結果、記載されている徘徊エピソードから、 【徘徊頻度とその変化】、【徘徊の契機・特 異的状況】、【徘徊への対処】、【迷子の有無】 など、10のカテゴリが得られた。カテゴリ 間の関係について相関分析を行った結果、 いくつかのカテゴリ間の関連が認められた。 今後認知症専門職や家族への詳細な聞き取 りを通じて徘徊の定義やその類型化を行う ことが重要と考えられる。

F. 研究発表

なし

- G. 知的財産権の出願・登録状況(予定を含む)
- 1. 特許取得なし
- 2. 実用新案登録なし

3.その他 なし

【引用文献】

大島千穂, 児玉桂子 (2012). 介護支援専門員のとらえる認知症高齢者への在宅環境配慮の効果. 老年社会科学; 34(3): 335-349.

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村山陽, 竹内瑠美, 大場宏美, 他 (2013). 世代間交流事業に対する社会的関心とその現状: 新聞記事の内容分析および実施主体者を対象とした質問紙調査から. 日本公衆衛生学雑誌; 60(3): 138-145.

表 1 徘徊内容に含まれるカテゴリおよびサブカテゴリ (N = 307)

カテゴリ	サブカテゴリ
【徘徊頻度とその変化】(122)	·頻度
	《頻回》《単発》《数回》
	·変化
	≪継続≫≪消失≫≪悪化≫≪開始≫≪改善≫
【徘徊が起きた時間帯】(95)	《夜間》《早朝·朝》《昼間》《夕方》
	≪パターンなし≫
【徘徊の契機・特異的状況】(79)	≪徘徊と併存する症状≫≪環境変化≫≪家族関係≫
	≪投薬·処方薬変更≫
【保護・助けた人】(56)	≪警察≫≪住民≫≪家族≫≪業者≫
【徘徊への対処】(55)	·対処内容
	≪投薬・処方薬変更≫≪捜索願≫≪家族の付き添い・説
	得≫≪施錠≫≪探索機器≫≪デイ利用変更≫
【発見場所】(46)	≪近隣≫≪他市町村·他県≫
【迷子の有無】(44)	・迷子になった外出先
	≪親族・知人宅≫≪買い物≫≪散歩≫≪トイレ≫≪ゴミ捨
	て≫
	・行けた/帰れってこられた外出先
	≪散歩≫≪最寄り駅≫≪デイサービス≫≪自宅周辺≫
【移動手段】(39)	≪徒歩・自転車≫≪車・タクシー・電車≫
【本人なりの理由】(34)	≪帰宅願望≫≪家族や知人に会う・探す≫
	《仕事·用事》
【徘徊の結果】(24)	《負傷·死亡》《転倒·事故》《入院·救急搬送》
	≪施設転帰≫

注)()内は当該カテゴリ内容を含むエピソード数を示す。

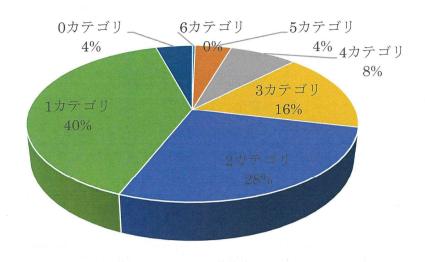


図1 徘徊の各エピソードが内包するカテゴリ数

表 2 サブカテゴリ間の相関(Spearman の順位相関) (N=173)

