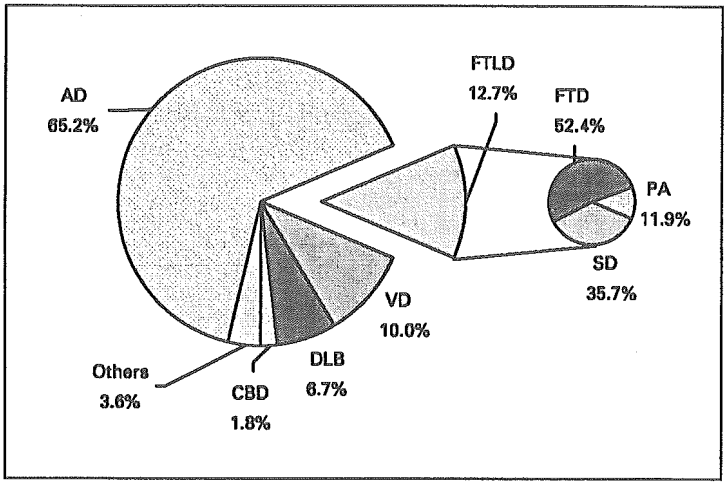

Fig. 1. Percentages of diseases at the Higher Brain Function Clinic in Ehime, Japan (January 1996 to December 2002; 330 outpatients). VD = Vascular dementia; DLB = dementia with Lewy bodies; CBD = corticobasal degeneration.

FTLD has been clinically underrecognized although the original center of the criteria suggested that FTD alone accounts for up to 20% of presenile dementia [3]. Due to the heterogeneity of FTLD, clinical diagnosis is challenging. A detailed linguistic evaluation is essential for the diagnosis of SD and PA, and FTD and SD often share the salient clinical characteristics, such as stereotyped behaviors and dietary changes [4–7]. SD cases are usually misdiagnosed as having atypical AD or Ganser's syndrome, even in a specialist setting [8].

Epidemiology of FTLD in Community-Based Studies

Onset of FTLD occurs most commonly between the age of 45 and 65. Epidemiologic studies of dementia typically survey people aged 65 and older, so they may exclude most cases of FTLD. Our recent community-based study with neuroimaging demonstrated that there were 22 with AD, 28 with vascular dementia, and 2 with FTLD among 60 demented people over 65 years of age [9].

A community-based study of early-onset dementia (i.e., less than 65 years of age) in two areas of London revealed that 12% of cases fulfilled the Lund-Manchester FTD criteria [10] in contrast to 34% with AD in a sample of 185 cases [11]. The Cambridge Group has recently investigated the prevalence of early-onset dementia in a community-based study [12]. Of the 108 cases, FTLD occurred in 15.7% and AD in 25% of cases. FTLD included 13 FTD cases, and 2 each with SD and PA.

Epidemiology of FTLD in Hospital-Based Studies

There are three hospital-based surveys in Japan for the type-specific prevalence of dementia. Of our consecutive 330 demented outpatients (without age limitation) including cases of our previous survey [13], 42 (12.7%) had FTLD (fig. 1). On the other hand, 215 (65.2%) patients met the criteria of probable AD as established by the NINCDS/ADRDA. The ratio FTLD/AD was about 1:5. In our series of patients, 22 FTD, 15 SD and 5 PA cases were identified (fig. 1). Twenty-two FTD cases who showed anterior cerebral symptoms with SPECT-detected marked blood flow reduction in the anterior cerebral region were divided into 12 frontal lobe degeneration (FLD) type cases without remarkable cerebral atrophy on structural imaging and 10 Pick type cases with striking circumscribed atrophy in the frontal and anterior temporal lobes on structural imaging (table 1). There was no family history in all subtypes of FTLD. Of the 75 outpatients in Kyushyu [14], FTD occurred in 6.8% and AD in 45.2% of cases. Of the 327 inpatients in Hyogo [15], there were 6.8% FTLD and 71.0% AD cases.

Snowden et al. [16] reported that they identified only 12 patients with SD over a consecutive period in which 100 patients with the typical behavioral disorder of FTD were referred to the Manchester Clinic.

Table 1. Demographic data of FTLD cases in Ehime (Japan)

	FTD	FLD type	Pick type	SD	PA
Age, years	66.2 ± 8.6	66.2 ± 10.7	66.1 ± 5.5	64.5 ± 9.4	70.9 ± 14.9
Sex (M; F)	9; 13	5; 7	4; 6	5; 10	2; 3
MMSE	17.6 ± 9.2	18.8 ± 8.2	16.3 ± 10.5	15.3 ± 11.1	14.8 ± 11.1
Duration, years	3.1 ± 2.0	2.4 ± 1.1	3.8 ± 2.4	2.7 ± 1.3	4.8 ± 3.7

Results are means ± standard deviation.

Heredity of FTLD

The above-mentioned epidemiologic studies, both community-based and hospital-based, demonstrate that FTLD is a more common cause of early-onset dementia than previously recognized. Regarding the subtypes of FTLD, in Japan, compared with the data from the UK, FTD is less common, SD may be more common and PA is equally common.

The reason for this discrepancy may be based on the role of heredity; namely, most Japanese cases of FTLD are solitary [17], while the FTLD cases of western countries were reportedly accompanied by an extensive family history. In a community-based study by the Cambridge Group, almost one third of cases (29%) with FTLD had a positive family history [12]. In a nationwide survey in the Netherlands, 38% of FTD patients had 1 or more first-degree relatives with dementia before the age of 80 compared with 15% of the control subjects [18]. In a hospital-based study by the Manchester group [16], a family history was seen in all subtypes of FTLD and 50% of FTD cases had a family history, as in a Swedish series [19]. In Japanese cases of FTLD, heredity is reported to be exceptional and quite rare [20]. A few recently reported familial cases in Japan had FTD and parkinsonism linked to chromosome 17 [21, 22].

Conclusions

Distinctive clinical features in FTLD include behavioral, affective, and cognitive symptoms. In particular, unusual behaviors of FTLD patients, such as disinhibition, loss of social awareness, overeating, perseverative and stereotyped behavior, and impulsivity are serious obstacles to managing and caring for patients with FTLD [23]. Finally, we would like to insist firstly that accurate diagnosis is indispensable to talk about the epidemiology of FTLD, and secondly that clinical accurate diagnosis needs neuropsychiatric symptomatology and clinical neuropsychology.

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〈研究成果3〉

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ORIGINAL ARTICLE

Problems family caregivers encounter in home care of patients with frontotemporal lobar degeneration

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Abstract

Aim: Frontotemporal dementia (FTD) is a degenerative dementia in which primary degeneration of the frontal region of the brain occurs. Because of the behavioral symptoms, the care of FTD patients has numerous problems. However, little has been clarified with regard to the actual care situation, especially in a family care setting. The aim of the present study was to elucidate the caregiver burden and problems associated with the care of FTD patients in home care settings.

Methods: Two patients were diagnosed with FTD on the basis of the Lund and Manchester group criteria at the clinic for outpatients of a hospital located in Aichi Prefecture, Japan. Semi-structured interviews were conducted with the family caregivers of the FTD patients. The content of the interview covered the patient course and any problems encountered in the home setting regarding activities of daily living (ADL), behavioral disorders and cognitive function.

Results: These FTD patients had abnormal eating behaviors such as cramming of food into one's mouth and the abnormal manner of eating. They had to be fed bit by bit with total caregiver assistance. They were also overactive, restless and distractable, which subsequently caused problems with ADL-assistance including extreme uncooperativeness toward their caregivers. Other behavioral symptoms associated with FTD, e.g. stereotypic behavior, distractability and high impulsivity, were also considerably burdening to the caregivers.

