Letter

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The relation between social cohesion and the care burden of family healthcare providers

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Summary **This study aimed to clarify the relationship between social cohesion and family care burden. The social capital indicators of Kondo et al. and the short version of the Zarit Care Burden Interview Scale in Japanese (J-ZBI_8) were used. Data were analyzed by multiple regression models. Seventy-one caregivers responded. Factors showing statistical significance in the multiple regression analysis included "receipt of emotional support" ($p = 0.009$) and "instrumental support provided" ($p = 0.010$). Social support was suggested to have a possible effect on the care burden of the main caregivers to relate to less burden. The gap between the original ideal loss and the social role caused by providing nursing care is likely to increase the degree of care burden.**

Keywords: Care burden, family caregivers, home care, social cohesion, Zarit Care Burden Interview Scale

The aging population in Japan is expected to increase as the overall population declines. The Ministry of Health is stressing the importance of offering comprehensive yet intermittent home nursing care to the elderly (*1*). Long-term care insurance systems provided in Japan to support elderly care currently classify patients based on their activities of daily life or level of dementia. The family structure is not considered for registration. Sudo et al. noted that in Japan, support for preventive care that encourages informal power including self-help and mutual aid has been spotlighted and strengthened by municipalities as authorized by support from the public, which may take the social cohesion for granted (*2*). Nevertheless, little evidence exists on whether social cohesion, an element of social capital, reduces the burden of caregivers who provide home nursing care (*3*). Our study aimed to clarify the relationship between social cohesion and family care burden.

We conducted a questionnaire survey in the isolated island of Tokunoshima. The study targets included caregivers living with patients aged 65 years or older who were visiting medical care services or using visiting nursing care services registered in Tokunoshima Tokushukai Hospital (TTH). The research was conducted from 1 September to 4 October 2015.

The questionnaire was based on the social capital indicators of Kondo *et al*. (*4*) and the Japanese short version of the Zarit Care Burden Interview scale (J-ZBI_8) (*5,6*). Confounding factors were the caregiver's sex, age, and occupation, length of caregiving, educational background, length of residence time, household, sex of the patient under care, and patient's age. Data were analyzed by multiple linear regression models.

The question items regarding social capital, especially on social cohesion, that were investigated were 1) Receipt of emotional support for the caregiver by the community, 2) Emotional support provided to others by the caregiver, 3) Instrumental support provided; care for the resident given by others when the caregiver cannot provide care, 4) Instrumental support provided by the caregiver and others, 5) Participant in organized activities – frequency of participation in the activities of a group organization, and 6) Caregiver's social network – using the frequency of meeting with friends and acquaintances. Questions 1) – 4) were classified into two categories, Yes or No. Questions 5) and 6) asked for a frequency and were divided into two categories. We also conducted a logistic regression using dichotomous classification of

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Table 1. Characteristic of the participants (*N* = 71)

Items	Total	(Missing)	Number	%	Mean (SD)	Median (25–75th percentile)
Social Capital scale	64	7			4.8 (1.3)	5 (4-6)
1) Social support: receipt of emotional support	70	1				
No			5	7.1		
Yes			65	92.9		
2) Social support: emotional support provided	67	4				
No			10	14.9		
Yes			57	85.1		
3) Social support: receipt of instrumental support	71	–				
No			9	12.7		
Yes			62	87.3		
4) Social support: instrumental support provided	68	3				
No			13	19.1		
Yes			55	80.9		
5) Participant in organized activities	71	–				
No			39	54.9		
Yes			32	45.1		
6) Caregiver's social network	71	–				
No			11	15.5		
Yes			60	84.5		
Caregiver						
Gender	71	–				
Male			28	39.4		
Female			43	60.6		
Age (years)	71	–			69.9 (13.9)	66 (61-83)
Length of residence time	67	4			34	30 (11.7-50)
Length of caregiving time	69	2			5.79	5 (2.0-10)
Family members present (excepting care recipient)	65	6				
Have			45	69.2		
Not have			20	30.8		
Working Status	69	2				
Working†			25	36.2		
Unemployed/Homemaker			44	63.8		
Education	70	1				
High school			20	28.6		
Graduated high school			28	40.0		
Higher than high school			22	31.4		
Home-care patient						
Gender	70	1				
Male			27	38.6		
Female			43	61.4		
Age	70	1			85.9 (13.3)	87.5 (82-93)
Pattern of care	70	1				
Elder to elder			30	42.9		
Next-generation primary caregivers¶			40	57.1		
Gender pattern¶¶	70	1				
Male-Male			3	4.3		
Male-Female			25	35.7		
Female-Male			23	32.9		
Female-Female			19	27.1		

†Part-time job is included. ¶Includes daughter, daughter-in-law, son, and grandchild. ¶¶Gender pattern (A-B) means the relation between (gender of elderly cared for – gender of primary caregivers). SD, standard deviation; CI, confidence interval.

the total score of the J-ZBI_8 (a variable of ≥ 13 *vs*. ≤ 12) and correspondence analysis.

