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### ANGST IN SHANGRI-LA: JAPANESE FEAR OF GROWING OLD

To the Editor: The proportion of Japanese people aged 65 and older reached 19.0% of the total population in 2003.<sup>1</sup> This is due to the longest life expectancy for men (78.4) and women (85.3), but also the longest healthy life expectancy in the world—72.3 for men and 77.7 for women.<sup>2</sup> Japan also has the lowest fertility rate in the world (1.32) next to Italy.<sup>1</sup> This fast-graying nation will soon face an unprecedented situation in which one in four will be an elderly person.<sup>3</sup> Japan's long-term care insurance system was established in 2000 precisely to manage this fast-graying population.<sup>3</sup> How does it feel personally to be among people promised the longest healthy life in the world?

To find out how Japanese people in general feel about aging, a survey was conducted in September 2004, asking the following three subjective questions.

- 1. Would you like to live long?
- 2. Do you worry about getting old?
- 3. What in particular makes you worry about growing old?

Survey participants were selected from a panel organized by the Social Survey Research Information Co. Ltd. in Japan. The panel consisted of 52,478 persons among the general population aged 20 and older. Some 2,224 people were selected using a quota sampling method.<sup>4</sup> The sample consisted of 444 adults aged 20 to 39, 546 adults aged 40 to 54, 563 adults aged 55 to 64, 532 adults aged 65 to 74, and 139 adults aged 75 and older. Each subject received a self-administered questionnaire; 2,031 returned the questionnaire, and the data from 2,025 participants were analyzed.

The survey revealed that 59% of the general public in Japan hoped to live long. Of those who answered that they did not wish to live long, neither age nor sex was associated with a "wish not to live long" (chi-square  $(\chi^2)$  = 6.822, degrees of freedom (df) = 4, P = .15) (Figure 1). Eighty-three percent of the sample answered that they worry about getting old. Again, neither their age nor sex was associated with their apprehensions in this regard  $(\chi^2 = 4.236, df = 4, P = .38)$  (Figure 1). The 1,680 "worried" subjects were then asked about what in particular made them worry about growing old. Specifically, they were asked whether any of the following eight issues caused them concern: becoming ill, becoming bedridden or demented, losing steady income apart from a pension, becoming widowed, spouse or partner becoming ill or bedridden, deteriorating relationship(s) with family members or becoming less close, having to change their way of living, and deteriorating relationship(s) with friends or becoming less close.

Examination of the reasons revealed three key concerns about becoming old. Seventy-eight percent answered that becoming bedridden or demented frightened them about growing old, 72% that becoming ill made them worry about growing old, and 68% that being left without a steady income other than a pension was a basis of their concern about growing old.

The present survey has revealed seemingly paradoxical results obtained from the general public in a country

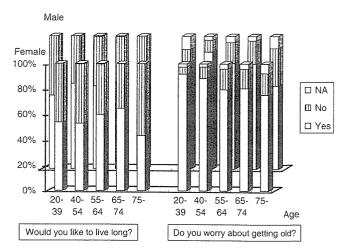


Figure 1. Two main concerns regarding growing old in questionnaire survey.

boasting the longest healthy life expectancy in the world. In fact, the Japanese surveyed in this study showed considerable apprehension about growing old that appeared out of proportion to the long and healthy lives that most can anticipate. These overly pessimistic attitudes may limit the possibilities for successful aging and need to be addressed. First, there needs to be dissemination among the general population of more factual information about aging, stressing that the Japanese are the world's healthiest and longest-living people in the world. The media has only heightened the fear of becoming "impaired." Only a small proportion of the population, not more than 16% of the elderly Japanese aged 65 and older, need care at all.

Second, although the general public must be given a far more realistic view of growing old as Japanese, the existing social system should also be improved so that people will be reassured that a safety net is in place when they become ill, impaired, or short of money in later life.

