Association between caregiving activities and care burden among caregivers of people with dementia

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Abstract The purpose of this study was to examine the difference in the association between caregiver's activities and caregiving burden according to gender and family relationship of caregivers of older people with dementia. This study used data from the Caregivers of Alzheimer's Disease Research survey (n=476). The association between caregiving activities and care burden was analyzed by multiple regression. In this study, the caregivers were predominantly spouses, followed by daughters. The care burden, especially personal burden, and depression were significantly higher in women than men. The spouses (either male or female), compared with the sons and daughters, spent significantly more time providing care. Care time and depression of caregivers and physical disability of the patient were significantly correlated with care burden. Among the caregiving activities, using transportation, dressing, eating, looking after appearance, and supervising were significantly associated with care burden. The daughters and daughters-in-law presented more care burden with higher number of care days, and the female spouse who were younger tended to experience higher care burden. Daughters who provided longer time looking after appearance exhibited higher care burden. For female spouse, eating time was significantly associated with care burden. The association between caregiving activities and care burden of caregivers of people with dementia differed by gender and family relationship with the patient. This study was characterized by analyzing the effect of caregiving activities on caregiving burden by gender and family relationship of caregivers.

Key Words : Caregiving activity, Care burden, Dementia, Family relationship of caregiver

1. Introduction

The number of older people with dementia in Korea is increasing every year, with 540,755 (9.2%) estimated to have dementia according to the 2012 National survey of dementia elderly. In addition, the Korean elderly with dementia doubles every 20 years and is estimated to reach 2.71 million in 2050[1]. Dementia requires supervision and help in daily life because it presents with physical problems as well as mental disabilities such as severe memory impairment, depression, psychosis, and sleep disorder[2]. Thus, patients with dementia need personal assistance with eating, personal hygiene, toilet use, communication, and social relationships[3].

The rapid increase in dementia patients increased the importance of the role of national system and caregivers of demented elderly people. In Korea, long term care insurance for the elderly has been implemented since July 2008, and the role of the national institution for the care of the elderly has expanded[4]. However, there was also a report that institutional service use increases satisfaction with the life of the caregiver and does not have a beneficial effect on mental health[5]. Also, devel

oped countries that institutionalize elderly care a head of us also emphasize family and community for continuous services in the community. In Korea, the interest and need for the role of family caregivers who live with demented elderly will not be diminished[5]. Families who care for patients with dementia have a burden of care in all areas, including life constraints, emotional problems, economic problems, value norms, and health care issues[6].

The factors affecting the care burden of dementia patient caregivers can be divided into characteristics related to the elderly with dementia and those related to the caregiver[5]. As for the care burden according to the characteristics of the patient, there are some previous studies that the caregiving burden is higher as the cognitive function and daily life performance of dementia patients are lower, and there are also studies showing that this factor is not related to the care burden[5],[7],[8]. The effects of more variable factors on care burden were examined in the study of caregiver characteristics. Previous studies reported that the care-related characteristics (duration of care, support details and strength, etc.) were affected by gender[4]. The results suggest that the intervention of social support should be changed according to the gender and family relationship of the caregivers.

The purpose of this study is to identify the difference of caregiver's activities and caregiving burden according to gender and family relationship of caregivers of demented elderly.

2. Methods

2.1 Participants and setting

This study used baseline data from Caregivers of Alzheimer's Disease Research (CARE) survey in the Clinical Research Center for Dementia of Sout

h Korea (CREDOS) study, a nationwide hospital-based, multi-center registry of people with dementia[9]. CARE survey was to identify characteristics of caregivers of patients who were diagnosed with Alzheimer's disease or subcortical vascular dementia. These 476 caregivers were family members living with or without the patient, who devote a considerable amount of time taking care of the patient. Caregivers were interviewed by well-trained nurses or surveyors, and completed self-reporting questionnaires. Informed consents were obtained from all the participants. Ethical approval for the study, including the study protocol, written informed consents, was approved by the institutional review boards (AJIRB-MED-SUR-12 -046).

