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Patient affect and caregiver burden in dementia

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Keywords:	Alzheimer’s disease, care, dementia, dementia with Lewy bodies, frontotemporal dementia, positive affect
Abstract:	Background: Numerous studies focusing on the burden of caregivers of dementia patients have been published. However, there have been few studies focusing on positive affect as an important factor affecting the caregiver burden, and only a few studies comparing the caregiver burden between different dementia diseases have been reported. Methods: Three hundred and thirty-seven consecutive caregivers of people with dementia participated in this study. The caregiver burden was evaluated by the short version of the Japanese version of the Zarit Burden Interview. Results: Positive affect scores had a significant relationship with the scores of the short version of the Zarit Burden Interview. Caregivers for patients with dementia with Lewy bodies or frontotemporal dementia suffered from a greater burden than those for patients with Alzheimer’s disease dementia. Conclusions: The caregiver burden differed between people caring for patients with different dementia diseases. Positive affect of dementia patients has a significant relationship with caregiver burden, independently from neuropsychiatric symptoms of patients.

Patient affect and caregiver burden in dementia

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Abstract

Background: Numerous studies focusing on the burden of caregivers of dementia patients have been published. However, there have been few studies focusing on positive affect as an important factor affecting the caregiver burden, and only a few studies comparing the caregiver burden between different dementia diseases have been reported.

Methods: Three hundred and thirty-seven consecutive caregivers of people with dementia participated in this study. The caregiver burden was evaluated by the short version of the Japanese version of the Zarit Burden Interview.

Results: Positive affect scores had a significant relationship with the scores of the short version of the Zarit Burden Interview. Caregivers for patients with dementia with Lewy bodies or frontotemporal dementia suffered from a greater burden than those for patients with Alzheimer's disease dementia.

Conclusions: The caregiver burden differed between people caring for patients with different dementia diseases. Positive affect of dementia patients has a significant relationship with caregiver burden, independently from neuropsychiatric symptoms of patients.

Key words: *Alzheimer's disease, care, dementia, dementia with Lewy bodies, frontotemporal dementia, positive affect*

INTRODUCTION

The number of persons with dementia is dramatically increasing, but the financial resources of the government are severely limited in Japan. Therefore, the professional care for persons with dementia is not sufficient, and the burden on family caregivers of the dementia patients is still severe.[1,2] Caring for persons with dementia is a challenging task for family members, and alleviation of the caregiver burden has become a primary public health goal.[3]

Numerous studies on the burden of caregivers for dementia patients were published.[4-8] Many characteristics of patients and/or caregivers have been investigated from the viewpoint of whether or not it affects the burden of caregivers. As a result, various neuropsychiatric symptoms and disturbance of activities of daily living (ADL) were reported to cause a higher burden in caregivers for dementia.

In the medical literature, researchers often focus on the negative aspects induced by the disease. Few studies focusing on the positive affect of patients as an important factor affecting on the caregiver burden have been reported.[9] However, recently, several positive concepts, such as resilience or post-traumatic growth, have been mentioned.[10] In the field of dementia research, more attention has been paid to examples of positive affect such as smiles.[9] In this study, we examined the factors affecting the burden of nursing care in order to clarify whether or not positive affect of patients influences the caregiver burden.

Recently, a few studies have reported a difference in the caregiver burden among different dementing diseases, including dementia with Lewy bodies (DLB).[11,12] However, no studies have compared the burden of caregivers for dementia patients between the different diseases, taking the positive affect of patients into consideration. Therefore, in this study, we additionally compared the caregiver burden of three diseases, Alzheimer's disease dementia (ADD), DLB, and behavioral variant frontotemporal dementia (bvFTD), paying attention to differences in the positive affect of patients.

METHODS

Study design

This is a retrospective cross-sectional study.

Setting and subjects

The current study included 337 caregivers of individuals who had been referred to the outpatient memory clinic of Okayama University Hospital between September 2008 and February 2012 for neuropsychological evaluation and were diagnosed as having dementia.

Inclusion criteria for caregivers were (1) being the family caregiver of an outpatient with dementia, (2) living with the patient or visiting him or her more than three times a week, and (3) being cognitively intact. Exclusion criteria were (1) being unable to come to the hospital with the patient, and (2) having a history of mental illness or substance abuse. The exclusion criteria for patients were (1) complications from other neurological diseases or illnesses; (2) a history of mental illness or substance abuse prior to the onset of dementia; and (3) treatment with antipsychotics, antidepressants, or anxiolytic drugs.