Conclusion: The behavioral symptoms peculiar to FTD pose huge problems and heavy burden to the family caregiver. More resources should be allocated to specific needs the FTD patients and their families.

Key words: caregiver burden, frontotemporal dementia, Pick's disease, qualitative study, semi-structured interview.

INTRODUCTION

Frontotemporal dementia (FTD) is a degenerative dementia in which the primary degeneration of the frontal region of the brain is exemplified by Pick's disease. It is the third most prevalent form of degenerative dementia, followed by Alzheimer's disease and dementia with Lewy bodies.[1] In the presenile stage, it has been reported along with Alzheimer's disease as the most common type of degenerative dementia.[2] Although no large-scale epidemiological surveys have been conducted in Japan, reportedly, it is not rare.[3] The clinical diagnostic criteria for FTD have been proposed by members of the international working group on frontotemporal lobar degeneration. Its main clinical characteristics beginning with the early course include a decline in social interpersonal conduct, impairment in regulation of personal conduct, emotional blunting and loss of insight.[1] Other recognized features of FTD included stimulus-bound behavior, disinhibition, impulsivity, stereotypic behavior, apathy,

indifference, and eating disorders.[4-9] Since these behavioral characteristics of the FTD patient translate into numerous problems at the care level, the treatment of such symptoms is said to be extremely difficult.[4] Despite the many clinical findings amassed on the behavioral symptoms of such FTD patients, little has been clarified with regard to the actual care situation, especially in a family care setting.[10] The aim of the present study was to elucidate the caregiver burden and problems associated with the care of FTD patients in home care settings.

METHODS

Two patients were diagnosed with FTD on the basis of the Lund and Manchester group criteria in July 2002 at the clinic for outpatients of a hospital located in Aichi Prefecture, Japan. Informed consent in writing was obtained from the co-residing principal caregiver who was also a member of the family of each patient.

Semi-structured interviews were conducted with the family caregivers regarding these patients in the home care setting. Interviews took place in a hospital consultation room, without the patient or any other involved parties. The intake took about 2 h in both cases. It was not recorded in deference to caregiver preferences, but the interviewer (KK) was allowed to take notes. The content of the interview covered the following topics: the patient course and any problems encountered when providing care in the home setting regarding activities of daily living (ADL) (feeding, mobility, dressing, grooming, bathing), behavioral disorders and cognitive function.

The severity of the dementia of the patients was assessed with the clinical dementia rating (CDR),[11,12] while the cognitive function of the patients was evaluated with the revised version of Hasegawa's dementia scale (HDS-R).[13] The HDS-R is equivalent to the mini-mental state examination (MMSE) for the evaluation of cognitive function and has been widely used in Japan.[14,15] Both the severity of the dementia (CDR) and the cognitive function of the patients (HDS-R) were assessed by one of the authors (NH) who was a consultant psychiatrist.

Activities of daily living and instrumental activities of daily living (IADL) of the patients were assessed by the interviewer (KK) using the following measurements: Barthel index (20-point version);[16,17] physical self-maintenance scale (PSMS);[18,19] and the instrumental activities of daily living scale (IADL).[18,19]

CASE REPORTS

Case 1

Case 1: female, 69 years at time of the interview.
Caregiver: 77-year-old husband.
Family make-up: Couple living alone. Their one daughter had moved away.
Care service used at time of interview: Day care (6 days a week).
Computed tomography scan findings: Circumscribed atrophy of the bilateral frontal and temporal lobes, and prominent atrophy of the caudate nuclei and amygdaloid bodies were evident, along with very mild atrophy of the parietal lobes (Fig. 1).
Evaluation at time of interview: Scores were as follows: CDR 3, HDS-R 0, Barthel index 6, PSMS 0 and IADL 0.
Life history: junior high school graduate. Married at age 20. Worked as an office part-timer, working at home and then as a shop lady.
Present history: In 1988, at the age of 54 years, she showed poverty of speech output and lost her job. Since her driving habits became increasingly dangerous (e.g. stopping in middle of intersections, driving against one-way traffic), consequently, her husband

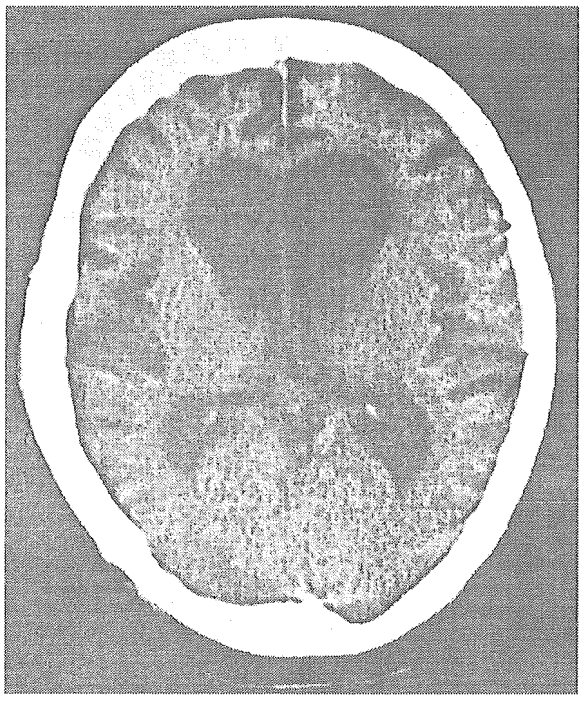

Figure 1 Computed tomography scan of patient 1.

told her not to drive any more so the car had to be disposed of. She was taken by a friend to a certain hospital, she was then diagnosed with Pick's disease. As her dementia gradually progressed, in 1993, at the age of 59 years, a number of times she would bicycle to the station or bus stop, board a train or bus, then lose her way and have to be taken into police custody. Her husband hid her bike, so after that she took walks on her own. She would go out somewhere, but then be unable to find her way home. Gradually, she could not go very far, but often went into homes in the neighborhood. Eventually, her mastication and swallowing became labored. She also started singing oldies, restlessly moving around the house and talking unceasingly. Since the husband was of advanced years and her care placed increasing demands on him, she was admitted to day care in 1998, at the age of 65, where she has remained ever since.

Present conditions of ADL: Since the patient rapidly forced huge amounts of food into her mouth, she often suffered from accidental ingestion. For meals at home, her husband prepares each meal and carefully feeds her by placing small amounts of food in her mouth.

Present conditions of behavioral disorders and cognitive function: An hour before fixed mealtimes, she follows her husband around repeatedly chanting: 'Mealtime, mealtime!' or 'Snack time, snack time!' She herself appears to have fixed the time to go to bed and get up; she growls angrily about them being too early, whereas mealtimes are never early enough. No matter what the demand, once she gets started, she often never desists. All of a sudden, she decides to go out somewhere, bolts out into the street or does something unpredictable. Vigilance is especially necessary in a store, where she touches everything and moves things about during shopping trips. At visits to a hospital or facilities, she shouts and sings loudly, and knocks things around.

Recently, she often falls asleep with the television on. Also she forces her way into neighbors' houses, and she shouts at passersby.

Even more recently, she can only gesture to make herself understood to a certain degree. Although she cannot read, she likes to count, and is especially fond of counting the number of items priced the same in the advertising inserts she comes across in the daily newspapers.

