

G. 粗大運動

① 寝返り等	3. 介助なしで自由に体位を変えられる 2. 動きはやや限られるが体幹や四肢は動かせる 1. 時々体幹や四肢を動かす (体圧の除去には有効な動きではない) 0. 介助なしでは体幹や四肢を動かせない
② 起きあがりの自立度 (背臥位から座位まで起きあがれるか)	3. 自立 2. 声かけ見守り準備 1. 部分介助 0. 全介助
③ 座位保持	2. 自力で安定 1. 不安定・体位を変えられる 0. 自力保持不可・ずり落ちる
④ 日中の起居	0. 寝たきり 1. 座位まで 2. 自宅内での活動 (時々室内を歩く) 3. 外出が多い
⑤ 屋外の移動 (屋外での歩行訓練なども含む)	3. 自立 2. 声かけ見守り準備 1. 部分介助 0. 全介助

H. 認知・覚醒

⑤ 場所の見当識	2. 問題なし 1. 拒否 0. 問題あり 0. 覚醒しない
⑥ 短期記憶 (5分位前のことが思い出せるか)	2. 問題なし 1. 拒否 0. 問題あり 0. 覚醒しない
⑦ 表現・伝達力	3. 問題なく表現可能 2. 困難が伴う 1. 限られた内容のみ 0. ほとんど不可
⑧ 理解力	3. 問題なく理解可能 2. 困難が伴う 1. 限られた内容のみ 0. ほとんど不可
① 覚醒水準	2. 覚醒している 1. 呼びかけや刺激で覚醒する 0. 刺激で覚醒しない
② 視力 (眼鏡使用の場合、矯正視力で評価)	4. 問題なし 3. 小さな字を読むのが困難 2. 目の前の指は数えられる 1. 動いているものは見える 0. 見えない。明るさのみわかる
③ 聴力 (補聴器利用も可)	3. 問題なし 2. 少し問題あり 1. あまり聞こえない 0. 実質的に聞こえない
④ 痛みなどに対する知覚：	3. 障害なし 知覚の欠損なし。呼びかけに反応し痛みや不快感を訴えることができる。 2. 軽度障害 部分的な痛覚等の知覚障害。不快感等を常に伝えられるわけではない。 1. 重度障害 体の半分以上で痛覚等の知覚障害。痛みのみで反応 (うめく・動くなど)。 0. 全く知覚なし (痛みに対する反応無し)。体のほぼ全体にわたる痛覚障害

I. 麻痺

① 運動麻痺	1. 無 0. 有 部位 ()
② 拘縮	1. 無 0. 有 部位 ()
③ 咀嚼の問題	1. 無 0. 有
④ 嚥下の問題	1. 無 0. 有

Network for improving the dementia care system

Yumiko ARAI and Keigo KUMAMOTO

Department of Gerontological Policy (Health Policy for the Aged), National Institute of Longevity Sciences, Aichi, Japan

Correspondence: Dr Yumiko Arai, Departmental Head, Department of Gerontological Policy (Health Policy for the Aged), National Institute for Longevity Sciences (NILS), 36-3 Gengo Morioka-cho, Obu-shi, Aichi 474-8522, Japan. Email: yarai@nils.go.jp

Key words: caregiver, dementia care, long-term care insurance.

INFORMAL NETWORK: TRADITIONAL WAY OF PROVIDING CARE FOR THE IMPAIRED ELDERLY

Informal care in Japan is unique for two reasons.¹ First, there has been tremendous social pressure on the family, particularly on female members, to provide care. This is partly due to Confucianism, where the virtue of filial piety has been strongly stressed, if not enshrined. Second, a caregiving role used to be a legal obligation for the eldest son of the family. Before World War II, Japanese civil law stipulated that the eldest son would inherit the assets of the family; in turn, the entire responsibility of caring for the parents fell to the wife of the eldest son, the daughter-in-law.

The government made good use of this Confucian-influenced norm, which has continued to be influential in Japanese society even after World War II. Indeed, the prime minister of Japan in 1979 strongly reiterated the importance of 'Japanese-style welfare', in which self-help, tolerance, and the solidarity of the family are the priorities. The government even stressed that the 'European-style welfare state' might discourage the prevailing notion of caregiving as a family duty. Under these circumstances, it was not surprising that the government was reluctant to provide social services. The development of domiciliary care in Japan has thus lagged far behind that in the UK or Scandinavian countries. Social services that were available had to have municipal approval after means testing.

An increase in the number of impaired elderly people and a concomitant decrease in the capacity

of informal care (partly due to the increasing prevalence of the 'nuclear family' and career-oriented women) have now made 'caregivers' burden' a social issue.²⁻⁴

Moreover, the overemphasis on family values and self-help at the policy level has enhanced the stigmatization of social services in Japan. Indeed, there has been a persistent notion that welfare is for those who have slipped out of the 'normal' social net where self-help and/or informal help can be provided. In turn, social services have been targeted at those who lack social support and have low incomes. Interestingly, 20% of the elderly surveyed by a government agency stated that caregivers should *not* use public services. Another 36% held that only a minimum number of public services should be used, and only when caregivers are about to reach burnout.⁵

In a rural area in Japan, 42% of healthy elderly people also declared that they would not wish their family to turn to social services even if they were to develop dementia.⁶ In addition, family caregivers overconcerned about others' opinions were five times less likely to use social services in a rural township in northern Japan.⁷

Overall, care based on the informal network in Japan may be characterized as follows: ample informal care based on Confucianism and family structure; and long-standing government indifference in providing sufficient and well-accepted social services. However, the informal network is no longer able to cope with the rapid increase in the number of frail elderly people, including those with dementia. This has

resulted in the increasing burden on caregivers. The government thus launched the long-term care insurance scheme to establish a formal network of care for frail elderly people, including those with dementia.