	サブカテゴリ 1 (【カテゴリ】)		サブカテゴリ 2 (【カテゴリ】)	Spearman's
				ρ
$\rho \geq .3$	投薬・処方薬変更(【対処】)		改善(【頻度と変化】)	.421
	投薬・処方薬変更(【対処】)	-	消失(【頻度と変化】)	.349
	家族関係(【状況】)		朝(【時間帯】)	.305
$\rho \geq .2$	環境変化(【状況】)	succession.	施設転帰(【結果】)	.298
	投薬・処方薬変更(【状況】)	_	開始(【頻度と変化】)	.282
	仕事・用事(【本人の理由】)		家族の付添い・説得(【対処】)	.259
	徒歩・自転車(【移動手段】)		他市町村・他県(【発見場所】)	.242
	家族関係(【状況】)		悪化(【頻度と変化】)	.240
	帰宅願望(【本人の理由】)		夕方(【時間帯】)	.213
	頻回(【頻度と変化】)		徒歩・自転車	208
	車・電車(【移動手段】)		警察(【保護・助けた人】)	.201
ρ < .2	家族や知人に会う		搜索願(【対処】)	.181
	単発(【頻度と変化】)	_	他市町村・他県(【発見場所】)	.174
	近隣(【発見場所】)		家族(【保護・助けた人】)	.173
	仕事・用事(【本人の理由】)	Name of the last o	単発(【頻度と変化】)	.166
	投薬・処方変更(【対処】)	**************************************	警察(【保護・助けた人】)	164
	併存症状(【状況】)	-	近隣(【発見場所】)	161
	家族関係(【状況】)		転倒·事故(【結果】)	.156
	夕方(【時間帯】)		負傷・死亡(【結果】)	.156
	夕方(【時間帯】)		施錠(【対処】)	.156
	迷子 (【迷子の有無】)		搜索願(【対処】)	.151
	家族や知人に会う		家族(【保護・助けた人】)	.151

注)Spearman's ρ の高い組み合わせ順に記載した。カテゴリ名やサブカテゴリには一部省略形を用いている。

IV. 研究成果の刊行に関する一覧表

研究成果の刊行に関する一覧表

書籍

著者氏名	論文タイトル名	書籍全体の 編集者名	書	籍	名	出版社名	出版地	出版年	ページ
なし									
								,	

雑誌

発表者氏名	論文タイトル名	発表誌名	巻号	ページ	出版年
ki C, Takeda A, Endo H, Sakur ai T, Toba K.	Developing an Inter-di sciplinary Program of Educational Support f or Early-Stage-Demen tia Patients and their Family Members -An Investigation Based o n Learning Needs an d Attitude Changes –	tol Int.	14(S2)	28-34	2014
rai T, Ogama N, Maki Y, Toba K.	Factors associated wit h increased caregiver s' burden in several c ognitive stages of Alz heimer disease.	tol Int.	14(S2)	45-55	2014
ako H, Doi T, L		s	2	71-76	2015

V. 研究成果の刊行物・別刷

Geriatr Gerontol Int 2014; 14 (Suppl. 2): 28-34

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

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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

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 \pm 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

•	v	
Sex (female) Age (years) Types of dementia Alzheimer's disease Vascular dementia Dementia with Lewy bodies Barthel Index MMSE (total score) DBD scale (total score) Living with family members (at home) family members' characteristics (n = 119) Sex (female) Older age group (from 60s to 80s) Patient's spouse Patient's daughter or son Patient's daughter or son-in-law Living with patients (at home)	n (%)	Mean ± SD
Patients characteristics $(n = 51)$		
Sex (female)	30 (58.8)	
Age (years)		78.8 ± 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 ± 15.9
MMSE (total score)		19.9 ± 4.5
DBD scale (total score)		13.1 ± 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 ± 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	Family members
			n = 27	n = 80
	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	Family members
			n = 30	n = 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 Disagree	21 (77.7%) 6 (22.3%)	60 (75.0%) 20 (25.0%)	P = 0.97
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree Disagree	19 (70.3%) 8 (29.7%)	58 (72.5%) 22 (27.5%)	P = 0.85
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree Disagree	19 (70.4%) 8 (29.6%)	54 (67.5%) 26 (32.5%)	P = 0.95
	Q4: Program content linked to understanding of dementia	Agree Disagree	22 (81.5%) 5 (18.5%)	66 (82.5%) 14 (17.5%)	P = 0.78
2. Medication	Q1: Program content is useful for future care and living methods	Agree Disagree	17 (62.9%) 10 (37.1%)	58 (72.5%) 22 (27.5%)	P = 0.09
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree Disagree	18 (66.6%) 9 (33.4%)	59 (73.7%) 21 (26.3%)	P = 0.42
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree Disagree	16 (59.2%) 11 (40.8%)	58 (72.5%) 22 (27.5%)	P = 0.06
	Q4: Program content linked to understanding of dementia	Agree Disagree	16 (59.2%) 11 (40.8%)	55 (68.7%) 25 (31.3%)	P = 0.30