Case 2

Case 2: male, 69 years at time of the interview.
Caregiver: 62-year-old wife.
Family make-up: The couple lived alone. A married son lived nearby. A married daughter lived far away.
Care service used at time of the interview: Day care (6 days a week).
Computed tomography scan findings: Circumscribed atrophy predominant on right frontal and temporal lobes. Atrophy also remarkable in caudate nuclei and amygdaloid bodies, with mild atrophy of the parietal lobes (Fig. 2).
Evaluation at time of interview: Scores were as follows: CDR 3, HDS-R 6, Barthel index 5, PSMS 0, IADL 0.
Life history: High school graduate. Married at age 30. After changing various jobs, the subject used to run a small company.
Present history: In 1996, at the age of 63 years, he frequently refused to take orders from his clients for no apparent reason. He kept complaining how 'cold' it was, even when he took walks in the summer heat. In 1998, at the age of 65 years, he visited his wife's mother's home every day to deliver the same kind of boxed sushi. In 1999, at the age of 66, he visited his son and daughter-in-law's home every day to bring

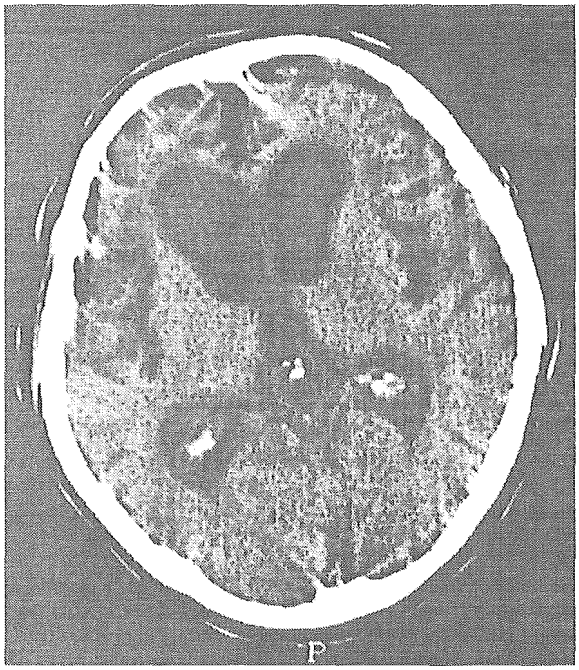

Figure 2 Computed tomography scan of patient 2.

the same kind of dolls to his grandchildren. Once there, he would take his daughter-in-law around to any number of coffee shops, but then would not return home. About the same time, he began to drive very slowly, and even had three car accidents (hit and run), so his wife had to get rid of the car. Once he could no longer drive, he began taking long taxi rides. When he could not scrape up enough money at home for the fare, he would borrow again and again from acquaintances. When his wife told the taxi companies they should no longer pick him up, he would take a train far from home, where he again boarded taxis, and then had to be held in police custody because he did not have the fare. Then, he would wander around on foot again and again from one all-night restaurant to another. He could not pay, so left his name and address to which the restaurant would then send the bills without informing the police.

In 2000, at the age of 67 years, the patient was diagnosed with Pick's disease. He often went out to nearby coffee shops or dropped into a friend's house, and did not return home. His wife changed the front door lock to a magnetic type, so he could not go out so often. Thanks to the cooperation of neighbors, however, his whereabouts became less of a problem. At home, he kept calling his wife, running around after her saying time after time: 'Let's go out', 'Let's go to a coffee shop', or 'Someone's here'. The level of caregiver burden increased so much that he eventually had to be put in day care, which has continued till this day.

Present conditions of ADL: The patient eats tremendous amounts impulsively day or night, eating extremely fast, simply forcing things into his mouth (e.g., he has kept asking for something to drink incessantly during the night; he wolfs down one banana after the other). He is unable to sit still and eat, gets up restlessly and walks around at home. It is impossible for him to stop. He requires total care to groom and dress himself, but keeps restlessly moving around all the time. He is vehemently opposed to taking a bath at home, and even when he does bathe, he often 'jumps out of the tub and runs naked around the house'. He always wears diapers, but moves about so agitatedly that 'the diapers come off; he then stomps on the feces and runs around the house that way'. When he jumps out of the bath, etc., he has taken to roaming around the house, randomly urinating and defecating all the while.

Present conditions of behavioral disorders and cognitive function: Any time the patient requests something, he repeats it over and over again. For example, until a meal or snack is served, he keeps exclaiming 'Mealtime, mealtime', or 'Snack time, snack time'. He is also unable to wait for things, constantly needling his wife when they are together: 'Let's go! Let's go!' and 'Let's go out! Let's go out!' or 'Let's go home! Let's go home!' He demands coffee or tea the minute he goes into a coffee shop or a friend's home, but then almost immediately insists on going home. His demands and behavioral changes are unpredictable. He strongly denies doing anything when asked to stop and rejects requests, making him next to impossible to deal with. In an institution or hospital visit, he always shouts wildly or sings loudly.

RESULTS

Activities of daily living care problems

Both patients ate huge amounts at a tremendously fast pace (hyperphagia). They foraged impulsively without masticating, simply forcing food into their mouths. Both were indeed able to carry food in their mouths, but their fast and reckless eating was a sorry sight to behold. As a result, they never ate adequate and appropriate amounts of food. For this reason, they had to be fed bit by bit with total caregiver assistance. On the ward or in facilities, 'food theft' at mealtime became a problem; they stole from others, from food carts, etc. Both patients suffered from dental caries, peridentitis and other dental problems, but strongly denied it and refused treatment; even if a tooth fell out, tooth replacement was impossible.

As for mobility, neither patient had any problem walking. On the contrary, they walked quickly and would suddenly break into a run, making it difficult to stop them.

The patients relied almost entirely on the caregiver to groom and dress them. They never did it on their own, and made things difficult for the caregiver by restlessly moving around and putting up great resistance to any assistance offered.

Bathing was another task requiring total care. The caregiver task was particularly onerous because the patients either absolutely refused to take a bath, or once in the tub would refuse to come out or suddenly jump out of the tub and dash out of the bathroom.

Caregivers replied that, in all their caregiving duties, the most difficult involved patient bowel move-

ments. Since they were physically fit, the patients had considerable evacuation of feces. Although they wore diapers, there was always leakage, taking the diapers off, or random urination and defecation. This meant a huge amount of cleaning up after them and an extremely high level of caregiver burden.

Behavioral disorders, cognitive function

Both patients underwent personality changes, and early in the course both caregivers had the impression that those in their charge 'lacked energy and were tired', 'weary', and that 'no matter what you ask, you never get a straight answer'. It appeared to them that the cause was psychological or due to patient fatigue. The caregiver of case 1 replied that the subsequent personality had become puerile, while the caregiver of case 2 indicated that she no longer knew what the patient was thinking.

Both patients endlessly repeated any demand they made. This was especially true at meal or snack time. Long before anything was served, they would keep saying 'Supper, supper!' or 'Snack time, snack time!' The caregivers took this to be obstinate pleading, and it indeed added to their burden.

Another factor burdening caregivers was the suddenness of the patient demands made on them, the patient behavior eruptions, their violent denials when forced to stop, and the resistance to demands placed on them. Either patient would run off at the drop of a hat; the caregiver could not take their eyes off of them even for a second. Both caregivers claimed: 'They don't listen to what you say, so you eventually end up hitting them'.

Both patients, moreover, shouted the same words over and over again (verbal stereotypes, palilalia), engaged in loud singing, struck various objects and pursued other such erratic behavior especially when away from home, or while in or visiting a hospital or other facilities. These inappropriate behaviors were often why they were refused access and treatment at hospitals, institutions and facilities.

Case 2 was consistently roaming around, a particularly vexing problem for his caregiver to deal with. Although case 1 early on would 'go around to the same places but seemed to come home', her caregiver did not seem to mind. While the roaming in either case continued for a relatively long time, no matter how far they wandered, the patients still managed to find their way home. With time they could no longer return home on their own, however, and so they only ventured out into the immediate neighborhood. Both patients could sneak out at any time, forcing caregivers to be alert and never let them out of their sight.

As for cognitive function, the caregivers and day care staff felt at the time of the examination that the patients seemed to understand what was told them to a certain degree. Moreover, both were still skillful in some activities (e.g., dicing vegetables (case 1) or writing their name (case 2)).