2.2 Assessments

Patients' daily activities performance were assessed using Activities of Daily Living (ADL) and Seoul-Instrumental ADL (S-IADL)[10](Ku et al., 2004). Higher the score of S-IADL (from 0 to 45) means lower performance of the daily activities necessary for social life. Higher the score of ADL (from 0 to 24) means it is more difficult to perform independent daily life activities.

Caregiving activity was measured by the Korean Version of Caregiver Activity Survey (CAS-K)[7] (Kim et al., 2004). CAS-K was to investigate information about the time spent by the caregivers for support patient with dementia during the last 24 hours from the time of the test. CAS-K was subdivided into 6 sub-domains (communicating with the person, using transportation, dressing, eating, looking after one's appearance, supervising the person) in relation to the daily life support and behavior management of dementia patients.

The care burden was measured by the Zarit Burden Interview[11]. The ZBI has 22 questions abo

ut caregivers' psychological health, finances, emotional wellbeing, social and family life, and degree of control over their life. Each question was scored on a five point Likert-type scale, and total scores ranged from 0 (low burden) to 88 (high burden). This questionnaire consists of two subscales: personal burden and role burden. The personal burden means that higher the score, higher the level of burden in the direct relationship with the caregiver (27 points or higher: higher, 36 points or higher: very high). Role burden means that higher the score higher the level of burden due to the roles and activities not directly related to the caring life of the patient (16 points or higher: higher, 23 points or higher: very high).

Depression was measured by the Beck Depression Inventory, a self-report tool (21-item). Each item is scored on a four-point Likert scale, ranging from 0 to 3. Total scores can range from 0 to 63, with higher total scores indicating more severe depressive symptoms[12](Steer, Beck, & Garrison, 1986).

2.3 Statistical Analysis

The collected data were analyzed using SPSS 23.0 and expressed as frequency, mean, and standard deviation. The differences in caregiving burden and caregiving activities according to caregiver characteristics were analyzed using t-test and ANOVA. Pearson's correlation coefficient was used for the correlation between caregiver burden and variables. Multiple linear regression analysis was used to determine the effect of the caregiving activities on the caregiver burden.

Table 1. Characteristics of Caregivers

Categories	mean ± SD / N (%)
Age (y)	57.0 ± 13.0
20-49	143(30.0)
50-59	144(30.3)
60-69	86(18.1)
70-89	103(21.6)
Gender	
Male	154(32.4)
Female	322(67.6)
Relationship with patient	
Spouse (M)	76(16.0)
Spouse (F)	107(22.5)
Daughter-in-law	82(17.2)
Son	72(15.1)
Daughter	127(26.7)
Others (Son-in-law)	12(2.5)
Education level	
No formal education	11(2.3)
Elementary school	46(9.7)
Middle school	61(12.8)
High school	170(35.7)
College or university	161(33.8)
Graduate school	27(5.5)
Household income (won)	
<150	153(32.2)
150-350	185(39.0)
³350	136(28.7)
Care burden (BI)	40.47± 20.22
personal burden	19.60± 9.19
role burden	11.87± 7.52
Duration of caregiving (y)	4.32± 4.58
Caregiving per month (d)	26.46± 8.18
Caregiving per day (h)	14.09± 8.43
CAS-K (h)	11.93± 11.46
Communicating	2.34± 2.96
Using transportation	0.79± 1.10
Dressing	0.45± 0.81
Eating	1.42± 1.50
Looking after apearance	0.42± 0.64
Supervising	6.49± 8.68
Depression	14.08± 10.04
IADL	28.5± 13.1
ADL	5.9± 6.5

3. Results

3.1 Characteristics of caregivers

The general characteristics of the subjects are shown in Table 1. In this study, the mean age of subjects was 57.53, and the female caregivers (67.6%) was more than twice that of males. About family relation with patient, spouse (38.4%, male; 16%, female; 22.5%) was the most, and daughter (26.7%), daughter-in-law (17.2%), son (15.1%) and others (2.5%) followed. More than 70.0% of the caregivers were high school graduates. In this study, IADL and ADL were 28.50 and 5.87, respectively. As for the caregiving characteristics of the subject, the mean duration of caregiving was 4.32 ± 4.58 years, and the time of care giving was 26.46 d/month and 14.09 h/day. Total time of caregiving activity was 11.93 h, and the sending time of supervising was the longest, and communicating, eating, using transportation, dressing, looking after one's appearance followed. The burden of care was 40.47± 20.22, and the scores of individual burden and role burden were 19.60 and 11.87, respectively. The average depressive score of the caregivers was 14.08.