[†]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

	0 1 1	8 1 8			
Program content	Questions inquiring about	Responses [†]	Patients $(n = 30)$	Family members $(n = 92)$	P-value (χ²-test)
3. Nursing care	Q1: Program content is useful for future care and living methods	Agree Disagree	19 (63.3%) 11 (36.7%)	65 (70.7%) 27 (29.3%)	P = 0.82
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree Disagree	18 (60.0%) 12 (40.0%)	70 (76.1%) 22 (23.9%)	P = 0.17
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree Disagree	19 (63.3%) 11 (36.7%)	67 (72.8%) 25 (27.2%)	P = 0.59
	Q4: Program content linked to understanding of dementia	Agree Disagree	17 (56.6%) 13 (43.4%)	72 (78.3%) 20 (21.7%)	P = 0.40
4. Welfare	Q1: Program content is useful for future care and living methods	Agree Disagree	19 (63.3%) 11 (36.7%)	67 (72.8%) 25 (27.2%)	P = 0.21
	Q2: Program content linked to a resolution of anxiety concerning life and care	Agree Disagree	19 (63.3%) 11 (36.7%)	66 (71.7%) 26 (28.3%)	P = 0.73
	Q3: Program content linked to improvement in future life and increase in motivation to live	Agree Disagree	20 (66.6%) 10 (33.4%)	62 (67.4%) 30 (32.6%)	P = 0.72
	Q4: Program content linked to understanding of dementia	Agree Disagree	19 (63.3%) 11 (36.7%)	63 (68.4%) 29 (31.6%)	P = 0.96

[†]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.

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Disclosure statement

The authors declare no conflict of interest.

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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.

ORIGINAL ARTICLE

Factors associated with increased caregivers' burden in several cognitive stages of Alzheimer's disease

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Aim: To investigate factors associated with caregiver burden (CB) in persons caring for older adults with various cognitive stages of Alzheimer's disease (AD).

Methods: Participants were 1127 outpatients and their caregivers. Participants comprised 120 older adults with normal cognition (NC), 126 with amnestic mild cognitive impairment (aMCI) and 881 with AD. AD patients were subclassified into four groups by Mini-Mental State Examination (MMSE) score: AD29–24 (n = 117), AD23–18 (n = 423), AD17–12 (n = 254) and AD11–0 (n = 87). Participants and their caregivers underwent comprehensive geriatric assessment batteries including Zarit Burden Interview (ZBI) Barthel Index, Lawton Index, Dementia Behavior Disturbance Scale (DBD) to evaluate CB, Instrumental and Basic Activity of Daily Living (IADL/BADL), and Behavioral and Psychological Symptoms of Dementia (BPSD). The comorbidity of geriatric syndrome and the living situation of the patient/caregiver were also assessed.

Results: ZBI score was higher in patients with lower MMSE score. Multivariate regression analysis identified that DBD was consistently associated with CB in all patients; symptoms related to memory deficit were related to CB in aMCI; differential IADL, such as inability to use a telephone, use transportation, manage finances, shop, cook and take responsibility for own medication, were related to CB in AD29–24, AD23–18 and AD17–12, and geriatric syndrome including falls and motor disturbance, sleep problems, urinary incontinence, and fatigue was related to CB in AD23–18 and AD17–12.

Conclusions: Multiple factors including BPSD, impaired life function and geriatric syndrome were cognitive stage-dependently associated with CB. Preventive treatment of BPSD and comorbidity, and effective assistance for IADL deficits could contribute to alleviation of CB. **Geriatr Gerontol Int 2014**; ••: ••-••.

Keywords: activity of daily living, Alzheimer's disease, behavioral and psychological symptoms of dementia, caregivers' burden, geriatric syndrome.

Introduction

Dementia is characterized by cognitive deficit and a loss of functional independence.¹ Because of the growing dependency associated with progression of dementia, caregivers bear an ever increasing burden of care and management of patients with dementia. As caregiving for patients with dementia is physically, emotionally and financially demanding, the burden has significant implications for caregivers' physical and mental health, personal and social life, and overall well being.²⁻⁸

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Furthermore, it is assumed that the chronic mental and physical burden on caregivers could result in reduced quality of care for patients with dementia, which might worsen the patients' health status, and cause behavioral and psychological symptoms of dementia (BPSD).

