

who is ultimately in charge of the decision on driving cessation of older adults with dementia.

**Objectives:** The present study investigated: (1) who played a major role in driving cessation of older adults with dementia (hereinafter "the patients"); (2) what were the current practices regarding attempts for driving cessation of the patients by their family caregivers; and (3) what were the necessary requirements for enabling the cessation of driving.

**Methods:** The study subjects were 79 pairs of family caregivers and consecutive outpatients satisfying the diagnostic criteria for dementia at Ehime University Hospital from June 2004 to March 2006. The patients were assessed according to cognitive function, neuropsychiatric disturbances, and severity of dementia. The family caregivers were asked by a self-administered questionnaire including patients' driving habits and plans for driving cessation.

**Results:** (1) Whereas 54% of the family caregivers (sample size  $n = 37$ ; multiple answer) answered that the patients themselves should determine whether to cease driving, 48% of the family caregivers actually made the decisions (sample size  $n = 21$ ).

(2) Out of those family caregivers who doubted the driving ability of the patients ( $n = 18$ ), only half attempted to encourage the patients to cease their driving.

(3) Availability of family members who can drive instead of the patients and encouragement from health professionals were raised as essential for enabling the cessation of driving.

**Discussion:** The findings regarding the necessary requirements for enabling the cessation of driving clearly indicated that whether the decisions would be made in practice were highly situation-dependent. It should therefore be a matter of policy, such as institutionalising the availability of transportation alternatives.

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#### P2-109

##### **Caring of the end of life for Alzheimer's disease patients: Some theoretical and practical issues**

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End-of-life care for patients with Alzheimer's disease has implications for patients, caregivers and society. End-of-life care for patients with dementia is extremely demanding of family caregivers. During the severe stage of the illness, patients lose the ability to communicate their needs and require significant assistance in activities of daily living. Physical consequences of the progression of dementia predispose persons with advanced Alzheimer's disease to infection and fever, especially aspiration pneumonia and urinary tract infections. Families of patients at this stage of dementia must determine if they can provide care at home or if the patients should be cared for in an institution. Quality of care in patients with end-stage dementia is an important factor when deciding where these patients should receive care. According to some authors, a major obstacle to quality home care is a lack of adequate training for caregivers. Caregivers who take advantage of programs such as support groups keep their Alzheimer's patient at home longer than those who do not. Patients who receive hospice care and pain control stay at home longer and are more likely to die at home. Patients who die at home have fewer symptoms and less discomfort than those who received care in other settings. If satisfactory care cannot be provided at home, patients with progressive dementia should receive end-of-life care in an institution. Deaths of demented patients raise a lot of ethical considerations. It is always difficult to know demented patients' awareness of the end of life. It is really difficult to accompany these patients, with whom communication is essentially nonverbal. During this delicate phase of the end of life, how can formal health professionals help the family members who are afraid of both death and dementia? A majority of authors conclude that end-of-life care for Alzheimer's patients can be provided at their home. This care can be facilitated by hospice programs, effective pain control and psychiatric care. Very important is the improvement of our communication skills with the patient and the facilitation of interdisciplinary exchanges with the caregiver's team and with the family members to allow acceptance of the death.

#### P2-110

##### **Comparison of proxy-patient assessment and self-reported evaluation of depressive symptoms in the elderly**

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# Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia?

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## SUMMARY

**Objective** To compare family caregiving situations for patients with early onset dementia (EOD) and late onset dementia (LOD), and to identify the specific problems experienced by relatives caring for EOD patients.

**Methods** The participants were chosen from 92 consecutive caregiver–patient dyads, comprising co-residing family caregivers and outpatients who fulfilled the diagnostic criteria for dementia. The patients were assessed according to cognitive function, neuropsychiatric disturbances and the severity of dementia. The caregivers completed a self-administered questionnaire that included items on their sociodemographic status and caregiving situation. Caregiver burden was assessed by the Japanese version of the Zarit Burden Interview.

**Results** In total, 68 dyads were eligible for the analysis. 14 of which included patients with EOD and 54 of which included patients with LOD. There were no significant differences between the two groups in terms of patient clinical features, duration of caregiving, number of hours during which caregivers were relieved per day or number of hours of caregiving per day. No significant associations were detected between the type of dementia and caregiver characteristics (such as health status) or caregiver burden, even after adjusting for confounding variables. However, the caregivers of EOD patients had greater perceived difficulties due to patient behavioural disturbances than did the caregivers of LOD patients.

**Conclusions** Our findings demonstrated that additional resources, such as care services, should be provided for sufferers of EOD, in order to allow family caregivers to cope with difficulties associated with patient behavioural problems. Copyright © 2007 John Wiley & Sons, Ltd.

**KEY WORDS**—family caregivers; early onset dementia; presenile dementia; late onset dementia; senile dementia; care services

## INTRODUCTION

It is well established that caring for a relative with dementia is a difficult task, which can lead to stress, physical and mental health problems, and even high

morbidity and mortality among family caregivers (Baumgarten *et al.*, 1992; Schulz *et al.*, 1995; Kiecolt-Glaser *et al.*, 1996; Schulz and Beach, 1999; Kiecolt-Glaser *et al.*, 2003; Vitaliano *et al.*, 2004). Most previous studies of this issue have focused on older patients with dementia (that is, individuals aged  $\geq 65$  years). However, Freyne *et al.* (1999) demonstrated that caregivers of early onset dementia (EOD) patients (that is, individuals aged  $< 65$  years) were more likely to have a longer duration of caregiving, less social support and a heavier

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caregiver burden than those caring for late onset dementia (LOD) patients. Previous studies have also indicated that situations involving younger caregivers and/or younger patients are associated with an increased caregiver burden (Freyne *et al.*, 1999; Schneider *et al.*, 1999).

Therefore, it is clearly important to assess the problems faced by caregivers of EOD patients, and to ensure that they receive appropriate external assistance and social support. The formal care services in Japan provided under the Long-Term Care (LTC) insurance scheme is one of the important sources of social support. Kumamoto *et al.* (2006) reported that the use of such care services reduced feelings of burden among the caregivers of frail elderly patients. However, the LTC insurance scheme might be less easy for sufferers of EOD to access, as it is mainly targeted at individuals aged  $\geq 65$  years. The shortage of service provision has been indicated in other countries such as Ireland and the UK (Freyne *et al.*, 1999; Chaston *et al.*, 2004; Coombes *et al.*, 2004). This might be partly due to the fact that the issue has yet to be recognized as a public-health concern, owing to the relatively small prevalence of EOD sufferers compared with LOD sufferers (Karasawa, 1992).

There is a need to raise awareness of EOD as a public-health concern, and to identify the unmet requirements of EOD sufferers and their family caregivers with respect to caregiving situations, specific difficulties and caregiver burden-associated factors. The objectives of the present study were thus to compare family caregiving situations for individuals with EOD and LOD, and to clarify the specific problems experienced by the caregivers of the former.

