

Original article

The role of caregiver burden in the familial functioning, social support, and quality of family life of family caregivers of elders with dementia

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Abstract

Objective: The present study aimed to examine the role that caregiver burden plays in the familial functioning, social support, and quality of family life (QOFL) of caregivers of elderly family members with dementia.

Methods: A survey was conducted with 200 primary caregivers of elderly dementia patients who resided in prefecture “S”. The questionnaire consisted of items that required demographic information, the Japanese versions of the Zarit Burden Inventory (ZBI) and the Family Adaptability and Cohesion Evaluation Scales (FACES II), and scales that measure quality of family life and social support. On the basis of the median ZBI score (i.e., 30.8), participants were divided into two groups: group A (i.e., ZBI score < 30) and group B (i.e., ZBI score > 30). Stepwise multiple regression analysis was conducted with QOFL as the dependent variable. Version 24 of the Statistical Package for the Social Sciences for Windows was used to conduct all the statistical analyses; the statistical significance level was specified as 0.05.

Results: Group A and B obtained average ZBI scores of 18.5 and 43.8, respectively. The study targeted 81 patients from group A (average age = 61.0 years) and 77 patients from group B (average age = 61.7 years). Time that was spent on caregiving tasks was significantly higher for group B, when compared to group A. In addition, significant differences in cohesion and adaptability, which are two dimensions that are measured by the FACES II, and QOFL emerged between the two groups. The results of the multiple regression analysis showed that cohesion ($\beta = 0.38$), practical support ($\beta = 0.32$), adaptability ($\beta = 0.30$), and living arrangement ($\beta = -0.12$) significantly predicted QOFL.

Conclusion: Family cohesion and adaptability are indicators of healthy familial functioning. In order to improve the QOFL of caregivers of elderly dementia patients, it is necessary to strengthen emotional ties, maintain emotional attachment, and flexibly respond to the burden of nursing care and changes in power structures and role relationships.

Key words: elderly dementia patients, caregiver burden, family caregiver, familial functioning, quality of family life

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Introduction

A super-aging society is characterized by a high number of elderly individuals¹. The number of dementia patients

was 4.62 million in 2012 (i.e., 1 out of 7 elders). Further, this number is likely to reach approximately 7 million (i.e., 1 out of 5 elderly patients) by 2025¹. The percentage of elders with dementia sharply increases with age: 7.1% of those who are between the ages of 75 and 79 years, and 27.3% of those who are 85 years or older have dementia¹. The percentage of care-need certificated persons is 3.0% for younger elders but substantially higher (i.e., 23.3%) for older elders. With the introduction of “the Vision for community medical care”, which is to be achieved by 2025, the government has been attempting to reduce inflated medical expenses by promoting home-based medical care². Over 60% of home caregivers are family members who live with patients³, such as spouses (25.7%), children (20.9%), and children’s spouses (15.2%). Because 64.8% of males and 60.9% of females are

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above the age of 60 years, the present caregiving scenario can be described as follows: “Old people provide care for other old people”³⁴). Similarly, when both the husband and wife suffer from dementia, the following statement accurately describes the caregiving scenario: “Dementia patients care for other dementia patients”; typically, a patient with mild dementia cares for a patient with severe dementia. These are problematic social arrangements. Given the sharp increase in the number of people with dementia, it is possible that a larger number of elderly nuclear families will emerge in the near future⁵). In Japan, the number of family members who care for working men has increased due to the relatively lower age that characterizes the current caregiving generation⁶). There are many difficulties that are involved in caring for individuals with dementia; it is estimated that 100,000 employees will be retired annually due to difficulties in balancing work and caregiving responsibilities⁷).