FORMAL NETWORK: LONG-TERM CARE INSURANCE

The long-term care (LTC) insurance scheme ostensibly pays for institutional and home-based care, not only for those aged 65 years or more who require care, but even for people over 40 years with ‘age-related’ diseases such as dementia.⁸ Under the scheme, each municipal government is a deemed insurer, and the level of services is determined by the clients’ degree of impairment. The extent of informal care available to clients is no longer taken into account when eligibility is determined. This has been regarded as a historic departure from conventional social policy in Japan.⁹

As shown in Figure 1, the LTC system has demonstrably changed the attitudes of caregivers. After only 1 year under the new program, many caregivers came to believe that society must look after the elderly.¹⁰ In the short space of a year, there was an obvious shift from the idea that the family must provide care for the aged, to the previously unheard-of notion that society must shoulder this burden in the world’s fastest-aging population.^{10,11}

Under the LTC insurance scheme, services are allocated based on the government-certified disability index (GCDI) (*Yokaigodo*). To calculate the GCDI, a

care manager who is assigned to a particular client conducts an assessment of the client’s disability, using a 79-item tool developed by the Ministry of Health, Labor and Welfare.⁸ These 79 items mainly deal with activities of daily living (ADL), with less emphasis on the cognition and behavioral problems presented by the client. A government computer program then uses an algorithm to calculate the client’s GCDI score from the data gathered by the care manager. Following the calculation of this score, a so-called ‘certification committee’, consisting of visiting nurses, physicians and, in some cases, a psychiatrist, reviews the computer-calculated GCDI score. The committee can accept or change the score, taking into account a report submitted by the client’s primary care physician. The final GCDI scores range from 0 to 6, and indicate the amount that can be spent on services for a particular client with a given score. Once this review has been completed, a care management agency in the area steps in to provide the services indicated by the GCDI score.

In order to compare the efficiency of care delivery for the physically disabled elderly with that for the elderly with dementia, we present the following two examples. In the case of the physically disabled elderly—for example, the elderly with stroke—they are treated by specialists at the acute stage, as shown in Figure 2. Then, when discharged from a hospital, they are treated by primary care physicians. Alternatively, the physically disabled elderly could apply to the municipal government for social services under the

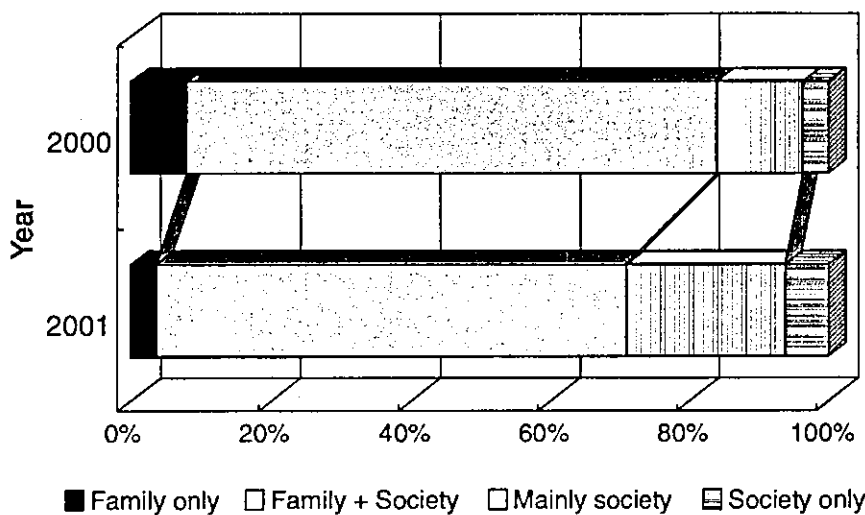


Figure 1 Changes in caregivers’ attitudes regarding who should care for the impaired elderly.

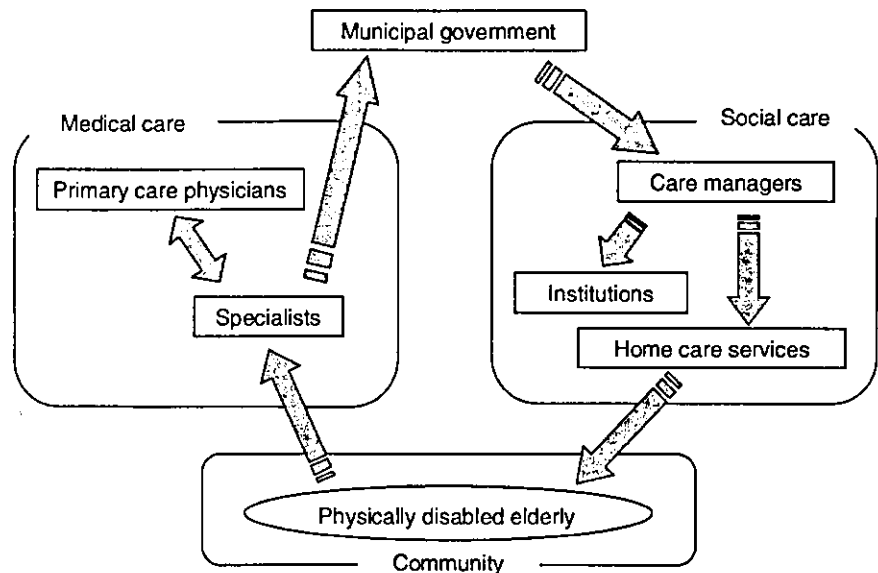


Figure 2 Care network for the physically disabled elderly.

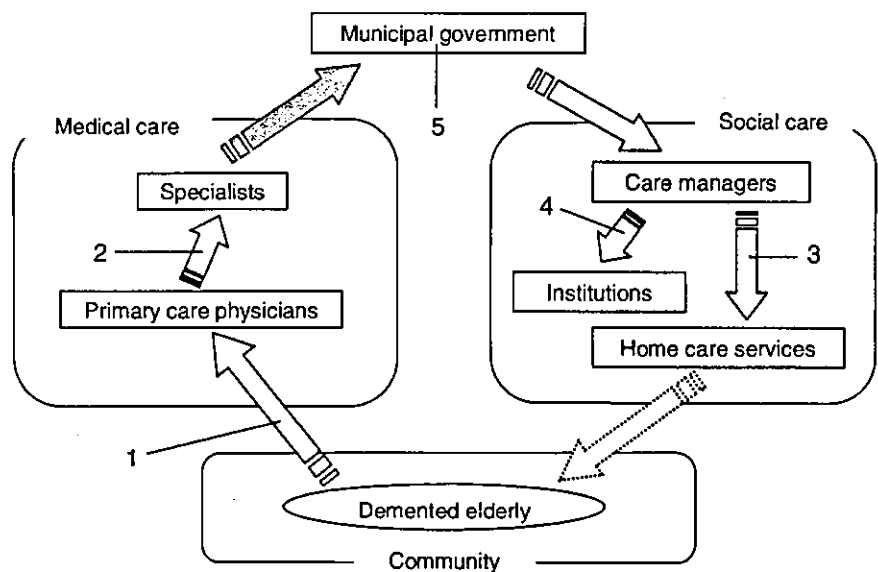


Figure 3 Care network for the elderly with dementia.