There were no reports of delusions or hallucinations.

DISCUSSION

In the present study, semi-structured interviews were conducted with the two family caregivers of the FTD patients, who had progressed their symptoms over the years. The interviews provided concrete details on what are still virtually unreported aspects of the family care of such patients, along with the problems and caregiver burden specifically associated with FTD patient care. The results clearly showed that the behavioral symptoms peculiar to FTD present huge problems and heavy burden to the family caregivers.

First, bizarre eating behavior is considered one form of behavioral abnormality, which is peculiar to FTD patients: the cramming of food into one's mouth[7,8] and the abnormal manner of eating.[8] Both cases in the present study showed such behavior, which meant much time had to be devoted to assistance, all of which made an immense burden for the caregivers. The frequent pilfering of food during short stays in the hospital or facilities also posed a problem. On the other hand, the changes in dietary preferences reported elsewhere[6–8,20] do not seem to have been much of a problem for the family caregivers in the present study.

While oral and dental care were considered to be serious problems, family caregivers considered these were matters they were not equipped to handle.

Problems related to ADL-assistance included extreme uncooperativeness against the caregivers; the patients were overactive, restless, distractable, rushing unproductively from one activity to another while being looked after. Such behaviors were taken to indicate absolute refusal or resistance by the caregivers. These behaviors are considered to result from a mix of symptoms that was regularly manifested

in their distractibility,[4,21] disinhibition,[5,7,22] impulsive violence and mood swings out of irritability.[6,7]

Even when the patient has no intention to resist care attempts, there is a tremendous burden on a single family caregiver who must dress the patient and chase around cleaning up after him or her following the disruptive random urinating, bowel movements and the like. The interruption of stereotypic behavior is reported to readily trigger violent acts,[9] but the caregivers in our study did not notice this, or took it rather as a sign of resistance or refusal to accept care.

Stereotypic behavior is also an abnormality peculiar to FTD, and it includes everything from simple repetitive acts to more complex behavior such as roaming.[4] In the cases under study here, repetitive irrelevant utterances, repetitive singing loudly and sudden repetitive knocking of objects within reach may be why facilities are so reluctant to accept such patients or not allow them off the premises once accepted. In both cases, despite the exhausting combination of mealtime demands, their stereotypic daily rhythm and verbal stereotypes, the caregivers appeared to give in to the patient's stubborn demands. Impersistence was recognized from the extreme behavior shown by case 2,[1] and his frequently changing demands took the form of verbal stereotypes. The caregiver appeared to be so intimidated that she gave in to his demands.

The distractability and the high impulsivity associated with FTD[21] are considered to make it almost impossible for caregivers to predict patient behavior. Since the cases reported here showed such sudden and dangerous behavior (e.g., running away, suddenly dashing out into the street), the burden was especially heavy on the caregivers, who had to constantly be on the alert. It took a long time before they could figure out what was behind their patients' behavior and be able to deal with it. 'I don't understand why he (she) does things like this' voices exactly the kind of caregiver frustration they experienced, the kind that does not go away. FTD is still a relatively unfamiliar disease compared to Alzheimer's, and the dissemination of more information would help people better understand both the carer and cared for, while lessening the caregiver burden.

Driving problems fairly early in the course also caused trouble with both patients. In Japan, hardly any medical studies have been devoted to driving-related problems with FTD patients and those with various types of dementia. Studies in this area are much awaited. The cases reported here could well have caused very serious accidents. Thus, there is an urgent need for society to establish safety measures covering driving issues involving elderly people with dementia.

The behavioral symptoms of FTD patients are quite different from those of Alzheimer's disease patients.[6,21,23] They are also reportedly different from those of vascular dementia patients presenting with frontal lobe syndrome.[24] Although short-term hospitalizations have various advantages both for the FTD patients and their family caregivers,[25] few hospitals or institutions will accept FTD patients because of their abnormal behaviors. Thus, it is desirable that hospitals or institutions will undertake improvements in order to provide the short-term stays needed by both patients and, indirectly, the family caregivers. Also, new rehabilitation approaches focusing on the frontal lobe syndrome of FTD patients[26,27] as well as the effectiveness of drug therapy have been reported.[28,29] These new approaches may improve the management of patients with FTD.

ACKNOWLEDGMENTS

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精神医学・46(10)：1063-1069，2004

特集 精神科医療における介護保険制度

地域から見た精神科医療と介護保険*

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Key words

Long-Term Care insurance system, Dementia, Psychiatry, Caregiver burden

はじめに

介護保険制度が導入されて4年が経過した。2003年の4月には介護報酬の見直しや認定ソフトの改訂・認定調査票の修正が行われたが，その時点からの正確な資料を得て分析する時期としては少し早いので，本稿では我々の経験(中山町研究)[13)]を中心に2003年3月までの，地域における介護保険と精神科医療のかかわりについて検討してみたい。

在宅サービスと施設サービスの利用

わが国では，長年にわたって介護は身内でするものとの考えが伝統的に強く[3)]，こうした風潮を反映して，介護者の中にはサービス利用を躊躇する者が多かった。しかし，介護保険の導入に伴い，サービスを利用するにあたって近所の目が気になると答える介護者の割合は確実に減少してきており[5)]，その結果，サービスを利用する者の割合も増加してきていると考えられる[4)]。

2004年4月には，サービス全体の利用者が303万人で介護保険導入時と比較して約2倍に増加，在宅サービス利用者は228万人で同じく約2.4倍増，施設サービス利用者は75万人で同じく約1.4倍増であった[17)](表1)。介護保険制度が順調に浸透し，本制度の眼目の1つである高齢者の自立支援という意味で在宅サービスの利用者が着実に増加していることも明らかである。しかし，施設介護サービスの利用者も増加し，介護給付費では在宅サービスを上回っている。

表2は1997年に開設された中山町唯一の小規模多機能の介護老人福祉施設の入所待機者の数をまとめたものであるが，待機者数が介護保険の導入前後から右肩上がりに増加している。このことは，上述したように制度の普及に伴ってサービスが利用しやすい環境が整いつつあるとも言えるが，従来は在宅介護で支えられていた要介護度の低い高齢者でも，介護者は施設介護を選択する傾向にあることを示しているとも言える。

施設サービスはコストの面でもハードの面でも限界があり，介護報酬についても在宅サービス重視の方針になりつつあるようだが，在宅サービス

* Roles which Psychiatrists should Play in the Era of the Long-Term Care Insurance in Japan

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表1　介護サービス利用者数[17]

	2000年4月	2001年4月	2002年4月	2003年4月	2004年4月
居宅介護サービス	97万人	142万人	172万人	200万人	228万人
施設介護サービス	52万人	65万人	69万人	72万人	75万人
合計	149万人	207万人	241万人	272万人	303万人

表2　なかやま幸梅園の待機者状況

年月	待機人数(人)	備考
1997年10月	0	
1998年4月	4	
1999年4月	20	
2000年4月	22	
2001年4月	39	
2002年4月	65	
2003年4月	68	
2004年4月	52	入所指針により順番制廃止

の利用を推進するためには，在宅介護の負担を軽減するために，痴呆疾患別のケアモデルを開発したり，在宅介護が破綻する要因である痴呆患者の精神症状や行動異常に対する治療法を開発したりする必要があり[14]，精神科医の役割は重要となる。