There is wide variation in the psychological symptoms and physical complications of dementia, depending on the severity of dementia, the population and differences among several diseases manifesting dementia. ^{9,10} Multifactorial mechanisms might underlie the increase in caregiver burden (CB). ^{11,12} However, little is known about factors associated with CB according to the progression of dementia. To date, comprehensive research has not been well carried out to clarify such factors in demented individuals. Therefore, in the present study, we aimed to identify the factors associated with CB according to the stage of cognitive decline

in older adults with Alzheimer's disease (AD), which is the causative disease in more than 50% of all dementia. Previous studies showed that BPSD of individuals with dementia is one of the largest factors contributing to CB,11,12 and individuals with AD require increased assistance in daily living as dementia progresses. Furthermore, patients might suffer from various comorbid conditions, which impose an additional burden on caregivers. We hypothesized that BPSD and activities of daily living (ADL), as well as comorbid diseases of geriatric syndrome, could be candidates for factors associated with CB. Understanding the factors associated with CB in each stage of cognitive decline should be informative not only for caregivers in order to alleviate CB, but also for medical and healthcare professionals for effective dementia treatment in daily practice.

Methods

Study participants

The study protocol was approved by the Ethical Review Board of Japan's National Center for Geriatrics and Gerontology (NCGG), and the patients and their caregivers provided informed consent before participation in the study. The participants were 1127 outpatients (362 male, 799 female; aged 78.5 ± 6.2 years) and their families, who attended the Medical Center for Dementia at Japan's NCGG during the period from September 2010 to August 2012. They were composed of 120 with normal cognition (NC), 126 with amnestic mild cognitive impairment (aMCI) and 881 with AD. NC, who visited NCGG with suspicion of dementia, were diagnosed as having normal cognitive function. aMCI was diagnosed based on the criteria defined by Petersen et al.,13 and AD was diagnosed as probable AD or possible AD based on the criteria published by the U.S. National Institute of Neurological and Communicative Disorders and Stroke, and the Alzheimer's Disease and Related Disorders Association.¹⁴ The AD patients were subclassified into four groups by their total scores of the Mini-Mental State Examination (MMSE):15 AD29-24 (MMSE score range 24–29; n = 117), AD23–18 (18–23; n = 423), AD17–12 (12–17; n = 254) and AD11–0 (0–11; n = 87). Patients with severe conditions, such as cardiac failure, renal disorder, liver dysfunction, neurological and psychiatric disorders such as depression, and alcohol abuse were excluded from the present study.

Assessment

On the first day when study participants attended the Medical Center for Dementia for consultation on the disease causing dementia, comprehensive geriatric assessment batteries were carried out to evaluate disability, mood and cognitive function of the patients, and

to measure CB of the caregivers. Global cognitive status was tested using the MMSE, and depressive mood was estimated by the self-rated Geriatric Depression Scale (GDS; 15 items). The patients' basic/instrumental activities of daily living (BADL/IADL) were assessed by the Barthel Index (BI) and Lawton Index (LI), respectively. LI is composed of five questions for men (telephone use, shopping, transportation, medication, handling finances) and three additional questions for women (food preparation, housekeeping, laundry). BPSD were assessed using the Dementia Behavior Disturbance Scale (DBD), and CB using the Zarit Burden Interview (ZBI). Care assessed using the Dementia Burden Interview (ZBI).

Comorbid conditions of geriatric syndrome and the living situation of the patient/caregiver were assessed by questionnaires administered to the patients and their caregivers. The following were assessed as comorbid conditions: presence or absence of geriatric syndrome symptoms including hearing disturbance, visual disturbance, pollakiuria, lumbago, falls, leg pain, diarrhea/constipation, fatigue, cough/sputum, edema, upper limb pain, itching, sleep disturbance, headache, ringing in the ear, numbness, palsy, palpitation, dysphasia, speech disturbance, urinary disturbance, back pain, tremor, chest pain, dyspnea, mastication disorder, syncope, abdominal pain, nausea/vomiting, fever and decubitus ulcer.