Home-based care for elders with dementia can pose serious social, mental, and economic problems for family caregivers^{8, 9}). Fujiwara *et al.*¹⁰) have noted that improving social support is not a sufficient strategy to reduce caregiver burden; recent studies have underscored the functional role that family members play in the lives of elders with dementia^{11–13}). Ozawa¹⁴) found that the cognitive symptoms of dementia increase the psychological strain and pressure on family caregivers, and in turn increase the risk of caregiver burden¹⁵); they also found a relationship between caregivers’ depressive symptomatology and patient scores on the Behavioral and Psychological Symptoms of Dementia (BPSD). Caregivers of elderly dementia patients experience higher levels of dysphoria and depression than non-caregivers¹⁶). However, Pessotti *et al.*¹⁷) found that resilient caregivers did not report high quality of life and melancholic symptoms, even though they cared for elders with severe dementia. Further, it has been established that caregivers experience chronic stress, psychological distress, and mental and physical health problems^{16, 18}). Since caring for elderly dementia patients is often a long-term responsibility, the incumbent psychological and social burden can deteriorate the quality of family life (QOFL)¹⁹). Indeed, Kitamura *et al.*²⁰) found that the QOFL of caregivers of dementia patients is strongly related to depressive symptomatology and subjective experiences of burnout. As noted in an earlier instance, mental disorders among family caregivers of elderly dementia patients greatly influence their physical and mental health, and adversely affect the functioning of the family. However, there are only a few studies that have examined the variables that influence the QOFL and familial functioning of caregivers. Thus, the present study aimed to examine the role that caregiver burden plays in the familial functioning, social support, and QOFL of family members who care for elders with dementia.

Definitions

In the present study, individuals above the age of 75 years were referred to as “middle-aged elders”, whereas those above the age of 85 years were referred to as “senior elders.” Caregiver burden refers to situations in which caregiving responsibilities adversely affect the health condition, happiness, economic status, and social life of the caregiver. On the other hand, QOFL refers to a sense of satisfaction with the physical, mental, economical, and social condition of one’s family²¹). Familial cohesiveness refers to mutual emotional ties that exist among family members^{11, 22}), whereas adaptability refers to flexibility in the structures, roles, and rules of the family, based on the changing developmental needs of the family^{11, 22}).

Method

Participants

The study targeted 200 family caregivers of elderly dementia patients; these patients received home-based care, were certified as requiring long-term care, and resided in prefecture “S”.

Procedure and measures

We requested 56 randomly selected care managers to select primary caregivers of elderly dementia patients who were receiving home-based care within prefecture “S”; we did not specify inclusion and exclusion criteria that pertained to the level of care that patients received. The authors and research collaborators used a survey questionnaire to conduct interviews with the participants. The questionnaire consisted of items that required demographic information (e.g., age, sex, relationship, occupational status, health conditions, etc.), the Japanese versions of the Zarit Burden Inventory (ZBI)²³) and the Family Adaptability and Cohesion Evaluation Scales (FACES II)²⁴), and scales that assess the QOFL²¹) and social support of caregivers²⁵). The reliability and validity of the ZBI has been established by Arai *et al.*²³) and has been used in many studies on caregiver burden. The ZBI records responses on a 5-point rating scale, ranging from 0 (Disagree) to 4 (Strongly agree); total scores are evaluated on an 88-point rating scale. It has 2 subscales: the Personal Strain Factor (i.e., the burden of caregiving) and the Role Strain Factor (i.e., the sense of burden that results from a loss of one’s daily routine, since the initiation of caregiving tasks). On the other hand, FACES II assesses the familial functioning of caregivers. This 30-item scale consists of 2 subscales, namely, cohesion and adaptability, and records responses on a 5-point rating scale. Items that assess cohesion pertain to the following: emotional ties, mutual involvement among family members, time, space, decision making, friends, and hobbies and leisure-time activi-