痴呆の有無と要介護認定

痴呆患者の一次判定が，痴呆を有さない患者の一次判定よりも低く判定されることがモデル事業の時点から指摘されてきた[10]。1998年のモデル事業では，中山町の在宅の参加者のうち一次判定と二次判定の結果がずれた者について検討し，痴呆を伴う群では一次判定に対して二次判定のほうがより重度に，痴呆を伴わない群では二次判定のほうが要介護度をより軽度に判定する傾向を明らかにした[11]。さらにそれに引き続き，1999年10月から中山町で行われた要介護認定の訪問調査全例(178名)に精神神経科医師が同行し，要介護者の痴呆の有無，重症度や精神症状について地元のかかりつけ医に情報を提供した。この要介護認定訪問調査において，実際に訪問調査を行った調査員および同行した精神神経科医師が，要介護度別の状態像例[16]に基づいて要介護度の推定(臨床推定)を行った。そのなかで痴呆の有無，また痴呆性疾患別で，コンピュータによる一次判定の結果と臨床推定がどのように異なるかを検討した[21]。この研究では，厚生労働省の定める寝たきり度C2の12名を除いた能動的に身体を動かすことが可能な166名(男52名，女114名，平均年齢82.4±7.9歳)を対象とした。まず痴呆あり群(87名)と痴呆なし群(79名)の2群に分け，臨床推定と一次判定の一致率を比較した。不一致例の内容については，一次判定が臨床推定よりも高かった割合，低かった割合を集計した(図1)。次に対象の63％を占めるアルツハイマー病(AD)群(35名)と脳血管性痴呆(VaD)群(41名)，ならびに痴呆を伴わない脳血管障害(CVD)群(29名)の3群で疾患別の臨床推定と一次判定の一致率について同様の検討を行った(図2)。

その結果，痴呆あり群のほうが痴呆なし群に比べ一次判定と臨床推定の一致率が低い傾向がみられた。不一致の内容は，痴呆あり群では一次判定が臨床推定より低い傾向が，痴呆なし群では一次判定が臨床推定より高い傾向がみられた。AD群では一次判定が臨床推定より低い傾向が，CVD群では臨床推定が一次判定より低い傾向がみられた。臨床推定と一次判定の間に2段階以上の差を認めた割合はAD群に多い傾向がみられた。本調査でもモデル事業での検討と同様の傾向がみられ，特にAD群ではその傾向が非常に強くみられた。一次判定と臨床推定に2段階以上の差があった割合がAD群で高かったことも，AD患者の一次判定ロジックでの認定調査が難しいことを示していると思われる。今回，一次判定が臨床推定よりも2段階以上低かったAD患者6例は，全例身体的には比較的元気で自力で移動できる(動き回って目が離せない)患者であったことも注目すべき点である。荒井らの調査においても，介護負担が同程度のADとVaDを比較すると，AD患者の要介護度は低く判定されることが指摘され

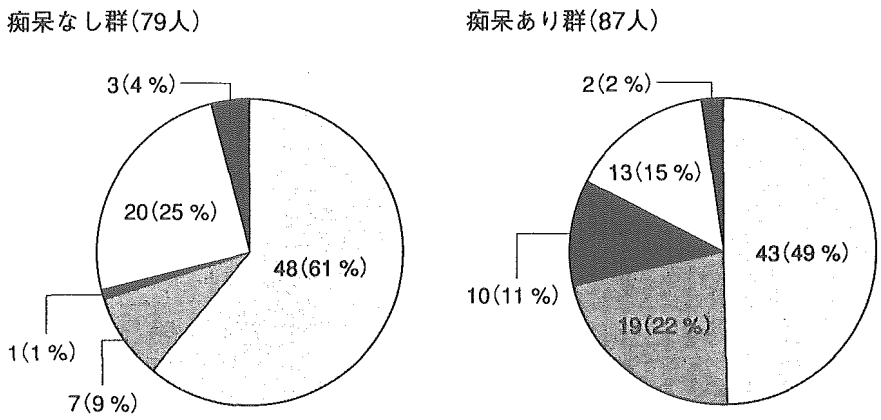

図1　痴呆の有無による臨床推定と一次判定の異同[12)]
推定＝一次：臨床推定と一次判定が一致
推定＞一次：臨床推定が一次判定よりも1段階高い
推定＞＞一次：臨床推定が一次判定よりも2段階以上高い
推定＜一次：臨床推定が一次判定よりも1段階低い
推定＜＜一次：臨床推定が一次判定よりも2段階以上低い

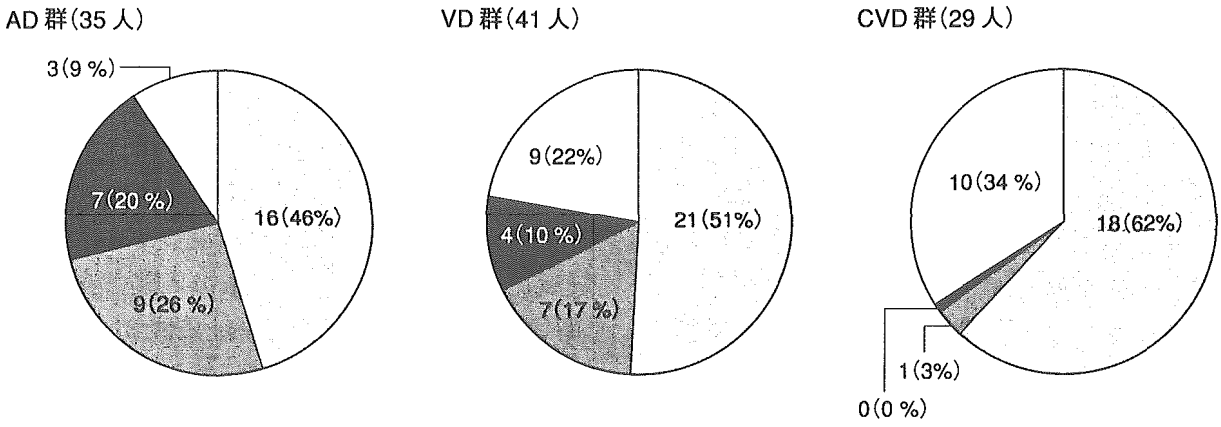

図2　疾患別臨床推定と一次判定の異同[12)]
推定＝一次：臨床推定と一次判定が一致
推定＞一次：臨床推定が一次判定よりも1段階高い
推定＞＞一次：臨床推定が一次判定よりも2段階以上高い
推定＜一次：臨床推定が一次判定よりも1段階低い

ている[6)]。

また，経験のある調査員でもAD患者に特徴的な「場合わせ，取り繕い反応」に気づかず，「何でも自分でできる」と言う患者本人の回答通りに訪問調査結果を提出し，その結果，訪問調査結果と主治医の意見書との状態像に大きな乖離がみられ，再調査になった例を，我々はモデル事業の段階で経験している[15)]。AD患者は，かなり進行した状態でも通常，人との接触性がよく礼節も保たれているため，一見しっかりしているようにみられるからである。短い訪問調査時間の間に，調査員がAD患者の病態像を正確に把握することは非常に難しいと思われる。外来通院患者を対象とした調査では，ADに加えて少数例ではあるが，前頭側頭葉変性症(FTLD)とLewy小体型痴呆(DLB)が臨床推定よりも介護度が低く認定されることが示唆された[19)]。FTLDは人格変化や社会的脱抑制などの行動変化を伴うために家族の介護負担は大きいと考えられるが[18)]，発症年齢が若く記憶障害や見当識障害が目立たないために十