The patients all (1) underwent general physical and neurological examinations and extensive laboratory testing, including thyroid function tests, serum vitamin B12, and syphilis serology; (2) received an evaluation by the Clinical Dementia Rating (CDR); and (3) and took the Mini-Mental State Examination (MMSE),[13, 14] and Frontal Assessment Battery (FAB).[15,16]

All patients with ADD, DLB, bvFTD, or vascular dementia (VaD) were diagnosed according to the criteria formulated by the National Institute on Aging-Alzheimer's Association,[17] the DLB diagnostic criteria formulated by McKeith *et al*.,[18] the FTDC criteria for bvFTD,[19] and the American Heart Association/American Stroke Association guidelines for VaD.[20]

Neuropsychological tests, behavioral symptoms, and activities of daily living

MMSE is a cognition screening test used widely, and it has a maximum score of 30 points. It is a brief and reliable instrument for the evaluation of global cognitive function, and assesses aspects of orientation, recall, language, and visual construction.[13,14] The FAB consists of six items, and the score on each item ranges from 0 to 3. A lower score indicates a greater degree of executive dysfunction.[15,16]

The Neuropsychiatric Inventory (NPI) is a valid and reliable instrument for measuring behavior in dementia.[21,22] It is a caregiver-based tool that assesses ten common behaviors in dementia. The Physical Self-Maintenance Scale (PSMS) and the Instrumental Activities of Daily Living

(IADL) scale are validated scales for the assessment of ADL.[23,24] PSMS is a 6-item scale that rates self-care ability in toileting, feeding, dressing, personal hygiene and grooming, locomotion (physical ambulation), and bathing. PSMS has a maximum score of 6. The IADL scale assesses patients' ability to perform eight complex daily tasks: ability to use the telephone, shop, prepare food, perform household tasks, do laundry, use public transportation, take responsibility for medications, and manage finances. Three tasks (food preparation, household tasks, and laundry) are scored only for females, and the original IADL scale has a maximum score of eight for women and five for men. In this study, the IADL score for men was calculated by multiplying the original IADL score x 1.6. Therefore, in this study, the IADL scale has a maximum score of eight for both men and women.

The quality of life questionnaire for dementia (QOL-D) is an objective QOL scale and comprises 31 items encompassing six domains: positive affect, negative affect and actions, communication, restlessness, attachment to others, and spontaneity.[25] Each item is ranked on a four-point scale (from 1 to 4) based on the frequency of appearance of the symptom. In this study, total scores of the positive affect domain, which includes seven items, were used as the Positive Affect score (from 7 to 28). The seven items of the Positive Affect domain are “Cheerful”, “Satisfied”, “Pleased with pets/children", "Enjoys eating", "Pleased with visitors", "Enjoys seeing others' activities" and "Living at ease". The Positive Affect domain of the QOL-D was evaluated by caregivers in this study. In the positive affect domain, a high score means a higher level of positive affect.

Caregiver burden assessment

Caregiver burden was measured using the short version of the Japanese version of the Zarit Burden Interview (sZBI),[26,27] which consists of eight items. The caregivers were asked to rate the degree of their burden on a Likert scale from 0 ("never") to 4 ("nearly always") points. Pearson's correlation coefficient between sZBI and ZBI was 0.92.[27] Consistent with previously published reports, caregivers who scored ≥9 on sZBI were deemed to have a clinically elevated burden[26] and a score ≥17 on sZBI was thought to indicate a severe burden.[28]

The ZBI is composed of two factors. Personal strain means how personally stressful the experience is, and role strain indicates the stress due to role conflict or overload.[29]

Ethics

This study adhered to the 1975 Helsinki Declaration of Human Rights. This study was approved by the Internal Ethical Committee of Okayama

University Graduate School of Medicine, Dentistry, and Pharmaceutical Sciences (approval number: 1506-010). After a complete description of the study to the subjects and their relatives, written informed consent was obtained.

Statistics

Statistical analysis was performed using the SPSS 23.0 software program (SPSS Inc., Chicago, IL). To identify which variables were significantly correlated with caregiver burden, we used a multiple linear regression with sZBI scores as a dependent variable. Independent variables were gender, age, duration of disease, education, gender of caregiver, age of caregiver, relationship of caregiver to patient, MMSE scores, FAB scores, NPI scores, IADL scores, PSMS scores, and Positive Affect scores. Subsequently, forward stepwise linear regression models (entrance criterion $p = 0.05$, exit $p = 0.10$) determined if disparate predictors accounted for a unique additive variance in the caregiver burden. The significance for the hypothesis testing analyses was set at $P < 0.05$.