LTC insurance scheme. After the degree of their physical disability is assessed, they can find out the number and type of services they would receive by consulting the care managers. In the case of the physically disabled elderly, this care network is operating fairly well, particularly after the implementation of the LTC insurance scheme.

In contrast, there are quite a few problems with the care network for the elderly with dementia, as shown in Figure 3. First, there are problems in obtaining medical care for the elderly with dementia. For example, family caregivers take 1–2 years to contact primary

care physicians after they notice ‘something wrong with their elderly’ (Fig. 3-1). Then, it usually takes another 1–2 years after the primary care physicians are consulted for the caregivers to contact the specialists; that is, psychiatrists (Fig. 3-2).

To investigate why primary care physicians are not contacted immediately when a problem is detected, in-depth interviews were conducted with family caregivers. First, the idea of their loved ones having ‘dementia’ never occurred to some family caregivers. They simply do not know what to do when they see ‘some sort of change in the personality’ or ability—for

Table 1 The shortened Japanese version of the Zarit Caregiver Burden Interview (J-ZBI_8)

1. Do you feel embarrassed over your relative's behavior?†‡	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
2. Do you feel angry when you are around your relative?†	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
3. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?‡	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
4. Do you feel strained when you are around your relative?†	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
5. Do you feel that your social life has suffered because you are caring for your relative?‡	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
6. Do you feel uncomfortable about having friends over because of your relative?‡	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
7. Do you wish you could just leave the care of your relative to someone else?†	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always
8. Do you feel uncertain about what to do about your relative?†	0. Never	1. Rarely	2. Sometimes	3. Quite frequently	4. Nearly always

†J-ZBI_8 Personal Strain; ‡J-ZBI_8 Role Strain.

example, in managing finances—of their loved ones (Fig. 3-1). Second, patients themselves often do not want to go and see a doctor. Primary care physicians and specialists often have difficulty working together as well. Primary care physicians are not always aware of the symptoms of dementia in its early stages (Fig. 3-2) and there is the lack of a referral system from primary care physicians to specialists (Fig. 3-2). Third, the family care burden is heavy, as measured by the Zarit Caregiver Burden Interview (J-ZBI_8) (Table 1).

It has also been revealed that there are two reasons why family caregivers do not contact specialists. First, family caregivers are hesitant in obtaining assistance from psychiatrists because of the stigma attached to mental illness in Japan (Fig. 3-1). Second, some family caregivers do not wish to know the truth; that is, that their loved ones have 'dementia'.

Since the LTC insurance scheme has been in place, more patients have been entitled to receive services, and the awareness of the benefits of patients receiving social services has increased among psychiatrists. However, the LTC insurance scheme is still a 'work in progress' in terms of care for dementia patients. For example, there are few domiciliary services which are targeted at the elderly with dementia under the LTC insurance scheme (Fig. 3-3). There are also few institutes to which the elderly with severe behavioral and psychological symptoms of dementia (BPSD) can be admitted so as to provide some respite for family caregivers (Fig. 3-4).

Our study investigated whether the GCDI scores under the LTC insurance program adequately

reflected the needs of people with dementia of Alzheimer's type (DAT) and vascular-type dementia (VaD). The results show that the GCDI score for DAT patients is lower than that for VaD patients, indicating that DAT patients are classified as 'less disabled' based on their GCDI score compared to VaD patients.¹² Since the number of care services patients can access under the LTC insurance scheme is determined solely by the GCDI score, it appears that patients with DAT in the study were allowed fewer care services despite the fact that the severity of their dementia was the same as that of VaD patients (Fig. 3-5).

The following measures could be implemented to improve the dementia care system. First, it is necessary to 'educate' not only the caregivers, but also the general public. This can be done by providing seminars on the early symptoms of dementia and what to do if a loved one shows symptoms. Second, primary care physicians should be trained to look for early warning signs of dementia. Third, assessment of the 'frail' elderly should be improved. That is to say, the severity of behavioral disturbances should be taken into account when the 'frail' elderly are assessed under the LTC insurance scheme. Finally, more care services specializing in dementia care should be set up.

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Regular Article

Factors related to feelings of burden among caregivers looking after impaired elderly in Japan under the Long-Term Care insurance system

YUMIKO ARAI, MD, PhD,¹ KEIGO KUMAMOTO, PhD,¹ MASAKAZU WASHIO, MD, PhD,^{1,2} TERUKO UEDA, BSC^{1,3} HIROKO MIURA, PhD^{1,4} AND KEI KUDO, MD, PhD^{1,5}

¹Research Unit for Nursing Caring Sciences and Psychology, National Institute for Longevity Sciences (NILS), Obu, ²Department of Public Health, School of Medicine, Sapporo Medical University, Sapporo, ³Faculty of Service Industries, Department of Health and Social Services, University of Marketing and Distribution Sciences, Kobe, ⁴Faculty of Health Science, Kyushu University of Health and Welfare, Nobeoka, ⁵Research Unit for Public Health, Miyagi University, Sendai, Japan

Abstract

Since the 1970s, the burden of caregiving has been the subject of rather intense study, a trend that will continue with the rapid graying of populations worldwide. Since the Long-Term Care insurance system began in 2000, few cross-sectional studies have attempted to identify factors related to the feelings of burden among caregivers looking after the impaired elderly in Japan. In the present report, among 46 pairs of caregivers and impaired elderly, the elderly receiving regular nurses' visits in Kyoto Prefecture, Japan were assessed for problems with activities of daily living, the severity of dementia, the presence of behavioral disturbance, and cognitive impairment. The caregivers were asked to complete questionnaires in relation to their feelings of burden and caregiving situation. The results indicated that caregivers of impaired elderly with behavioral disturbances were more likely to feel a 'heavier burden.' Those temporarily relieved of caregiving three or more hours a day were less likely to experience 'heavier' caregiver burden than those who were not. Moreover, caregivers who found it 'inconvenient' to use care services tended to be more likely to feel a 'heavier' caregiver burden than those who did not. Recourse to respite services, which are ideally positioned to help, proved inconvenient because of their advance reservation system. More ready access to respite services in emergencies could do much to reduce caregiver burden.