## METHODS

### *Participants*

The subjects were chosen from a total of 92 caregiver-patient dyads, comprising co-residing family caregivers and consecutive outpatients seen at Ehime University Hospital, Japan, between June 2004 and December 2005. Informed consent was obtained from all of the subjects. Differential diagnoses were made by employing the NINCDS-ADRDA (McKhann *et al.*, 1984) for probable Alzheimer's disease, consensus criteria (Neary *et al.*, 1998) for Frontotemporal lobar degeneration, DSM-IV (American Psychiatric Association, 1994) for Vascular dementia, and consensus guidelines (McKeith *et al.*, 1996) for Dementia with Lewy bodies. Patients were assessed in terms of their

cognitive function, neuropsychiatric disturbances and the severity of dementia, using the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975), the Neuropsychiatric Inventory (NPI; Cummings *et al.*, 1994; Hirono *et al.*, 1997) and the Clinical Dementia Rating (CDR) scale (Hughes *et al.*, 1982), respectively. The age at first hospital visit of the patients was identified from their charts.

### *Measures*

The caregivers responded to a set of self-administered questions that included items addressing their socio-demographic status. The caregivers were also asked to state the number of hours per day they provided care for the patients and the number of months that they had cared for them. In addition, they were asked to estimate the number of hours per day that they were temporarily relieved of their duties or were able to leave the patients.

The health status of the caregivers was evaluated using two subscales of the 28-item General Health Questionnaire (GHQ; Goldberg and Hillier, 1979; Narita, 1994): the somatic symptoms subscale, and the anxiety and insomnia subscale. The sums of the scores in each subscale according to a four-point Likert scale were used as indices of the somatic symptoms and anxiety and insomnia of the caregivers, respectively, and ranged from 0 (healthiest) to 21 (least healthy). The Cronbach's coefficient alpha values for the somatic symptoms and anxiety and insomnia were 0.858 and 0.898, respectively.

The perceived difficulties caused by patient behavioural disturbances were assessed using 15 items from the Troublesome Behaviour Scale (Asada *et al.*, 1994, 2000). The caregivers were asked to state how much difficulty they experienced due to patient behavioural disturbances according to a four-point Likert scale. All of the items were summed, in order to reveal the perceived difficulties caused by patient behavioural disturbances, with scores ranging from 0 (little difficulty) to 45 (a lot of difficulty). The Cronbach's alpha value was 0.879.

Caregiver burden was assessed using the Japanese version of the Zarit Burden Interview (J-ZBI), which has well-documented validity and reliability (Arai *et al.*, 1997).

### *Statistical analyses*

We divided the caregiver-patient dyads into two groups based on the age of the patient at their first visit to the hospital: those aged  $< 65$  years were assigned to

the EOD group, and those aged  $\geq 65$  years were assigned to the LOD group. The characteristics of the two groups were compared using Fisher's exact tests or Mann-Whitney tests. The associations among the patient variables and the caregiver variables were analyzed using the Spearman's rank order correlation coefficients for both groups. The associations between the probability of EOD and the caregiver variables were evaluated by calculating the odds ratios (OR) with 95% confidence intervals (CI). Logistic regression models were used to estimate the crude ORs and the ORs adjusted for the potential confounding factor. The independent variables were assumed to be continuous in view of their goodness-of-fit to the data. In addition, Mantel extension tests were used to assess linear trends across the tertile categories of the caregiver measures, with the exceptions of anxiety and insomnia, and perceived difficulties due to patient behavioural disturbances. These variables were classified into three groups, in order to include a similar number of subjects in each category.

The criterion for statistical significance was  $p < 0.05$  for all analyses. All calculations were performed using SAS version 9.1.3 for Windows (SAS Institute Inc., Cary, NC).

## RESULTS

### *Characteristics of patients and caregivers*

In total, 24 of the 92 caregiver-patient dyads were excluded from the analysis due to missing data (14 dyads) or because the individuals were not living together (10 dyads). Of the 68 dyads that were eligible for further analyses, 14 were assigned to the EOD group and the remaining 54 were assigned to the LOD group.

Table 1 shows the characteristics of the patients and their caregivers in the two groups. There were no significant differences in cognitive function (MMSE), behavioural disturbances (NPI) or the severity of dementia (CDR) between the EOD and LOD patients. The caregivers in the EOD group were significantly younger and more likely to have a job than those in the LOD group.

### *Family caregiving situations in the EOD and LOD groups*

There were no significant differences between the two groups in the caregiving situations (Table 2). The perceived difficulties caused by patient behavioural disturbances appeared to be greater in the EOD group, although this trend was not statistically significant.

### *Correlations of caregiver and patient variables*

Among the EOD group, the caregivers' anxiety and insomnia and J-ZBI score were positively correlated with the patient NPI score (Table 3). On the other hand, among the LOD group, there were significant associations between most of the caregiver variables and the patient NPI and CDR scores (Table 4).

### *Health, difficulties and burden of caregivers in the EOD and LOD groups*

The crude ORs of the EOD and LOD groups showed no significant differences in any of the caregiver variables (model 1; Table 5). Adjusting for patient age slightly increased the ORs (model 2). Additional adjustments were made for the NPI and CDR scores (model 3), because they were strongly correlated with the caregiver variables (see above). The results demonstrated that caregivers of EOD patients were more likely to perceive difficulties due to patient behavioural disturbances than caregivers of LOD patients ( $p$  value for trend = 0.041). Although the OR for the anxiety and insomnia of caregivers was found to be significant, no linear trend was observed across the categories of the variable ( $p$  value for trend = 0.182).

## DISCUSSION

Patients with EOD and LOD in the present study did not show differences in their clinical features, including cognitive function, behavioural disturbances and disease severity. Nevertheless, a multiple logistic regression analysis demonstrated that the caregivers of the EOD patients had greater difficulties in coping with patient behavioural disturbances than the caregivers of LOD patients. This implied that a difference in a factor other than patient clinical features caused additional difficulties for caregivers coping with behavioural disturbances of EOD sufferers.

Although relatively few studies have compared the psychosocial effects of differences in the onset of dementia on patients, previous finding should be noted. Prohaska *et al.* (1987) noted that people generally tend to attribute their symptoms to aging, especially older individuals or those with less-severe symptoms. Hence, the psychosocial effects of a disease might vary between patients depending upon the point in their lives at which the symptoms occur.

The early onset of disease could potentially have a greater impact on their behaviour and clinical features,

Table 1. Characteristics of patients and caregivers in the EOD and LOD groups

	Early onset ( <i>n</i> = 14)	Late onset ( <i>n</i> = 54)	<i>p</i> value <sup>a</sup>
<i>Patient</i>			
Age	60.5 [59.0, 63.0]	78.0 [72.0, 80.0]	<0.001
Years since first visit to the hospital	1.5 [0.0, 4.0]	1.0 [0.0, 2.0]	0.255
Female	7 (50.0)	24 (44.4)	0.769
<i>Diagnosis</i>			
Alzheimer's disease	10 (71.4)	32 (59.3)	0.081
Vascular dementia	1 (7.1)	7 (13.0)	
Frontotemporal lobar degeneration	3 (21.4)	2 (3.7)	
Dementia with Lewy bodies	0 (0.0)	9 (16.7)	
Other types of dementia	0 (0.0)	4 (7.4)	
Cognitive function (MMSE) <sup>b</sup>	20.0 [13.0, 23.0]	22.0 [18.0, 25.0]	0.220
Behavioural disturbances (NPI)	11.5 [9.0, 19.0]	8.5 [4.0, 24.0]	0.832
<i>Severity of dementia (CDR)</i>			
0	0 (0.0)	1 (1.9)	0.344
0.5	4 (28.6)	19 (35.2)	
1	3 (21.4)	17 (31.5)	
2	5 (35.7)	10 (18.5)	
3	2 (14.3)	7 (13.0)	
<i>Caregiver</i>			
Age	61.5 [57.0, 66.0]	70.0 [63.0, 74.0]	0.011
Female	8 (57.1)	44 (81.5)	0.078
<i>Relationship to the patient</i>			
Spouse as caregiver	13 (92.9)	39 (72.2)	0.152
Adult child as caregiver	0 (0.0)	7 (13.0)	
Daughter-in-law as caregiver	0 (0.0)	7 (13.0)	
Other	1 (7.1)	1 (1.9)	
Employment status <sup>c</sup> /employed	8 (57.1)	14 (26.4)	0.052
<i>Subjective economic status</i>			
High	2 (14.3)	8 (14.8)	0.771
Middle	7 (50.0)	32 (59.3)	
Low	5 (35.7)	14 (25.9)	