ties. Scores on the cohesion subscale can be divided into 4 levels that range from “disintegration” to “strong ties.” Mid-range scores represent optimal familial functioning whereas extreme scores are indicative of familial problems and dysfunction²⁴. Items that assess adaptability pertain to the following: leadership, discipline, discussion style, role relationship, and rules. Scores on the adaptability subscale can be divided into 4 levels, with regard to the following: family decision making, power relationship, and role relationship. Similar to cohesion, mid-range scores represent optimal familial functioning whereas extreme scores represent familial problems and dysfunction²⁴. In other words, families whose cohesion and adaptability scores are in the mid-range tend to function better, whereas those whose scores are extremely low or high tend to be dysfunctional²⁴. In the present study, we also used a scale that assesses QOFL; its reliability and validity has been established by Nakano *et al.*²¹ The maximum possible score that one can obtain on this scale is 185 points; it consists of 9 items that assesses harmony, peaceful state of mind, family value, active effort, broadmindedness, freedom, social participation, relationships with relatives, and social support. Higher scores are indicative of higher QOFL.

The Social Support Scale for Caregivers²⁵ was used to measure social support; its reliability and validity has been established by Ishikawa *et al.* It consists of the following subscales: emotional support, practical support, and ineffective support. Scores can be classified into 4 levels ranging from 0 (None) to 4 (Many). Higher scores are indicative of greater social support; conversely, lower scores are indicative of ineffective support.

Analysis

A total of 158 valid responses were collected and subjected to statistical analyses; questionnaires with missing responses were excluded. Similar to previous studies^{10, 11}, group comparisons were undertaken for each study variable using t-test, Mann-Whitney test, and χ^2 test. The median ZBI score (i.e., 30.8) was used to create two groups: group A (i.e., score < 30) and group B (i.e., score > 30). We also conducted stepwise multiple regression analysis with QOFL as the dependent variable. Version 24 of Statistical Package for the Social Sciences (SPSS) for Windows was used to conduct all the statistical analyses; the level of significance was specified as 0.05.

Ethical considerations

We requested the cooperation of participants and debriefed them about the purpose and requirements of the study. Adequate verbal and written instructions informed them that their participation is absolutely voluntary and that they would not be penalized if they choose to not participate. Written consent was obtained from agreeable partici-

pants. In addition, we ensured that the data were processed anonymously and that personal information was not disclosed. The present study was approved by the ethics review committee of S University (Approval number: 25-28).

Results

Basic attributes of caregivers and care receivers

Group A consisted of 81 individuals (17 males, 60 females, average age = 61.0 years, SD = 12.8) whereas group B consisted of 77 individuals (17 males, 60 females, average age = 61.7 years, SD = 12.8). A total of 42 elderly caregivers refused to participate in the study, were busy at work, or failed to respond to the questionnaire. A significant difference in the time invested in caregiving tasks emerged between the 2 groups; specifically, caregiving time was significantly higher for group B than group A. No significant difference in the average age of caregivers emerged between group A (M = 84.0, SD = 11.6) and group B (M = 82.0, SD = 14.8). With regard to nursing level, 51 patients (63.8%) in group A required Support Need Grade 2 and Care Need Grade 1; 57 patients (74.1%) in group A required Support Need Grade 1 and Care Need Grades 2 and 3. Further, significantly higher nursing levels were required for patients who belonged to group B. With regard to the degree of self-reliance among elderly dementia patients, 29 patients (35.8%) and 45 patients (55.6%) in group A were assigned the rating “I” and “II” whereas 18 patients (23.4%) and 44 patients (57.1%) in group B were assigned the rating “I” and “II”, respectively; no significant group differences emerged. A total of 90% of participants in both group A and group B were using care services; daytime service was the most commonly used service (i.e., approximately 50% in both groups; Table 1). The average ZBI score was 18.5 for group A and 43.8 for Group B. The average personal strain factor score was 10.0 for group A and 22.6 for group B. The average role strain factor score was 4.9 for group A and 12.6 for group B.