3.2 Caregiving activities and care burden by gender and family relationship with patient

Caregiving activities and care burden of caregivers according to gender were presented in Table 2. The time of caregiving showed a significant difference according to gender. The CAS-K results show that male caregivers had significantly higher communicating time with the person , and female caregivers had significantly more time in dressing, eating and looking after one's appearance. The total care burden was significantly higher in female than male, especially in personal burden.

Caregiving activities and care burden of caregivers according to family relationship with patient were presented in Table 3. The spouses (male, female) had significantly more time to care than the son and daughter. Total CAS-K time showed significant differences according to family relations. In the detailed activity, there were significant differences according to family relations in eating, looking after one's appearance, and supervising. There was a significant difference in care burden due to family relationship with the patient, and the female spouse was significantly higher in total care burden and role burden. The depression score according to the family relationship with the patient was significantly different, and the daughter had the highest depression score.

Table 2. Caregiving Activities and Care Burden of Caregivers by Gender

Categories	Male	Female	p
Care burden (BI)	37.10± 18.39	42.08± 20.88	.010
personal burden	18.37± 8.20	20.18± 9.58	.013
role burden	10.81± 7.27	12.34± 7.60	.228
Duration of caregiving (y)	4.07± 4.29	4.34± 4.71	.246
Caregiving per month (d)	27.26± 7.14	26.08± 8.62	.003
Caregiving per day (h)	13.77± 8.93	14.25± 8.20	.019
CAS-K (h)	11.53± 11.69	12.11± 11.36	.369
Communicating	2.56± 3.63	2.24± 2.57	.037
Using transportation	0.76± 1.18	0.80± 1.06	.609
Dressing	0.32± 0.44	0.52± 0.93	.012
Eating	1.06± 1.29	1.60± 1.60	.013
Looking after appearance	0.34± 0.50	0.46± 0.69	.047
Supervising	6.48± 8.84	6.50± 8.62	.578
Depression	12.07± 9.32	15.10± 10.24	.060

Table 3. Caregiving Activities and Care Burden by Family Relationship with Patient

Categories	Spouse (Male)	Spouse (Female)	Daughter-in-law	Son	Daughter	Others	p
Care burden (BI)	39.62± 16.46bc	48.50± 20.15a	41.06± 19.28ab	34.96± 20.73bc	37.85± 20.83bc	30.92± 20.01c	.000
personal burden	18.92± 6.96	21.64± 9.33	19.87± 8.58	18.00± 9.77	19.37± 9.95	15.83± 10.47	.073
role burden	11.99± 6.97b	15.36± 7.32a	12.02± 7.59b	9.71± 7.49b	10.28± 7.06b	9.03± 7.13b	.000
Duration of caregiving (y)	3.43± 2.70	4.31± 3.75	5.16± 6.46	4.64± 5.38	4.24± 4.26	3.00± 1.48	.271
Caregiving per month (d)	29.32± 4.27a	29.75± 2.18a	26.67± 8.42ab	24.88± 8.97bc	22.71± 10.57c	27.00± 7.68ab	.000
Caregiving per day (h)	17.46± 7.35a	18.99± 6.25a	12.37± 7.90b	10.14± 8.78b	11.64± 8.25b	10.23± 8.22b	.000
CAS-K (h)	14.43± 11.62ab	15.71± 12.00a	9.75± 10.83bc	8.49± 11.12c	10.54± 10.54abc	11.47± 10.50abc	.000
Communicating	2.60± 2.72	2.49± 2.97	1.83± 2.37	2.24± 3.84	2.27± 2.36	4.31± 5.91	.118
Using transportation	0.97± 1.28	0.90± 1.17	0.81± 0.98	0.54± 1.00	0.71± 1.04	0.79± 1.10	.187
Dressing	0.37± 0.45	0.58± 0.81	0.45± 0.54	0.27± 0.39	0.51± 1.19	0.53± 0.75	.157
Eating	1.31± 1.40ab	1.90± 1.45a	1.50± 1.58a	0.78± 1.06b	1.40± 1.66ab	1.33± 1.30ab	.000
Looking after appearance	0.38± 0.52	0.55± 0.90	0.41± 0.49	0.29± 0.45	0.43± 0.61	0.37± 0.60	.000
Supervising	8.79± 9.4ab	9.29± 9.17a	4.74± 8.24b	4.37± 7.84b	5.33± 7.86bc	4.18± 7.14b	.000
Depression	13.08± 8.76ab	17.00± 10.38a	14.13± 9.09ab	11.19± 10.06bc	14.36± 10.66ab	8.58± 6.89c	.001