Data are shown as the median [25 percentile, 75 percentile] or *n* (%).

<sup>a</sup>Calculated using the Fisher's exact test for nominal variables and the Mann-Whitney test for ordinal/interval variables between the EOD and LOD groups.

<sup>b</sup>One missing data point in each group.

<sup>c</sup>One missing data point in the LOD group.

which might increase the difficulties and burdens experienced by their caregivers. Young age among caregivers of dementia patients has also been identified as a predictor of increased burden (Freyne *et al.*, 1999; Schneider *et al.*, 1999). This implies that younger caregivers are less likely to be sufficiently prepared for the role, perhaps due to reduced understanding and acceptance of the disease.

In the current study, we did not identify a greater caregiver burden, but rather greater perceived difficulties by the caregivers of the EOD group. However, behavioural disturbances of patients with dementia

clearly increase the risk of caregiver burden (Coen *et al.*, 1997; Donaldson *et al.*, 1998; Arai and Washio, 1999; Coen *et al.*, 1999; Rymer *et al.*, 2002). Thus, the fact that the caregivers in our study perceived difficulties in coping with patient behavioural disturbances could be regarded as a precursor of caregiver burden. The difficulties perceived by the caregivers of the EOD patients might therefore eventually lead to caregiver burden if appropriate assistance is not provided.

The assistance provided to family caregivers can include formal care services that are intended to

Table 2. Caregiving situation in the EOD and LOD groups

Caregiving situation	Early onset ( <i>n</i> = 14)	Late onset ( <i>n</i> = 54)	<i>p</i> value <sup>a</sup>
Duration of caregiving (months)	24.0 [13.0, 36.0]	24.0 [6.0, 55.0]	0.574
Hours of caregiving per day	4.5 [3.3, 8.0]	2.0 [0.0, 4.5]	0.054
Hours caregivers are relieved per day	2.0 [1.5, 8.0]	4.0 [2.0, 24.0]	0.368
Caregiver measure (score)			
Somatic symptoms <sup>b</sup>	8.5 [7.0, 13.0]	9.0 [4.0, 12.0]	0.474
Anxiety and insomnia <sup>b</sup>	10.0 [9.0, 13.0]	8.0 [5.0, 12.0]	0.106
Perceived difficulties due to patient behavioural disturbances <sup>c</sup>	9.0 [4.0, 15.0]	4.0 [0.0, 13.0]	0.053
Caregiver burden (J-ZBI) <sup>d</sup>	21.0 [15.0, 36.0]	18.0 [11.0, 34.0]	0.686

Data are shown as the median [25 percentile, 75 percentile].

<sup>a</sup>Calculated using the Mann-Whitney test for ordinal/interval variables between the EOD and LOD groups.

<sup>b</sup>Scores ranging from 0 to 21.

<sup>c</sup>Scores ranging from 0 to 28.

<sup>d</sup>Scores ranging from 0 to 88.

Table 3. Correlations between patient and caregiver variables in the EOD group (*n* = 14)

	1	2	3	4	5	6	7	8	9
1. Patient age	1.000								
2. Caregiver age	0.709*	1.000							
Patient measure									
3. Cognitive function (MMSE)	-0.146	-0.135	1.000						
4. Behavioural disturbances (NPI)	0.115	0.138	-0.284	1.000					
5. Severity of dementia (CDR)	0.058	0.079	-0.626**	0.307	1.000				
Caregiver measure									
6. Somatic symptoms	-0.114	-0.180	0.095	0.368	0.065	1.000			
7. Anxiety and insomnia	0.027	-0.100	-0.077	0.544**	0.087	0.652**	1.000		
8. Perceived difficulties due to patient behavioural disturbances	0.353	0.414	-0.178	0.440	0.485	0.159	0.527	1.000	
9. Caregiver burden (J-ZBI)	0.058	0.176	-0.287	0.774*	0.450	0.449	0.641**	0.413	1.000

Spearman's rank order coefficient;

\**p* < 0.01; \*\**p* < 0.05.

Table 4. Correlations between patient and caregiver variables in the LOD group (*n* = 54)

	1	2	3	4	5	6	7	8	9
1. Patient age	1.000								
2. Caregiver age	-0.021	1.000							
Patient measure									
3. Cognitive function (MMSE)	-0.104	0.041	1.000						
4. Behavioural disturbances (NPI)	0.076	-0.181	-0.219	1.000					
5. Severity of dementia (CDR)	0.130	-0.105	-0.678*	0.535*	1.000				
Caregiver measure									
6. Somatic symptoms	0.332**	-0.153	0.056	0.315**	0.264	1.000			
7. Anxiety and insomnia	0.248	-0.123	-0.140	0.488*	0.396*	0.760*	1.000		
8. Perceived difficulties due to patient behavioural disturbances	0.224	-0.167	-0.253	0.572*	0.523*	0.355**	0.366*	1.000	
9. Caregiver burden (J-ZBI)	0.138	-0.147	-0.189	0.630*	0.576*	0.583*	0.735*	0.504*	1.000

Spearman's rank order coefficient;

\**p* < 0.01; \*\**p* < 0.05.

Table 5. ORs of the EOD and LOD groups associated with caregiver variables pertaining to health, perceived difficulties and caregiver burden

Caregiver measure	Model 1	Model 2		Model 3	
	Crude OR (95% CI)	Age-adjusted OR* (95% CI)	<i>p</i> -value for trend <sup>†</sup>	Age-/NPI-/CDR- adjusted OR** (95% CI)	<i>p</i> -value for trend <sup>†</sup>
Somatic symptoms	1.05 (0.92, 1.21)	1.17 (0.91, 1.62)	0.558	1.33 (0.95, 2.19)	0.731
Anxiety and insomnia	1.09 (0.96, 1.25)	1.24 (0.94, 1.80)	0.112	2.18 (1.06, 9.98)	0.182
Perceived difficulties due to patient behavioural disturbances	1.05 (0.99, 1.14)	1.22 (1.03, 1.68)	0.062	1.29 (1.05, 2.06)	0.041
Caregiver burden (J-ZBI)	1.00 (0.97, 1.04)	1.05 (0.97, 1.15)	0.669	1.08 (0.98, 1.25)	0.731

\*Adjusted for patient age by a logistic regression model.