A comparison of FACES II scores between group A and B

Groups A and B obtained average cohesion scores of 49.6 and 47.4, and average adaptability scores of 43.2 and 41.0, respectively; a significant difference emerged between the groups ($p < 0.05$). With regard to familial functioning, groups A and B had 21 and 7 participants who obtained mid-range scores, and 38 and 45 participants who obtained extreme scores, respectively; no significant difference emerged between these groups (Table 2). However, significant group differences emerged for 7 out of the 30 questions. Furthermore, participants in group B endorsed the following statements to a greater extent those who belonged to group A: “It is easier for me to talk with others about a prob-

Table 1 Demographic characteristics

	Total 158 persons	Group A (81 persons)	Group B (77 persons)	Significance probability
Caregiver				
Average age ¹⁾ (years old)	61.7 SD12.78 (29–89)	61.2 SD13.0	62.3 SD12.7	0.59
Average nursing care period ¹⁾ (month)	59.3 SD57.2 (3–420)	34.9 SD21.3	41.2 SD24.5	0.81
Gender				
Male	32 (20.3)	15 (18.5)	17 (22.1)	5.03
Female	126 (79.7)	66 (81.5)	60 (77.9)	
Occupation				
Not working	75 (51.4)	41 (50.6)	34 (44.7)	0.12
Working	71 (48.6)	28 (58.3)	43 (55.3)	
Relationship				
Husband	11 (7.0)	7 (8.6)	4 (5.2)	0.48
Wife	30 (19.0)	14 (17.3)	16 (20.8)	
Son	21 (13.3)	8 (9.9)	13 (16.9)	
Daughter	40 (25.3)	21 (25.9)	19 (24.7)	
Daughter-in-law	46 (29.1)	25 (30.9)	21 (27.3)	
Living together				
Yes	137 (86.7)	70 (86.4)	67 (87.0)	0.93
No	21 (13.3)	11 (13.6)	10 (13.0)	
Cooperator				
Yes	136 (91.9)	71 (91.0)	65 (92.9)	0.35
No	12 (8.1)	7 (8.6.0)	5 (7.1)	
Care time ¹⁾ (hours)	3.1 (SD1.5)	2.8 (SD1.5)	3.5 (SD1.4)	p<0.01
Care receiver				
Average age ¹⁾ (years old)	84.8 SD8.6 (60–102)	84.0 SD11.6	82.0 SD14.8	0.63
Gender				
Male	52 (33.1)	21 (26.3)	31 (40.3)	0.48
Female	105 (66.9)	59 (73.8)	46 (59.7)	
Cear level				
Support Need Grade 1	14 (8.9)	7 (8.8)	5 (6.5)	0.65
Support Need Grade 2	35 (22.3)	26 (32.5)	9 (11.7)	
Care Need Grade 1	49 (31.2)	25 (31.3)	24 (31.2)	
Care Need Grade 2	23 (14.7)	7 (8.8)	16 (20.8)	
Care Need Grade 3	23 (14.7)	6 (7.5)	17 (22.1)	
Care Need Grade 4	7 (4.5)	3 (3.8)	4 (5.2)	
Care Need Grade 5	6 (3.8)	5 (6.3)	1 (1.3)	
Independence degree of elderly dementia patient				
I	47	29	18	0.08
II	38	21	17	
IIa	30	10	20	
IIb	31	14	17	
III	6	2	4	
IIIa	3	3	0	
IIIb	1	1	0	
IV	2	1	1	
Usage of nursing care service				
Yes	153 (96.8)	78 (96.3)	75 (97.4)	0.09
No	5 (3.2)	3 (3.7)	2 (2.6)	
Contents of nursing care service (multiple answers allowed)				
Home-visit nursing care	25 (15.2)	13 (16.1)	12 (15.6)	0.12
Day service	80 (54.0)	42 (51.9)	38 (49.4)	
Daycare service	44 (27.8)	25 (30.9)	19 (24.7)	
Leasing for welfare equipment	44 (27.8)	22 (27.2)	22 (28.6)	

χ^2 test, ¹⁾t-test, (%).