Table 4. Correlation of Caregiving Activities and Care Burden in Caregivers

Categories	Care burden	Caregiving per month (d)	Caregiving per day (h)	Communicating	Using transportation	Dressing	Eating	Looking after appearance	Supervising	CAS-K (h)	Depression	S-IADL	S-ADL
Care burden	1												
Caregiving per month (d)	.305**	1											
Caregiving per day (h)	.280**	.325**	1										
Communicating	.066	.111*	.243**	1	.								
Using transportation	.128**	.101*	.255**	.170**	1								
Dressing	.229**	.166**	.230**	.120**	.174**	1							
Eating	.385**	.279**	.450**	.120**	.208**	.542**	1						
Looking after appearance	.390**	.154**	.236**	.189**	.232**	.589**	.421**	1					
Supervising	.280**	.239**	.530**	.230**	.248**	.253**	.475**	.229**	1				
CAS-K (h)	.330**	.276**	.577**	.483**	.381**	.414**	.604**	.398**	.934**	1			
Depression	.561**	.137**	.156**	.069	.051	.140**	.266**	.198**	.218**	.244**	1		
IADL	.468**	.233**	.267**	.042	.087	.280**	.339**	.339**	.319**	.344**	.241**	1	
ADL	.433**	.159**	.208**	.008	.022	.295**	.335**	.372**	.287**	.307**	.296**	.721**	1

*. Correlation is significant at the 0.01 level (2-tailed).   *. Correlation is significant at the 0.05 level (2-tailed).

Table 5. Multiple linear regression analyses of caregiver variables on caregiver burden by relationship with patient

Categories	Total	Relationship with patient ( )				
		Spouse (M)	Spouse (F)	Daughter-in-law	Son	Daughter
Gender	.085*					
Relationship with patient	-.047					
Age	.034	.017	-.203*	.063	.130	.082
Education level	.035	-.019	-.016	.144	.149	-.007
Household income	-.047	-.095	-.082	-.204	-.092	.017
Duration of caregiving	-.019	.187(.063)	.052	-.112	-.072	-.032
Caregiving per month	.152***	.179(.086)	.111	.333**	.053	.280**
Caregiving per day	.017	-.003	-.111	-.023	-.050	.161(.069)
Communicating	-.017	-.008	-.088	-.202*	.089	.097
Using transportation	.010	-.111	-.147	-.036	.060	.050
Dressing	-.143**	.139	.168	-.025	.020	-.302
Eating	.102*	.217	.242*	.030	-.012	.062
Looking after appearance	.227***	.018	.111	.267	.164	.323***
Supervising	-.009	.071	-.061	.060	.001	-.190*
Depression	.398***	.372**	.328**	.255*	.399***	.526***
IADL	.185**	.104	.374**	-.167	.394**	.142
ADL	.081	.076	-.251(.057)	.411**	.128	-.038
R2	.510	.595	.487	.618	.698	.602

*p<0.05, **p<0.01, ***p<0.001

3.3 The effect of caregiving activities of dementia patient caregivers on care burden

Correlation of care activities and care burden was presented in Table 4. The care time, CAS-K and depression of caregivers were significantly correlated with care burden. In the caregiving activities, using transportation, dressing, eating, looking after appearance and supervising were significantly correlated with care burden. S-IADL and S-ADL of patients were significantly correlated with care burden of caregivers.