\*\*Adjusted for patient age, and CDR and NPI scores by a logistic regression model.

<sup>†</sup>*p*-value for trend calculated by the Mantel extension method using categorized variables.

address caregiving needs and to promote social networking. Recent community-based studies have supported the notion that relatively few services are available for EOD patients and their family caregivers (Freyne *et al.*, 1999; Chaston *et al.*, 2004; Coombes *et al.*, 2004). Moreover, it has been suggested that poor provision of care services could prolong the duration of caregiving, consequently leading to the isolation of caregivers of EOD patients. It is therefore essential that additional resources should be allocated to sufferers of EOD, in order to allow family caregivers to better cope with the difficulties caused by patient behavioural problems and to develop more appropriate formal and informal sources of social support.

A couple of limitations to the present study should be noted. First, the small sample size made it difficult

to generalize the findings. Second, patient age at first visit to the hospital was used to distinguish EOD patients from LOD patients. This cut-off point remains possible that misclassification could induce bias into the results. Third, as the present study focused on one time point of a long disease trajectory, further investigation will be needed to assess whether the clinical features of the EOD and LOD patients progress differently over a longer time span.

Despite these considerations, our study has several strengths. First, it is one of only a few studies to compare the psychosocial effects of the onset of dementia on patients and their family caregivers. Second, we found a significant difference in the perceived difficulties caused by patient behavioural disturbances in the caregivers of the two groups. Overall, our findings provide valuable insights that could be used to improve the current services for EOD patients and their family caregivers. We strongly believe that improved knowledge will enhance public awareness, and promote more accessible care services, which will benefit both EOD patients and their caregivers.

#### CONFLICT OF INTEREST

None.

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#### KEY POINTS

- Previous reports have indicated the shortage of service provision for patients with EOD and their family caregivers. However, relatively few studies have compared the psychosocial effects of differences in the onset of dementia on patients.
- The caregivers of EOD patients in the present study had greater perceived difficulties due to patient behavioural disturbances than did the caregivers of LOD patients, although patients with EOD and LOD did not show differences in their clinical features.
- Additional resources, such as care services, should be provided for sufferers of EOD, in order to allow family caregivers to cope with difficulties associated with patient behavioural problems.

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RESEARCH LETTER

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## Factors related to institutionalization among disabled older people; a two-year longitudinal study

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### INTRODUCTION

Nursing home placement among disabled older people means discontinuing home care provision by family caregivers. Care recipient factors related to their institutionalization, such as activities of daily living (ADL), instrumental activities of daily living (IADL) and some medical conditions have been well examined in previous studies (e.g. Andel *et al.*, 2007). By contrast, caregiver factors (e.g. caregiver burden, care recipient-caregiver kinship) with respect to institutionalization have not been well examined. However, such caregiver factors need the same level of investigation as has been given to care recipient factors (e.g. Oura *et al.*, 2006).

In addition, concern about potentially harmful behaviors (PHB) by family caregivers that affect disabled older people (Williamson *et al.*, 2001; Beach *et al.*, 2005) or mistreatment of disabled older people has been increasing. Such a caregiver factor needs to be included in order to help identify those factors related to institutionalization among disabled older people.

The authors recently reported factors related to PHB towards disabled older people in a cross-

sectional study (Sasaki *et al.*, 2007). The present study is a two-year follow-up study. This longitudinal study aimed to identify factors related to institutionalization among community-dwelling disabled older people.

### METHODS

Four hundred and twelve pairs of community-dwelling disabled older adults who used visiting nursing services under the public Long-Term Care insurance system in Japan and their co-residing family caregivers participated in the study. The present study was approved by the Ethical Committee of the National Institute for Longevity Sciences.

At Time 1, the family caregivers were asked to provide the following information: PHB towards their older family adults; family caregiver burden; care recipient-caregiver kinship; age and sex; behavioral disturbances and cognitive impairment of their older adults. In addition, visiting nurses obtained the following information regarding the older adults: severity of dementia; severity of physical impairment; vision problems; hearing problems; age and sex. The details of the survey and the characteristics of the subjects have been described elsewhere (Sasaki *et al.*, 2007).

At Time 2 (two years later), care recipients' subsequent institutionalization was identified from nursing documentation.

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Data from the 398 pairs of disabled older adults and their caregivers were subjected to analyses. The factors at Time 1 related to institutionalization at Time 2 among disabled older people were examined by  $\chi^2$  tests. Subsequently, the relative risk (RR) and its 95% confidential interval (95%CI) were calculated.

## RESULTS

At Time 2, 6.8% ( $n=27$ ) of the older people were institutionalized and 52.5% ( $n=209$ ) remained in their own home (with or without their caregiver). Table 1 compares the following two groups regarding the variables concerned; those who had remained in their own home and those who had been institutionalized after the survey at Time 1. Among the variables concerned, PHB by family caregiver at Time 1 was the only factor that was related to institutionalization of the disabled older adult at Time 2 ( $\chi^2=4.31$ ,  $RR=2.43$ ,  $95\%CI=1.02-5.78$ ). The other variables at Time 1 had no correlations with institutionalization among disabled older people.

## DISCUSSION

In the present study, PHB towards disabled older people by family caregivers at the previous time

point was the only factor associated with institutionalization among disabled older people at the follow-up. It was suggested that detection of PHB by family caregivers is a warning sign for future nursing home placement for disabled older people. In order to assist disabled older people to remain in their own homes, it is necessary to provide interventions that will help prevent family caregivers from engaging in PHB.

In our previous study (Sasaki *et al.*, 2007), behavioral disturbances of older people and an adult child as the caregiver have been found to be associated with PHB towards disabled older people. Thus, these two factors should be taken into account in order to prevent PHB from family caregivers; thereby delaying institutionalization among community-residing disabled older people.

## CONFLICT OF INTEREST

None.

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Table 1. Comparisons between institutionalized disabled older people and those remaining in their own home

	Remaining in home	Institutionalized	$\chi^2$	p
<b>Care recipients</b>				
Sex (Female vs Male)	130 vs 79 $n=209$	16 vs 11 $n=27$	0.088	0.834
Age (Years) (-80 vs 81+)	108 vs 101 $n=209$	11 vs 16 $n=27$	1.144	0.312
Behavioral disturbance (TBS) (0 vs 1+)	89 vs 41 $n=130$	9 vs 8 $n=17$	1.630	0.273
Severity of dementia (no problem, I, II vs III, IV, M)	141 vs 63 $n=204$	18 vs 9 $n=27$	0.067	0.826
Severity of physical impairment (no problem, J, A vs B, C)	88 vs 116 $n=204$	13 vs 14 $n=27$	0.243	0.682
Cognitive impairment (SMQ) (-39 vs 40+)	120 vs 16 $n=136$	18 vs 3 $n=21$	0.109	1.000
Hearing problems (0 vs 1)	143 vs 52 $n=195$	18 vs 8 $n=26$	0.195	0.815
Vision problems (0 vs 1)	149 vs 43 $n=192$	19 vs 7 $n=26$	0.266	0.622
<b>Caregivers</b>				
Sex (Female vs Male)	165 vs 44 $n=209$	21 vs 6 $n=27$	0.020	1.000
Age (Years) (-62 vs 63+)	106 vs 102 $n=208$	9 vs 18 $n=27$	2.972	0.103
Hours of caregiving/day (-5.9 vs 6+)	75 vs 98 $n=173$	10 vs 10 $n=20$	0.321	0.638
Duration of caregiving (year) (-3.9 vs 4+)	91 vs 109 $n=200$	15 vs 11 $n=26$	1.373	0.298
Hours caregivers can be relieved/day (-1.9 vs 2+)	74 vs 118 $n=192$	11 vs 14 $n=25$	0.277	0.665
Spouse as caregiver (no vs yes)	120 vs 89 $n=209$	15 vs 12 $n=27$	0.034	1.000
Adult child as caregiver (no vs yes)	136 vs 73 $n=209$	19 vs 8 $n=27$	0.298	0.671
Daughter-in-law as caregiver (no vs yes)	168 vs 41 $n=209$	21 vs 6 $n=27$	0.102	0.798
Caregiver burden (J-ZBI) (-27 vs 28+)	79 vs 93 $n=172$	8 vs 13 $n=21$	0.464	0.643
Potentially harmful behaviors (0 vs 1+)	123 vs 63 $n=186$	8 vs 11 $n=19$	4.313	0.046