Statistical analysis

Analysis of covariance (ANCOVA) with covariates of age and sex was applied to compare six groups of NC, aMCI, AD29–24, AD23–18, AD17–12 and AD11–0, followed by post-hoc analysis (Scheffe) to detect statistically significant differences.

Factor analysis (principal factor method and promax rotation) was carried out on 28 subitems of DBD in patients with AD. Items with a factor loading of <0.4 were deleted, and six factors were extracted as shown in Table 1. These factors were interpreted as "Behavioral disturbance" (factor 1), "Verbal aggressiveness" (factor 2), "Memory impairment" (factor 3), "Motor aggressiveness" (factor 4), "Incontinence" (factor 5) and "Apathy" (factor 6).

The factors associated with CB were analyzed using multiple linear regression analyses in six groups. The dependent variables were summed scores of ZBI, and the candidates for associated factors were total scores of BI, LI, DBD, number of conditions of geriatric syndrome with age and sex, which were entered in a stepwise fashion into multiple linear regression analyses. For analysis of DBD, we entered factors 1–6 identified by factor analysis as independent variables. We carried out similar analyses for BI, LI and comorbid conditions of geriatric syndrome, but symptoms whose frequency were 10% or lower were excluded from the analysis.

 Table 1
 Factor loading for Dementia Behavior Disturbance Scale subitems in Alzheimer's disease

	Factor 1 Behavior disturbance	Factor 2 Verbal aggressiveness	Factor 3 Memory impairment	Factor 4 Motor aggressiveness	Factor 5 Incontinence	Factor 6 Apathy
21. Wanders aimlessly in or outside house during day	1.006	-0.105	-0.072	-0.012	0.081	-0.213
17. Gets lost outside	0.790	-0.109	-0.035	0.085	-0.049	-0.002
07. Paces up and down	0.786	0.012	0.078	-0.102	-0.015	-0.075
16. Wanders in house at night	0.784	-0.002	-0.069	0.079	-0.063	0.019
14. Moves arms or legs in restless or agitated way	0.494	0.305	-0.144	-0.041	0.061	0.022
04. Wakes up at night for no obvious reason	0.471	0.023	-0.006	0.027	-0.013	0.267
08. Repeats the same action over and over	0.395	0.188	0.193	-0.122	-0.055	0.044
09. Is verbally abusive, swears	-0.130	0.897	0.007	-0.029	-0.033	0.016
05. Makes unwarranted accusations	-0.019	0.690	0.070	-0.006	-0.017	-0.004
23. Screams for no reason	0.059	0.604	-0.136	0.267	-0.090	-0.050
11. Cries or laughs inappropriately	0.199	0.484	0.042	-0.062	0.044	-0.024
12. Refuses to be helped with personal care	0.128	0.290	0.186	0.041	0.052	0.020
19. Overeats	0.098	0.245	-0.015	-0.076	0.150	0.239
02. Loses, misplaces, or hides things	-0.111	0.024	0.877	0.030	0.009	-0.167
01. Asks the same question repeatedly	-0.036	-0.060	0.515	0.051	-0.090	0.043
13. Hoards things for no obvious reason	0.067	0.099	0.452	-0.048	-0.049	0.109
15. Empties drawers or closets	0.255	0.091	0.294	0.027	0.077	-0.054
28. Throws food	0.018	-0.114	0.048	0.741	0.137	-0.069
26. Destroys property or clothing	0.015	0.034	0.024	0.733	-0.172	0.167
22. Makes physical attacks (hits, bites, scratches,	-0.051	0.301	0.018	0.466	0.197	-0.149
kicks, spits)						
27. Is incontinent of feces	0.024	-0.077	-0.016	0.116	0.709	0.007
20. Is incontinent of urine	-0.033	0.031	-0.077	-0.067	0.689	0.184
06. Sleeps excessively during day	-0.173	0.032	-0.124	-0.003	0.081	0.718
03. Lack of interest in daily activities	0.068	-0.109	0.152	0.007	0.056	0.490
10. Dresses inappropriately	0.177	-0.094	0.264	0.047	0.117	0.302
18. Refuses to eat	0.198	0.103	0.006	0.153	-0.087	0.217

Factor analysis: principal factor method and promax rotation. Items with significant loading (≥0.4) are shown in bold.