Key words burden, caregivers, carers, dementia, Japan, Long-Term Care insurance, service use.

INTRODUCTION

Informal care for the disabled elderly has proved to be a heavy burden for family caregivers in many countries, and numerous studies have been conducted in relation to the burden of caregiving since the 1970s.^{1–9} In all of these cross-sectional studies, behavioral disturbances of the impaired elderly were found to be factors related to caregiver burden. In contrast, factors such as activ-

ities of daily living (ADL) of the impaired elderly have not shown consistent relationships with caregivers' burden.^{1,7,9} Longitudinal studies conducted in various countries have also yielded inconsistent results as to how caregivers' burden changes over the course of caregiving.^{10–14}

In April 2000, a new public Long-Term Care (LTC) insurance scheme (Kaigo Hoken) was launched in Japan, making it only the third country, after The Netherlands and Germany, to provide such insurance. For Japan, the new system departed from the Confucian-based tradition and policy according to which the family is considered the prime resource for the long-term care of its members.¹⁵ The new eligibility criteria do not take into account the extent of informal family care available to clients. As in Nordic countries, the ultimate

Correspondence address: Dr Yumiko Arai, Research Unit for Nursing Caring Sciences and Psychology, National Institute for Longevity Sciences (NILS), 36-3 Gengo Morioka-cho, Obu-shi, Aichi 474-8522, Japan. Email: yarai@nils.go.jp

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responsibility lies with the State rather than with the family itself. In addition, the LTC insurance system has brought about a fundamental change in how care services are provided to the impaired elderly. Prior to the system, most services were made available by order of the municipal government. Hence, neither the impaired elderly nor caregivers were entitled to ask the municipal government what kind or the amount of services they wished to use. In contrast, after the system was in place, services have been allocated based on the Government Certified Index (GCDI)(Yokaigodo); the impaired elderly are entitled to decide both the kind and the amount of services they wish to use within the parameters which the GCDI allows.¹⁶ Under the LTC insurance system, the impaired elderly and/or caregivers are now in a position to express their views regarding the quality of services, for example, their convenience in using services.

There have been few cross-sectional studies regarding caregiver burden conducted after April 2000. Thus, the objectives of the present study were to identify factors related to the feelings of burden among a group of caregivers looking after the impaired elderly under the LTC insurance system. We were especially interested in exploring whether or not their feelings of burden were related to the inconvenience in using services experienced by caregivers looking after the impaired elderly under the new system.

METHOD

Subjects

As the first step, 53 impaired elderly were identified who had been registered with a practice nurse clinic attached to U general hospital in the vicinity of Kyoto City. In the second step, these 53 elderly and their family principal caregivers were contacted by letter to explain the objectives of the present study. Informed consent was obtained from all of these pairs in March 2001. This study was endorsed by the ethical committee of the National Institute of Longevity Sciences.

All of the primary caregivers were co-residing with the patients at the time. Among these 53 pairs, 51 pairs participated in the present study. As the third step, the medical records of these 51 impaired elderly were reviewed by the first author. Of these 51 elderly, 46 were found to suffer from dementia. These 46 pairs were analyzed in the present study.

Measures

In the present investigation, the impaired elderly were assessed for problems in carrying out ADL, the severity of their dementia, the presence of behavioral dis-

turbances, and cognitive impairment. The nurses assessed the patients' physical disability using the Barthel Index (BI), a widely used 10-item ADL scale.¹⁷ A cut-off point of nine on the BI represented the threshold between moderate and severe dependence.¹⁷ Severity of dementia was assessed by nurses using criteria developed by The Ministry of Health, Labor and Welfare; severity of dementia was rated from I (very mild) to IV (very severe), and M was defined as 'very severe with extremely disruptive behavior.'¹⁸ The same Ministry suggested that those who were rated I or II were relatively easy to care for at home albeit having dementia, and hence we used this classification for the statistical analyses in the present study.

The frequency of behavioral disturbances observed by primary caregivers was assessed using the Troublesome Behavior Scale (TBS), which was designed to quantify the specific observable behavior usually associated with dementia.^{19,20} Cognitive impairment of the elderly was assessed with the Japanese version of the Short Memory Questionnaire (SMQ),²¹ which was developed as an objective tool for the assessment of memory difficulties found in dementia²² and has proved useful for screening of dementia in a Japanese population.²³ The SMQ consists of 14 items concerning everyday memory problems; the scoring range is 4-46 points. A score of less than 40 is suggestive of dementia.

These caregivers were asked to complete the following questionnaires in relation to their feelings of burden, depression and caregiving situation. The questionnaires included: the Japanese version of the Zarit Burden Interview (J-ZBI); questions regarding demographic variables of the caregivers and patients; and questions regarding the hours spent in caregiving and the duration of caregiving.

Caregivers' burden was assessed by the J-ZBI, a 22-item self-report inventory that examines the burden associated with functional behavioral impairments in the home care setting.²⁴ A short version of the J-ZBI (J-ZBI_8) has recently been released.²⁵⁻²⁷ The original version of the ZBI is one of the most common scales used in North America and European countries for assessing the burden of caregiving.²⁸ Caregivers were asked to indicate how many hours per day they provided care for the patient as well as how many months' duration they had cared for him or her. Caregivers were also asked to estimate the number of hours per day they were able to be temporarily relieved of their duties or to leave the side of the patient to go out.