Table 2 A comparison of the study variables between Group A and Group B

	Group A	Group B	Significance probability
	Average		
FACES II ²⁾ (SD)			
Cohesion	49.6 (6.59)	47.3 (6.67)	0.04
Adaptability	43.1 (7.44)	40.9 (6.97)	0.05
Family type ¹⁾			
Mid-range (%)	21 persons (25.6)	7 persons (9.1)	0.54
Extreme (%)	38 persons (45.6)	45 persons (19.7)	
Score for quality of family life ²⁾ (SD)			
Harmony	125.7 (20.2)	118.8 (23.6)	0.04
Peaceful state of mind	19.1 (4.4)	17.5 (4.9)	0.02
Family value	14.0 (2.2)	14.0 (2.3)	0.92
Active effort	24.3 (4.7)	23.2 (4.5)	0.13
Breadth of mind	18.6 (3.9)	17.7 (4.4)	0.19
Freedom	7.7 (2.1)	7.2 (2.2)	0.15
Social participation	9.3 (1.9)	9.0 (1.6)	0.15
A relation of relative	6.0 (1.9)	5.7 (1.8)	0.37
Social support	15.5 (3.4)	14.0 (4.5)	0.10
Scale of social support for caregiver ²⁾ (SD)			
Emotional support	10.9 (3.03)	10.6 (3.7)	0.67
Practical support	21.7 (4.4)	19.9 (4.4)	0.01
Ineffective support	5.6 (1.2)	5.3 (1.4)	0.36
Ineffective support	5.0 (1.7)	5.6 (1.6)	0.04

FACES II: Family Adaptability and Cohesion Evaluation Scales. ¹⁾ χ^2 test, ²⁾t-test.

lem compared to my own family” ($p < 0.05$); “It is difficult to understand the rules in my family” ($p < 0.05$); “It is difficult to find something to do by the whole family” ($p < 0.01$); “I feel a sense of closeness with others more than my own family” ($p < 0.05$); “We occasionally avoid seeing each other at home” ($p < 0.05$); and “It is difficult for me to talk with other family members about my honest thoughts” ($p < 0.05$).

A comparison of QOFL between group A and group B

Significant differences in QOFL emerged between group A ($M = 125.8$) and group B ($M = 118.8$, $p < 0.05$). With regard to the subscales, significant differences emerged for harmony ($p < 0.05$) and relationships with relatives ($p < 0.01$); the respective scores were higher for Group A (Table 2). Furthermore, significant group differences emerged for 14 out of the 41 questions. Group A obtained higher scores than group B on the following items: “My family holds a warm atmosphere” ($p < 0.01$); “People consider my family as happy family” ($p < 0.01$); “I am glad to be born in my family” ($p < 0.05$); “I enjoy family life everyday” ($p < 0.01$); “My family is very harmonious” ($p < 0.01$); “My family always care for me” ($p < 0.05$); “When a problem arises, everybody actively tries to find a solution” ($p < 0.05$); “There is a free atmosphere in my family” ($p < 0.01$); “We keep our family policy without any influence by surrounding people/environment” ($p < 0.05$); “My family frequently communicates

with relatives” ($p < 0.01$); “My family and relatives help with each other in daily life” ($p < 0.05$); and “My relatives accept/recognize freedom of our family” ($p < 0.05$). Group B obtained significantly higher scores on the following items: “I will be depressed when I think of my family” ($p < 0.01$) and “Occasionally, I have a disappointing experience with my family” ($p < 0.01$; Table 3).

A comparison of social support between group A and group B

Emotional support was significantly higher among group A participants ($M = 21.7$), when compared to group B participants ($M = 19.9$, $p < 0.01$). Ineffective support was significantly higher among group B ($M = 5.6$), when compared to group A ($M = 5.0$, $p < 0.05$; Table 2). Further, significant group differences emerged for 6 out of the 13 questions. Group B obtained higher scores than group A on the following items: “Some people become frustrated with your activities in care” and “Some people interfere in a way of nursing care”.