The details of the dichotomization for the above variables have been described elsewhere (Sasaki *et al.*, 2007).

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## Factors related to potentially harmful behaviors towards disabled older people by family caregivers in Japan

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### SUMMARY

**Objective** The purpose of the present study was to examine factors related to potentially harmful behaviors (PHB) by family caregivers towards their older family members.

**Methods** Four hundred and twelve pairs of disabled older adults and their family caregivers participated in the study. All of these disabled older adults were users of visiting nursing services under the public Long-Term Care insurance system, who resided in one of the eight catchment areas of visiting nursing services in Kyoto Prefecture, Japan. The caregivers were asked to complete questionnaires in relation to their PHB towards their older family members, caregiver burden, patient-caregiver kinship, behavioral disturbances of their older adult, age and sex. Visiting nurses obtained the following information regarding the older adults: the severity of dementia; the severity of physical impairment; age and sex.

**Results** More than 30% of the caregivers admitted PHB towards their older family members. The most frequently reported PHB included verbal aggression (16.8%) and ignoring (13.6%). A logistic regression analysis revealed that adult children (OR = 2.69, 95%CI = 1.23–5.89,  $p = 0.013$ ) and caregivers of disabled older people with behavioral disturbances (OR = 3.61, 95%CI = 1.65–7.90,  $p < 0.01$ ) were more likely to show PHB.

**Conclusions** In the present study, PHB towards the older people by family caregivers was associated with patients' behavioral disturbances and patient-caregiver kinship, i.e. an adult child as a caregiver. These findings should be taken into account when planning strategies to prevent PHB by family members. Copyright © 2006 John Wiley & Sons, Ltd.

**KEY WORDS** — potentially harmful behaviors; behavioral disturbances; patient-caregiver kinship; adult child; caregiver burden

### INTRODUCTION

Recently, concern about elder abuse or mistreatment by informal family caregivers has been increasing (Lachs *et al.*, 1998; Mosqueda *et al.*, 2004). Lachs and Pillemer (2004) reviewed reports on elder abuse and indicated that it is regularly encountered in daily clinical practice. Moreover, elder mistreatment was found to be associated with shorter survival in the elderly (Lachs *et al.*, 1998). In order to prevent elder abuse, in the United States, provision for prevention of

abuse, neglect and exploitation was established in the amended Older Americans Act in 1992. Also in the United Kingdom, the Protection of Vulnerable Adults scheme, as set out in the Care Standards Act 2000, has been implemented since 2004. Moreover, in Japan, the Protection of Vulnerable Adults Law was passed in the diet and took force in April of 2006. Indeed, the prevention of elder abuse is a world-wide issue.

Various kinds of risk factors have been investigated regarding elder abuse. As for patient factors, Bredthauer *et al.* (2005) showed that patients with low cognitive status, serious mobility impairments, and inability to perform ADL activities were at very high risk of being physically restrained. It was also indicated that greater care recipient ADL/IADL needs were a predictor of potentially harmful behaviors (Beach *et al.*, 2005) and that cognitive impairment

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(Lachs *et al.*, 1997) was a predictor of abuse and neglect by family caregivers. From these findings, severity of patient impairment seems to be one of the important risk factors for potentially harmful behaviors, abuse, and neglect by family caregivers. In addition, behavioral disturbance has been found as a predictor of patient institutionalization (Asada *et al.*, 2000) and elder abuse (Compton *et al.*, 1997; Bredthauer *et al.*, 2005). Coen *et al.* (1997) and Arai *et al.* (1999, 2004) also indicated that behavioral disturbance is one of the predictors of caregiver burden. These findings have suggested that behavioral disturbance in disabled older people may be an important risk factor for burden and abuse in caregivers.

As for caregiver factors, Steinmetz (1988) suggested that caregivers with more burden tend to abuse. Moreover, the patient-caregiver kinship was examined as a possible predictor of potentially harmful behaviors. Beach *et al.* (2005) suggested that spouse caregivers were more prone to conduct potentially harmful behaviors, while Coen *et al.* (1997) found that daughters were especially prone to burden. On the other hand, Fulmer *et al.* (2005) showed that patient-caregiver kinship was not associated with elder neglect. Since the above-mentioned findings are inconsistent, it is necessary to examine whether there is a specific patient-caregiver kinship in which elder abuse is likely to occur.

In Japan, the proportion of adult child as caregiver is as high as that of spouse as caregiver and daughter-in-law as caregiver (i.e. approximately 20% according to the Ministry of Health, Labour and Welfare, 2004). Thus, the various kinship relations between patients and their caregivers should be taken into account in investigations on elder abuse in Japan.

In previous studies, diverse terms such as abuse, mistreatment, and potentially harmful behaviors were employed to imply abusive behaviors. Among them, Williamson *et al.* (2001) and Beach *et al.* (2005) focused on potentially harmful behaviors by family caregivers, which were defined as behaviors detrimental to the physical and psychological well-being in disabled older people but not necessarily severely abusive. Williamson *et al.* (2001) included the following five physically-related items of potentially harmful behaviors: withholding food; hitting or slapping; shaking; handling roughly in other ways; and making them afraid of being hit or hurt. The following five items were included as the psychological items: screaming and yelling; threatening with nursing home placement; threatening to use physical

force or threatening to abandon; using a harsh tone of voice; insulting; calling names; and swearing at him/her. Beach *et al.* (2005) regarded potentially harmful behaviors as an 'early warning sign' to full-blown elder abuse and suggested that its assessment may be amenable to preventive intervention efforts. Following Williamson *et al.* (2001) and Beach *et al.* (2005), we take the term 'potentially harmful behaviors' to mean potential detrimental behaviors by a family caregiver including physical and psychological components. In a preventive perspective, the detection of potentially harmful behaviors will provide valuable information as a warning sign of more serious elder abuse.

Because of lack of comprehensive investigations on risk factors including patient-caregiver kinship for harmful behaviors, the present study examined the patient factors (e.g. behavioral disturbance and physical or cognitive function), caregiver factors (e.g. caregiver burden), patient-caregiver kinship, and other demographic variables to identify factors related to potentially harmful behaviors on the part of family caregivers.