Analyses

The caregivers in the present study were divided into two groups: those who felt a relatively heavier burden;

Table 1. Characteristics of subjects ($n = 46$)

	No.	Mean (SD)
Patients		
Age		79.8 (9.8)
Sex		
Male	16	
Female	30	
Barthel Index		
Less than 9	30	7.5 (6.1)
Severity of dementia		
I	5	
II	14	
III	6	
IV	19	
M	2	
Troublesome Behavior Scale		6.0 (8.1)
Short-Memory Questionnaire		9.0 (8.1)
Caregivers		
Age		60.5 (13.7)
Sex		
Male	11	
Female	35	
Relationship		
Wife	13	
Husband	4	
Daughter	10	
Son	5	
Daughter-in-law	11	
Other	3	
Japanese version of the Zarit Burden Interview		40.1 (18.3)
Hours of caregiving/day		5.0 (4.1)
Duration of caregiving/months		55.0 (52.7)
Hours caregivers can be relieved		2.9 (2.9)
No. of services used		2.4 (1.1)

burden score of 40 or more (i.e. group 1), and those who felt less burden; burden score under 40 (i.e. group 2). The score was put at 40, since the cut-off point as the median ZBI score in the present study was 40.

First, the χ^2 test was conducted to determine differences between the more heavily and less burdened groups (i.e. associations between ZBI and the variables concerned). Second, Spearman's rank correlation tests were conducted on the variables found to be statistically significant on the above univariate analysis ($P < 0.05$). Then, the variables found to be highly correlated with one another were excluded from further analyses in order to avoid multicollinearity. Third, a multiple logistic regression analysis was employed to determine which of the remaining variables was significantly related to the caregivers experiencing heavier feelings of burden. Then the Statistical Package for Social Science (SPSS, version 11.5) was used for the above statistical analyses.

Characteristics of subjects

Table 1 shows the characteristics of the subjects in our study. The average age of the caregivers was 60.5 years old, and three-quarters were female. The mean age of the elderly (patients) was 79.8 years old, and two-thirds were female. The average hours of caregiving were 5 h/day, and the average duration of caregiving (months) was 55 months (i.e. approximately 5 years). All of these 46 impaired elderly scored less than 40 in the Short Memory Questionnaire (SMQ), indicating that all of them were cognitively impaired.

RESULTS

Table 2 compares group 1 (less burdened caregivers) and group 2 (more burdened caregivers) regarding the variables concerned. The following four variables were significantly different between the two groups: the pro-

Table 2. Comparisons between 'less burdened' and 'more burdened' caregivers

	Less burdened caregiver (J-ZBI score = 0-39)		More burdened caregiver (J-ZBI score = 40+)		χ^2	P-value
Patients						
Sex (male vs. female)	9 vs. 14	n = 23	7 vs. 16	n = 23	0.38	0.54
Age (years) (-79 vs. 80+)	8 vs. 15	n = 23	13 vs. 10	n = 23	2.19	0.14
Barthel Index (0-9 vs. 10+)	13 vs. 10	n = 23	17 vs. 6	n = 23	1.53	0.22
Behavioral disturbances (0 vs. 1+)	15 vs. 8	n = 23	6 vs. 17	n = 23	7.10	0.01***
Severity of dementia (I, II vs. III, IV, M)	13 vs. 9	n = 22	6 vs. 16	n = 22	4.54	0.03**
Caregivers						
Sex (male vs. female)	5 vs. 18	n = 23	6 vs. 17	n = 23	0.12	0.73
Age (years) (-59 vs. 60+)	12 vs. 11	n = 23	13 vs. 10	n = 23	0.09	0.77
Hours of caregiving/day (-4 vs. 5+)	15 vs. 7	n = 22	9 vs. 14	n = 23	3.81	0.05*
Duration of caregiving/ months (-54 vs. 55+)	17 vs. 6	n = 23	13 vs. 10	n = 23	1.53	0.22
Find it convenient to use services (+ vs. -)	13 vs. 8	n = 21	6 vs. 16	n = 22	5.23	0.02**
Support from others (+ vs. -)	12 vs. 11	n = 23	13 vs. 9	n = 22	0.22	0.64
Occupation (+ vs. -)	10 vs. 13	n = 23	4 vs. 18	n = 22	2.28	0.13
Caregiving experiences (+ vs. -)	9 vs. 13	n = 22	12 vs. 11	n = 23	0.57	0.45
Belong to support group (+ vs. -)	2 vs. 21	n = 23	6 vs. 17	n = 23	2.42	0.12
Consulted physicians within last 1 month (yes vs. no)	17 vs. 6	n = 23	17 vs. 6	n = 23	0.00	1.00
Spouse as caregiver (yes vs. no)	10 vs. 11	n = 21	7 vs. 16	n = 23	1.37	0.24
Child as caregiver (yes vs. no)	7 vs. 14	n = 21	8 vs. 15	n = 23	0.01	0.92
Hours caregivers can be relieved (-2 vs. 3+)	9 vs. 13	n = 22	17 vs. 6	n = 23	5.02	0.03**

* $P < 0.1$, ** $P < 0.05$, *** $P < 0.01$.

J-ZBI, Japanese version of the Zarit Burden Interview.

Table 3. Correlations between ADL, behavioral disturbances, no. of family members and caregivers' experience of having consulted physicians

	J-ZBI score (-39 vs. 40+)	Behavioral disturbances (0 vs. 1+)	Severity of dementia (1-2 vs. 3-4)	Find it convenient to use services (+ vs. -)	Hours caregivers can be relieved (-2 vs. 3+)
J-ZBI score (-39 vs. 40+)	1.00	0.39 $P = 0.01$	0.32 $P = 0.03$	0.35 $P = 0.02$	-0.33 $P = 0.03$
Behavioral disturbances (0 vs. 1+)		1.00	0.13 $P = 0.42$	0.11 $P = 0.49$	0.04 $P = 0.79$
Severity of dementia (1-2 vs. 3-4)			1.00	0.31 $P = 0.05$	-0.29 $P = 0.06$
Find it convenient to use services (+ vs. -)				1.00	-0.21 $P = 0.18$
Hours caregivers can be relieved (-2 vs. 3+)					1.00

J-ZBI, Japanese version of the Zarit Burden Interview.

portion of disabled elderly who had behavioral disturbances; the proportion of disabled elderly with III, IV or M severity of dementia; the proportion of caregivers who found it convenient to use services; and the proportion of caregivers who were able to go out (leave the patients) more than 3 h/day.