Predictors of QOFL among caregivers of patients with dementia

We tested for multicollinearity by computing the variance inflation factor (VIF) before conducting multiple regression analysis. The VIFs between explanatory variables were not large (i.e., ranged from 1.0 to 2.3); this indicated

Table 3 A comparison of the quality of family life between Group A and Group B

		Group A	Group B	Significance probability
Harmony	My family often helps each other well.	3.4	3.1	0.10
	My family has a warm atmosphere.	3.3	2.9	p<0.01
	Surrounding people consider my family as “Happy family”.	3.3	2.8	p<0.01
	Surrounding people consider my family as “Harmonious family”.	3.3	3.1	0.07
	My family holds its specific characteristics.	3.2	3.0	0.12
	Surrounding people consider my family as “Lively family”.	2.9	2.8	0.22
Peaceful state of mind	I will be depressed when thinking of family.	2.2	2.8	p<0.01
	Sometimes, I am disappointed with my family.	2.0	2.6	p<0.01
	I am glad to be born as a member of this family.	3.4	3.0	0.02
	I enjoy family life every day.	3.2	2.8	p<0.01
	My family is very harmonious.	3.3	2.8	p<0.01
Family value	My family always watches over me.	3.3	3.0	0.02
	I think we always value and care for family matters.	3.2	3.2	0.48
	We always put importance on family health.	3.7	3.6	0.26
	We can obtain a feeling of fullness by spending time with family.	3.2	3.1	0.38
	I think it is important to put importance on family life.	3.6	3.5	0.26
	I think family is very important.	3.9	3.8	0.53
	I always have a pride as a family member.	3.4	3.3	0.23
Active effort	We talk about our family now as considering our future.	3.0	2.8	0.40
	When a problem arises, we actively work on getting a solution.	3.5	3.1	p<0.01
	We make an effort to be an ideal family.	3.1	2.9	0.32
	We make a united effort to achieve a family goal.	2.9	2.8	0.26
	We value consciousness as a family member.	3.3	3.1	0.21
	We make various improvements for better and rich family life.	3.0	3.1	0.84
Breadth of mind	My family is active/energetic.	2.8	2.6	0.14
	I always enjoy leisure/free time with my family.	2.6	2.4	0.11
	I enjoy recreation with my family on holiday.	2.2	2.2	0.54
Freedom	Each member in my family freely makes a decision.	3.0	3.0	0.49
	There is a free atmosphere in my family.	3.3	3.0	p<0.01
	We value family policy without any influence by surrounding people.	3.3	3.0	0.40
Social participation	My family actively participates in community activity.	3.1	2.9	0.34
	My family actively participates in community event and social activity.	2.9	2.8	0.55
A relation of relative	My family often visits relatives and vice versa.	3.2	2.8	p<0.01
	Relatives provide us advice in various ways when a problem arises.	3.0	2.7	0.98
	Relatives respect my family’s values and thoughts.	3.2	2.9	0.69
	My family lives as helping each other with relatives.	2.9	2.6	0.02
	Relatives respect the freedom of my family.	3.3	3.0	0.02
Social support	Family friends respect values and thoughts of my family.	3.0	2.9	0.67
	Family friends provide advice when a problem arises.	2.9	2.8	0.50
	My family has an active relationship with family friends.	2.6	2.5	0.57
	My family and family friends always help each other for anything.	2.6	2.6	0.86

Mann-Whitney test. **p<0.01, *p<0.05, n. s.: not significant.

that there was no multicollinearity between variables. The results of multiple regression analysis showed that cohesion ($\beta = 0.4$), practical support ($\beta = 0.3$), adaptability ($\beta = 0.3$), and living arrangement ($\beta = -0.1$) significantly predicted QOFL (Table 4).

