

Caregivers of patients with urinary incontinence have higher levels of stress and depression than those caring for people with other conditions, and incontinence leads to early institutionalization.³³⁻³⁵

Regarding IADL, deficits in handling domestic finances and transportation were common factors associated with CB in men and women. It is time-consuming and often stressful for caregivers to take over the financial responsibilities of the household.^{29,36} Non-compliance with medication in women would cause caregivers mental stress. Regarding BADL, dressing was a candidate factor for CB in AD patients with more severe cognitive dysfunction. AD patients might often refuse to be helped with personal care including changing their clothes, which causes stress to their caregivers.

In cognitive stage of AD17-12, BPSD, IADL and geriatric syndrome were also associated with CB. BPSD were worse and care burden became more severe. Regarding IADL, caregivers were annoyed with the patients' deficits in their own personal tasks, such as in the use of transportation (in men and women) and in self-medication (men). Deficit in handling finances was still shown to be an associated factor in women. This could have been related to a lack of awareness by patients of a deficit.³⁶ Patients who are unaware of functional deficits often overestimate their ability and believe they are capable of activities beyond their capabilities, which can cause problems and stress in caregivers. As comorbidity, falls indicate further deterioration of motor function, and fatigue might reflect and accelerate passiveness.

In AD11-0, prominent factors for CB were BPSD, including Motor aggressiveness and Behavior disturbance. The frequency of BPSD related to CB markedly increased at this stage. For instance, agitation is a symptom related to frontal lobe dysfunction, with a prevalence of nearly 50% in AD.^{37,38} It can be triggered by physical problems, such as pain and lack of sleep; psychiatric problems, such as anger, aggressiveness, anxiety and depression; environmental stresses, such as noisiness and inadequate temperature; and as a side-effect of medication. Agitation can also be a single determinant of early institutionalization.²⁵⁻²⁸

Although sleep disturbance and ringing in the ears could be associated with CB in this stage, the contribution of geriatric syndrome to CB was not obvious (Table 3). In this connection, it should be noted that participants in the present study were outpatients without serious physical complications. Alternatively, the increment of BPSD might have obscured the role of geriatric syndrome as a burden factor in the analysis with a relatively small number of participants ($n = 87$).

This study clearly indicated that various differential factors were cognitive stage-dependently associated with CB. It should be stressed that the higher prevalence of BPSD, geriatric syndrome and impairment of life

function in particular cognitive stages was not always a burden factor. For instance, symptoms of Behavior disturbance in AD29-24 were not as frequent as in AD11-0, but were factors responsible for CB. Urinary incontinence was markedly increased in cognitive stages of AD11-0, but was associated with CB even in AD23-18. It seems likely that caregivers are surprised and embarrassed by their first experience of problematic symptoms of dementia in patients who have moderate cognitive dysfunction. It is therefore important to know and predict these burden factors in advance. Second, even if certain factors showed an association with CB in one cognitive stage, they did not always remain burden factors in subsequent cognitive stages. Different activities of IADL were shown to be burden factors in particular cognitive stages.

The results of the present study suggested that prevention of BPSD and comorbidity of geriatric syndrome is an essential consideration in the management of AD. At the same time, life care support for deteriorated IADL should be considered even for patients belonging to AD29-24. Treatment of BPSD and comorbidity could be beneficial in ameliorating CB, as comorbidity can cause various BPSD, and BPSD increase the risk of geriatric syndrome, such as falls and muscle weakness, and vice versa. It was reported that half of BPSD were caused by comorbidity and medication; in AD, 23% of BPSD are caused by medication, 18.3% by comorbidity and 6.7% by a combination of the two.³⁹ It is well established that physical rehabilitation is effective for not only the prevention of falls/motor disturbance, but also improvement of mood, apathy and day-night reversal.

Previous studies have shown that individualized educational and support programs for caregivers are effective to ameliorate CB.^{40,41} Educational programs should provide prognostic information on the disease of dementia, as well as factors associated with CB. In this respect, the findings of the present study might be informative for caregiver education.

The present study had several limitations. It was a cross-sectional study. A second limitation was selection bias of the study participants, although the participants were composed of a large number of patients consecutively selected in the Medical Center for Dementia at the NCGG. All data were obtained from outpatients, and inpatients suffering from various physical complications, such as recurrent pneumonia and fractures, were not included. Finally, CB is comprised of multidimensional factors including patient factors, such as the severity of disease, premorbid characteristics, and financial and social status, caregiver factors, and other environmental factors, all of which are highly individualized.⁴² The present study mainly analyzed burden factors on the patients' side. To clarify the multifactorial mechanisms of CB, more detailed information on

demographics, socioeconomic conditions and use of several care services need to be analyzed. However, our observation provides important information on CB, which might reflect general attitudes of caregivers to demented older adults, when they first attended a medical center for consultation on dementia. Longitudinal follow-up studies of demented older adults with detailed information on CB are required.

Acknowledgements

This study was financially supported by grants from Choju (24–24), Japan's Ministry of Education, Culture, Sports, Science and Technology (22590654), and Japan's Ministry of Health, Labor and Welfare (H25-Ninchisho-008). We also thank the BioBank at NCGG for quality control of the clinical data.

Disclosure statement

The authors declare no conflict of interest.

References

- 1 American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington, DC: American Psychiatric Association, 2013.
- 2 Joling KJ, van Hout HP, Schellevis FG *et al.* Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. *Am J Geriatr Psychiatry* 2010; **18**: 146–153.
- 3 Wimo A, Jonsson L, Bond J, Prince M, Winblad B. The worldwide economic impact of dementia 2010. *Alzheimers Dement* 2013; **9**: 1–11.e3.
- 4 Epstein-Lubow G, Gaudiano B, Darling E *et al.* Differences in depression severity in family caregivers of hospitalized individuals with dementia and family caregivers of outpatients with dementia. *Am J Geriatr Psychiatry* 2012; **20**: 815–819.
- 5 Romero-Moreno R, Marquez-Gonzalez M, Mausbach BT, Losada A. Variables modulating depression in dementia caregivers: a longitudinal study. *Int Psychogeriatr* 2012; **24**: 1316–1324.
- 6 Norton MC, Smith KR, Ostbye T *et al.* Greater risk of dementia when spouse has dementia? The Cache County study. *J Am Geriatr Soc* 2010; **58**: 895–900.
- 7 Oken BS, Fonareva I, Wahbeh H. Stress-related cognitive dysfunction in dementia caregivers. *J Geriatr Psychiatry Neurol* 2011; **24**: 191–198.
- 8 Ankri J, Andrieu S, Beaufile B, Grand A, Henrard JC. Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. *Int J Geriatr Psychiatry* 2005; **20**: 254–260.
- 9 Ropacki SA, Jeste DV. Epidemiology of and risk factors for psychosis of Alzheimer's disease: a review of 55 studies published from 1990 to 2003. *Am J Psychiatry* 2005; **162**: 2022–2030.
- 10 Lopez OL, Becker JT, Sweet RA *et al.* Psychiatric symptoms vary with the severity of dementia in probable Alzheimer's disease. *J Neuropsychiatry Clin Neurosci* 2003; **15**: 346–353.
- 11 Richardson TJ, Lee SJ, Berg-Weger M, Grossberg GT. Caregiver health: health of caregivers of Alzheimer's and other dementia patients. *Curr Psychiatry Rep* 2013; **15** (7): 367.
- 12 Hebert R, Dubois MF, Wolfson C, Chambers L, Cohen C. Factors associated with long-term institutionalization of older people with dementia: data from the Canadian Study of Health and Aging. *J Gerontol A Biol Sci Med Sci* 2001; **56**: M693–M699.
- 13 Petersen RC, Doody R, Kurz A *et al.* Current concepts in mild cognitive impairment. *Arch Neurol* 2001; **58**: 1985–1992.
- 14 McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology* 1984; **34**: 939–944.
- 15 Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; **12**: 189–198.
- 16 Yesavage JA, Brink TL, Rose TL *et al.* Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res* 1982; **17**: 37–49.
- 17 Mahoney FI, Barthel DW. Functional evaluation: the barthel index. *Md State Med J* 1965; **14**: 61–65.
- 18 Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969; **9**: 179–186.
- 19 Baumgarten M, Becker R, Gauthier S. Validity and reliability of the dementia behavior disturbance scale. *J Am Geriatr Soc* 1990; **38**: 221–226.
- 20 Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; **20**: 649–655.
- 21 Brown PJ, Devanand DP, Liu X, Caccappolo E. Alzheimer's Disease Neuroimaging Initiative. Functional impairment in elderly patients with mild cognitive impairment and mild Alzheimer disease. *Arch Gen Psychiatry* 2011; **68**: 617–626.
- 22 Koyano W, Shibata H, Nakazato K, Haga H, Suyama Y. Measurement of competence: reliability and validity of the TMIG Index of Competence. *Arch Gerontol Geriatr* 1991; **13**: 103–116.
- 23 Nygård LSS. Telephone use among noninstitutionalized persons with dementia living alone: mapping out difficulties and response strategies. *Scand J Caring Sci* 2003; **17**: 239–249.
- 24 Youn JC, Lee DY, Jhoo JH, Kim KW, Choo IH, Woo JI. Prevalence of neuropsychiatric syndromes in Alzheimer's disease (AD). *Arch Gerontol Geriatr* 2011; **52**: 258–263.
- 25 Ferrara M, Langiano E, Di Brango T, De Vito E, Di Cioccio L, Baucò C. Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health Qual Life Outcomes* 2008; **6** (6): 93.
- 26 Hurt C, Bhattacharyya S, Burns A *et al.* Patient and caregiver perspectives of quality of life in dementia. An investigation of the relationship to behavioural and psychological symptoms in dementia. *Dement Geriatr Cogn Disord* 2008; **26**: 138–146.
- 27 Craig D, Mirakhur A, Hart DJ, McIlroy SP, Passmore AP. A cross-sectional study of neuropsychiatric symptoms in