Third, there needs to be attention paid to the possibilities for successful aging. The survey results may reflect the Alzheimerization of aging; all the publicity given to dementia has raised worries among the entire population. These worries must be balanced with views of successful aging and with prevention programs that could ensure good mental and physical health and perhaps even forestall the development of dementia.<sup>5</sup>

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### Regular Article

### Feelings of burden and health-related quality of life among family caregivers looking after the impaired elderly

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#### Abstract

The aim of the present study was to examine the relationship between feelings of burden and health-related quality of life (HRQOL) among family caregivers looking after the impaired elderly residing in a community located in southern Japan. Subjects were 85 pairs comprising elderly individuals requiring care and their respective family caregivers. Questionnaire items for the family caregivers related to demographic variables, caregivers' burden, HRQOL, use of public services, hours spent caregiving, duration of caregiving, and satisfaction with verbal communication with family. Questionnaire items for the elderly recipients of care concerned demographic variables, activities of daily living, and cognitive status. According to bivariate analysis, caregivers' burden was significantly related to cognitive status, hours spent caregiving, and each HRQOL subscore except physical function. From multiple regression analysis, subscore of HRQOL with respect to mental health and satisfaction with verbal communication were extracted as influential factors. Final regression coefficient was 0.72~(P < 0.01) and coefficient of determination was 0.53. These results suggest that satisfactory mental health status plays an important role in limiting family caregivers' burden.

Key words

burden, caregivers, HRQOL, impaired elderly, Japan, verbal communication.

#### INTRODUCTION

In Japan, a rapid increase in the elderly population has resulted in an unprecedented rise in the number of elderly requiring social assistance. As a result of the new public long-term care insurance scheme, many impaired elderly individuals with long-term and complex health problems are being cared for by family caregivers.<sup>1</sup>

Some investigators have reported that the mental or emotional strain associated with caregiver status is an independent risk factor for mortality among elderly spousal caregivers.<sup>2</sup> Furthermore, several studies have documented a strong relationship between caregiving and elevated levels of depressive symptoms among caregivers, including high rates of clinical depression and anxiety.<sup>3,4</sup> Thus, in order to maintain the health status of family caregivers, it is very important to elucidate the physical and/or mental influences on the family caregiver that occur during long-term caregiving.

Studies on perceived caregivers' burden have identified certain factors to be associated with feelings of burden. 5-7 However, few studies have examined the direct association between perceived burden and health-related quality of life (HRQOL) including physical and mental health among family caregivers. The present study therefore aimed to analyze the relationship between feelings of burden and HRQOL among family caregivers using various scales.

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#### **METHODS**

#### Subjects

The survey was conducted from October 2003 to January 2004 in Nobeoka City, Miyazaki Prefecture, southern Japan, using a self-administered questionnaire. As the first step, we randomly selected 115 impaired elderly individuals (36 men, 79 women) who were above 65 years of age, resided in the community with their family, and received a public welfare service under the national long-term care insurance system. In the second step, all 115 impaired elderly and their family principal caregivers were contacted by mail to explain the objectives of the present study. Informed consent was obtained from 85 pairs (response rate = 73.9%). Differences between participants and non-participants of the study, in terms of age, sex, and physical or mental status, were not statistically significant. All family caregivers who decided not to participate in the present study cited lack of time in their schedules as their reason. This study was endorsed by the ethical committee of Kyushu University of Health and Welfare.