Statistical analyses were conducted using SAS Ver. 9.3, and a two-sided level of 5% was considered to indicate statistical significance. Ethics approval was granted by Teikyo University (No. 15-038) and the ethics committee of TTH (TGE00526-018).

Ninety-nine people were approached to participate in the study, and 71 caregivers responded to the survey (response rate 72%). The average age of the primary caregivers was 69.9 ± 13.9 years old (28 men, 43 women), and that of the person receiving care was 85.9 ± 13.3 years old (Table 1). Cronbach's α for the J-ZBI_8 was 0.89. The results of the multiple regression analysis are shown in Table 2. In terms of social support, the factors showing a significant difference included "receipt of emotional support" (p = 0.009) and "instrumental support provided" (p = 0.010).

The presence of "someone who heard the worries and complaints" resulted in a significant difference (β = 0.49; Table 2). That "there are people who listen to the worries and complaints" was the result of increasing the care burden. This result suggests a link to self-disclosure (*7*).

We interpreted from the analysis of the correspondence that the next-generation primary caregivers (son, daughter, daughter-in-law, son-in-law or grandchildren) tended to rely on friends and neighbors for support, whereas the elderly primary caregivers tended to rely on relatives. A high care burden was a concern if the next-generation primary caregiver did not

Table 2. Results of liner regression analysis

Items	Simple regression analysis			Multiple regression analysis		
	β (beta)	SE	*p*-value	β (beta)	SE	*p*-value
Social Capital total†	-0.03	0.04	0.529			
1) Social support: receipt of emotional support	0.33	0.19	0.085	0.49	0.18	0.009
2) Social support: emotional support provided	0.03	0.14	0.823		-	
3) Social support: receipt of instrumental support	-0.33	0.14	0.024	-0.37	0.14	0.01
4) Social support: instrumental support provided	-0.1	0.13	0.433		-	
5) Participant in organized activities	-0.1	0.1	0.313	-0.13	0.09	0.171
6) Caregiver's social network	-0.07	0.14	0.602		-	
Caregiver						
Gender	0.02	0.1	0.84		-	
Age (10-year units)	0	0.04	0.922		-	
Length of residence time (1-year units)	-0.02	0.02	0.35		-	
Length of caregiving time (1-year units)	-0.01	0.12	0.901		-	
Family members present (excepting care recipient)	0	0.11	0.975		-	
Working status	-0.16	0.01	0.1		-	
Education						
High school	0.02	0.1	0.84		-	
Graduated high school	0.19	0.1	0.06		-	
Higher than high school	-0.17	0.1	0.1		-	
Home-care patient						
Gender	0.11	0.1	0.253		-	
Age (10-year units)	0.04	0.04	0.35		-	
Gender pattern¶						
Age	0.03	0.1	0.8		-	
Gender				-0.42	0.22	0.066
Male-Male	-0.41	0.24	0.09			
Male-Female	0.05	0.1	0.6		-	
Female-Male	-0.04	0.1	0.7		-	
Female-Female	0.13	0.11	0.23		-	

†Not included in the linear regression analysis. A stepwise method was used for variable selection in the multiple linear regression analysis with the inclusion and exclusion criteria of 20%. A variable that was not selected in the stepwise method is indicated by "-". ¶Gender pattern (A-B) means the relation between (gender of elderly cared for – gender of primary caregivers). J-ZBI_8, short version of the Zarit Care Burden Interview scale in Japanese; SE, standard error.

receive support from friends and neighbors and did not participate in organized activities.

The Japanese Cabinet Office conducted "Consciousness research on elderly housing and living environment" in 2010. About 10% of single-person households were unable to form relationships with others in the neighborhood, responding that "there is no relationship" with the neighborhood. Households comprising one adult and a child also had few relationships with their neighbors (*8*). Considering a wide variety of family situations and backgrounds, the primary caregiver may well feel loneliness and a burden for caregiving. In addition, the gap between the loss of ideal world and the social role caused by the nursing care is also likely to increase the care burden (*9*). To support caregivers, maintaining social roles is important.

A community support system that includes not only medical personnel but also community residents is needed. Development of such a system is suggested to provide community support to patients and their families living at home.

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