One-way analysis of variance (ANOVA) with Tukey's HSD test was used to test for differences among the three diagnostic groups in means of age, duration of disease, years of education, and scores of MMSE, FAB, NPI, IADL, PSMS, and Positive Affect. The sex differences between the three groups were examined by chi-square test.

RESULTS

Participants

Clinical characteristics of patients and caregivers are listed in Table 1. Most patients suffered from very mild (CDR 0.5) or mild (CDR 1) dementia. Patients with dementia were diagnosed with probable ADD (n=242, 71.8%), possible ADD with vascular lesion (n=30, 8.9%), DLB (n=26, 7.7%), bvFTD (n=17, 5.0%), VaD (n=12, 3.6%), and others (n=10, 3.0%). Results of neuropsychological tests are also shown in Table 1.

The mean age of caregivers was about 10 years younger than the mean age of patients (patients, 75.4 years; caregivers, 63.8 years). About two-thirds of caregivers were female. The numbers of caregivers with an sZBI total score ≥9 (clinically elevated burden) or ≥17 (severe burden) were 133 (33.5%) and 39 (11.6%).

Factors related to caregiver burden

The multiple linear regression analysis showed that sZBI scores were predicted by NPI scores, duration of disease, IADL score, Positive Affect score, and sex of the caregivers according to the following formula (Table 2): the scores of sZBI = 0.259 (NPI scores) +0.051 (duration of disease) -0.421 (IADL scores) -0.121 (Positive Affect scores) -1.141 (sex of caregivers) +11.144. The sZBI scores of personal strain were predicted by the following formula: the scores of sZBI personal strain = 0.152 (NPI scores) +0.032 (duration of disease) -0.276 (IADL scores) -0.090 (Positive Affect scores) -0.831 (sex of caregivers) +5.854. The sZBI scores of role strain were predicted by the following formula: the scores of sZBI role strain = 0.113 (NPI scores) +0.017 (duration of disease) -0.144 (IADL scores) +1.412.

Comparison between ADD, DLB, and bvFTD

The profiles of patients with ADD, DLB or bvFTD are shown in Table 3. There were no significant differences in the sex and years of education among patients with AD, DLB, and bvFTD. The mean age of the bvFTD patients was significantly lower than those of the patients with AD or DLB. There were no significant differences in the sex, age, and relationship among caregivers for patients with AD, DLB, and bvFTD.

The total score, personal strain score, and role strain score of the caregivers on the sZBI of DLB and bvFTD patients were higher than those of AD patients (Table 3). There were no significant differences in the MMSE and IADL scores between AD, DLB, and FTD groups. The NPI scores of DLB patients were significantly higher than those of AD patients. The Positive Affect scores of DLB patients were significantly lower than those of AD patients.

The mean MMSE score of ADD patients tends to be higher than that of FTD patients (ANOVA, p=0.051). In order to exclude the effect of the general cognitive level on caregiver burden, we investigated the subgroup of ADD patients with an MMSE score of 22 or less. As a result, even for AD patients with an MMSE score of 22 or less (n= 146, mean age was 74.5 years), the mean MMSE score was 18.0 ± 3.8 and mean sZBI score was 7.6 ± 5.6.

DISCUSSION

Positive affect and caregiver burden

Not a few systemic reviews of caregiver burden for dementia have recently been reported in the medical literature.[4-8] In most studies, behavioral problems and/or psychological symptoms are the primary factor associated with the caregiver burden for dementia patients.[5] Among various neuropsychiatric symptoms, irritability, agitation, sleep disturbance, anxiety, apathy, and delusion impacted the caregiver burden the most.[8] However, in almost all studies, the positive aspects of behavioral or psychological factors such as appreciative words and smiles have not been taken into consideration.[5-8] The resilience of caregivers for patients with dementia has been extensively investigated, and higher levels of resilience were associated with less depression and greater physical health of caregivers.[4] Regarding patient characteristics, we think we should pay more attention to positive aspects. As far as we know, this is the first study to show that positive affect such as patients' contentment is related to lower caregiver burden.

The sZBI is composed of two factors. Personal strain means how personally stressful the experience is, and role strain indicates the stress due to role conflict or overload.[29] Positive affect scores had a significant relationship to sZBI personal strain scores, but not to sZBI role strain scores in this study. Patients' smiles might reduce the mental stress of caregivers, but do not decrease the amount of time spent caring. Therefore, we suppose that the results in this study are convincing.