- 435 patients with Alzheimer's disease. *Am J Geriatr Psychiatry* 2005; **13**: 460–468.
- 28 Matsumoto N, Ikeda M, Fukuhara R *et al*. Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community. *Dement Geriatr Cogn Disord* 2007; **23**: 219–224.
- 29 Razani J, Kakos B, Orieta-Barbalace C *et al*. Predicting caregiver burden from daily functional abilities of patients with mild dementia. *J Am Geriatr Soc* 2007; **55**: 1415–1420.
- 30 Boyle PA, Malloy PF. Treating apathy in Alzheimer's disease. *Dement Geriatr Cogn Disord* 2004; **17**: 91–99.
- 31 Levy R, Dubois B. Apathy and the functional anatomy of the prefrontal cortex-basal ganglia circuits. *Cereb Cortex* 2006; **16**: 916–928.
- 32 Starkstein SE, Petracca G, Chemerinski E, Kremer J. Syndromic validity of apathy in Alzheimer's disease. *Am J Psychiatry* 2001; **158**: 872–877.
- 33 Drennan VM, Cole L, Iliffe S. A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC Geriatr* 2011; **11**: 75.
- 34 Luppia M, Luck T, Braehler E, Konig HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord* 2008; **26**: 65–78.
- 35 Olazaran J, Reisberg B, Clare L *et al*. Nonpharmacological therapies in Alzheimer's disease: a systematic review of efficacy. *Dement Geriatr Cogn Disord* 2010; **30**: 161–178.
- 36 Seltzer B, Vasterling JJ, Yoder JA, Thompson KA. Awareness of deficit in Alzheimer's disease: relation to caregiver burden. *Gerontologist* 1997; **37**: 20–24.
- 37 Okura T, Plassman BL, Steffens DC, Llewellyn DJ, Potter GG, Langa KM. Prevalence of neuropsychiatric symptoms and their association with functional limitations in older adults in the United States: the aging, demographics, and memory study. *J Am Geriatr Soc* 2010; **58**: 330–337.
- 38 Senanarong V, Cummings JL, Fairbanks L *et al*. Agitation in Alzheimer's disease is a manifestation of frontal lobe dysfunction. *Dement Geriatr Cogn Disord* 2004; **17**: 14–20.
- 39 Nakano M, Miyamura T, Hirai S. Investigation of the actual condition of medical care for behavioral and psychological symptoms of dementia. *Jpn J Geriatr Psychiatry* 2011; **22**: 313–324.
- 40 Pinquart M, Sorensen S. Correlates of physical health of informal caregivers: a meta-analysis. *J Gerontol B Psychol Sci Soc Sci* 2007; **62**: 126–137.
- 41 Hepburn KW, Tornatore J, Center B, Ostwald SW. Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *J Am Geriatr Soc* 2001; **49**: 450–457.
- 42 Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990; **30**: 583–594.

Supporting information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Figure S1 Prevalence of Dementia Behavior Disturbance Scale (DBD) subitems in subjects with normal cognition (NC), amnesic Mild cognitive impairment (aMCI) and Alzheimer's disease (AD)29–24, AD23–18, AD17–12, and AD11–0.

Figure S2 Prevalence of symptoms of geriatric syndrome in participants with normal cognition (NC), amnesic mild cognitive impairment (aMCI) and varying stages of Alzheimer's disease (AD).

ORIGINAL ARTICLE

Developing an interdisciplinary program of educational support for early-stage dementia patients and their family members: An investigation based on learning needs and attitude changes

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Aim: The National Center for Geriatrics and Gerontology has begun to provide educational support for family caregivers through interdisciplinary programs focusing on patients in the early stage of dementia. These interdisciplinary programs have established two domains for the purpose of “educational support”: cure domains (medical care, medication) and care domains (nursing care, welfare). In the present study, we examined the learning needs and post-learning attitude changes of patients and their families who participated in these programs in order to assess the effectiveness of an interdisciplinary program of educational support in each of these domains.

Methods: A total of 170 participants (51 dementia patients, 119 family members) were included in the study. Data were obtained from electronic health records, and through a written survey administered before and immediately after each program.

Results: A high percentage of patients and family members desired knowledge about the progression and symptoms of dementia, as well as measures to prevent progression, both of which fall under the medical care content. For patients, education in the medical care content increased their motivation to live. For families, education in the medical and nursing care contents promoted their understanding of dementia, while education in medication and welfare contents improved their skills for handling dementia patients and their symptoms.

Conclusion: Both patients and family members expressed a need to learn medical care content, including the progression and disease symptoms of dementia, and methods to prevent the progression of dementia symptoms. Their responses showed that learning medical care was effective for understanding dementia. We suggested that medical care content was the core of interdisciplinary educational support for early-stage dementia patients and their family members. *Geriatr Gerontol Int* 2014; 14 (Suppl. 2): 28–34.

Keywords: attitude changes, early-stage-dementia, educational support, interdisciplinary, learning needs, medical care content.

Introduction

The number of dementia patients in Japan is steadily increasing. In response to this situation, the “Future Direction of Dementia Policy –June 2012–” highlighted “early diagnosis and early care” as the foundation of

care.¹ The Japanese Ministry of Health, Labor and Welfare advocates the strengthening of day-to-day family support in the community, irrespective of the stage of dementia.² Previous studies have shown that providing family caregivers of dementia patients with a psycho-educational program for a fixed period improves the trust between caregivers and patients, and provides caregivers with an understanding of the disease and coping ability for caregiving.^{3,4} Chien *et al.* stated that when care managers provided sessions on self-care and restoring or building family relationships, the patients’ symptoms stabilized, caregivers felt their care to be less burdensome, and the admission rates and periods of admission to medical institutions decreased.⁵ In

Accepted for publication 10 January 2014.

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addition, counseling for dementia patients' family members enabled prolonged home care.^{6,7} However, all of these studies have methodological shortcomings. For example, when selecting study subjects from the population of dementia patients requiring care, these studies categorized symptoms too broadly, ranging from slight to severe. In addition, study program providers (interveners) were only chosen from the paramedic profession rather than from an interdisciplinary group.

In order to address some of these issues, the Center for Comprehensive Care and Research on Memory Disorders (Monowasure-Center) of the National Center for Geriatrics and Gerontology (NCGG) embarked on an interdisciplinary program of educational support for dementia patients and their families immediately after the definitive diagnosis of dementia. We examined the learning needs and post-learning attitude changes of patients and their families in order to assess the effectiveness of this interdisciplinary program of educational support.

Methods

Operational definition

First, the interdisciplinary research team set up two operational definitions. We defined the first few months after a definitive dementia diagnosis as the "early stage." Next, we set up a program offered through an interdisciplinary collaboration as "early-stage educational support."

Psycho-educational program

We divided the program structure broadly into two domains: the "cure domain" concerned with diagnosis,

treatment and medication for dementia, and the "care domain" concerned with care methods and social support for dementia patients. Furthermore, the cure domain consisted of medical care content and medication content, the care domain consisted of nursing care content and welfare content. We then set up four content categories for each domain (Table 1), and assigned physicians, pharmacists, nurses and psychiatric social workers as interveners.

Participants

The study protocol was approved by the institutional review board of the NCGG of Japan. Candidate patients and their family caregivers submitted informed consent before participating in the study. The total number of participants was 170. This research included several cases in which there were two or more family participants to one patient. In these cases, all participating family members in the household were counted in the number of participants. Following are the details of the 170 study participants (Fig. S1).

The study participants were 51 dementia patients (henceforth referred to as "patients") who had been given a definitive dementia diagnosis only a few months before participation in the program (August 2012 to August 2013). The 51 patients targeted in the study comprised 41 patients who participated in both the cure and the care domains, and 10 patients who participated in only the care domain. Furthermore, the study also targeted 119 family members of patients, raising the total number of participants to 170. These 119 family members comprised 53 who participated in both the cure and the care domains, and 66 who participated in only one domain. Of these 66 single-domain participants, 27 participated in the cure domain, and 39

Table 1 Structure of educational program

Domain	Program content	Intervener	Time provided (min)	No. times	Theme
Cure	Medical care	Physician	15	One time/one month	Basic knowledge about dementia
	Medication	Pharmacist	15	One time/one month	Pharmacological treatment and management through medication
Care	Nursing care	Nurse	15	One time/one month	Understanding dementia patients as "people with dementia" and coping methods
	Welfare	Psychiatric social worker	15	One time/one month	Provision of information concerning social resources that help patients and their caregivers in the community

participated in the care domain. Participation in each domain was based on request rather than random allocation.

Assessment and questionnaires

The items of type of dementia, Barthel Index (BI),⁸ Mini-Mental State Examination (MMSE),⁹ Dementia Behavior Disturbance Scale (DBD)¹⁰ and Zarit Burden Interview (ZBI)¹¹ were collected through patients' electronic health records, and descriptive questionnaires issued before and after each program. The questionnaire items administered before attending the program inquired about personal attributes and what the participant desired to learn. After completion of the program, we examined participants' learning needs and attitude changes for each domain, using four items: (i) degree of usefulness for future life and caregiving; (ii) degree to which anxieties about life and care are resolved; (iii) degree of improvement in future life and increase in incentive for care; and (iv) degree to which understanding of dementia is promoted. For the responses, we used a five-point Likert scale with possible answers to each question being: (i) completely disagree; (ii) disagree somewhat; (iii) cannot say either way; (iv) agree considerably; and (v) agree very much.

Statistical analysis

We carried out a statistical analysis of the quantitative data and categorized the qualitative data. For the data

analysis of χ^2 -test, we used the SPSS windows version 21.0 program (SPSS, Chicago, IL, USA).

Results

Characteristics of patients and family members

Characteristics of both patients and family member participants were analyzed (Table 2). Patients' clinical characteristics were analyzed according to sex, age, type of dementia, the BI, the MMSE score and the DBD. Among the clinical characteristics, Alzheimer's disease was the most common type of dementia (88.2%). In addition, some participating patients showed early-stage dementia with MMSE (mean \pm SD) scores of 19.9 ± 4.5 .