## METHODS

### *Subjects*

The present study was conducted in one of eight catchment areas of visiting nursing services in Kyoto Prefecture, Japan. There are 14 visiting nursing service agencies in this catchment (population, approximately 300,000), which covers Uji City, Jyoyou City, and Kumiyama Town. All of these 14 visiting nursing service agencies agreed to participate in the study and identified all 589 older adults, who used visiting nursing services under the public Long-Term Care insurance system. Subsequently, a principle family caregiver of each older adult was identified. This survey was conducted on these 589 pairs of older adults and his/her caregivers. Among these caregivers, 412 caregivers (70.0%) participated in the study and responded to a set of self-administered questionnaires. The inclusion criteria of the caregivers were: (1) principle caregiver of an older adult; (2) family caregiver of the older adult; and (3) living together with the older adult. Three hundred and ninety-eight pairs of disabled older people and caregivers (67.6%) met these criteria, and data from these pairs were subjected to further analyses. Written informed consent was obtained from all subjects. This study was endorsed by the ethical committee of the National Institute for Longevity Sciences.

### Measures

In the present study, the following variables were assessed.

For the older people, the frequency of behavioral disturbances and severity of cognitive impairment were assessed by the caregivers. The frequency of behavioral disturbances observed by the primary caregiver was assessed using the Troublesome Behavior Scale (TBS; Asada *et al.*, 1994, 1999), which is designed to quantify the specific observable behavior usually associated with dementia. This scale consists of 14 items and the scoring range is 0–56 points. Cronbach's  $\alpha$  coefficient of the scale in this study was 0.80. Cognitive impairment of the elderly was assessed with the Japanese version of the Short Memory Questionnaire (SMQ; Maki *et al.*, 1998, 2000), which was developed as an objective tool for the assessment of memory difficulties of dementia in a Japanese population. The SMQ consists of 14 items concerning everyday memory problems; the scoring range is 4–46 points. A score of less than 40 is suggestive of dementia. Cronbach's  $\alpha$  coefficient of the scale in this study was 0.90.

The severity of dementia, the severity of physical impairment, problems in hearing, and problems in vision of the older people were assessed by the visiting nurses. The severity of dementia was assessed by the nurses using the following criteria developed by the Ministry of Health and Welfare (MHW) (1993); the severity of dementia was rated from I (very mild) to IV (very severe), and M was defined as 'very severe with extremely behavior disturbance'. The MHW suggested that those who were rated I or II were relatively easy to care for at home, albeit having dementia, and hence we used this classification [not severe (I and II) vs severe (III, IV, and M)] for the statistical analyses in the present study. The severity of physical impairment was assessed by the nurses using the following criteria developed by the MHW (1991); rating the severity of physical impairment from J (very mild) to C (very severe). The Ministry criteria suggested that those rated J or A were relatively easy to care for at home, and hence we used this classification [not severe (J and A) vs severe (B and C)] for the statistical analyses. These indexes developed by the MHW are often used by home care professionals in Japan. In addition, the hearing and vision problems of the older people were assessed by the visiting nurses.

For the caregivers, the relationship to the disabled older people was assessed; spouse as caregiver, adult child as caregiver, and daughter-in-law as caregiver.

The Japanese version of the Zarit Burden Interview (J-ZBI; Arai *et al.*, 1997) was also included to assess caregiver burden. This questionnaire is a 22-item self-report inventory that has been widely used in Japan. The original version of the ZBI is one of the most common scales used in North America and European countries for assessing the burden of caregiving (Zarit and Zarit, 1990). A short version of the J-ZBI (J-ZBI\_8) has recently been released (Arai *et al.*, 2003; Kumamoto and Arai, 2004; Kumamoto *et al.*, 2004). Cronbach's  $\alpha$  coefficient of J-ZBI in this study was 0.93.

The potentially harmful behaviors by the family caregivers were assessed using a checklist developed by Ueda (2000). This checklist was similar to the one developed by Williamson and Shaffer (2001). The caregivers' self-report checklist includes nine items; ignoring, leaving alone, verbal aggression, neglecting to care, slapping or pinching, restriction to their bedroom, physical restriction, deprivation of health services, and deprivation of money. Caregivers were asked to indicate how many kinds of behavior listed in the checklist (see Table 2) they had engaged in during the previous six months.

Caregivers were also asked to indicate how many hours per day they provided care for their older family members as well as how many years they had cared for him or her. They were also asked to estimate the number of hours per day they were able to be temporarily relieved of their duties or to leave the side of their older family members to go out.

### Analyses

First, pairs of disabled older adults and caregivers were divided into two groups; caregivers who had engaged in at least one of the potentially harmful behaviors and those who had not.

Second, continuous variables except for behavioral disturbance (TBS) and cognitive impairment (SMQ) were dichotomized based on the median. The variable of behavioral disturbance (TBS) was dichotomized based on a score of zero or more than 1, while for cognitive impairment (SMQ), a score of less than 40 was used since it is suggestive of dementia for the dichotomization. The details of the dichotomization for all variables were presented in Table 3. Then, a  $\chi^2$  test was conducted to determine differences between the two groups.

Third, Spearman's rank correlation tests were conducted on the variables found to be statistically significant in the univariate analysis.

Finally, a multiple logistic regression analysis was employed to determine which of the explanatory

Table 1. Characteristics of subjects ( $n = 398$ )

	n (%)	Mean (SD)
<b>Patients</b>		
<b>Sex</b>		
Male	159 (39.9)	
Female	239 (60.1)	
Age		80.5 (9.2)
Behavioral disturbance (TBS) ( $n = 327$ )		3.2 (5.4)
<b>Severity of dementia (<math>n = 386</math>)</b>		
No problem	89 (23.1)	
I	98 (25.4)	
II	94 (24.4)	
III	51 (13.2)	
IV	42 (10.9)	
M	12 (3.1)	
<b>Severity of physical impairment (<math>n = 387</math>)</b>		
No problem	4 (1.0)	
J	29 (7.5)	
A	143 (37.0)	
B	118 (30.5)	
C	93 (24.0)	
Cognitive impairment (SMQ) ( $n = 261$ )		15.06 (13.92)
Hearing problems ( $n = 373$ )	108 (29.0)	
Vision problems ( $n = 371$ )	91 (24.5)	
<b>Caregivers</b>		
<b>Sex</b>		
Male	86 (21.6)	
Female	312 (78.4)	
Age ( $n = 396$ )		63.4 (11.4)
Hours of caregiving/day ( $n = 326$ )		9.40 (7.69)
Duration of caregiving (year) ( $n = 384$ )		5.58 (5.54)
Hours caregivers can be relieved/day ( $n = 362$ )		2.90 (2.90)
Spouse as caregiver	176 (44.2)	
Adult child as caregiver	134 (33.7)	
Daughter-in-law as caregiver	77 (19.3)	
Caregiver burden ( $n = 329$ )		31.36 (17.03)
<b>Potentially harmful behaviors (<math>n = 341</math>)</b>		
Caregivers with at least a kind of potentially harmful behavior	119 (34.9)	
Caregivers with no potentially harmful behavior	222 (65.1)	

variables was significantly related to the caregivers' experience of the potentially harmful behaviors to their older family member. The odds ratio (OR) and the 95% confidence interval (CI) were calculated for each factor.