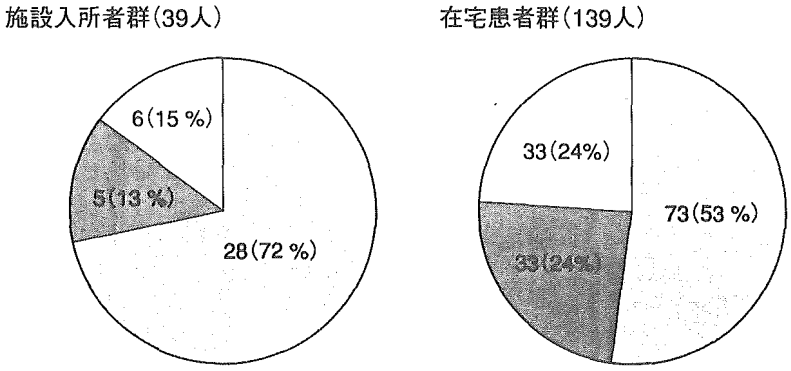

図3　施設入所者と在宅患者における臨床推定と一次判定の異同[12)]
推定＝一次：臨床推定と一次判定が一致
推定＞一次：臨床推定が一次判定よりも高い
推定＜一次：臨床推定が一次判定よりも低い

分な認定が困難であったと考えられる。同様にDLBは初期から幻視などの幻覚症状を呈し，パーキンソン症状が出現し転倒しやすいが，症状の変動が激しいために，一度だけの調査では，たまたま調子の良い時期に調査が行われると実態に比べて著しく低く認定される可能性がある。

このような痴呆を伴う高齢者の要介護度が低く評価されているという指摘を受けて，2003年4月から，介護保険一次判定ソフトが改訂され，認定調査項目も85項目からより厳選された79項目になった。また，全国の介護認定審査会における二次判定に関する過去のデータを活用することにより，運動能力は低下していないが痴呆症状のある高齢者の要介護度について，重度への変更の必要性を一次判定の段階で反映させることができるなど，より効率的な二次判定が可能になるとされた。改訂の結果は，これから慎重に解析していく必要があるが，上記のように，とくにADやFTLD，DLB患者については短時間に調査員が病態像を正確に把握することは非常に難しい。したがって，疾患別の精神症状の評価に日頃から通じている精神科医が主治医となり，意見書の特記事項に正確な症状とそれに基づく介護上の医学的助言を記載することが期待されている[24)]。

在宅患者と施設入所者における要介護認定[22)]

現在の一次判定プログラムが施設データのみに基づいて構築されているため，在宅高齢者への適応妥当性に問題があることが指摘されていた[10)]。しかしその検証はいまだなされていない。本研究では施設データに基づいて作られた一次判定プログラムが，在宅高齢者の要介護度に妥当に反映されているかを検討の目的とし，在宅患者と施設入所患者間で，コンピュータによる一次判定結果と我々が推定した要介護度がどのように異なるかを比較した。上述の中山町訪問調査178名のうち，在宅患者群(139名)と病院への入院を含む施設入所者群(39名)(介護老人福祉施設31名，介護老人保健施設2名，病院6名)の2群に分け，臨床推定と一次判定の一致率を集計した。不一致例の内容については，一次判定が臨床推定よりも高かった割合，低かった割合を集計した。その結果(図3)，在宅患者群は施設入所者群に比べ一次判定と臨床推定の一致率が有意に低かった。臨床推定が一次判定より低い割合，高い割合はともに在宅患者で高かったが，有意な差は認められなかった。

介護保険制度においては，現在までに介護時間からみた在宅介護と施設介護間の整合性の検証は行われていない。我々の行った臨床推定は厚生労働省の示す要介護度別の状態像例に基づいて立てたものであり，本来であればコンピュータの一次判定と差が大きく出ないことが望まれた。しかし，在宅患者群のほうが施設入所者群に比べ一次判定と臨床推定の一致率が低い結果となった。こ

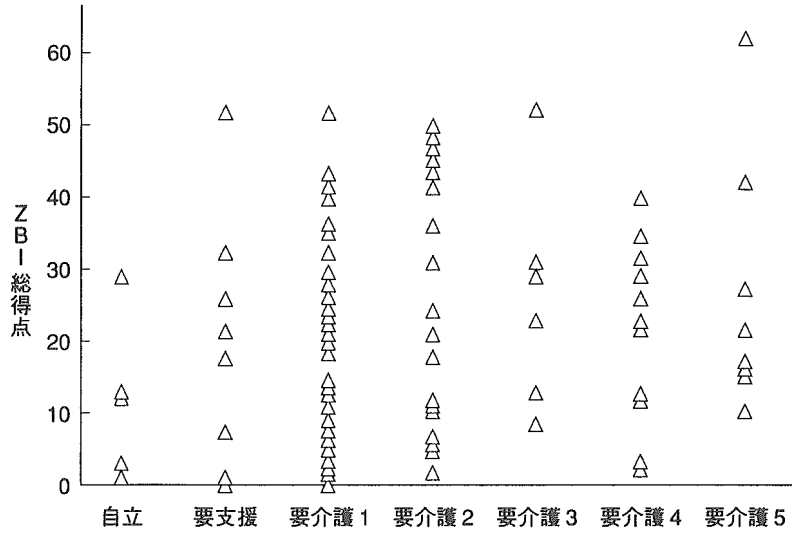

図4　要介護度別の介護負担[12)]
J-ZBI：the Japanese version of Zarit Caregiver Burden Interview

のことは従来から懸念されていたように，施設介護のデータのみに基づいて作られた一次判定ロジックを在宅介護に当てはめることの困難さを示唆しているものと思われる。この検討では，不一致例の要介護度には在宅患者のほうが低く出る，高く出るといった一定の傾向はみられなかった。こうした不一致例の傾向のばらつきも，在宅患者の判定が施設入所者に比べて画一化され難いことを表していると思われる。

上述したように，介護保険の大きな柱の1つは要介護者の自立支援にあり，その点では施設における介護だけでなく，在宅における介護を正しく評価していくことが不可欠である。現状では，これらの一次判定のずれは二次判定で修正されることになっているので，主治医意見書，とくに特記事項の記載内容は重要である。

要介護度と介護負担の関係

今後解決すべき介護保険の課題の1つに，要介護度と介護者の介護負担の関係があげられる。現在の介護保険の一次判定ロジックには介護者の介護負担を評価する項目はない。しかし，介護保険制度創設の目的の1つには家族介護の介護負担軽減があげられている。そこで我々は日本語版Zarit Caregiver Burden Interview[2,7)](J-ZBI)を用いて，中山町で行われた介護保険施行時の要介護認定者の要介護度と主介護者の介護負担の関係を検討した。本研究では今回の同行調査の対象者のうち施設入所者と独居の者を除く，家族が主介護者である在宅患者102名(男32名，女70名，平均年齢82.2±9.0歳)を対象とした。各要介護度の対象者数は要支援：9名，要介護1：38名，要介護2：21名，要介護3：8名，要介護4：13名，要介護5：13名である。その結果，全体として介護保険の要介護度と介護負担の間には相関関係はないと考えられた[20)](図4)。要介護度と介護負担の間に正相関がみられなかったことは，介護負担に影響を及ぼす要因が介護時間だけではないことを示唆していると思われる。

また，筆者の一人である荒井も介護保険導入半年後，宮城県の一地域で同様の調査を実施し，認定された要介護度はJ-ZBIで測定された介護者の介護負担を反映していないことを示した[5)]。この調査は，介護保険によるサービス利用開始後に実施されていることから，各要介護度に応じてサービスが提供されているので要介護度別の介護負担の差はみられなかったと解釈されている。

介護保険導入直後の介護負担の変化については，荒井らの調査では40％近くの介護者が負担は減少したと回答しており，増加したとする約

10％を大きく上回った[5]。また，三重県における調査[9]でも同様の結果であり，介護保険制度が在宅での介護負担をある程度軽減させていると評価できる。しかし，荒井らの調査[8]や我々の外来通院例での検討[19]では，介護保険導入前後で介護負担は変わらないとする介護者も多いので，今後，特に在宅での介護負担に影響を及ぼす介護上の要因を詳細に検討し，介護負担を増大させる要因を十分に考慮した一次判定ロジックに改良していくことが必要である。