Discussion

Caregiver burden among family caregivers of elderly dementia patients

Elderly dementia patients may force their family caregiv-

Table 4 Stepwise multiple regression analysis with the quality of family life as the dependent variable

Factor	Standardizing Coefficient β	Significance probability	95% for B Lower limit	95% for B Upper limit
Cohesion	0.38	p<0.01	0.735	1.636
Emotional support	0.32	p<0.01	0.987	2.004
Adaptability	0.30	p<0.01	0.466	1.329
With/without living together	-0.12	0.026	-13.642	-0.865
R ² (decision coefficient)		0.66		
Adjusted R ² (decision coefficient)		0.65		

ers to bear the burden of significant mental and physical suffering; additionally, the Behavioral and Psychological Symptoms of Dementia (BPSD) as well as cognitive dysfunction are likely to greatly influence the daily lives of caregivers²⁶. Caregiver factors as increasing a sense of care burden on family caregivers would be the case of “Caregiver is younger and female” and “Care receiver is a spouse”²⁷. Very old receivers of care engage in low levels of activities of daily living (ADL); further, caregiver burden among family caregivers tends to be higher when BPSD are often manifested²⁸. In a study conducted by Saeki *et al.*¹¹, 80% of caregivers were female; their average ZBI score was 32.6. Similarly, in the present study, women accounted for 80% of the caregivers and were the daughters-in-law, daughters, and wives of the patients; however, their average ZBI score was slightly lower (i.e., 30.8). With regard to the level of nursing care, 60% of the patients required Support Need Grades 1 and 2, and Care Need Grade 1. Further, their life independence levels (i.e., I, II, and IIa) accounted for more than 70% of elderly dementia patients’ ADL, which was at an intermediate level. Tsuboi *et al.*²⁹ found that there was no significant difference in caregiver burden and family health condition between those who used and did not use care services. In the present study, approximately 90% of the participants in both groups used care services; there was no significant difference in the frequency with which home-visit care and day services were used. When symptoms emerge with the progression of dementia, daily care time that addresses BPSD and ADL can alleviate caregiver burden³⁰. In the present study, we found a significant difference in caregiving time between the two groups. The life independence level of elderly dementia patients was higher in group B than in group A because of the longer labor and care that dementia-related symptoms require. Onishi *et al.*²⁸ pointed out that the sense of obligation that constant monitoring of elderly dementia patients necessitates could increase caregiver burden. On the other hand, studies that have been conducted with elderly receivers of care who do not have dementia have shown that ADL is not related to caregiver burden³⁰. Thus, caregiver burden among those who care for elderly dementia patients may be related to severe dementia symptomatology; activities such as

monitoring a patient’s decline in ADL, assistance, and BPSD may increase the time spent on caregiving tasks. Caring for dementia patients can often be extended for long periods of time and can deteriorate the health condition of the primary caregiver, hasten aging, and result in care fatigue. Therefore, social support for family caregivers of dementia patients has become an increasingly important issue. Accordingly, care services and informal services that can alleviate caregiver burden must be developed within the community.

QOFL of family members who care for elderly dementia patients

Homma³¹ has contended that care for elderly dementia patients, aimed at improving independent living, and maintaining safety and psychological stability, must consider individual differences in abilities. Such services should address the following issues that elderly dementia patients often face: confusion in social life and daily life, instrumental ADL, decision making, and selection process³². In the preceding studies, quality of life (QOL) was found to be lower among family caregivers of elderly dementia patients than among family caregivers of non-dementia patients^{33–35}. Age, health condition, emotional support, and social activities of caregivers as well as the BPSD of elderly dementia patients are factors that influence the QOL of family caregivers³². It has been reported that burdened caregivers have lower QOL than non-burdened caregivers³³. In the present study, QOFL was lower among group B participants, when compared to group A participants; further, consistent with these findings, there was a significant correlation between ZBI and QOFL. Saeki¹¹ has contended that caregiver burden can be reduced by improving interaction among family members of patients with dementia. Tanaka *et al.*³⁶ have observed that emotional support, as measured by items such as “Providing encouragement through listening to caregiver’s concern and complaint,” and practical support, as measured by items such as, “Care/staying with a patient at home on behalf of family caregiver,” reduce the burden of family caregivers. In the present study, the following items tapped on one dimension of QOFL, namely, harmony: “Family actively deals with a solution when a problem arises”; “There is a free atmosphere

in my family”; and “My family place importance on a family approach without any influence by surrounding people or circumstances”. Families with high QOL are characterized by active interactions, mutual cooperation, an optimal degree of freedom, and solidarity with regard to solving problems in times of difficulty. Furthermore, the presence of a care cooperater, emotional support, and practical support are also factors that can reduce caregiver burden.