The family member characteristics analyzed were sex, age group, family relationship to patient, living with patients and the ZBI. Approximately 70.0% of family member participants were females, and approximately 50.0% of family member participants were in the old age group. In the family member's relationship to patient group, "spouse" accounted for the highest proportion of responses (47.9%).

Learning needs according to program contents and change in participant attitude

Cure domain (program content: Medical care/ Medication).

Table 2 Baseline characteristics of patients and family members

The items	n (%)	Mean \pm SD
Patients characteristics (n = 51)		
Sex (female)	30 (58.8)	
Age (years)		78.8 \pm 6.6
Types of dementia		
Alzheimer's disease	45 (88.2)	
Vascular dementia	5 (9.8)	
Dementia with Lewy bodies	1 (2.0)	
Barthel Index		94.5 \pm 15.9
MMSE (total score)		19.9 \pm 4.5
DBD scale (total score)		13.1 \pm 8.1
Living with family members (at home)	47 (92.1)	
Family members' characteristics (n = 119)		
Sex (female)	83 (69.7)	
Older age group (from 60s to 80s)	59 (49.5)	
Patient's spouse	57 (47.9)	
Patient's daughter or son	41 (34.5)	
Patient's daughter or son-in-law	14 (11.8)	
Living with patients (at home)	114 (95.8)	
ZBI (total score)		19.6 \pm 4.5

DBD, Dementia Behavior Disturbance Scale; MMSE, Mini-Mental State Examination; ZBI, Zarit Burden Interview.

Learning needs

A total of 27 patients and 80 family members gave complete answers regarding learning needs (Table 3). The majority of the patients' answers were categorized as "Understand how the advance of dementia can be prevented" and "Gained a general understanding of dementia." Many patients expressed a desire to know how to slow down the progress of dementia, as well as general things to keep in mind when going about their daily lives. Patients also stated their desire to confirm whether their current disease and symptoms were real.

With regard to family members, the majority of answers were in the categories "Gain understanding about dementia" and "How to cope with dementia and the patient."

Attitude change

With regard to program 1, "Leads to understanding of dementia" and "Useful for future care and living methods" had high values of more than 80.0% for patients, and more than 70.0% for family members

(Table 4). We did not find a statistical difference, but more than 70.0% of the patients answered "Leads to increased motivation to live," and similarly, more than 70.0% of family members answered that it "Leads to a resolution of anxiety about life and care."

For program 2, results for "Led to a resolution of anxiety about life and care" were approximately 70.0% for both patients and family members. In this program, family members' attitudes appeared to change, with 72.5% of family members, a markedly high result, answering that the program is "Useful for future care and living methods" and "Leads to increased motivation to live."

Care domain (Program content: Nursing care/Welfare).

Learning needs

On the topic of learning needs, 30 patients and 92 family members gave complete answers (Table 3). An extremely high proportion of patients (90.0%) answered that the program helped them to "Gain a general understanding of dementia." This result showed patients'

Table 3 Learning needs according to program contents

Domain	Content	Category	Patients <i>n</i> = 27	Family members <i>n</i> = 80
Cure	Medical care/Medication	†Gain a general understanding of dementia	8 (29.6%)	35 (43.8%)
		†Learn how to prevent dementia from progressing	10 (37.0%)	5 (6.3%)
		Gain knowledge on the treatment methods for dementia	5 (18.5%)	16 (20.0%)
		Learn how to approach dementia	0 (0.0%)	18 (22.5%)
		†Resolution of psychological anxiety and conflict	4 (14.8%)	3 (3.8%)
		Find fellow dementia patients and caregivers	0 (0.0%)	2 (2.5%)
		Examine ways in which to announce dementia	0 (0.0%)	1 (1.3%)
			Patients <i>n</i> = 30	Family members <i>n</i> = 92
Care	Nursing care/Welfare	Learn care methods	0 (0.0%)	56 (60.8%)
		†Gain a general understanding of dementia	27 (90.0%)	17 (18.5%)
		†Learn how to prevent dementia from progressing	12 (40.0%)	0 (0.0%)
		Learn living methods	0 (0.0%)	5 (5.4%)
		Learn theories of coping with dementia patients	1 (3.3%)	6 (6.5%)
		Acquire information on the various types of social support	0 (0.0%)	4 (4.3%)
		Connection with community and whether or not to announce dementia	0 (0.0%)	2 (2.2%)
		†Resolution of psychological anxiety and conflict	1 (3.3%)	2 (2.2%)
		Learn ways to make use of social resources	0 (0.0%)	1 (1.1%)
Other	4 (13.3%)	0 (0.0%)		

†Categories raised (as needs) in both categories.

Table 4 Cure domain: Change in participants' attitude according to program contents

Program content	Questions inquiring about	Responses [†]	Patients (n = 27)	Family members (n = 80)	P-value (χ^2 -test)
1. Medical care	Q1: Program content is useful for future care and living methods	Agree	21 (77.7%)	60 (75.0%)	P = 0.97
		Disagree	6 (22.3%)	20 (25.0%)	
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree	19 (70.3%)	58 (72.5%)	P = 0.85
		Disagree	8 (29.7%)	22 (27.5%)	
Q3: Program content linked to improvement in future life and increase in motivation to live	Agree	19 (70.4%)	54 (67.5%)	P = 0.95	
	Disagree	8 (29.6%)	26 (32.5%)		
	Q4: Program content linked to understanding of dementia	Agree	22 (81.5%)	66 (82.5%)	P = 0.78
		Disagree	5 (18.5%)	14 (17.5%)	
2. Medication	Q1: Program content is useful for future care and living methods	Agree	17 (62.9%)	58 (72.5%)	P = 0.09
		Disagree	10 (37.1%)	22 (27.5%)	
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree	18 (66.6%)	59 (73.7%)	P = 0.42
		Disagree	9 (33.4%)	21 (26.3%)	
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree	16 (59.2%)	58 (72.5%)	P = 0.06
		Disagree	11 (40.8%)	22 (27.5%)	
	Q4: Program content linked to understanding of dementia	Agree	16 (59.2%)	55 (68.7%)	P = 0.30
		Disagree	11 (40.8%)	25 (31.3%)	

[†]For each question, we calculated the answers by using a five-point Likert scale whereby we combined the number of participants who selected "Agree very much" and "Agree considerably" as those who selected "Agree"; we counted those who selected "Completely disagree," "Disagree somewhat" and "Cannot say either way" as "Disagree." We additionally used a χ^2 -test.

desires to learn the means to prevent their dementia from worsening. In other words, patients wanted to learn about treatments and living methods that could stop the progression of their dementia.

As for family members, 60.8% showed a desire to "Learn care methods." Family members desired to know more about the ways to approach problem behaviors in dementia patients.

Attitude change

In program 3, the degree of attitude change among patients was polarized at approximately 60.0% (Table 5). Those whose degree of attitude change was 60.0% or above answered that it was "Useful for future living methods" and "Leads to increased motivation to live." As for the degree of attitude change among family members, the results were high (70.0%) on all four items. The highest items were "Leads to a resolution of anxiety about life and care," and "Leads to understanding of dementia," at 76.1% and 78.3% respectively. A significant difference was observed in the latter (χ^2 -test, $P < 0.05$).

With regard to program 4, the degree of attitude change among patients remained at approximately 60.0% for all four items, with the highest of these, at 66.6%, being "Leads to increased motivation to live."

As for family members, no significant difference was observed, but "Useful for future life and care" and "Leads to a resolution of anxiety about life and care" were high at 72.8% and 71.7%, respectively.

Discussion

Although educational support programs typically target family caregivers,¹² the present study was unique in that it targeted patients as well. As very little time had passed since the definitive dementia diagnosis, both patients and family members might have been confused or anxious,^{13,14} but they showed high expectations for learning. In considering these concerns and expectations, it is important to examine the learning needs and attitude changes throughout the program.

As shown in Table 2, both patients and family members were aging. We reasoned that there was elderly care by the elderly because of the high rate of "spouse" in the family relationship to patient. Dementia conditions will worsen little by little from diagnosis, even if patients have early-stage dementia. Therefore, the necessity for learning about the cure and care of dementia was suggested as preparation for preventing care burden and care breakdown.

Many patients and their family members showed learning needs for medical care content in the cure

Table 5 Care domain: Change in participants' attitude according to program contents

Program content	Questions inquiring about	Responses [‡]	Patients (<i>n</i> = 30)	Family members (<i>n</i> = 92)	<i>P</i> -value (χ^2 -test)
3. Nursing care	Q1: Program content is useful for future care and living methods	Agree	19 (63.3%)	65 (70.7%)	<i>P</i> = 0.82
		Disagree	11 (36.7%)	27 (29.3%)	
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree	18 (60.0%)	70 (76.1%)	<i>P</i> = 0.17
		Disagree	12 (40.0%)	22 (23.9%)	
4. Welfare	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree	19 (63.3%)	67 (72.8%)	<i>P</i> = 0.59
		Disagree	11 (36.7%)	25 (27.2%)	
	Q4: Program content linked to understanding of dementia	Agree	17 (56.6%)	72 (78.3%)	<i>P</i> = 0.40
		Disagree	13 (43.4%)	20 (21.7%)	
	Q1: Program content is useful for future care and living methods	Agree	19 (63.3%)	67 (72.8%)	<i>P</i> = 0.21
		Disagree	11 (36.7%)	25 (27.2%)	
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree	19 (63.3%)	66 (71.7%)	<i>P</i> = 0.73
		Disagree	11 (36.7%)	26 (28.3%)	
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree	20 (66.6%)	62 (67.4%)	<i>P</i> = 0.72
		Disagree	10 (33.4%)	30 (32.6%)	
	Q4: Program content linked to understanding of dementia	Agree	19 (63.3%)	63 (68.4%)	<i>P</i> = 0.96
		Disagree	11 (36.7%)	29 (31.6%)	

[‡]For each question, we calculated the answers by using a five-point Likert scale whereby we combined the number of participants who selected "Agree very much" and "Agree considerably" as those who selected "Agree"; we counted those who selected "Completely disagree," "Disagree somewhat" and "Cannot say either way" as "Disagree." We additionally used a χ^2 -test.

domain, including dementia progression, symptoms and ways to prevent progression. Family members tended to desire information about the progression of dementia and treatment methods appropriate for stopping it, as well as the symptoms that appear. Such results support the demand for a program with continuity between cure and care.