Interfactor correlations

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Factor 1	1.000					
Factor 2	0.646	1.000				
Factor 3	0.563	0.544	1.000			
Factor 4	0.305	0.447	0.096	1.000		
Factor 5	0.472	0.429	0.307	0.215	1.000	
Factor 6	0.578	0.514	0.549	0.197	0.500	1.000

All analyses were carried out using the Japanese version of SPSS for Windows version 19.0 (IBM Corporation, Armonk, NY, USA), and statistical significance was set as P < 0.05.

Results

Demographics

The clinical profiles of the patients and their social conditions are shown in Table 2. Total scores of DBD and ZBI increased (indicating worsening), and those of BI and LI decreased (indicating worsening) in patients with worse performance of the MMSE. Social conditions were not different among the six groups. The frequencies of DBD subitems and conditions of the geriatric syndrome are shown in Supporting Information Figs S1 and S2, respectively.

Factors associated with ZBI

First, we carried out comprehensive analysis to identify the impact of BPSD, life function and number of conditions of geriatric syndrome on ZBI (Table 3). Because there was no difference in ZBI score according to the presence or absence of family members at their house, subsequent regression analyses to investigate the association with ZBI were adjusted for age and sex. Total score of DBD was consistently associated with ZBI in all groups (P < 0.001 for all). LI total score was associated with aMCI and cognitive stages from AD29–24 to AD17–12, whereas total BI score was not. Geriatric syndrome had an effect on ZBI in AD23–18 and AD17–12.

To precisely show which DBD factors contribute to increment of ZBI, we carried out regression analyses using the six DBD factors detected by factor analysis (Table 4). Factor 1 (Behavioral disturbance) was associated with ZBI in all stages of AD. In AD29-24, frequency of #4 (Wakes up at night for no obvious reason) was 24.3%, #7 (Paces up and down) 20.6%, and #14, #16, #17 and #21 < 20%. In AD23-18, the frequency of #4 was 35.8%, #7 26.6% and #14 (Moves arms or legs in a restless or agitated way) 23.7%. In AD17-12 and AD11-0, all subitems of factor 1 were present in more than 30% of cases. Factor 2 (Verbal aggressiveness) was associated with ZBI in aMCI and cognitive stages of AD23-18 and AD17-12. In aMCI, the frequency of #5 (Unwarranted accusations) was 28.4% and of #9 (Verbally abusive, swears) was 28.4%. In AD23-18, the frequency of #5 was 37.2%, #9 37.1% and #11 (Cries or laughs inappropriately) 26.1%. In AD17-12, all subitems of factor 2 were observed at a frequency of 20~42%. Factor 3 (Memory impairment) was associated with ZBI in aMCI. The frequency of #1 (Asks same question repeatedly) was 46.8%, #2 (Loses, misplaces or hides things) 47.8% and #13 (Hoards things for no obvious reason) 30.6%. Factor 4 (Motor aggressiveness) was associated with ZBI in AD29–24 and AD11–0. In AD29–24, the frequency of #26 (Destroys property or clothing) was 13.1%. In AD11–0, the frequency of #22 (Makes physical attacks) was 35.2%, and of #26 and #28 (Throws food) was 23.7%. Factor 5 (Incontinence) was associated with ZBI in AD23–18. The frequency of #20 (Urine) 35.8% and #27 (Feces) was 18.0%. Factor 6 (Apathy) was associated with ZBI in aMCI and all stages of AD except AD11–0. The frequency of #3 (Lack of interest) and #6 (Sleeps excessively during the day) was approximately 50% of patients in all subclasses.

Regarding IADL, impaired function of telephone use, transportation, finance handling and responsibility for own medication were associated with CB in men. In women, transportation, shopping, food preparation, medication and finance were important functions for their caregivers (Table 5). Although BADL was not associated with CB in comprehensive analysis (Table 3), we explored possible factors associated with CB by using subitems of BI. As a result, deficit related to motor disturbance (Climbing stairs) was an associated factor in aMCI, impaired bathing and grooming in AD29–24, and inability to dress in AD23–18, AD17–12 and AD11–0 (Table 5).

Regarding geriatric syndrome, comorbidity-related motor function (Falls and palsy), urinary disturbance, sleep disturbance, and fatigue were associated factors in AD23-18 and AD17-12 (Table 6).