#### Measurements

Family caregivers were asked to complete a questionnaire regarding the following areas related to perceived burden and caregiving: (i) demographic variables; (ii) caregivers' burden; (iii) HRQOL; (iv) use of public services; (v) hours spent caregiving per day; (vi) duration of caregiving; and (vii) satisfaction with verbal communication with family. Caregivers' burden was evaluated using the short version of Japanese version of the Zarit Caregiver Burden Interview (J-ZBI\_8), which has been demonstrated to have similar validity to the full version, the J-ZBI.89 HRQOL among family caregivers was evaluated using the Japanese version of the short-form 36 health survey questionnaire (SF-36). 10,111 The SF-36 is widely used to assess QOL including health status and comprises eight health subscales: physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH). Regarding use of welfare services, respondents were asked about their use of the following six types of available services within the previous month: home-help, home nurse visits, respite care, meals on wheels, bathing service, and residential day care. Levels of satisfaction with verbal communication with family members were measured by the question: 'Are you satisfied with your ability to communicate with the family verbally?' in accordance with our previous survey. 12 Subjects categorized themselves as either 'satisfied' or 'dissatisfied' in this respect.

For the impaired elderly subjects, questionnaire items were grouped into the following aspects: (i) demographic variables; (ii) activities of daily living (ADL); and (iii) cognitive status. Impairment and disability were evaluated using the ADL-20.13 This scale consists of 20 items from four major categories of basic activities of daily living (ADL): (i) mobility, five items; (ii) self-care, six items (iii) instrumental ADL (IADL). seven items, and (iv) communication ADL (CADL), two items. It has been reported that ADL-20 is useful as a comprehensive measure of ADL in the elderly with a variety of handicaps. Cognitive impairment was rated using the revised Hasegawa Dementia Rating scale (HDS-R), a Japanese screening test for dementia that measures overall cognitive function, including verbal orientation and memory, with scores ranging from 0 to 30. The HDS-R is equivalent to the Mini-Mental State Examination and has been widely used in Japan. 14

#### Analyses

Bivariate analyses were performed using Spearman's rank correlation coefficients, unpaired t-tests, Welch test, and anova. Then, a stepwise multiple regression analysis was performed with the J-ZBI\_8 score treated as the dependent variable for each independent variable (F = 3.0) in order to detect the factors with the largest influence on burden among family caregivers. All statistical analyses were performed using SPSS version 12.0 (Chicago, IL, USA).

#### RESULTS

Tables 1 and 2 show the characteristics of the impaired elderly and their family caregivers. For the impaired elderly, mean age was  $80.81\pm7.62$  and mean HDS-R score was 14.54, indicating that most of the elderly participants suffered from cognitive impairment. For caregivers, mean age was  $64.33\pm12.92$ . Average number of welfare services used was 2.15, with all caregivers reporting to having used at least one service. Only around 55% of caregivers reported being satisfied with verbal communication with the family.

Table 3 shows correlation coefficients between J-ZBI\_8 score and certain variables including ADL capability of the impaired elderly, and caregiving-related factors and SF-36 subscores among the family caregivers. Caregivers' burden was correlated with HDS-R score of the impaired elderly (P < 0.05) and with the following SF-36 subscores: RP (P < 0.05), RE (P < 0.01), SF (P < 0.01), MH (P < 0.01), BP (P < 0.05),

**Table 1.** Characteristics of impaired elderly individuals and their caregivers (n = 85)

Variable	Mean	SD
Impaired elderly		
Age	80.81	7.62
ADL-20 score	38.17	16.55
HDS-R score	14.54	8.24
Caregiver		
Age	64.33	12.92
J-ZBI_8 score	12.85	7.23
Hours spent caregiving (h/day)	6.24	5.75
Duration of caregiving (years)	5.69	6.22
Short-form 36 health survey questionnaire		
Physical functioning	70.35	29.48
Role physical	58.54	43.52
Role emotional	56.91	45.49
Social functioning	71.65	22.88
Mental health	60.80	21.26
Bodily pain	54.12	22.65
Vitality	52.60	24.77
General health	50.15	20.93
No. public services used	2.15	1.20

**Table 2.** Characteristics of the impaired elderly and caregivers (n = 85)

Variable	Number	%
Impaired elderly		
Gender		
Male	27	31.76
Female	58	68.24
Caregiver		
Gender		
Male	19	22.35
Female	66	77.65
Relationship to the elderly person		
Spouse	25	29.41
Child	29	34.11
Daughter-in-law	20	23.53
Others	11	12.94
Verbal communication		
Satisfied	47	55.29
Dissatisfied	38	44.71

VT (P < 0.01), and GH (P < 0.01). However, J-ZBI\_8 score demonstrated no significant correlation to age of the impaired elderly, age of their caregivers, hours spent caregiving, duration of caregiving. PF subscore of SF-36, or the number of welfare services used.