介護予防に向けて

厚生労働省社会保障審議会・介護保険部会は，2004年7月30日に「介護保険制度見直しに関する意見」をとりまとめた[17]。その概要は，年々増加する介護給付費の伸びを抑えるため，要介護度が低い対象者は，新たに創設される「新・予防給付」の対象とし，介護保険以外の制度も一体となった「総合的な介護予防システム」の導入を盛り込んだことである。

とりわけ，「総合的な介護予防システム」においては，介護予防には介護が必要になる前からの取り組みが大切であることから，現在，介護保険とは別に各市町村などが実施している介護予防事業・地域支えあい事業などを再編し，介護保険の事業と一元化して各市町村などが計画的に管理・運営することとした。これにより，各市町村などの介護予防・痴呆予防における役割と権限が強化されることになった。

我々は，2002年7月から中山町において痴呆予防事業を展開しており，ごく軽度の痴呆症対象者に対して，積極的に予防介入を行ってきた[23]。こうした予防介入は，既存の介護保険サービスの利用へ比較的スムーズに移行できるメリットがある一方，的確に対象者の状態を把握できる評価尺度がないため，客観的な評価に結びつきにくい。したがって，新たな評価尺度の開発も，これからの課題である。また，高齢者の引きこもり予防のための生きがい活動支援通所事業(生きがい対応型デイサービス事業)で相談員が痴呆疑いの高齢者を発見したり，地域住民から情報が上がったりしても，若い世代の同居家族がそれを認識できないことも課題となっている。対象者本人だけでなく，家族を含めた在宅地域全体を痴呆予防事業に取り込んでいくことも，精神科の地域医療の課題の1つである。

おわりに

精神科医は，日常臨床において主治医としてかかりつけ医の意見書の記載，認定委員として介護認定審査会への参加，ケアマネジャーとしてケアプランの作成，などさまざまな形で介護保険とかかわりを持っている。その中でも，他科の医師や他職種からとくに求められているのは，痴呆患者における意見書の作成や認定業務に関する役割であろう。介護認定審査会での適切な介護度への修正を可能にするためには，調査員の特記事項，主治医の意見書に，一次判定では浮かび上がってこない，それぞれの痴呆性疾患特有の認知機能障害，精神症状や行動異常とその重症度，介護状況を詳細に記載することが非常に重要である。また我々精神医学に携わる者は，痴呆性疾患の精神症状などがどのように介護に影響を及ぼすのか検討し，痴呆疾患別のケアモデルを開発したり，在宅介護の破綻する要因である痴呆患者の精神症状や行動異常に対する治療法[14]を開発したりすることが急務であると思われる。

さらに，精神科医にとって，介護保険制度と前後して発足した地域福祉権利擁護事業と成年後見制度の適切な利用を促進していくことも重要な役割の1つであろう。介護保険制度は契約であり，痴呆患者は成年後見制度を通して介護保険契約をするという趣旨から，これらは同時に導入されたのである。しかし，契約者が痴呆患者の場合，ほとんど家族が痴呆患者の介護保険契約を代行しているのが現状である。これは法的には無効であるという法律家の指摘もある[1]。また，自分の能力がなくなった後の自己決定を確保するという任意後見制度や軽度痴呆患者のための補助の新設も，有効に機能しているとは言い難い。これらの有効

利用とは不可分の痴呆の告知に関する問題など，精神科医療に突きつけられている課題は重い。

本研究の一部は，平成16年度老人保健事業推進費の補助を受けて行ったものである。

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Young Investigator Award Winner's Special Article

Family Caregiver Burden in the Context of the Long-Term Care Insurance System

Yumiko Arai.[1]

This paper covers our recent work regarding family caregiver burden for elderly. The topics are as follows: cross-sectional studies on caregiver burden; changes in caregiver burden; appropriateness of the Long-Term Care insurance assessment scheme; attitude towards caregiving among caregivers; and the development of the short version of the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI_8).
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Key words: burden, caregiver, Japan, long-term care.

Introduction

An increase in the number of impaired elderly people and a concomitant decrease in the capacity of informal care (partly due to the increasing development of the nuclear family and more career-oriented women) have now made caregivers' burden a social issue not only in Japan but many in developed countries.

It was Professor Steven Zarit of Pennsylvania State University that first proposed an operational definition of caregiver burden as the extent to which caregivers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relative. He then developed an assessment tool for the feelings of caregiver burden based on the above definition, the Zarit Burden Interview (ZBI).[1,2] The ZBI is now the instrument most widely used in North America and Europe for assessing the burden experienced by family caregivers who look after the community-residing impaired elderly.

We developed a Japanese version of this assessment scheme, called J-ZBI,[3] which is currently the most widely used assessment tool for caregiver burden in Japan. This paper is a review of our most recent work related to caregiver burden.

Cross-sectional studies on caregiver burden

A study was conducted using the J-ZBI in Japan in 1998 in order to identify the factors related to the feelings of burden experienced by family caregivers who looked after the impaired elderly. As in previous studies in North America and Europe, it was found that behavioural disturbances were a strong correlate of the feelings of caregiver burden (odds ratio = 4.75, 95% confidence interval = 1.45-15.54, p=0.01).[4] The above findings did not differ after the Long-Term Care (LTC) insurance system was implemented; behavioural disturbances have remained a strong correlate of the feelings of caregiver burden (odds ratio = 7.16, 95% confidence interval = 1.48-34.70, p=0.01).[5]

Changes in caregiver burden

We conducted a survey every year from 1998 through 2001 targeting all disabled elderly and their principal caregivers residing in Matsuyama Town located in rural northern Japan. The design of this Matsuyama Caregiver study was described in detail elsewhere.[6,7]

As a part of the study, a longitudinal analysis was conducted between October 1998 and October 2000. This analysis was an

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attempt to determine how caregiver burden may have changed before and after the implementation of the LTC insurance system. It was found that the number of services used in 2000 was significantly greater than in 1998. However, caregiver burden itself did not change from 1998 to 2000, the first year in which the new system had been in place.[8] We conducted a similar analysis to compare caregiver burden between 1999 and 2001. As shown in Figure 1, there was no significant difference between the mean J-ZBI score in 1999 and 2001.[9] Overall, these longitudinal studies show that the degree of caregiver burden did not change among the caregivers who had been providing care prior to the launch of the LTC insurance scheme.

We also made comparisons between caregivers of the disabled elderly in 1999 and those entrusted with their care in 2001 in terms of their degree of caregiver burden by Analysis of Co-variance (ANCOVA), adjusting for other variables. As shown in Figure 2, the adjusted J-ZBI mean score in 2001 was not significantly different from that in 1999, indicating that feelings of burden among caregivers did not change after the implementation of the LTC insurance system.[9]

Appropriateness of LTC insurance assessment scheme

In the LTC insurance, services are allocated based on the Government-certified Disability Index (GCDI) (Yokaigodo).[10] We were interested in whether the LTC insurance system in Japan indeed developed a fair and appropriate way of allocating resources to the nation's disabled elderly population, especially those with dementia. Specifically, our study investigated whether the GCDI scores under the LTC insurance program adequately reflected the needs of people with DAT (dementia of Alzheimer's type) and VD (vascular-type dementia). As a result, the GCDI score among the DAT patients proved to be lower than among the VD patients, indicating that DAT patients were classified as "less disabled" on their GCDI than VD patients, as shown in Figure 3.[11] Since the amount of care services patients are allowed to use under the LTC insurance plan is determined solely by the GCDI score, it appears that the people with DAT in the study were allowed fewer care services despite the fact that the severity of their dementia was the same as for a VD patient.

