent care activity. And transfer was the greatest risk of physical injury.

### Correlations among caregiver's age, pain, sleep duration, ADL of patients with SCI, and caregiver burden

Caregiver burden was positively correlated with age ( $p = 0.002$ ) and pain severity ( $p < 0.001$ ) whereas negatively correlated with sleep duration ( $p = 0.001$ ) and ADL of patients with SCI ( $p = 0.002$ ; Table 2).

### Multiple regression to identify the predictors of caregiver burden

Multiple regression analysis findings are shown in Table 3. Caregiver's age ( $B = 0.339$ ,  $p = 0.049$ ), sleep duration ( $B = -2.896$ ,  $p = 0.012$ ) and pain ( $B = 2.558$ ,  $p < 0.001$ ) predicted caregiver burden ( $y$ ) and these factors explained 36% of the variance in caregiver burden ( $\text{adj } R^2 = 0.360$ ).

## DISCUSSION

Caregiver burden was significantly higher among older caregivers, spouse, or parent caregivers, as opposed to child caregivers, those who slept for 8 hours or less, and those who had an underlying disease. Caregivers aged 70 or older had significantly greater caregiver burden than other age groups. And predictors of caregiver burden were caregiver's age, sleep duration and pain.

**Table 2.** Correlations among caregiver burden, age, pain severity, duration of caregiving, sleep duration, and SCI patient's ADL ( $N = 87$ ).

Category	Age	Pain	Sleep duration	ADL
$r$	0.324	0.429	-0.353	-0.324
$p$	(0.002)	(<0.001)	(0.001)	(0.002)

Caregiver burden was positively correlated with age and pain severity, whereas negatively correlated with sleep duration and ADL of patients with SCI.

ADL Activities of daily living, SCI Spinal cord injury.

The most difficult and time consuming caregiving task was toileting assistance-bowel and the greatest concern for physical injury task was transfer.

The mean age of individuals with SCI was 51 years and SCI caregivers was 57 years in this study. The 2021 SCI data published by the National Spinal Cord Injury Statistical Center (NSCISC) showed that the age at injury rose from a mean of 29 years in the 1970s to 43 years in 2015 [16]. The mean age of individuals with SCI also increased, as reported in Korean studies [12–14, 16, 17], which is attributed to primary caregivers are usually family

**Table 3.** Multiple regression for the predictors of caregiver burden ( $N = 87$ ).

	<b>B</b>	<b>SE</b>	<b>B</b>	<b>t</b>	<b>p</b>	<b>VIF</b>
Constant	54.008	15.376		3.513	0.001	
Gender(Male)	3.734	4.725	0.075	0.790	0.432	1.188
Relationship(spouse)	5.454	3.793	0.131	1.438	0.154	1.085
Age	0.339	0.170	0.187	1.994	0.049	1.155
Sleep duration	-2.896	1.133	-0.236	-2.556	0.012	1.113
Pain	2.558	0.651	0.380	3.928	<0.001	1.224
ADL	-0.097	0.062	-0.151	-1.568	0.121	1.217

$adj R^2 = 0.360$ ,  $F = 8.875$  ( $p < 0.001$ )

Caregiver's age, sleep duration and pain predicted caregiver burden.

ADL Activities of daily living.

members such as spouses or parents, the increase in the mean age of individuals entails an increase in the mean age of caregivers. Similarly, Gajraj-Singh et al. found that the mean age of caregivers was late 50s, accompanied by an increase in caregiver burden with advancing age [18].

In this study, 79.3% of the caregivers were women, which was similar to the percentage of female caregivers (82%) of stroke individuals in Korea [19], but was higher than caregivers of individuals with SCI in other studies [5, 20]. This seems to be a natural result of the higher incidence of stroke and SCI in men than in women [17, 21, 22]. Moreover, women in Korea have more often been involved in patient caregiving in the past as they tend to be less involved in social activities than men [17]. In our study, most common caregivers of male patients were spouse(40.6%). But caregivers who took care of female were more common with employed caregivers (50.0%), followed by spouse (22.2%). In general, men tend to report less burden not because they do less, but because they are more likely to ask for help. This results in a multitude of other problems such as musculoskeletal pain, resulting in a vicious cycle of increased caregiver burden without proper measures and preventions.