Familial functioning among caregivers of elderly dementia patients

Studies have been increasingly focusing on familial functioning because it can reduce caregiver burden³⁷⁾. Fujiwara *et al.*³⁸⁾ found that caregiver burden could be related to familial functioning. Indeed, they found a significant difference in familial functioning between burdened and non-burdened female caregivers; however, no such difference emerged among male caregivers. Family caregivers in Japan tend to be female (i.e., daughters-in-law, daughters, and wives) and account for more than 50% of caregivers³⁹⁾; however, the number of male caregivers has been gradually increasing in recent times⁴⁰⁾. Since 80% of family caregivers were female in the present study, a significant group difference in cohesion and adaptability may have emerged. According to a study conducted by Saeki *et al.*^{11, 38)}, more than 60% and approximately 20% of scores were representative of mid-range and extreme scores, respectively. In the present study, extreme scorers accounted for approximately 50% of the participants in both group A and group B; however, there was no significant group difference. Family caregivers in the present study were characterized by unique features such as a weak emotional bond (e.g., “I feel closer to others than to my own family members”; “It is easier for me to talk with others than with my own family members”), rigid power structures and role relationships (e.g., “I have a difficulty to express my honest thoughts in my family”; and “It is difficult for me to find something to do together with a whole family”), and a poor ability to change relationship standards (e.g., “It is difficult to understand the roles of my family”). When dementia progresses, patients manifest various psychological and behavioral symptoms. Family caregivers are likely to be confused about these unexpected changes, extremely tired of their caregiving responsibilities, and confronted with critical situations. In the preceding studies^{11, 38)}, a change in family ties and the decision-making process was found to accompany caregiving tasks; changes in emotional bonds, role relationships, and family roles were also observed among

family caregivers. Takeda *et al.*⁴¹⁾ has noted that family cohesion does not always have to be of a moderate level; even extreme emotional bonds can help caregivers overcome critical dementia-related situations. In the present study, active and timely problem-solving strategies among Group A participants were linked to enhanced cohesion; on the other hand, coping with caregiving responsibilities and achieving goals through united efforts were linked to adaptability. With regard to the influence of caregiver burden on QOFL, a long-term perspective that carefully considers emotional bonds, power structures, role relationships, and changes in relational roles through the caregiving process is important.

This study has a few limitations. The participants belonged to only one prefecture; therefore, their socioeconomic statuses of the participants may not be uniform. This is because there may be disparities in socioeconomic statuses across different regions. Accordingly, the generalizability of the results of this study is limited. Considering these limitations, further research should use a larger and more diverse set of participants.

Conclusion

Caring for a dementia patient often leads to hardships within the family; specifically, family caregivers face difficulties that are related to family development, economic factors, social factors, and health problems. Therefore, Nishioka *et al.*⁸⁾ has noted that it is important to nurture coping behaviors that pay “Careful attention for prevention” and prevent caregiving problems through the “Discovery and utilization of resources” so that caregivers can stabilize their daily lives and continue to provide care. It was hypothesized that caregiver burden will play a role in the familial functioning, social support, and QOFL of family caregivers. In general, healthy familial functioning entails an optimal balance between cohesion and adaptability. However, in order to improve the QOL of family caregivers of elderly dementia patients, it is important to ensure that power structures and role relationships flexibly change in accordance with caregiver burden; this should be accompanied by a commitment to forge strong emotional ties and emotional attachment between family members. In order to provide care to elderly dementia patients whose families do not function optimally, management of the progress and symptoms of dementia and appropriate primary support for family caregivers are important.

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