Of course, it is difficult to determine the cause-effect relationship of the caregiver burden to patients' neuropsychiatric symptoms and positive affect. It is possible that a severe burden reduces the mental allowance in caregivers, and that caregivers without emotional leeway react severely to the behaviors of patients. As a result, neuropsychiatric symptoms increase and smiles of patients decrease. Maybe, conversely, intervention to increase the positive affect of dementia patients alleviates the caregiver burden. However, further study, such as cohort studies, is needed to clarify the cause-effect relationship.

Comparison between different dementias

Two studies comparing the caregiver burden or care distress between ADD and DLB have been reported.[11,12] Caregiver distress was more severe in caregivers of DLB patients than in those of ADD,[11] and caregivers of DLB patients experienced significantly more burden compared to those of ADD.[12] More severe neuropsychiatric symptoms and more impaired ADL functioning were thought to cause the more severe burden on DLB caregivers.[11,12] The results in this study were in line with previous reports.

Comparison of the caregiver burden between ADD and bvFTD was investigated in five studies.[12,30-33] In four studies, bvFTD increased the levels of caregiver burden.[12,30,31,33] In the one other study, there was no significant difference in the perceived burden between caregivers for ADD and bvFTD patients, but caregivers of bvFTD patients experienced higher levels of distress than those of ADD patients.[33] In most studies, more severe neuropsychiatric symptoms were reported in bvFTD compared to ADD, and were supposed to cause higher levels of caregiver burden or caregiver distress.[12,31-33] In this study, bvFTD patients caused higher levels of caregiver burden, but no significant differences were observed in NPI, IADL, Positive Affect, duration of disease, and caregiver sex ratio. The small number of bvFTD patients in this study made the contribution of each factor obscure.

Limitations

This study has several limitations. First, the detailed characteristics of caregivers, such as education, coping skills, personality, and mental state, were not collected. Second, dementia patients in this study included various diseases. The clinical diagnosis of dementia is fairly reliable. Therefore, we did not do statistical analysis in subgroups, for example, only patients with ADD. Third, in this study, only relatively mild dementia was included because the study was performed at an outpatient memory clinic of a University Hospital. In the future, studies including more advanced patients should be done. Regardless of these limitations, this study first suggests the possibility that dementia patients' positive affect might ameliorate the psychological burden of caregivers, independently from neuropsychiatric symptoms.

Conclusions

Positive affect of dementia patients has a significant relationship with a lower psychological burden of caregivers, independently from neuropsychiatric symptoms of patients. We should pay more attention to positive aspects of patients' affect. Patients' smiles might reduce the mental stress of caregivers.

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Disclosure statement

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Conflicts of interest

The authors have no conflicts of interest to disclose.

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Table 1. Clinical characteristics of patients and caregivers (n=337)

Patients with dementia		
Gender, % female (n)	59.3	(200)
Age in years, M ± SD (range)	75.4 ± 7.6	(47-91)
Duration of disease (months), M ± SD (range)	33.1 ± 21.5	(1-120)
Education (years), M ± SD (range)	10.9 ± 2.7	(6-18)
Clinical Dementia Rating, % (n)		
0.5	49.5	(167)
1	37.1	(125)
2	12.5	(42)
3	0.9	(3)
Test (full score), M ± SD (range)		
MMSE (30)	20.1 ± 4.5	(4-27)
FAB (18)	10.3 ± 3.2	(0-17)
NPI (120)	9.0 ± 11.3	(0-78)
IADL (8)	5.8 ± 2.0	(0-8)
PSMS (6)	4.9 ± 1.6	(0-6)
Positive Affect (28)	21.0 ± 5.3	(7-28)
Caregivers		
Gender, % female (n)	65.6	(221)
Age in years, M ± SD (range)	63.8 ± 13.2	(25-86)
Relationship, % (n)		
Spouse	57.3	(193)
Child	32.3	(109)
Others	10.4	(35)
ZBI, total score (32)	8.3 ± 6.4	(0-30)
ZBI, personal strain (20)	6.2 ± 4.1	(0-20)
ZBI, role strain (12)	2.2 ± 2.7	(0-12)

n, number; M, mean; SD, standard deviation

MMSE, Mini-Mental State Examination; FAB, Frontal Assessment Battery

NPI, Neuropsychiatric Inventory

IADL, Instrumental Activities of Daily Living scale

PSMS, Physical Self-Maintenance Scale

Positive Affect, positive affect scores of QOL-D

ZBI, Zarit Burden Interview

Table 2. Stepwise multiple regression analysis for scores of ZBI (n=337)