In this study, caregivers with underlying disease had greater caregiver burden. The underlying disease may have existed before the caregiver, or it could be caused by caregiving. More than 50% of the caregivers had an underlying disease; 44.4% of whom had musculoskeletal disorders, such as lumbar disc herniation and arthritis. Caregivers' physical health also contributed to their caregiver burden [23]; knee osteoarthritis or mechanical back pain contributed to caregiver burden and deteriorated the quality of care [12]. Thus, it is necessary to research and prevent caregivers' sources of pain by reducing physical loading through means such as caregiver education, human support, or developing care-assistive devices and equipment.

Among the various types of caregiving burden, time-dependence burden was the highest, followed by physical burden and developmental burden. A study on the spouse caregivers of individuals with SCI reported similar results, where caregivers showed a high level of time-dependence burden, physical burden, and developmental burden [5, 9]. In the analysis of caregiver burden by age group, caregivers 70 years or older showed the highest level of time-dependence, physical, social, and financial burden. As mentioned earlier, the ageing of the caregivers is a crucial concern, with older caregivers (especially over 70 years) challenged with higher various burdens. Therefore, further social, health care, and medical consideration are needed for elderly caregivers.

In contrast to previous studies, we surveyed different caregiving tasks in this study. The most burdensome caregiving task for individuals with SCI was toileting assistance (bowel), which was rated as a high level of difficulty, time burden, and physical injury

risk. Inskip et al. reported that neurogenic bowel dysfunction is present in nearly 80% of individuals with SCI; 24% of individuals take more than one hour for bowel movement, and 59% require digital rectal stimulation [24]. Toileting assistance, the most burdening task is attributed to the relatively unpleasant and complicated nature of the procedure.

Caregiver's age, sleep duration and pain were predictors of caregiver burden. In other words, it is necessary to reduce the physical burden of the elderly caregivers, ensure sleep time of the caregivers, and prevent exacerbation or new occurrence of pain during care. In the short term, social attention and policy support are needed, and medical staff should also consider methods such as educating older caregivers and using assistive devices such as electric lifts. In the long term, research and development of care-assistive devices and equipment such as robots could reduce the burden of caregivers.

In this study, we enrolled 87 caregivers of individuals with SCI who received care at a rehabilitation hospital in Seoul. Owing to the limited sample, the findings have limited generalizability. Additionally, the sample consisted of 46 in-patients (52.9%), 41 out-patients (47.1%), and their caregivers; it is possible that individuals with poor access to healthcare facilities were excluded. Therefore, subsequent studies should expand the sample to caregivers of individuals with SCI nationwide and recruit a larger sample to examine the association between caregiver burden and quality of life.

We used MBI instead of Spinal Cord Independence Measure-III(SCIM-III). Because Korea public institutions and hospitals still use MBI more than SCIM-III. But SCIM-III is more specific for assessing the capacity of persons with SCI to perform daily tasks.

In addition, the factor such depression is very essential in caregivers, its evaluation and management have also been emphasized as important [25]. However, it's not included in this study. Sleep are also important factors in caregiver burden analysis, it was not evaluated in this study, except for sleep time. The source of financial support for the employed caregiver is important, but we did not separately examine whether there was external support such as insurance. Nevertheless, this study is significant in that it was the first to identify the predictors of caregiver burden among caregivers of individuals with SCI in Korea amid a lack of relevant literature.

In conclusion, as caregivers are an integral part of the lives of individuals with SCI, it is necessary to increase the awareness of caregiver burden and implement social support and public systems that assist in caregiving. It needs to reduce caregiver burden with special consideration of caregiver's characteristics such as the elderly caregivers, sleep problems and pain prevention. Finally, nursing rehabilitation and social policies should be targeted according to caregiver's age and type of assistance.



**DATA AVAILABILITY**

Additional data are available from the corresponding author on reasonable request.

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**AUTHOR CONTRIBUTIONS**

SHK was responsible for conducting the search, extracting and analyzing data, and creating tables and figures. OYK was responsible for designing the study, updating reference lists and screening potentially eligible studies. All authors (SHK, OYK, BSL, WKS, JEH, YHB and DIC) were responsible for writing the protocol and report, interpreting results, approving the final version of the manuscript.

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**COMPETING INTERESTS**

The authors declare no competing interests.

**ADDITIONAL INFORMATION**

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