Discussion

The present study clearly showed that ZBI score is higher in patients with more severe cognitive decline, and that multiple factors, including BPSD, impaired life function and geriatric syndrome, are independently associated with CB. A variety of positive and passive BPSD were consistent burden factors in aMCI or all patients with AD. Symptoms related to memory deficit were factors related to CB in aMCI. Differential IADL, such as inability to use a telephone, transportation, finance handling, shopping, cooking and responsibility for own medication, and geriatric syndrome were also associated with CB in individual cognitive groups of AD. As components of geriatric syndrome, falls and motor disturbance, sleep disturbance, urinary incontinence, and fatigue were related to CB in AD. Thus, the present study carried out a comprehensive analysis to clarify the factors for CB in several cognitive stages of AD. This information could be important for caregivers to lessen CB, but also for medical professionals for successful management of AD.

aMCI is characterized by memory disturbance without substantial interference with work, usual social activities or other ADL. ¹³ Therefore, BPSD related to memory deficit was the prominent factor associated

Table 2 Clinical profiles and social conditions of study participants

	NC	aMCI	AD29-24	AD23-18	AD17-12	AD11-0	All
\overline{n}	120	126	117	423	254	87	1127
Sex (male/female)	50/70	44/82	42/75	121/302	67/187	25/62	362/799
Age (years)	73.6 ± 5.7	77.0 ± 5.7^{a}	77.7 ± 5.7^{a}	$78.8 \pm 5.8^{\mathrm{a}}$	$80.6 \pm 5.9^{\rm a,b,c,d}$	$80.6 \pm 7.2^{a,b,c}$	78.5 ± 6.2
Education (years)	11.5 ± 2.6	11.1 ± 2.6	10.8 ± 2.5	10.3 ± 2.6^{a}	$9.4 \pm 2.4^{\rm a,b,c,d}$	$8.6 \pm 2.2^{\rm a,b,c,d}$	10.2 ± 2.6
Comprehensive geriatric assessment batteries							
Mini-Mental State Examination	27.8 ± 2.2	$26.0\pm1.8^{\mathrm{a}}$	$25.4 \pm 1.5^{\mathrm{a}}$	$20.5 \pm 1.6^{a,b,c}$	$15.0 \pm 1.6^{\rm a,b,c,d}$	$7.8 \pm 3.2^{\rm a,b,c,d,e}$	20.2 ± 5.8
Geriatric Depression Scale	4.1 ± 2.9	4.2 ± 2.7	4.2 ± 2.6	4.4 ± 2.8	4.9 ± 3.2	5.3 ± 2.9	4.5 ± 2.9
Dementia Behavior Disturbance scale	6.4 ± 6.2	8.6 ± 7.2	12.8 ± 8.5^{a}	$15.6 \pm 9.7^{a,b}$	$20.6 \pm 13.4^{\text{a,b,c,d}}$	$31.8 \pm 17.9^{a,b,c,d,e}$	15.9 ± 12.6
Zarit Burden Interview	9.0 ± 10.5	9.4 ± 8.0	15.7 ± 13.5^{a}	$20.8 \pm 15.2^{a,b}$	$25.5 \pm 16.3^{\mathrm{a,b,c,d}}$	$32.3 \pm 18.8^{a,b,c,d,e}$	19.8 ± 16.0
Barthel index	99.0 ± 3.9	98.8 ± 4.8	98.2 ± 5.2	96.2 ± 9.0	$91.7 \pm 14.1^{\mathrm{a,b,c,d}}$	$75.9 \pm 23.5^{\mathrm{a,b,c,d,e}}$	94.4 ± 12.7
Lawton Index							
Male	4.9 ± 0.6	4.3 ± 1.0	3.7 ± 1.1^{a}	$3.2 \pm 1.4^{a,b}$	$2.6 \pm 1.4^{\rm a,b,c}$	$1.2 \pm 1.2^{\rm a,b,c,d,e}$	3.4 ± 1.5
Female	7.7 ± 0.8	7.1 ± 1.4	6.7 ± 1.4^{a}	$5.7 \pm 1.8^{a,b,c}$	$4.3 \pm 1.9^{a,b,c,d}$	$2.3 \pm 1.9^{\rm a,b,c,d,e}$	5.5 ± 2.2
Social condition: Living with							
Children (%)	33.0	39.2	31.3	46.1	51.4	51.7	44.1
Spouse (%)	56.5	43.2	53.0	34.1	31.9	25.3	38.2
Others (%)	2.6	2.4	0.8	5.5	2.8	10.3	4.1
None (%)	7.8	15.2	14.8	14.3	13.9	12.6	13.6