When we attempted to verify the efficacy of each program according to attitudinal change, we found that the results were different depending on participants' attributes. The most notable results among patients were in the medical care content (program 1) "Degree of usefulness for future life," "Degree of increased motivation to live" and "Degree to which the program helped participants understand dementia." Many patients felt this program helped to them seek a way of life that prevents dementia from worsening.

With regard to family members, "Degree of resolution of anxiety about life and care" was markedly high across all the programs. Examining the programs individually, "Degree to which understanding of dementia was promoted" was markedly high for medical care content (program 1) and nursing care content (program 3), and "Degree of usefulness for future life and care" was markedly high for medication content (program 2) and welfare content (program 4). We could infer that, in

each case, cure and care were shown to be effective as one unit, with "gaining understanding of dementia patients and their symptoms" in the former, and "learning methods for sustainable care" in the latter. Interdisciplinary educational support, consisting of both cure and care content, can provide appropriate psychological care. Another benefit of interdisciplinary educational support is that, through learning the knowledge and skills necessary for living with dementia, patients and their family members spontaneously involved themselves in medical consultations and treatment. This benefits healthcare providers by facilitating medical consultations, and empowers patients and family members about cure and care.

The present study provides evidence for three assertions:

- 1 Both patients and family members feel a need to learn medical care content including dementia progression, symptoms and methods to prevent progression.
- 2 Learning medical care content would lead to their use of knowledge and an increased motivation to live.
- 3 Learning medical care content is effective in helping family members understand dementia, and leads to the acquisition of skills for coping with dementia patients and their symptoms.

Following these three points, we suggest that medical care content was the core of interdisciplinary educational support for early-stage dementia patients and their family members. Finally, there is a need to continue research to verify this program's effectiveness.

Acknowledgments

We express our gratitude to the NCGG, the Uehiro Foundation on Ethics and Education, Professor Carl Becker and fellow researcher Jason Danely, research assistants Yoko Kajino and Sakie Miyamoto, participating patients, and family members. This study could not have been carried out without the NCGG's research and development fund (24–24), and we hereby express our gratitude. Finally, we also thank the Bio-Bank at NCGG for quality control of the clinical data.

Disclosure statement

The authors declare no conflict of interest.

References

- 1 Toba K, Washimi Y, Awata S et al. *Basic Research Projects for Creating Support Services Focused on the Early Stage of Dementia*. Aichi: National Center for Geriatrics and Gerontology, 2013; 1–13.
- 2 Ministry of Health, Labour and Welfare. Outline of future direction of dementia policy .Tokyo: Japan. 2012 June [Cited 1 Sep 2013.] Available from URL: <http://www.mhlw.go.jp/topics/kaigo/dementia/dl/houkousei-02.pdf>.
- 3 De Rotrou J, Cantegreil I, Fauconau V et al. Do patients diagnosed with Alzheimer's disease benefit from a psycho-educational programme for family caregivers? A randomized controlled study. *Int J Geriatr Psychiatry* 2011; **26**: 833–842.
- 4 Hepburn KW, Tornatore J, Center B, Ostwald SW. Dementia family caregiver training: affecting beliefs about caregiving and caregiver outcomes. *J Am Geriatr Soc* 2001; **49**: 450–457.
- 5 Chien WT, Lee IYM. Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *J Adv Nurs* 2011; **64**: 774–787.
- 6 Eloniemi-Sulkava U, Notkola IL, Hentinen M et al. Effects of supporting community living demented patients and their caregivers: a randomized trial. *J Am Geriatr Soc* 2001; **49**: 1282–1287.
- 7 Mittelman MS, Ferris SH, Shulman E et al. A family intervention to delay nursing home placement of patients with Alzheimer disease, A randomized controlled trial. *JAMA* 1996; **276**: 1725–1731.
- 8 Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud* 1988; **10**: 64–67.
- 9 Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975; **12**: 189–198.
- 10 Baumgarten M, Becker R, Gauthier S. Validity and reliability of the dementia behavior disturbance scale. *J Am Geriatr Soc* 1990; **38**: 221–226.
- 11 Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feeling burdened. *Gerontologist* 1980; **20**: 649–655.
- 12 Suganuma N et al. Literature review of interventions for family caregivers of the elderly with dementia. *J Japan Acad Gerontol Nurs* 2012; **17**: 74–82.
- 13 Yamaguchi H. Family Caregivers' Guidebook. *Basic Research Projects for Creating Support Services Focused on the Early Stage of Dementia*. Aichi: National Center for Geriatrics and Gerontology, 2013; 88–89.
- 14 Pam O, Nancy G, Lucy B. *Responding Creatively to the Needs of Caregivers*. Tokyo: Tutsui Publishing, Inc, 2005; 52–61.

Supporting information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Figure S1 Flow chart of the study protocol.

REVIEW ARTICLE

Educational program in Japan for Dementia Support Doctors who support medical and care systems as liaisons for demented older adults in the community

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Now that the number of elderly people has increased and the number of dementia patients is rapidly increasing, dementia might be regarded as a common disease. Under these circumstances, the establishment of systems to support the elderly with dementia from the early stages, and to provide primary care doctors and care workers with necessary education is an urgent issue. Up to the end of 2012, a total of 2680 doctors had been certified as Dementia Support Doctors (DSD). The DSD's function and roles are: (i) to support primary care doctors and care specialists involved in the medical care, and general care of dementia patients; (ii) to facilitate multidisciplinary cooperation led by a Community General Support Center; and (iii) to give lectures about dementia to primary care doctors and educate people in the community. DSD are more skilled than primary care doctors in the following functions: differential diagnosis; outpatient services to deal with behavioral and psychological symptoms of dementia; community liaison; and home care. *Geriatr Gerontol Int* 2014; 14 (Suppl. 2): 11–16.

Keywords: community liaison, Dementia Support Doctor, educational program for Dementia Support Doctors.

Introduction

Now that the number of patients with dementia is rapidly increasing with the increase of the number of elderly people, dementia might be regarded as a common disease. In fact, primary care doctors are now more frequently engaged in the care of patients with dementia, regardless of their specialty, and, consequently, it has become necessary for all of them to have a certain level of ability to treat the disease. Furthermore, in dementia care, appropriate role-sharing among medical professionals is important, while it is necessary to cooperate with care workers and administrative institutions.¹ Under these circumstances, the establishment of systems to support the elderly with dementia from the early stages, and provide primary care doctors and care workers with the necessary education is an urgent issue. To address this, the Ministry of Health, Labor, and Welfare launched a plan in 2005 to train Dementia Support Doctors (DSD), playing a central

role in community-based activities to support dementia patients. Subsequently, in 2006, another plan called the Skill-up Program of Dementia Medicine for Primary Care Doctors was initiated mainly by DSD, and, up to the end of 2012, a total of 2680 doctors had been certified as DSD. The total number of doctors who had completed the Skill-up Program of Dementia Medicine for Primary Care Doctors by the end of 2011 was 28 024. The government aims to increase the number of DSD to 4000, and that of doctors who have completed the Skill-up Program of Dementia Medicine for Primary Care Doctors to 50 000 by 2017.² The present article reports appropriate DSD training systems, while discussing the roles and activities of DSD. It also provides an outline of training programs focusing on long-term care services.

Educational program for DSD

With a Grant for Plans to Promote Health and Medical Services for the Elderly, the Ministry of Health, Labor, and Welfare launched the Research Project on Community Systems to Provide Early Identification and Appropriate Care for the Elderly with Dementia in 2004. In line with this, a working group was organized to examine methods to provide the Skill-up Program of Dementia Medicine for Primary Care Doctors,³ with a

Accepted for publication 17 December 2013.

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view to discussing the content of such training, as well as methods and systems to cooperate with doctors specializing in dementia care, who support Primary Care Doctors' medical practice and roles in the community. The DSD Training Program was initiated in 2005, and the Skill-up Program of Dementia Medicine for Primary Care Doctors in 2006. The former, aiming to train DSD who provide primary care doctors with advice regarding the early diagnosis of dementia, and play a central role in dementia care, was initially led by the National Center for Geriatrics and Gerontology as a commissioned business. In 2005, training materials, such as texts and DVDs, were developed, and, in 2006, training seminar sessions took place in Sapporo, Tokyo, Fukuoka and Obu (twice), producing a total of 318 DSD (covering 44 prefectures and 13 ordinance-designated cities). Following this, five seminar sessions a year have been held mainly in Tokyo, Nagoya, Osaka or Kyoto, and Fukuoka. Those who want to participate in these sessions should be recommended by the medical associations located in relevant ordinance-designated cities or their prefectures. Although those with medical associations' recommendation initially accounted for the majority, an increasing number of participants in recent years have made requests for participation to the medical associations located in ordinance-designated cities or their prefectures. To follow changes in clinical trial methods and systems, and reflect participants' opinions, training texts have been revised every year; up to 2012, four versions had been published. A major revision took place in 2012, and, in 2013, new texts have been adopted. The purposes of such revisions include: to focus on DSD-specific issues more closely, rather than conventional primary care doctor training; to provide the latest information regarding diagnosis and treatment; to increase sections related to medical liaison

systems in order to enhance participants' understanding of the importance of cooperation between medical and care professionals when supporting the elderly with dementia requiring long-term care; and to promote case studies and discussions. Each training session takes place from a Saturday afternoon to the following Sunday morning. In addition to learning methods to teach primary care doctors the content of each domain, participants are provided with lectures regarding the importance of DSD and primary care doctor training programs by an officer invited from the Office for Dementia and Elder Abuse Prevention, the Ministry of Health, Labor, and Welfare, and officers invited from the Japan Medical Association. Participants also freely discuss challenges for DSD in the establishment of systems to facilitate the early diagnosis and treatment of dementia in the community. By promoting discussions among doctors based in different areas, it is possible to clarify the status of each area's approach and points for improvement.