The criterion for statistical significance was a  $p$ -value less than 0.05 for all analyses.

The Statistical Package for Social Science for Windows (version 12.0J, SPSS, Inc.) was used for the above analyses.

## RESULTS

### *Characteristics of subjects*

Table 1 shows the characteristics of the subjects in the present study. The mean age of the disabled older

people was 80.5 (SD 9.2) years, and 60.1% were female. The mean age of the caregivers was 63.4 (SD 11.4) years, and 78.4% were female.

Among caregivers who responded to the question concerning the potentially harmful behaviors, 119 (34.9%) reported that they had engaged in at least one of the potentially harmful behaviors in the checklist. Table 2 presented the percentage of each potentially harmful behavior by family caregivers. The most frequently reported behaviors were verbal aggression (16.8%) and ignoring (13.6%). Of 119 caregivers who reported that they had mistreated the elderly, 81 (68.1%) had engaged in one such behavior, 29 (24.4%) in two behaviors, eight (6.7%) in three behaviors, and one (0.8%) in four behaviors.

Table 3 compares the following two groups regarding the variables concerned; those who had

Table 2. Potentially harmful behavior by family caregivers

	<i>n</i> (%)
Ignoring	54 (13.6)
Leaving alone	13 (3.3)
Verbal aggression	67 (16.8)
Neglecting to care	11 (2.8)
Slapping, pinching, or kicking	18 (4.5)
Restricted to bedroom	2 (0.5)
Physical restriction	0 (0.0)
Deprivation of health services	1 (0.3)
Deprivation of money	1 (0.3)

engaged in at least one type of potentially harmful behavior and those who had not. The following five variables were significantly different between the two groups: the proportion of the disabled older people who had behavioral disturbance; the proportion of those with more severe (level B or C) physical impairment; the proportion of those with hearing problems; the proportion of adult child caregivers; and the proportion of caregivers who felt highly burdened.

Table 4 presents the Spearman's rank correlations between the above four variables. First, the existence of potentially harmful behaviors was correlated with the older people having behavioral disturbances ( $\rho = 0.30$ ,  $p < 0.01$ ), the severity of physical impairment ( $\rho = -0.13$ ,  $p < 0.05$ ), hearing problems ( $\rho = 0.12$ ,  $p < 0.05$ ), adult child as caregiver ( $\rho = 0.11$ ,  $p < 0.05$ ), and caregiver burden ( $\rho = 0.20$ ,

$p < 0.01$ ). Since the correlation between those with hearing problems and adult child as caregiver was significant but too weak to cause multicollinearity, these variables were also included in the following analysis.

A logistic regression analysis was employed to determine which of the following five variables were significantly related to the potentially harmful behaviors: behavioral disturbance (0 vs 1); severity of physical impairment (no problem, J, A vs B, C); problems in hearing (0 vs 1); adult child as caregiver (no vs yes); and caregiver burden (J-ZBI score 27 and less vs 28 and more). As shown in Table 5, two of these variables proved to be significant factors related to the potentially harmful behaviors: behavioral disturbance and adult child as caregiver. Family caregivers who looked after their older family members with behavioral disturbances were more likely to show potentially harmful behaviors towards them (OR = 3.61, 95% CI = 1.65–7.90,  $p < 0.01$ ). Adult child as caregiver also tended to engage in them (OR = 2.69, 95% CI = 1.23–5.89,  $p = 0.013$ ).

## DISCUSSION

The present study showed that 34.9% of the caregivers had engaged in potentially harmful behaviors towards their older family members. Similar results were obtained in the previous studies using the same checklist, 32.4% in Ueda's (2000) study and 34.9% in

Table 3. Comparisons between caregivers with at least one type of potentially harmful behavior and those with none

	Caregivers with no potentially harmful behavior	Caregivers with at least one type of potentially harmful behavior	$\chi^2$	<i>p</i>
<b>Patients</b>				
Sex (Female vs Male)	134 vs 88 <i>n</i> = 222	74 vs 45 <i>n</i> = 119	0.11	0.816
Age (Years) (-80 vs 81+)	112 vs 110 <i>n</i> = 222	54 vs 65 <i>n</i> = 119	0.80	0.426
Behavioral disturbance (0 vs 1+)	127 vs 35 <i>n</i> = 162	27 vs 30 <i>n</i> = 57	19.45	<0.001
Severity of dementia (no problem, I, II vs III, IV, M)	159 vs 60 <i>n</i> = 219	82 vs 29 <i>n</i> = 111	0.06	0.896
Severity of physical impairment (no problem, J, A vs B, C)	89 vs 130 <i>n</i> = 219	61 vs 51 <i>n</i> = 112	5.72	0.020
Cognitive impairment (SMQ) (-39 vs 40+)	130 vs 17 <i>n</i> = 147	78 vs 4 <i>n</i> = 82	2.83	0.101
Hearing problems (0 vs 1)	155 vs 54 <i>n</i> = 209	69 vs 41 <i>n</i> = 110	4.51	0.039
Vision problems (0 vs 1)	161 vs 45 <i>n</i> = 206	81 vs 30 <i>n</i> = 111	1.07	0.333
<b>Caregivers</b>				
Sex (Female vs Male)	174 vs 48 <i>n</i> = 222	92 vs 27 <i>n</i> = 119	0.05	0.891
Age (Years) (-62 vs 63+)	117 vs 104 <i>n</i> = 221	59 vs 60 <i>n</i> = 119	0.35	0.571
Hours of caregiving/day (-5.9 vs 6+)	84 vs 103 <i>n</i> = 187	45 vs 52 <i>n</i> = 97	0.06	0.900
Duration of caregiving /year (-3.9 vs 4+)	110 vs 108 <i>n</i> = 218	59 vs 56 <i>n</i> = 115	0.02	0.909
Hours caregivers can be relieved/day (-1.9 vs 2+)	78 vs 122 <i>n</i> = 200	36 vs 78 <i>n</i> = 114	1.73	0.223
Spouse as caregiver (no vs yes)	126 vs 96 <i>n</i> = 222	71 vs 48 <i>n</i> = 119	0.27	0.646
Adult child as caregiver (no vs yes)	154 vs 68 <i>n</i> = 222	69 vs 50 <i>n</i> = 119	4.44	0.042
Daughter-in-law as caregiver (no vs yes)	171 vs 51 <i>n</i> = 222	101 vs 18 <i>n</i> = 119	2.96	0.091
Caregiver burden (-27 vs 28+)	105 vs 92 <i>n</i> = 197	31 vs 66 <i>n</i> = 97	11.91	0.001



Table 4. Correlations between potentially harmful behaviors, behavioral disturbances, severity of impairment, hearing problems, adult child as caregiver, and caregiver burden

	Potentially harmful behaviors	Behavioral disturbances	Severity of physical impairment	Hearing problems	Adult child as caregiver
Behavioral disturbances	0.30**				
Severity of physical impairment	-0.13*	-0.11			
Hearing problems	0.12*	0.10	-0.07		
Adult child as caregiver	0.11*	0.07	-0.04	0.11*	
Caregiver burden	0.20**	0.10	0.05	0.05	-0.07

\* $p < 0.05$ .\*\* $p < 0.01$ .

a study conducted by Kumamoto *et al.* (2004) in Japan. As indicated in Table 2, ignoring and verbal aggression were frequent. It would be difficult for home care professionals to detect the above-mentioned behaviors such as ignoring and verbal aggression on their visits for the following two reasons. First, unlike physical abuse, ignoring and verbal aggression would not leave any traces of abuse on the abused older people. Second, such behavior is often covert. Therefore, self-reports either by the older people or family caregivers may provide more information than observations by home care professionals on their visits. However, self-reports by the older people may not be reliable if they suffer from severe dementia. In the present study, we used self-reports by family caregivers, which may have more reliable and detailed information on potentially harmful behaviors, even if their self-reports may have a response bias regarding more implicit behaviors such as ignoring and verbal aggression. Thus, health professionals should routinely assess potentially harmful behaviors through self-reports by caregivers in order to detect the person and kind of potentially harmful behavior for preventive intervention.