Table 3 presents the Spearman's rank correlation between the above four variables. First, caregivers' burden was correlated with the patients having behavioral disturbances ($\rho = 0.39$, $P = 0.01$), severity of dementia ($\rho = 0.32$, $P = 0.03$), level of convenience the caregivers experienced in using services ($\rho = 0.35$,

Table 4. Factors related to caregivers' 'heavier' burden

	Odds ratio	95% CI	P-value
Behavioral disturbances (0 vs. 1+)	7.16	1.48-34.70	0.01
Hours caregivers can be relieved (-2 vs. 3+)	0.20	0.04-0.97	0.04
Find it convenient to use services (+ vs. -)	3.62	0.81-16.22	0.09

$P = 0.02$), and hours caregivers were temporarily relieved of their duties ($\rho = -0.33$, $P = 0.03$). Second, the severity of the patients' dementia was correlated with the level of convenience the caregivers experienced in using services ($\rho = 0.31$, $P = 0.05$). In summary, there was a close relationship between the severity of dementia and the level of convenience caregivers encountered in using services. As we were interested in investigating whether or not their feelings of burden were related to the convenience expressed by caregivers looking after the impaired elderly under the LTC insurance system, we excluded 'the severity of patients' dementia' variable from the following multivariate analysis.

A logistic regression analysis was employed to determine which of the following three remaining variables were significantly related to the caregivers' heavy feelings of burden: behavioral disturbances (0 vs. 1); hours during which caregivers were temporarily relieved (< 3 vs. ≥ 3 h/day); and caregivers' convenience in obtaining services (Yes vs. No).

As shown in Table 4, two of these three variables proved to be significant factors related to the caregivers' heavier burden: behavioral disturbances and hours during which caregivers can be relieved. Those who looked after the disabled elderly with behavioral disturbances were more likely to experience 'heavier' caregiver burden (odds ratio = 7.16; CI = 1.48-34.70, $P = 0.01$). In contrast, those able to leave their patients for 3 h or longer were less likely to experience 'heavier' caregiver burden (odds ratio = 0.20, CI = 0.04-0.97, $P = 0.04$). Caregivers who found it convenient to use services tended to belong to the 'less burdened' group, although the difference between groups was not statistically significant (odds ratio = 3.62; CI = 0.81-16.22, $P = 0.09$).

DISCUSSION

The present study confirmed the well-documented relationship between caregiver burden and behavioral disturbances.^{7-9,12,29} Some studies have even reported that behavioral disturbances were the strongest correlate of caregiver burden.^{7,8} On this point, our study is thus consistent with the above studies conducted in the

West as well as with our previous study conducted in Japan prior to the implementation of the LTC insurance system. This result can be interpreted to mean that behavioral disturbances have remained a strong correlate of caregiver burden even after the LTC insurance system was in place. One of the goals of this system is to reduce caregiver burden.³⁰ Most of the care services currently available under the LTC insurance scheme are intended to assist the impaired elderly with ADL. The services are not intended to provide medical/pharmacological treatments. Thus, all interventions possible under the present system are non-pharmacological. The problem, of course, is that there is little unequivocal evidence that such interventions are effective.

Some evidence suggests that caregiver intervention can possibly reduce the severity of patients' behavioral disturbances³¹⁻³³ or at least improve the caregivers' ability to tolerate particular symptoms.³⁴ Thus, it would be desirable if such caregiver intervention would be possible under the LTC insurance system.

Second, those who were completely relieved of their caregiving duties for 3 h/day (or longer) were less likely to feel caregiver burden than those who did not, even after statistically controlling for confounding factors. Indeed, the break from caregiving duties in order to spend time away from the patient and engage in activities other than caregiving is certainly a key reason why caregivers were less likely to feel a 'heavier' burden in the present study.³⁵ Therefore, steps must be taken to temporarily relieve caregivers, allowing them more time away from their patients or duties. A first step would be for caregivers to have someone they could ask to take over for them when necessary, for example, a family member (informal help). Indeed, informal instrumental support has been demonstrated to be effective in alleviating caregiver burden.³⁶ When asking for professional help, of course, the use of more home help services would be desirable. A second step would be for caregivers to rely on respite services. However, virtually no studies to date have shown that respite care directly alleviates caregiver burden itself, although its use is reportedly related to caregivers' satisfaction³⁷ and to delay institutionalization.^{38,39} Thus, care services which could completely release caregivers

from home-caregiving temporarily would serve to alleviate their burden.

Third, although the difference was not significant, those who felt it inconvenient to use care services tended to be more likely to feel a 'heavier' caregiver burden than those who did not. In order to clarify what makes currently available services 'inconvenient', the first author interviewed four 'heavily burdened' caregivers who had expressed inconvenience in using services in the present study. When this subsample of caregivers was asked just what they meant by 'inconvenient' services, they defined them as 'services which are not available when you want them.' For example, in order to use respite services, caregivers many times had to apply several months in advance to avail themselves of such services; and even when these caregivers themselves suddenly became ill and became unable to look after the elderly in their care, neither respite nor home help services were an option because the requisite 'reservation' had not been made. Also, caregivers who suddenly had to attend funerals found such services unavailable. In particular, respite services were very often beyond reach because of the need for long-standing reservations. In the present LTC insurance system, services must be requested well in advance. Unexpected conditions are not foreseen. This appears to be why caregivers found them 'inconvenient', especially the respite services.

The issue of the convenience of access to services deserves further discussion.⁴⁰ As mentioned at the outset, prior to the LTC insurance, neither caregivers nor the elderly were in any position to express their views regarding the quality of services, for example, their inaccessibility or so-called 'inconvenience.' Apparently, the 'caregiver inconvenience' first emerged as a factor after the LTC insurance system was in place. This welcome 180-degree change in the history of social policy in Japan may have made more caregivers aware of not only the availability of services but also their quality, especially in terms of accessibility. Thus, measures must be taken to allow caregivers immediate access to services when the unexpected happens. For example, a fixed number of respite beds must be set aside by each municipality to accommodate the emergency needs of the impaired elderly on a reservation-free basis.

In conclusion, behavioral disturbances and the length of time caregivers were totally relieved of caregiving were identified as factors related to caregiver burden even after the LTC insurance was implemented. Also, the 'caregiver inconvenience' in using such care services first emerged as a factor after the LTC insurance system was in place. Thus, services which can totally release caregivers from caregiving

and also allow them emergency access as needed may well serve to alleviate their feelings of burden.