Current status and challenges of DSD

The roles of DSD include: (i) supporting primary care doctors and care professionals engaged in dementia care; (ii) establishing multiprofessional liaison systems led by the Community General Support Center; and (iii) giving lectures about dementia-specific training for primary care doctors and education for residents. In short, it is expected that DSD will promote cooperation between different medical professions, and between medical and care professions. (Fig. 1) As previously mentioned, the current total number of DSD is 2680; those specialized in fields generally related to dementia, such as psychiatry, neurology, geriatric medicine and neurosurgery, account for 42%, and those specialized in

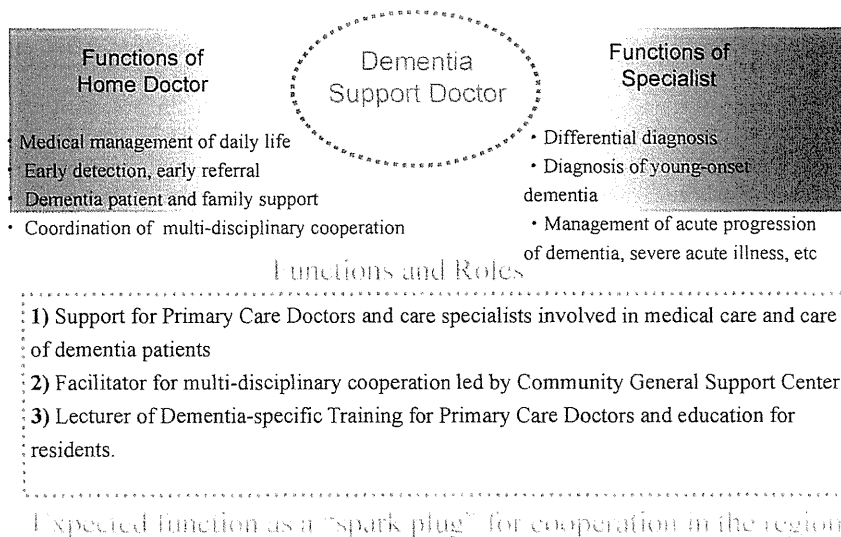


Figure 1 Functions and roles of Dementia Support Doctor.

Dementia Support Doctors in Japan

[n=957] Questionnaire to 1,974 Dementia Support Doctors undergoing training between 2005-2011

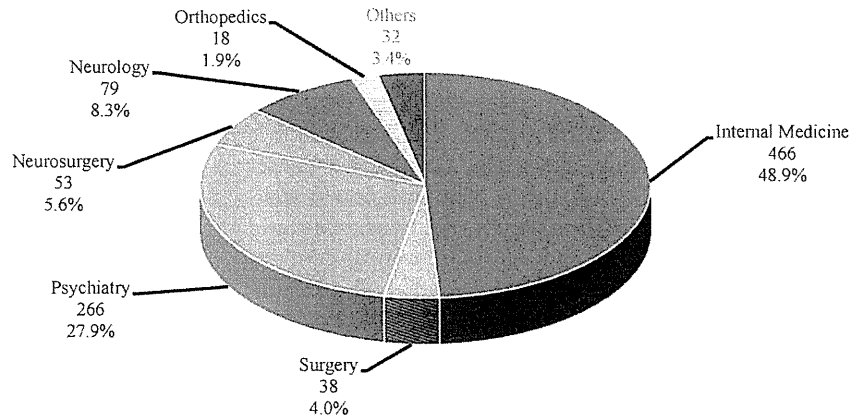


Figure 2 Breakdown of clinical departments of Dementia Support Doctors.

other fields of internal medicine, orthopedics, and urology account for 58%. Although DSD of the former group are frequently required for specialized medical services, such as the differential diagnosis of dementia, diagnosis of early-onset dementia, and treatment of advanced symptoms and severe somatic complications, those of the latter group are frequently required for primary care doctor functions, such as daily medical management, early identification and treatment of diseases, patient and family support, and multiprofessional cooperation. Considering that the necessary DSD functions also vary among different areas, it has been pointed out that the roles of DSD are unclear. According to a survey carried out from January to February 2011 involving DSD-related departments of a total of 66 municipalities, including 47 prefectures and ordinance-designated cities, those with 10–19 DSD accounted for the majority (24), followed by those with 30 or more (13) and those with fewer than 10 (16).⁴ The number of DSD was highest in Tokyo (284), followed by Chiba (88) and Hiroshima (72). Support for The Skill-up Program of Dementia Medicine for Primary Care Doctors was available in 95.5%, and education for residents was provided in 48.5%, whereas community liaison systems were not established, or their establishment was uncertain in 60%. As a reason for the latter, a large number of municipalities answered that community liaison was regarded as part of community-based activities, and they were not actively engaged in them; this shows that administrative bodies might not have been involved in the establishment of community liaison systems. Furthermore, information regarding accessibility to DSD in each area is important; however, DSD lists were available to the Community General Support Center in 70%, to residents in 50% and not available in 30% of all areas. Regarding networks among DSD, broad area networks

(the metropolitan area and districts) had been established in 14 (21.5%), and local networks (local demographic division of medical services where the DSD gives medical care) had been established in 12 (18.5%) areas. In 2012, a direct questionnaire survey was carried out to clarify the status of DSD,⁵ involving 1974 doctors who had completed the training program within the period between 2005 and 2011. The questionnaire sheet was distributed by mail, and 957 responded (response rate: 48.5%). Respondents were specialized in: internal medicine (48.9%), psychiatry (27.2%) and neurology (8.3%). Specialists certified by dementia-related academic associations accounted for 41.4% (Fig. 2). Their daily DSD activities included: (i) medical care for dementia patients (904: 94.5%); (ii) medical and multiprofessional liaison activities (804: 84.0%); and (iii) training and education (614: 64.2%; Fig. 3). The contents of (i) included treatment (96.9%), early identification (88.9%) and diagnosis (87.3%), nearly 90% of all DSD were carrying out these activities daily. A liaison system had been established with residents in 87.4%, long-term care support specialists in 78.0%, and the Community General Support Center in 73.9%; nearly 80% answered that a liaison system had been established. In contrast, a liaison system with primary care doctors had been established at a relatively low rate of 65.9%. The respondents participated in the planning and development of training and educational programs, such as dementia-specific training for primary care doctors (83.1%), multiprofessional training (79.3%) and educational seminars for residents (83.4%). These activities were carried out daily by approximately 80% of all DSD. These results suggest that individual DSD might be carrying out activities, such as medical services, liaison activities and education, daily in general; however, a liaison system with primary care doctors,

[n=957] Responses from 1,974 who completed DSD training program between 2005 and 2011

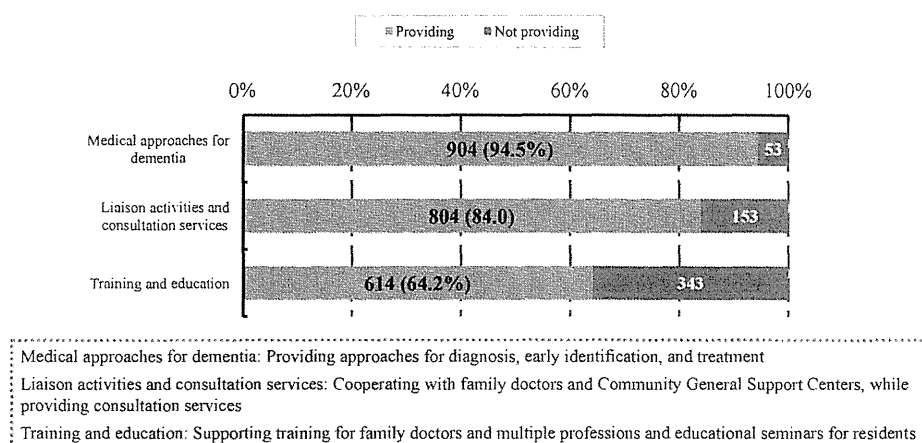


Figure 3 Activities of Dementia Support Doctors.

compared with residents and the Community General Support Center, had been established less frequently, showing the necessity of promoting and improving approaches in this respect. Regarding the large number of DSD (and medical institutions) as available resources, it might be necessary to sufficiently utilize them as a medical base supporting residents, care providers and primary care doctors engaged in dementia care. It might also be necessary to discuss and determine their roles, functions, and directionality in consideration of the statuses of related medical fields and association-certified specialists. In order to appropriately utilize DSD in the community, the municipalities' and Community General Support Centers' understanding is indispensable; in line with this, it might be desirable to develop community systems, while discussing appropriate methods to promote DSD activities, including grants for comprehensive dementia support plans among municipalities, Community General Support Centers and medical associations.

Awata carried out a study using the Medical Service Questionnaire Sheet for Dementia to evaluate the ability of general clinics located in the Tokyo metropolitan area to deal with dementia, and reported that medical institutions with doctors who had completed The Skill-up Program of Dementia Medicine for Primary Care Doctors showed a significantly greater ability than those without this training in the following respects: primary care doctor functions; differential diagnosis; outpatient services to deal with behavioral and psychological symptoms of dementia; community liaison; and home care.⁶ He also pointed out that medical institutions with DSD showed even higher levels of these functions (Fig. 4).

To promote liaison among DSD, and provide a basis for their information exchange, a portal site named the DSD Network (<http://www.dsd-network.jp>) was launched in May 2011, with a Grant for Geriatric Medicine Research and Development. The contents shown in Table 1 are viewable on this site, with a view to facilitating DSD activities. As another approach to support DSD, follow-up training programs have been used in some areas since 2009 to provide the DSD with opportunities to acquire new knowledge and learn other areas' approaches. In addition, as described in the following section, multiprofessional simulation conferences are being planned to enhance the knowledge of long-term care and liaison systems.