Behavioral disturbance of the older people was identified as a factor related to potentially harmful behaviors. This finding is consistent with a previous study which presented a significant relation between the behavioral disturbance of the older people and abuse by caregivers (Compton *et al.*, 1997). Many

studies revealed that behavioral disturbance correlates to caregiver burden, after other confounding factors are statistically controlled, regardless of the sample characteristics and the place of study (Coen *et al.*, 1997; Arai *et al.*, 1999, 2004). Indeed, coping with behavioral disturbances is one of the most demanding tasks for caregivers, as Coen *et al.* (1997) and Arai *et al.* (2004) also suggested. The present study supports the previous findings.

In order to prevent potentially harmful behaviors of caregivers, it is necessary to provide interventions on behavioral disturbances to both older people and caregivers. As pharmacological interventions for older people with behavioral disturbances, typical/atypical antipsychotic medications or antidepressants is often used in clinical settings. However, typical/atypical antipsychotic medications should be provided with caution due to the fact that these would be expected to increase the risk of death in older people (e.g. Wang *et al.*, 2005). Clinicians may also provide pharmacological interventions to caregivers if necessary (e.g. those depressed because of the behavioral disturbances of older people they look after).

Regarding non-pharmacological interventions, Haupt *et al.* (2000) reported that psychoeducative group intervention with caregivers alleviated agitation and anxiety of demented older people. Moreover, Burgio *et al.* (2003) indicated that African-American caregivers' appraisal of the behavioral disturbances as bothersome was decreased by cognitive-behavioral

Table 5. Factors related to potentially harmful behaviors by family caregivers

Variables	Odds ratio	95% Confidence intervals	<i>p</i>
Behavioral disturbance (0 vs 1+)	3.61	1.65–7.90	0.001
Severity of physical impairment (no problem, J, A vs B, C)	1.11	0.50–2.46	0.794
Hearing problems (0 vs 1)	1.34	0.58–3.11	0.491
Adult child as caregiver (no vs yes)	2.69	1.23–5.89	0.013
Caregiver burden (-27 vs 28+)	1.67	0.76–3.67	0.205

skills training. They also showed that white caregivers' appraisal of the behavioral disturbances as bothersome was decreased by telephone support. These pharmacological and non-pharmacological interventions for behavioral disturbances may lead to the preventions of potentially harmful behaviors by family caregivers.

Another factor related to potentially harmful caregiver behaviors was patient-caregiver kinship, especially adult child as caregiver. Studies in the USA suggested that spouse caregivers were more likely to engage in potentially harmful caregiver behaviors (Beach *et al.*, 2005) or that the patient-caregiver kinship was not associated with neglect (Fulmer *et al.*, 2005). In the present study on Japanese people, adult child as caregiver was identified as a factor related to potentially harmful behaviors. The process in which being an adult child as a caregiver increases the risk for potentially harmful behaviors is still unclear. Strawbridge *et al.* (1991) indicated that relationship quality with the parent had both a direct effect on caregiver burden and an indirect one through family conflict. It would be useful to include the quality of patient-caregiver relationship as well as in future studies in order to clarify the underlying process of potentially harmful behaviors.

A limitation of our study is that we were unable to confirm whether the two factors identified in the present study actually cause potentially harmful behaviors due to the methodological limitation attached to cross-sectional studies.

Nonetheless, our study has the following strengths. It is one of the few studies conducted in a community setting in Japan in order to investigate factors related to potentially harmful behaviors towards the older people by using a self-report by family caregivers.

Second, we investigated various types of patient-caregiver kinship (i.e. spouse, daughter-in-law, and adult child) in order to identify factors related to potentially harmful behaviors. As mentioned in the Introduction, the proportion of each kind of kinship is almost equal among Japanese people (Ministry of Health, Labour and Welfare, 2004). However, adult child as caregiver was the only kinship which was found to be a factor in Japanese family caregivers. It may be useful to include various types of patient-caregiver kinship in the investigation of risk factors of potentially harmful behaviors.

Lastly, this study can be regarded as a comprehensive investigation of the factors related to potentially harmful behaviors including the demographic data of the older people and caregivers, behavioral disturbances and cognitive impairment in the older people,

caregiver burden in the family caregivers, and patient-caregiver kinship. To our knowledge, such a comprehensive investigation has been rarely undertaken.

In conclusion, our study revealed that behavioral disturbances in disabled older people and adult child as caregiver were significant factors related to potentially harmful behaviors by informal family caregivers. These findings should be taken into account when planning preventive strategies for potential harmful behaviors by family members.

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# Frequency and Clinical Characteristics of Early-Onset Dementia in Consecutive Patients in a Memory Clinic

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## Key Words

Early-onset dementia · Alzheimer's disease · Frontotemporal lobar degeneration · Dementia with Lewy bodies · Memory clinic

## Abstract

**Aims:** To investigate the frequency, rate of causes of dementia, and clinical characteristics of early-onset dementia in consecutive patients of a memory clinic. **Methods:** A total of 668 consecutive demented patients were involved in this study. We examined the distribution of patients' diagnosis, differences in sex, education, dementia severity and cognitive function at the first visit, and the duration from onset to consultation. We also examined the changes in the proportion of subjects during the research period. **Results:** There were 185 early-onset patients, 28% of all demented patients. No significant differences were observed between the early-onset and late-onset dementia groups in Clinical Dementia Rating and Mini-Mental State Examination score at the first consultation, but the duration from onset to consultation was significantly longer in the early-onset group. In the early-onset group, the rates of patients with Alzheimer's disease and dementia with Lewy bodies were relatively low and the rate of patients with frontotemporal lobar degeneration was

relatively high. There were no significant differences in the proportion between either demented subjects and nondemented subjects or early-onset dementia patients and late-onset dementia patients during the research period. **Conclusion:** We conclude that early-onset dementia is not rare and its clinical characteristics and causes are different from late-onset dementia.

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## Introduction

Early-onset dementia (EOD), with onset in those younger than 65 years, has a large psychological and economical impact on patients and caregivers because of their leading role in the society and family at the disease onset. However, EOD has been underrecognized until today and social support services for EOD patients are not enough compared with those for late-onset dementia (LOD) patients.

Although there are some studies about early-onset Alzheimer's disease (AD) [1–3], there are few systematic studies about cognitive function in and clinical features of EOD of the non-Alzheimer type [4, 5]. Further, epidemiologic data on relatively rare causes of dementia, in-

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