The patients were divided into six groups: normal cognition (NC), amnestic mild cognitive impairment (aMCI), Alzheimer's disease (AD) 29–24, AD23–18, AD17–12 and AD11–0 (AD patients were subclassified into four groups by Mini-Mental State Examination score). Data are shown as mean \pm SD. ^{a}P < 0.05; comparison versus NC, ^{b}P < 0.05; comparison versus aMCI, ^{c}P < 0.05; comparison versus AD29–24; ^{d}P < 0.05; comparison versus AD23–18, ^{c}P < 0.05, comparison versus AD17–12 (ANCOVA, ageand sex-adjusted, Scheffe).

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Table 3 Factors associated with caregiver burden regarding behavioral and psychological symptoms of dementia, instrumental/basic activities of daily living, total number of geriatric syndrome conditions, age, and sex

•	NC		aMCI		AD29-24		AD23-18		AD17-12		AD11-0	
	β	P	β	P	β	P	β	P	β	P	β	P
DBD total score Barthel Index total score	0.466	<0.001	0.53	<0.001	0.489	<0.001	0.491	<0.001	0.394	<0.001	0.701	<0.001
Lawton Index total score No. conditions of geriatric syndrome Age	-0.208	0.018			-0.263	0.002	-0.25 0.093	<0.001 0.017	-0.172 0.123	0.007 0.039		
Sex (male)							0.082	0.035				

The patients were divided into six groups: normal cognition (NC), amnestic mild cognitive impairment (aMCI), Alzheimer's disease (AD) 29-24, AD23-18, AD17-12 and AD11-0 (AD patients were subclassified into four groups by Mini-Mental State Examination score). Behavioral and psychological symptoms of dementia, and instrumental/basic activities of daily living were evaluated using the Dementia Behavior Disturbance Scale (DBD), Lawton Index, and Barthel Index, respectively. Lawton Index scores were calibrated to a full score of 8 to show the mean of the total participants including men. Dependent variables were summed scores of Zarit Burden Interview, and independent variables were total scores of DBD, Lawton Index, and Barthel Index, and number of conditions of geriatric syndrome, which were entered in a stepwise fashion into multiple linear regression analyses. Standardized β-values and P-values are shown.

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Table 4 Factors associated with caregiver burden regarding behavioral and psychological symptoms of dementia, age and sex

		NC		aMCI		AD29-24		AD23-18		AD17-12		AD11-0	
		β	P	β	P	β	P	β	P	β	P	β	P
Factor 1	Behavior disturbance					0.238	0.009	0.194	< 0.001	0.216	0.001	0.484	< 0.001
Factor 2	Verbal aggressiveness			0.471	< 0.001			0.328	< 0.001	0.26	< 0.001		
Factor 3	Memory impairment			0.166	0.029								
Factor 4	Motor aggressiveness					0.211	0.018					0.229	0.022
Factor 5	Incontinence							0.209	< 0.001				
Factor 6	Apathy	0.336	< 0.001	0.271	< 0.001	0.329	< 0.001	0.134	0.002	0.168	0.006		
	Age							0.104	0.014				
	Sex (male)							0.105	0.012				

The patients were divided into six groups: normal cognition (NC), amnestic mild cognitive impairment (aMCI), Alzheimer's disease (AD) 29-24, AD23-18, AD17-12 and AD11-0 (AD patients were subclassified into four groups by Mini-Mental State Examination score). Behavioral and psychological symptoms of dementia were evaluated using the Dementia Behavior Disturbance Scale (DBD). Factors associated with care burden were analyzed using multiple linear regression analyses in six groups. Dependent variables were summed scores of Zarit Burden Interview, and dependent variables were factors 1-6 identified by factor analysis, which were entered in a stepwise fashion into multiple linear regression analyses. Standardized β -values and P-values are shown.