Long-term care training programs for doctors

In dementia care, it is essential to have a viewpoint based on a daily living activity model, in addition to a medical model. In other words, dementia care aims to improve patients' quality of life, rather than providing treatment and life-saving approaches, and focuses on disabilities (maintenance of activities of daily living), rather than diseases (maintenance of a normal physiological state). In line with this, it might be necessary to establish appropriate systems to provide team-based approaches with cooperation from multiple professions, as well as medical professionals. Honma pointed out that it is not reasonable to draw a line between medical and long-term care services when supporting dementia patients, and it is necessary to share knowledge and ideas among all those involved in dementia care, based

Dementia Support Doctors in Japan

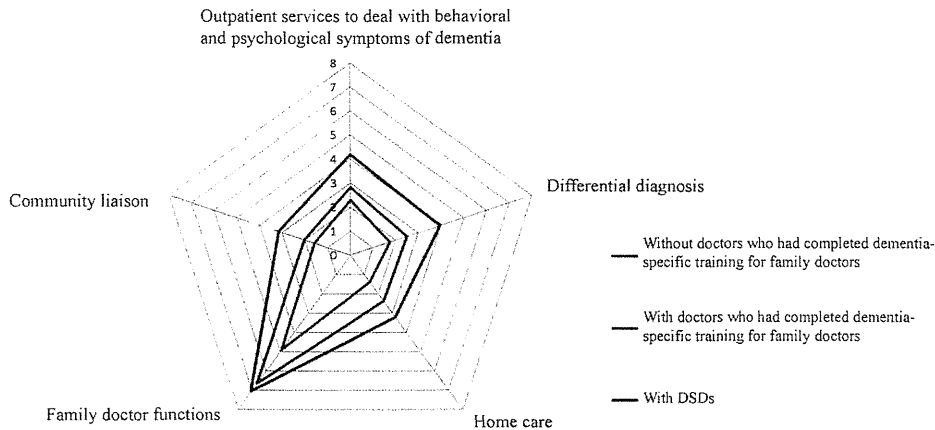


Figure 4 Outcomes of Dementia Support Doctors (DSD) and dementia-specific training programs for primary family doctors.

Table 1 Contents of the Dementia Support Doctors portal site

Category 1	Examples of community-based activities
Contents	Nagata-ku, Kobe City, Tokyo Metropolitan Area, Nagoya City, Shiga Prefecture, Nagano Prefecture
Category 2	Dementia-related issues
Contents	Roles of DSD: Development of new dementia guidelines, vascular dementia, development of neuroimaging for diagnosis of dementia, dysphagia due to dementia, non-pharmacological therapies, treatment of delirium, early-onset dementia (presenile dementia)
	Status of long-term care insurance systems (under commission), status of medical centers specialized in dementia care
Category 3	Materials, texts and DVDs previously used for DSD training
Category 4	List of DSD (by prefecture)
Category 5	Case studies
Category 6	Activities of academic study groups

DSD, Dementia Support Doctors.

on common training programs; however, such programs have not yet been developed.⁷ Furthermore, although study visits to long-term care facilities and nursing training programs have already been adopted in some medical schools as part of education regarding long-term care, these approaches are completely insufficient. Considering that Japan is becoming a super-aged society, this might be a serious problem, requiring prompt solutions.

Conclusion

Increasing the numbers of medical and care professionals specializing in dementia, and establishing systems to provide them with necessary education is urgently required.

Acknowledgement

This work was supported in part by a Grant-in-Aid from the Intramural Research Program of the National Center for Geriatrics and Gerontology (24-24 2012).

Disclosure statement

The authors declare no conflict of interest.

References

- 1 Washimi Y. Care and medical support for the person with Alzheimer's disease. *J Clin Exp Med* 2007; **220**: 456–462.
- 2 Ministry of Health, Labour, and Welfare. Five-year plan for the promotion of dementia care (orange plan). 2012.

- 3 Japan Public Health Association. Report of the study group for the development of primary care doctor training programs to deal with an increasing number of dementia patients, 3, 2004.
- 4 Silver Age Institute. Report of a research project for the development of dementia support doctor follow-up training programs. 53–67, 2011 [Cited 31 March 2011.] Available from URL: http://www.silver-soken.com/jisseki/html/h22_support.html
- 5 NLI Research Institute. Report of a research project on the roles of dementia support doctors and systems and educational materials to train them. pp. 36–39, 2013.
- 6 Awata S. Functions of doctors working in clinics – significance of community-based support activities in dementia care-. *Geriatr Med* 2013; **151**: 35–38.
- 7 Honma A. Status and challenges of dementia-related education and future perspectives. *Jpn J Geriatr Psychiatry* 2010; **21**: 1116–1118.



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Original Study

Regional White Matter Lesions Predict Falls in Patients With Amnesic Mild Cognitive Impairment and Alzheimer's Disease

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ABSTRACT

Keywords:

White matter lesions
falls
amnesic mild cognitive impairment
Alzheimer's disease

Objectives: Preventive strategy for falls in demented elderly is a clinical challenge. From early-stage of Alzheimer's disease (AD), patients show impaired balance and gait. The purpose of this study is to determine whether regional white matter lesions (WMLs) can predict balance/gait disturbance and falls in elderly with amnesic mild cognitive impairment (aMCI) or AD.

Design: Cross-sectional.

Settings: Hospital out-patient clinic.

Participants: One hundred sixty-three patients diagnosed with aMCI or AD were classified into groups having experienced falls ($n = 63$) or not ($n = 100$) in the previous year.

Measurements: Cognition, depression, behavior and psychological symptoms of dementia, medication, and balance/gait function were evaluated. Regional WMLs were visually analyzed as periventricular hyperintensity in frontal caps, bands, and occipital caps, and as deep white matter hyperintensity in frontal, parietal, temporal, and occipital lobes, basal ganglia, thalamus, and brain stem. Brain atrophy was linearly measured.

Results: The fallers had a greater volume of WMLs and their posture/gait performance tended to be worse than nonfallers. Several WMLs in particular brain regions were closely associated with balance and gait impairment. Besides polypharmacy, periventricular hyperintensity in frontal caps and occipital WMLs were strong predictors for falls, even after potential risk factors for falls were considered.

Conclusions: Regional white matter burden, independent of cognitive decline, correlates with balance/gait disturbance and predicts falls in elderly with aMCI and AD. Careful insight into regional WMLs on brain magnetic resonance may greatly help to diagnose demented elderly with a higher risk of falls.

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The incidence of falls increases with age. Falls often cause fractures, disability, and injury-related death. Even if falls are not accompanied by fractures, the elderly are reluctant to be active for fear of falls.¹ In Japan, a super-aged society, falls have become not only a medical problem, but also a social and medico-economic concern.

Falls are induced by the interaction of intrinsic, pharmacologic, and environmental factors in older persons. Intrinsic risks include balance impairments and muscle weakness, which are caused by

a number of sensory, neurologic, depressive, or musculoskeletal diseases. Age-related physical changes, medications, and cognitive decline also affect gait function in the elderly.^{2,3} Although gait impairment is not typically seen early in the course of Alzheimer's disease (AD), patients with AD show balance impairment and a slower walking pace, and the incidence of falls in this population is approximately 3-fold higher than that of age-matched controls.^{2,4} Clinical features of AD might play a role in increasing falls in the early stages of the disease. The involvement of executive dysfunction, visuoconstructional deficits, and behavior and psychological symptoms of dementia (BPSD) has been suggested.^{5,6} Another factor accounting for impaired balance and gait could be the underlying burden of white matter lesions (WMLs) in AD patients.

Previous studies of the aging brain have reported the correlation of WMLs with measurements of balance, gait, and falls in the elderly.^{7–14} Frontotemporal cortex and periventricular white matter are particularly vulnerable to hypoperfusion, and WMLs in these

This work was supported by the research fund for Longevity Sciences (22-5, 25-5) from the National Center for Geriatrics and Gerontology, Japan and Health and Labor Sciences Research Grants (H21-choju-005, H25-Ninchisho-008).

The authors declare no conflicts of interest.

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structures could have the consequence of impaired balance and gait in the elderly.¹⁴ However, little is known about the interaction between WMLs and gait disturbance in dementia disorders.^{7,8}

The purpose of the present study is to clarify the effects of WMLs on balance/gait function and falls in patients with amnesic mild cognitive impairment (aMCI) and AD. In the present study, we hypothesized that white matter burden (both its location and volume) is critical for manifesting clinical symptoms. We investigated the features of regional distribution of WMLs, which are responsible for deterioration of posture control and gait. Finally, we aimed to determine whether regional WMLs could be predictive to find high risk individuals for falls among elderly with aMCI and AD.

Methods

Participants

The protocol of the study was approved by the Institutional Review Board of the National Center for Geriatrics and Gerontology (NCGG), Japan. Candidate patients and their caregivers submitted informed consent before participation in the study.

We enrolled 163 patients (111 females) consecutively. Patients were >65 years old, visited the NCGG hospital in 2010 and 2011, and were diagnosed with aMCI ($n = 14$) or AD ($n = 149$). Patients were classified into a group that had experienced falls (fallers group; 63 subjects) and a group that had not experienced falls (nonfallers group; 100 subjects) in the past year. Mild to moderate AD was diagnosed as possible or probable AD according to the criteria from the National Institute of Neurological and Communicative Disorders and Stroke, and the Alzheimer's Disease and Related Disorders Association,¹⁵ and their total Mini-Mental State Examination (MMSE) scores were 15 or over. Patients with aMCI were diagnosed based on the criteria defined by Petersen et al.¹⁶ Patients with severe conditions of cardiac failure, renal disorder, liver dysfunction, musculoskeletal disease, optic or neurological disorders other than AD, and patients with a history of stroke or cortical lesions on brain magnetic resonance (MR) imaging were excluded.