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RESEARCH LETTER

Caregiver burden not 'worse' after new public long-term care (LTC) insurance scheme took over in Japan

Yumiko Arai* and Keigo Kumamoto

Research Unit for Nursing Caring Sciences and Psychology, National Institute for Longevity Sciences, (NILS), Obu-shi, Aichi, Japan

The Long-Term Care (LTC) insurance scheme was implemented in Japan in 2000. Under this scheme, services are allocated based not on the availability of informal care but the degree of mental and physical disability of the clients themselves (MHLW, 2003). This scheme is unprecedented in making the government rather than the family responsible for the care of the elderly (Arai, 1997). The idea behind the scheme appeared to be praiseworthy (Campbell and Ikegami, 2003). However, in reality, much of the Japanese media called the LTC insurance scheme a failure, claiming that family caregivers were more 'burdened' since the LTC insurance system was implemented. We previously stated that such claims were not based on scientific studies and called for a new study with sound methodology to see if the claims were true (Arai, 2001).

Were family caregivers who looked after the impaired elderly residing in the community more 'burdened' since the LTC insurance system was put in place? In order to answer the above question, we conducted the following two studies in a town located in rural northern Japan—Matsuyama Town (population: 7126). First, we used a paired *t*-test to compare the degree of caregiver burden measured in 1999 and that in 2001 among the caregivers who had provided continuous caregiving one year before and after

the implementation of the LTC insurance program. Second, we compared caregiver burden between those who looked after the disabled elderly in 1999 and those who began caring for the disabled elderly in 2001 by Analysis of Co-variance (ANCOVA). The above two studies were conducted as part of the Matsuyama Caregiver Study which commenced in 1998. In this study, all caregivers co-residing with registered disabled elderly in the town were surveyed; the degree of their feelings of burden was measured yearly between 1998–2001 by the Japanese version of the Zarit Caregiver Burden interview (J-ZBI) (Zarit *et al.*, 1980; Arai *et al.*, 1997), which is the most widely used caregiver burden scale in Japan. In 1999, of the 99 registered disabled elderly residing in the community, 76 disabled elderly and their co-residing caregivers were surveyed. Of these, we were able to follow 31 pairs of caregivers and disabled elderly, who had kept co-residing and looking after the elderly from 1999 to 2001. In 2001, 51 new caregivers co-residing with the disabled elderly started to provide caregiving in the town, and were included in the survey. The design of the Matsuyama Caregiver Study has been described in detail elsewhere (Arai *et al.*, 2000; Arai *et al.*, 2002).

The results of the first study are presented in Table 1. It was found that the number of services used in 2001 was significantly greater in 1999. However, the mean J-ZBI score in 2001 was not significantly different from that of 1999, indicating that caregiver burden itself did not change from 1999 to 2001 (Table 1). The following reason was postulated for the lack of change in burden. The degree of impairments among the disabled elderly worsened, as reflected by a measure of the Activities of Daily

*Correspondence to: Dr Y. Arai, Head of Research Unit, Research Unit for Nursing Caring Sciences and Psychology, National Institute for Longevity Sciences (NILS), 36-3 Gengo Moriokacho, Obu-shi, Aichi 474-8522, Japan. Tel: +81-562-46-2311 (ext. 5611). Fax: +81-3-5204-9159. E-mail: yarai@nils.go.jp

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Table 1. Comparisons of caregiver burden and other variables between 1999 and 2001 using paired *t*-test

	1999		2001		<i>p</i> -value
	Mean	(SD)	Mean	(SD)	
J-ZBI	29.9	(17.95)	32.71	(14.60)	0.41
Barthel Index	10.32	(6.59)	7.55	(6.43)	0.02
No. of services used	0.87	(1.02)	1.58	(0.96)	0
Hours of caregiving/day	5.14	(4.22)	5.08	(4.74)	0.94

J-ZBI: Japanese version of Zarit Burden Interview.

Living (ADL), i.e. the Barthel Index score of impaired elderly. And, because this ongoing deterioration was so severe, of course, caregiver's burden was not alleviated—even if more care services were used.

The second study was aimed at investigating whether caregivers in 1999 before the insurance system began were 'better off' than those who started to use social services in 2001 after the insurance program was in place. Specifically, caregiver burden, measured by J-ZBI, was compared between those who looked after the disabled elderly in 1999 and those who began caring for the disabled elderly in 2001 using the Analysis of Co-variance (ANCOVA), adjusting for caregiver's age, sex, age of the disabled elderly, duration of caregiving (months), number of family members, ADL score (Barthel Index), and score of behavioral disturbance (TBS). The adjusted mean J-ZBI score of 28.7 in 2001 was not significantly different from the 32.5 score in 1999, indicating the media claims were unfounded.

Overall, the above studies demonstrated that, contrary to media claims, family caregivers who looked after the impaired elderly residing in the community

had not become more 'burdened' since the LTC insurance scheme was implemented. The system has not been failure, at least from a scientific standpoint; media claims were unfounded. However, these data were obtained only by one municipal government, and ongoing nationwide studies of this issue must be conducted.

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

Yumiko Arai.



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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¹ Research Unit for Nursing Caring Sciences and Psychology, National Institute for Longevity Sciences (NILS).

Address for correspondence: Dr. Yumiko Arai, Head of Research Unit, Research Unit for Nursing, Caring Sciences and Psychology, National Institute for Longevity Sciences (NILS), 36-3 Gengo Morioka-cho, Obu-shi, Aichi 474-8522, Japan.

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.