Multiple linear regression analyses of caregiver variables on care burden by relationship with patient were presented in Table 5. The factors affecting care burden of caregiver were gender, caregiving period (care giving per month), depression, and IADL. Among the caregiving activities, dressing, feeding, and looking after appearance affected care burden. The overall explanatory power of these

factors was 51.0%. In other words, caregiver burden increased with high care days, the high depression score, the dementia elderly's low ability to perform daily activities, and the time of care activities (feeding, looking for appearance) increased. In the multiple regression analysis, according to the family relationship of the caregivers, the daughter and daughter-in-law presented with more care burden as the number of care days increased, and lower age of female spouse was associated with higher care burden. In daughters, the longer time of looking after appearance was significantly associated with higher care burden. In female spouse, eating time significantly affected the care burden. With higher depression scores in all of caregivers, the care burden increased. Higher IADL scores of dementia patients was associated with higher care burden among the female spouse and son.

4. Discussion

Until the 1990s, caregivers of elderly with dementia in Western country reported that there were more spouses and close-up daughters, while in Asian countries there were more children, especially daughter-in-law, than spouses[13], [14]. In this study, the caregivers of elderly with dementia had the highest number of spouses, followed by their daughters. This result reflects that current Korean family culture closed to Western culture. Most studies on care burden of caregivers by gender reported that the care burden of female was higher than male, but a previous study reported that care burden was not related to gender[15]. This study found that the care burden of the female caregivers was higher, and individual burden was greater than role burden in female caregivers. Besides, multiple regression analysis showed that the care burden of female caregivers increased as the age of female spouse became younger and the number of days spent taking care a month increased. This result can explain that having less personal time affected care burden of female caregivers more than the role of spouse and child.

A study reported that long-term care services did not reduce the care burden of caregivers[16], and it is necessary to develop new services to alleviate the burden due to social activity restrictions. Other studies of gender differences in caregiving burden reported that care-related characteristics (duration of care, support details and strength, etc.) were affected[4]. These results suggest that the intervention of social support should be changed by the family relationship of the caregivers.

The CAS-K used in this study reflected the cognitive function of the demented elderly, the impairment of daily living, the care burden of caregiver and the general psychopathology, and is an excellent tool to investigate the time for the caregivers to care for Korean elderly with dementia[9]. In this study, it was shown that helping to eat affected the care burden of female spouses. In addition, although it is not statistically significant in the multiple regression analysis, the increase in care burden as the son has less time to eat can affect the nutritional status of the elderly with dementia, so more detailed analysis is needed. Differences in care burden according to the condition of patients suggest different results for each research, and realistic improvement of patient is not easy[16]. As for the care burden according to the patients, there are some previous studies that show that caregiving burden is higher as the cognitive function and daily life performance of dementia patients are lower, and there are studies that show that this factor is not related to the care burden[4],[5],[8]. Therefore, present study tried to identify the care burden through the difference of caregiving activities according to gender and family relationship of the caregiver and to help build support system of the caregiver. The increase in caregivers' perceptions of unmet patient needs leads to the burden of caregiving and it is reported to be related to the possibility of admission to the nursing facility [17].

5. Conclusion

This study indicated that among the caregiving activities, using transportation, dressing, eating, looking after appearance, and supervising were significantly associated with care burden. The daughters and daughters-in-law presented more care burden with higher number of care days, and the female spouse who were younger tended to experience higher care burden. Daughters who provided longer time looking after appearance exhibited

higher care burden. For female spouse, eating tim e was significantly associated with care burden. T he association between caregiving activities and c are burden of caregivers of people with dementia differed by gender and family relationship with th e patient.

This study tried to identify the care burden thr ough the difference of caregiving activities accor ding to gender and family relationship of the care giver and to help build support system of the care giver.

However, present study did not investigate whe ther the unmet needs of patients with dementia w ere investigated, and whether they were skilled or avoided in areas with low care time. Therefore, a follow-up study on the above part is required. Thi s study was characterized by analyzing the effect of caregiving activities on caregiving burden by g ender and family relationship of caregivers.

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