Evaluation of Fall Risk Factors

Experience of falls was ascertained by interviews with patients and their caregivers. Risk of falls was evaluated by the Fall Risk Index, comprising 21 questionnaires for physical function, geriatric syndrome, and environmental hazards.¹⁷ The presence or absence of knee joint pain was examined as a subitem of the FRI. Information about previous history and medication was obtained from the patients' clinical charts. Polypharmacy was defined as taking 5 or more types of oral medicine.¹⁸ The patient's drinking habit was assessed by 1 of the questionnaires on a 4-point scale (0: daily drinking ≥ 56 g ethanol, 1: daily drinking < 56 g ethanol, 2: occasional drinking, 3: none). Anemia was assumed to be present if the patient's hemoglobin was less than 11.0 g/dL.

Cognitive function was evaluated by MMSE, Alzheimer's Disease Assessment Scale (ADAS), and digit span.^{19,20} Depression and BPSD were estimated by the Geriatric Depression Scale-15 and Dementia Behavior Disturbance Scale, respectively.^{21,22}

Balance control was assessed from the center of gravity sway during 1 minute of standing on a stabilometer (Stabilometry analysis SYSTEM GP-5000; ANIMA Co., Tokyo, Japan) with eyes opened and closed. Parameters of the postural sway included enveloped area (ENV-AREA), which is an area inside of the envelope of the center of gravity sway, total trajectory length of traced sway (LNG), and trajectory length of X direction (X-LNG) and Y direction (Y-LNG), which

measure the length from displacement of sway in mediolateral and anteroposterior directions, respectively.

Gait function was evaluated by the Timed Up and Go test (TUG), tandem gait steps, and time of standing on one leg. Muscle strength was measured by a hand grip test.

Brain MR Imaging

A standard series of axial T1-weighted (repetition time [TR], 485 ms; echo time [TE], 11 ms), T2-weighted (TR, 3800 ms; TE, 93 ms) and fluid-attenuated inversion recovery (TR, 8000 ms; TE 101 ms; inversion time, 2500 ms; a 256×256 matrix) MR sequences of the brain were performed using 1.5 T MR scanner (Siemens Avanto, Munich, Germany). Scans in parallel with the anterior commissure-posterior commissure line were performed from the vertex to the foramen magnum with 6-mm thick slices and an interslice gap of 1.2 mm.

Rating of WMLs and Brain Atrophy

WMLs appeared as hyperintense on T2-weighted images but did not leave a clear hypointense hole on T1-weighted images. WMLs were visually assessed as periventricular hyperintensity (PVH) or deep white matter hyperintensity (DWMH). WMLs were considered periventricular if the largest diameter was adjacent to the ventricular lining; they were otherwise considered subcortical.²³ PVH was classified by a 5-point scale measured at frontal caps, wall of the lateral ventricle (bands), and occipital caps (0: no, 1: pencil thin lining < 3 mm, 2: smooth halo or thick lining 3–10 mm, 3: extending caps 10–25 mm, 4: large confluent white matter > 25 mm). The overall degree of PVH was calculated by adding up the scores for the 3 separate compartments.²³ The number and size of DWMH were counted in the frontal, parietal, temporal, and occipital lobes, basal ganglia, thalamus, and brain stem. The size of DWMH was classified according to the largest diameter: small (1–3 mm), medium (3–10 mm), or large (> 10 mm). To calculate the volume, DWMH was assumed to be spherical with a fixed diameter of 2, 6, and 12 mm for each of the 3 respective categories.²³

For analysis of brain atrophy, Evans ratio (ER), inverse cella media index (iCMI), caudate head index (CHI), and basal cistern index (BCI) were calculated.²³ The following were measured with slide calipers: the maximum distance between the tips of the anterior horns (A); the width between the bilateral heads of the caudate nuclei (B); the maximum transverse inner diameter of the intracranial space (C); the maximum width of the cella media (D); the maximum transverse inner diameter (E); the internal width between the bilateral temporal lobe (F); and the maximum transverse inner diameter (G). The ER, iCMI, CHI, and BCI were calculated with the following respective formulae: $ER = A/C$; $iCMI = D/E$; $CHI = B/C$; and $BCI = F/G$, respectively.

WMLs in all participants were collectively evaluated by 2 trained raters, who had no knowledge of the clinical data. To test the inter-rater reliability, the results of the 2 raters were subjected to correlation analysis for comparison in a random sample of 10 subjects. The analysis showed a strong correlation ($r = 0.87\text{--}0.91$, $P < .0001$), which suggested that the method of measurement used for this study was reliable.

Statistical Analysis

Statistical analysis was performed using SPSS 18.0 for Windows (SPSS Inc, Chicago, IL). Since WMLs did not show normal distribution, they were converted to rank variables and analyzed by nonparametric tests. Clinical information and results of neuropsychological tests, posture sway, and gait were compared between the fallers and the nonfallers by Mann–Whitney U-test. Association between WMLs and balance/gait functions was analyzed by partial Spearman rank order correlation analysis. Independent risk factors of falls were

Table 1
Clinical Characteristics

	Fallers (n = 63)	Nonfallers (n = 100)	P Value
Age, years	78.6 (4.9)	76.4 (5.9)	.020
Females, n (%)	45 (71.4)	68 (68.0)	.644
Education, years	10.4 (2.5)	10.5 (2.4)	.713
Polypharmacy, n (%)	27 (42.9)	21 (21.0)	.003
Dementia Behavior Disturbance Scale	18.9 (11.1)	15.1 (10.8)	.013
Geriatric Depression Scale	5.0 (2.4)	3.9 (2.9)	.008
Fall Risk Index	9.0 (2.3)	2.5 (2.1)	<.001
Mini-Mental State Examination	21.1 (3.9)	20.9 (3.6)	.709
Alzheimer's Disease Assessment Scale	16.7 (6.0)	16.2 (6.2)	.659

SD, standard deviation.

Data are presented as mean (SD) unless otherwise indicated.

analyzed by the multivariate logistic regression, and prediction of falls was tested by receiver operating characteristic analysis. Significance was considered at $P < .05$.

Results

Clinical Characteristics and Balance/Gait Performance

The subjects in the fallers group were older than the nonfallers (Table 1). The percentage of patients on polypharmacy was higher in the fallers group. The fallers group had higher total scores of BPSD and depression. Total score of FRI was elevated in the fallers, while environmental factors were not different (data not shown). The prevalence of hypertension, diabetes mellitus, heart disease, anemia, and knee joint pain as well as drinking habit and use of psychotropic medicine were not significantly different among the groups (data not shown). Concerning cognitive status, there was no difference between the groups in terms of performance of MMSE and ADAS, as well as performance of constructional praxis in a subscale of ADAS and digit span, an indicator of attention (data not shown).

Among measurements with the stabilometer, ENV-AREA was enlarged in the fallers compared with the nonfallers with eyes opened or closed (Table 2). In gait performance, the number of steps in tandem gait was significantly fewer in the fallers, whereas results of TUG tended to be worse in the fallers. There was no difference in the grip strength between the groups.

Regional WMLs and Brain Atrophy

The PVH total score and overall products of DWMH were significantly higher in the fallers (Table 3). This group showed higher PVH in

Table 2
Balance and Gait Performance

	Fallers	Nonfallers	P Value
Measurements of balance			
ENV-AREA, cm ² Eyes open	6.0 (3.4)	4.7 (2.3)	.032
LNG, cm	121.6 (39.4)	113.5 (39.5)	.185
X-LNG, cm	77.4 (24.3)	70.3 (25.0)	.062
Y-LNG, cm	76.4 (29.0)	74.2 (29.3)	.540
ENV-AREA, cm ² Eyes closed	8.9 (5.4)	7.1 (4.3)	.017
LNG, cm	172.8 (58.5)	163.0 (73.6)	.117
X-LNG, cm	107.1 (33.7)	99.5 (44.9)	.052
Y-LNG, cm	112.0 (44.8)	108.3 (53.9)	.303
Gait performance			
Timed Up and Go, s	11.4 (4.0)	10.6 (3.0)	.077
Tandem gait, steps	11.4 (7.1)	14.2 (6.9)	.021
One-leg stand, s	26.7 (28.7)	32.8 (33.5)	.177
Grip strength, kg	20.0 (7.5)	22.2 (8.5)	.151

ENV-AREA, enveloped area of the center of gravity sway; LNG, total trajectory length of traced sway; SD, standard deviation; X-LNG, trajectory length of X direction; Y-LNG, trajectory length of Y direction.

Data are presented as mean (SD).

Table 3
Regional WMLs and Brain Atrophy

	Fallers	Nonfallers	P Value
PVH			
Frontal caps	4.4 (1.0)	3.6 (1.0)	<.001
Bands	3.1 (1.0)	2.9 (0.9)	.302
Occipital caps	4.5 (1.4)	3.5 (1.4)	<.001
Total	12.0 (2.6)	10.0 (2.8)	<.001
DWMH, μ L			
Frontal	2179.4 (1967.1)	1606.6 (1582.3)	.023
Parietal	878.2 (867.5)	700.7 (845.9)	.031
Temporal	273.4 (281.2)	160.8 (188.8)	.007
Occipital	193.7 (217.2)	93.1 (97.1)	<.001
Basal ganglia	354.7 (365.8)	252.8 (303.7)	.026
Thalamus	177.5 (202.2)	124.2 (157.3)	.011
Brain stem	220.0 (228.9)	170.2 (173.6)	.100
Total	4277.0 (3143.3)	3108.4 (2765.2)	.005
Atrophy			
Evans ratio	0.27 (0.04)	0.27 (0.03)	.813
Caudate head index	0.16 (0.03)	0.16 (0.02)	.567
Inverse cella media index	0.24 (0.04)	0.22 (0.03)	.018
Basal cistern index	0.20 (0.02)	0.20 (0.03)	.865

DWMH, deep white matter hyperintensity; PVH, periventricular hyperintensity; SD, standard deviation; WML, white matter lesion.

Data are presented as mean (SD).

frontal caps and occipital caps, and higher DWMH in all regions measured except the brain stem. Concerning progression of brain atrophy, inverse cella media index increased in the fallers, whereas the other indices were unchanged.