	Variable	B	SE	Beta	*t* value	*P* value
ZBI, total score	Constant	11.144	1.969		5.660	<0.001
	NPI	0.259	0.029	0.461	8.933	<0.001
	Duration	0.051	0.013	0.173	3.924	<0.001
	IADL	-0.421	0.150	-0.133	-2.797	0.005
	Positive Affect	-0.121	0.058	-0.103	-2.121	0.035
	Sex of CG	-1.141	0.555	-0.088	-2.054	0.041
ZBI, personal strain	Constant	5.854	1.362		4.298	<0.001
	NPI	0.152	0.019	0.417	7.865	<0.001
	Duration	0.032	0.009	0.167	3.696	<0.001
	IADL	-0.276	0.101	-0.135	-2.739	0.006
	Positive Affect	-0.090	0.039	-0.116	-2.329	0.020
	Sex of CG	-0.831	0.383	-0.096	-2.171	0.031
ZBI, role strain	Constant	1.412	0.547		2.580	0.010
	NPI	0.113	0.012	0.467	9.394	<0.001
	Duration	0.017	0.006	0.134	2.855	0.005
	IADL	-0.144	0.069	-0.106	-2.078	0.038

ZBI, Zarit Burden Interview; NPI, Neuropsychiatric Inventory
Duration, duration of disease; IADL, Instrumental Activities of Daily Living scale
Positive Affect, positive affect scores of QOL-D
CG, caregiver; Sex of CG, man=1 and woman=2

Table 3. Clinical characteristics of ADD, DLB, and FTD

Patients with dementia	**ADD**	**DLB**	**FTD**	**ANOVA**		**Post HOC (Tukey)**
				F	**p**	
Number	242	26	17			
Gender, male/female (n)	90/152	13/13	8/9	2.120	0.346	
Age in years, M ± SD	75.0 ± 7.6	76.7 ± 4.9	70.4 ± 7.8	3.905	0.021	ADD > FTD, p <0.05; DLB > FTD, p <0.05
Duration of disease (months), M ± SD	31.3 ± 19.1	25.8 ± 19.4	42.5 ± 33.3	3.551	0.030	DLB < FTD, p <0.05
Education (years), M ± SD	11.0 ± 2.7	9.9 ± 2.1	10.5 ± 1.8	2.190	0.114	
Test (full score), M ± SD						
MMSE (30)	20.5 ± 4.4	19.3 ± 3.8	18.1 ± 6.9	3.017	0.051	
FAB (18)	10.7 ± 2.8	8.7 ± 3.2	8.3 ± 5.4	8.266	< 0.001	ADD > DLB, p <0.05; ADD > FTD, p <0.01
NPI (120)	7.8 ± 10.7	18.4 ± 16.0	13.4 ± 9.9	11.643	< 0.001	ADD < DLB, p <0.001
IADL (8)	6.0 ± 1.9	5.6 ± 2.5	5.5 ± 2.4	1.052	0.351	
PSMS (6)	5.2 ± 1.3	4.4 ± 2.0	4.2 ± 2.2	7.035	0.001	ADD > DLB, p <0.05; ADD > FTD, p <0.05
Positive Affect (28)	21.5 ± 5.2	18.0 ± 6.0	18.6 ± 4.9	6.757	0.001	ADD > DLB, p <0.01
Caregivers						
Gender, male/female	91/151	6/20	6/11	2.152	0.341	
Age in years, M ± SD	63.9 ± 13.3	67.2 ± 11.3	62.0 ± 14.5	0.945	0.390	
Relationship, Spouse/Child/Others	142/74/26	17/7/2	11/3/3	2.182	0.702	
ZBI, total score (32)	7.6 ± 6.0	11.6 ± 7.7	12.2 ± 5.7	8.887	< 0.001	ADD < DLB, p <0.01; ADD < FTD, p <0.01
ZBI, personal strain (20)	5.8 ± 3.9	8.0 ± 4.7	8.5 ± 3.5	6.816	0.001	ADD < DLB, p <0.05; ADD < FTD, p <0.05
ZBI, role strain (12)	1.8 ± 2.5	3.6 ± 3.4	3.8 ± 2.8	8.674	< 0.001	ADD < DLB, p <0.01; ADD < FTD, p <0.05

ADD, Alzheimer's disease dementia; DLB, dementia with Lewy bodies; FTD, behavioral variant frontotemporal dementia
Post HOC, post-hoc analysis; Tukey, Tukey's HSD test; ZBI, Zarit Burden Interview; M, mean; SD, standard deviation