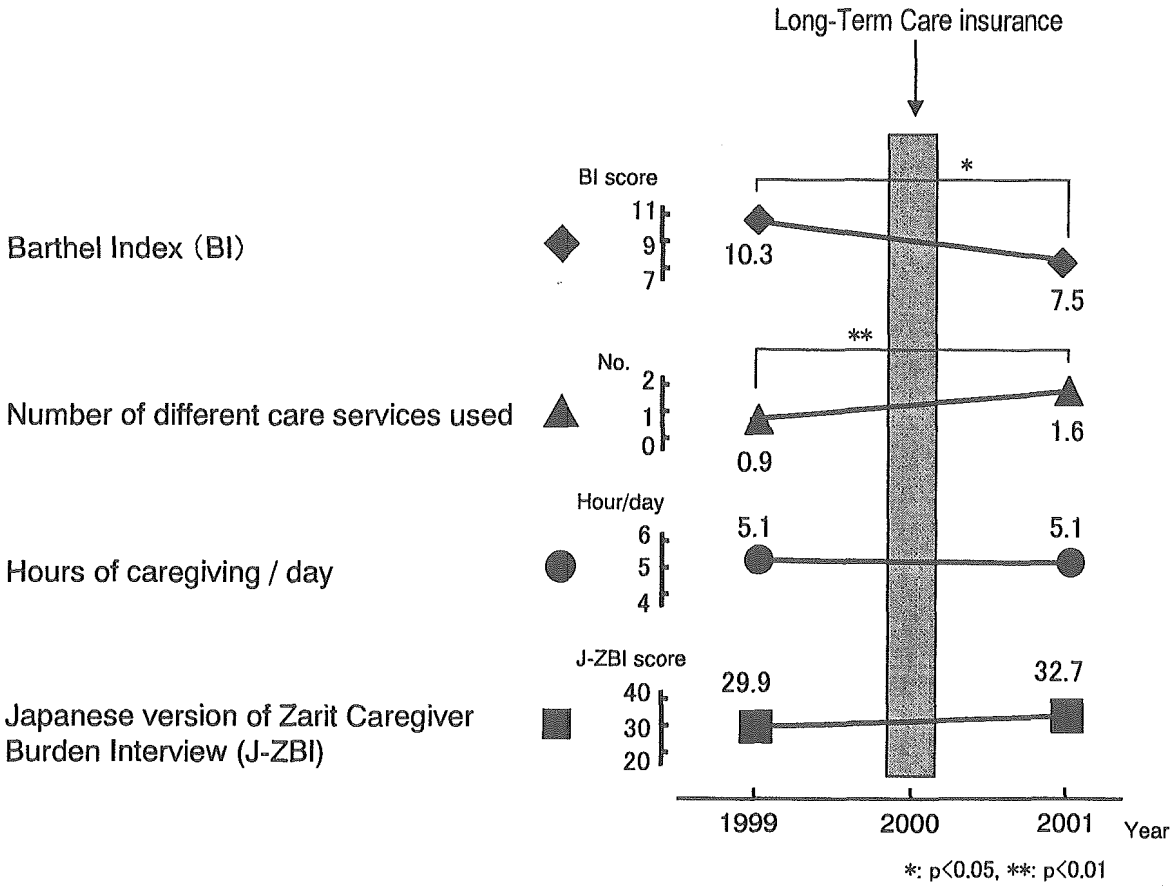

Figure 1. Changes in variables between 1999-2001.

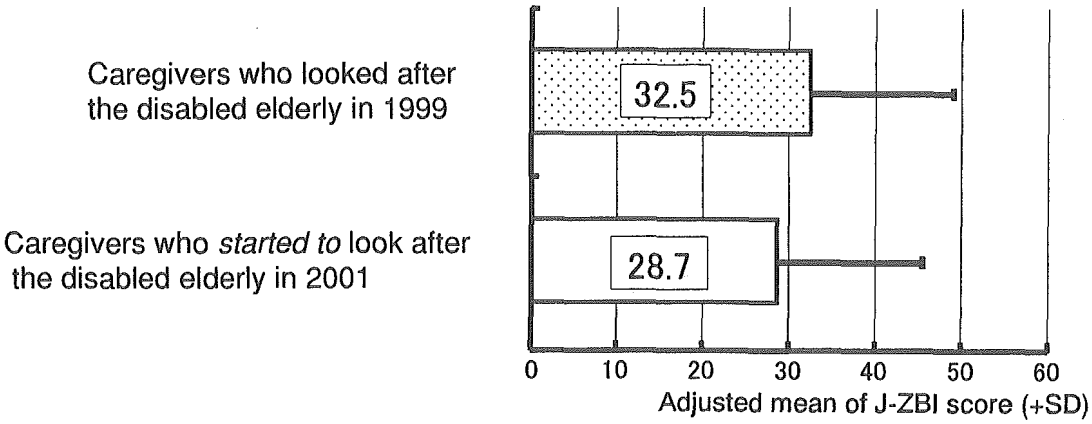

Figure 2. Comparisons of J-ZBI score between caregivers who looked after the disabled elderly in 1999 and those who *started to* look after the disabled elderly in 2001. Adjusted by caregivers' age, caregivers' sex (female=1), age of disabled elderly, duration of caregiving(month), no. of family members, ADL score (Barthel Index), score of behavioral disturbances (TBS).

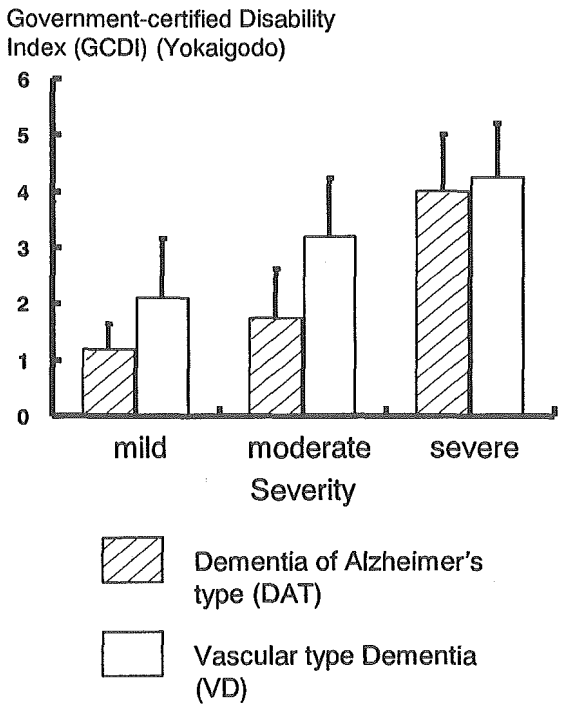

Figure 3. Government-certified Disability Index(GCDI) (Yokaigodo) and severity in DAT and VD patients.

Attitude toward caregiving among caregivers

The LTC system has demonstrably changed the attitudes of caregivers. It was found that more caregivers came to believe that society must look after the elderly after only one year under the new program.[12] In the short space of a year, there was an obvious shift from the idea that the care of old folks falls to the family to the virtually unheard-of notion that society must shoulder the problems of the world's fastest-graying population.[12,13]

Development of short version of Japanese version of Zarit Caregiver Burden Interview (J-ZBI_8): its reliability and validity

In the era of LTC insurance, it has become even more important to monitor the well-being of not only the impaired elderly but also the family caregivers. In this regard, in order to facilitate the assessment of family caregiver burden in clinical settings, we proposed a short version of the J-ZBI, consisting of the following two factors: Personal strain (5 items) and Role strain (3 items). These eight items are presented in Table 1. It was demonstrated that the newly proposed short version, J-ZBI_8, had high reliability, concurrent validity and construct validity.[14] Subsequently, the cross validation was conducted.[15,16] Overall, the J-ZBI_8 produced results comparable to those of the full version, i.e., the J-ZBI. The shorter yet no less reliable and valid eight-item version will thus lead to easier administration of the instrument for assessing family caregiver burden in clinical settings.

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