Correlation of WMLs With Balance/Gait Function

Figure 1 summarizes the correlation between WMLs and posture control for the entire cohort. Absolute values of the partial Spearman rank order correlation after adjusting for age, sex, and MMSE are shown on the Y-axis. PVH total, as well as PVH frontal and occipital caps correlated with Y-LNG with eyes opened ($P = .008$, $P = .019$, and $P = .011$, respectively) and with eyes closed ($P = .015$, $P = .042$, and $P = .044$, respectively). Total PVH also correlated with LNG with eyes closed ($P = .049$). Total DWMH and parietal DWMH correlated with Y-LNG with eyes closed ($P = .032$ and $P = .013$, respectively). Temporal DWMH correlated with Y-LNG with eyes open ($P = .013$), and DWMH in basal ganglia correlated with eyes-closed ENV-AREA ($P = .019$).

Similarly, correlation of WMLs with gait performance was demonstrated (Figure 2). PVH scores at frontal caps, bands, occipital caps, as well as PVH total correlated with performance of TUG ($P = .005$, $P = .001$, $P = .013$, and $P < .001$, respectively). PVH in frontal caps also correlated with 1-leg standing time ($P = .007$). Frontal DWMH and temporal DWMH correlated with performance of 1-leg standing and TUG ($P = .040$ and $P = .030$, respectively). In contrast, muscle strength did not show any correlation with WMLs. Caudate head index was negatively correlated with 1-leg standing ($P = .008$), but no other correlation was found between brain atrophy and balance/gait function.

Association of WMLs With Previous History of Falls

The effect of regional WMLs on falls was tested by multivariate logistic regression (Table 4). Cofactors included age, sex, MMSE, polypharmacy, Dementia Behavior Disturbance Scale, Geriatric Depression Scale-15, and brain atrophy. The analysis indicated that polypharmacy, PVH frontal caps, and occipital DWMH were specific risk factors for falls. The predicted probabilities for fallers from the multivariate logistic regression analysis were as follows: $\text{Log } p/(1-p) = -0.0534x_1 + 0.0282x_2 + 0.0948x_3 + 0.0140x_4 + 0.0852x_5 + 0.0069x_6 + 0.0061x_7 + 0.0004x_8 + 0.0130x_9 + 0.0041x_{10} +$

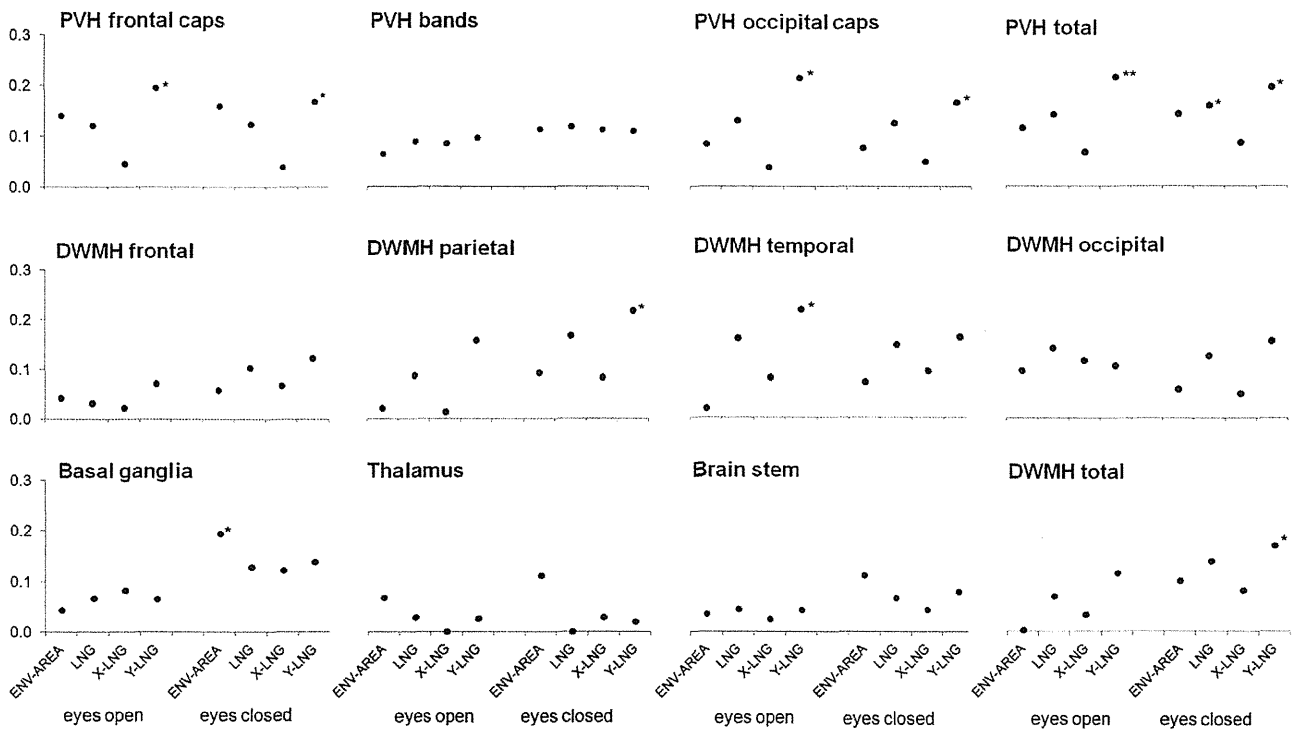


Fig. 1. Effects of regional white matter lesions (WMLs) on posture control. Effects of regional periventricular hyperintensity (PVH) and deep white matter hyperintensity (DWMH) on balance function are shown. The Y-axis denotes the absolute values of the partial Spearman rank order correlation after adjusting for age, sex, and Mini-Mental State Examination (MMSE). **P* < .05, ***P* < .01. ENV-AREA, enveloped area of the center of gravity sway; LNG, total trajectory length of traced sway; X-LNG, trajectory length of X direction; Y-LNG, trajectory length of Y direction.

$$0.0082x_{11} - 0.0027x_{12} - 0.0236x_{13} + 0.0525x_{14} + 0.239x_{15} + 0.0500x_{16} - 0.0797x_{17} + 0.9387x_{18} - 10.4655; \text{ where } x_1 = \text{Sex (Male:1, Female:0)}, x_2 = \text{Age (years)}, x_3 = \text{MMSE}, x_4 = \text{Dementia}$$

$$\text{Behavior Disturbance Scale}, x_5 = \text{Geriatric Depression Scale}, x_6 = \text{frontal DWMH } (\mu\text{L}), x_7 = \text{parietal DWMH } (\mu\text{L}), x_8 = \text{temporal DWMH } (\mu\text{L}), x_9 = \text{occipital DWMH } (\mu\text{L}), x_{10} = \text{basal ganglia DWMH}$$

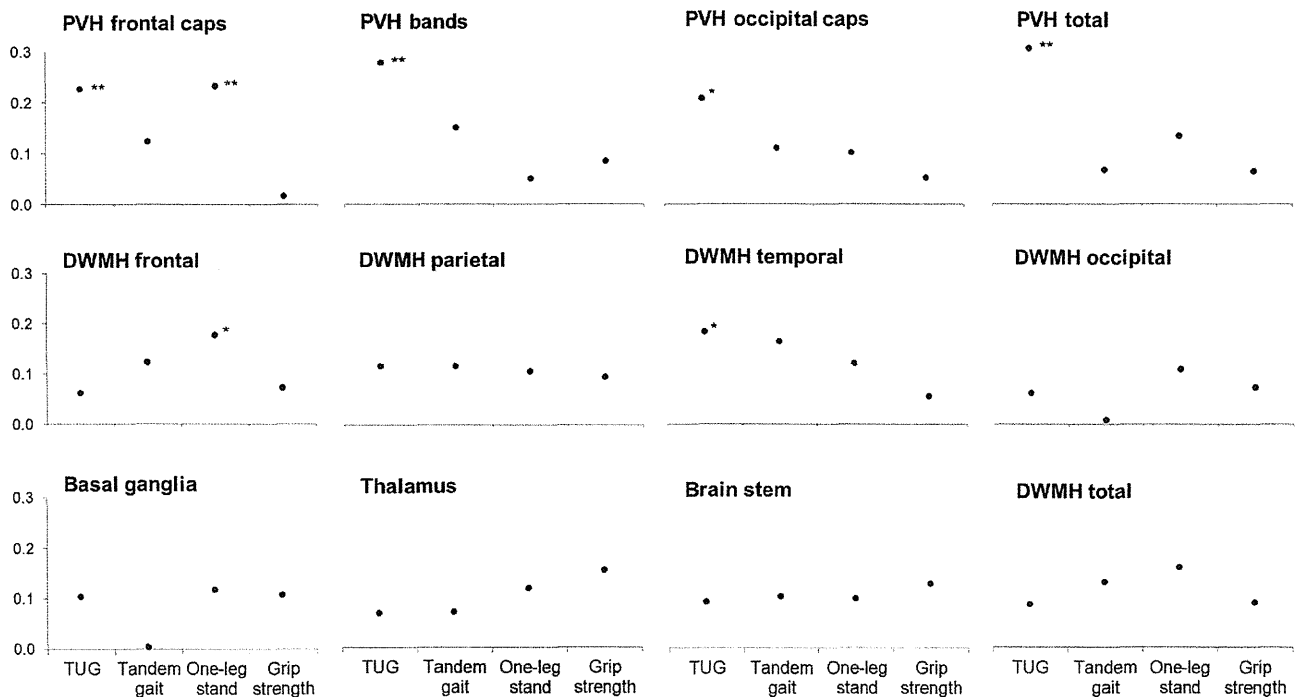


Fig. 2. Impacts of regional white matter lesions (WMLs) on gait performance. Effects of regional periventricular hyperintensity (PVH) and deep white matter hyperintensity (DWMH) on motor performance are demonstrated. The Y-axis indicates absolute values of the partial Spearman rank order correlation after adjusting for age, sex, and Mini-Mental State Examination (MMSE). **P* < .05, ***P* < .01. TUG, Timed Up and Go.