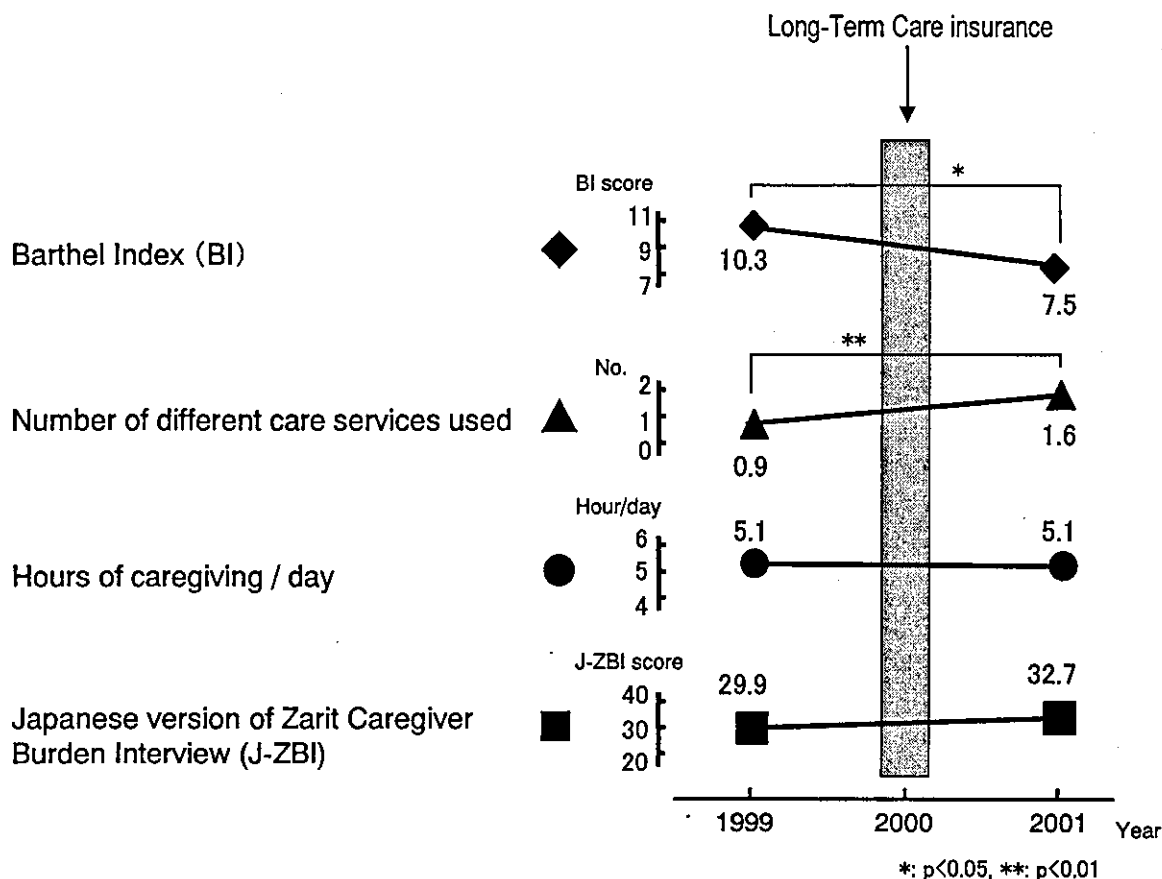


Figure 1. Changes in variables between 1999-2001.

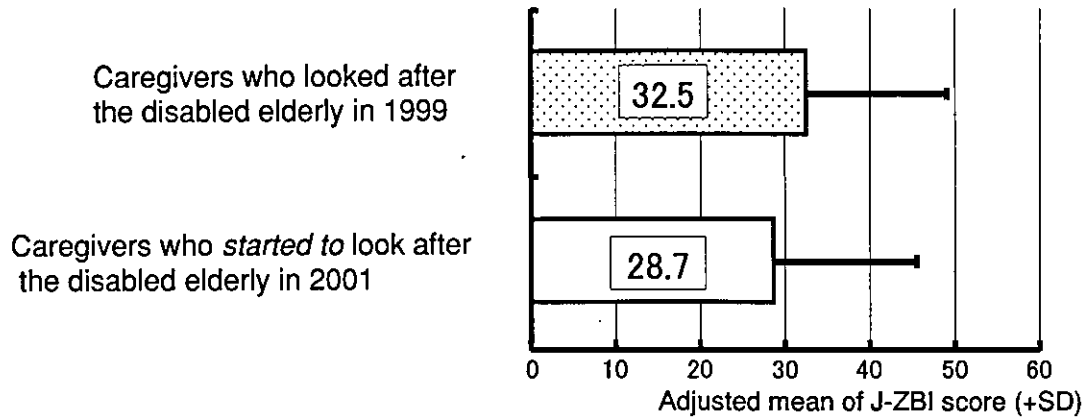


Figure 2. Comparisons of J-ZBI score between caregivers who looked after the disabled elderly in 1999 and those who started to look after the disabled elderly in 2001. Adjusted by caregivers' age, caregivers' sex (female=1), age of disabled elderly, duration of caregiving(month), no. of family members,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

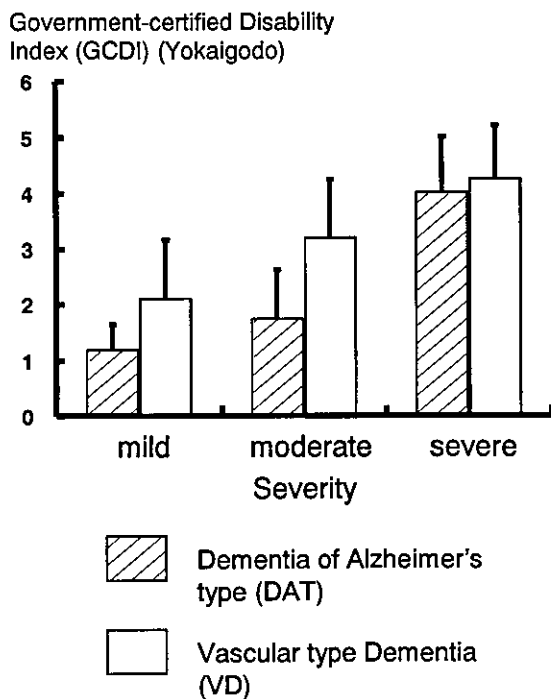


Figure 3. Government-certified Disability Index(GCDI) (Yokaigodo) and severity in DAT and VD patients.

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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Table 1. The short version of the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI_8).¹⁴⁻¹⁶

For each question, chose one of the following answers:

0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

Questions

1. Do you feel embarrassed over your relative's behavior? *
 2. Do you feel angry when you are around your relative? *
 3. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way? †
 4. Do you feel strained when you are around your relative? *
 5. Do you feel that your social life has suffered because you are caring for your relative? †
 6. Do you feel uncomfortable about having friends over because of your relative? †
 7. Do you wish you could just leave the care of your relative to someone else? *
 8. Do you feel uncertain about what to do about your relative? *
-

*: J-ZBI_8 Personal Strain

†: J-ZBI_8 Role Strain

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