Table 4 shows the relationship between J-ZBI\_8 and certain variables including gender of the impaired eld-

**Table 3.** Spearman rank correlation coefficients between caregiver burden (J-ZBI\_8 score) and various independent variables

Independent variable	Coefficient	P-value	
Impaired elderly			
Âge	0.08	0.44	
ADL-20 score	-0.05	0.67	
HDS-R score	-0.29	0.01	
Caregiver			
Age	-0.17	0.10	
Hours spent caregiving (h/day)	0.23	0.05	
Duration of caregiving (years)	-0.09	0.41	
SF-36			
Physical functioning	0.06	0.56	
Role physical	-0.21	0.04	
Role emotional	-0.41	0.00	
Social functioning	-0.53	0.00	
Mental health	-0.56	0.00	
Bodily pain	-0.24	0.02	
Vitality	-0.51	0.00	
General health	-0.36	0.00	
No. public services used	0.17	0.09	

**Table 4.** Relationship between caregivers' burden evaluated by J-ZBI\_8 and the following variables: gender of impaired elderly person and their caregiver, caregiver's relationship to the impaired elderly, and satisfaction with verbal communication

Variable	J-ZBI_8 (mean ± SD)	P-value
Impaired elderly		
Gender		
Male $(n = 27)$	$12.04 \pm 8.36$	$0.33^{\dagger}$
Female $(n = 58)$	$10.22 \pm 6.73$	
Caregiver		
Gender		
Male $(n = 19)$	$9.52 \pm 5.84$	$0.48^{2}$
Female $(n = 66)$	$10.79 \pm 7.61$	
Relationship to the elderly		
person		
Spouse $(n = 25)$	$10.58 \pm 8.16$	0.120§
Child $(n = 29)$	$11.45 \pm 6.09$	
Daughter-in-law $(n = 20)$	$8.33 \pm 5.59$	
Others $(n = 11)$	$13.90 \pm 8.90$	
Verbal communication		
Satisfied $(n = 47)$	$13.66 \pm 7.85$	< 0.01
Dissatisfied $(n = 38)$	$8.37 \pm 5.73$	

<sup>&</sup>lt;sup>†</sup>Calculated by Welch test.

<sup>\*</sup>Calculated by unpaired *t*-test.

ECalculated by ANOVA.

**Table 5.** Factors related to caregivers' burden on stepwise multiple regression analysis

Variable	Beta	t	P-value
SF-36 MH	-0.58	-5.32	<0.01
Self-rated verbal communication	-0.03	-2.89	<0.01

Multiple correlation coefficient (R) = 0.72; coefficient of determination  $(R^2) = 0.53$ .

erly individual and their caregiver, family relationship between the pair, and caregivers' satisfaction with verbal communication. Satisfaction with verbal communication was significantly related to caregivers' burden (P < 0.01). However, no significant relationship was demonstrated between J-ZBI\_8 score and gender of the impaired elderly person or caregiver, or family relationship between the pair.

Table 5 shows the results of a stepwise multiple regression analysis conducted to find the most influential factor on caregivers' burden. MH subscore of SF-36 was extracted in the first step, and satisfaction with verbal communication was extracted in the second step. Final regression coefficient was 0.72~(P < 0.01), and coefficient of determination was 0.53.

#### DISCUSSION

These results indicated a close association between feelings of burden and HRQOL in family caregivers looking after the impaired elderly. In particular, the results of multiple regression analysis showed that quality of life associated with mental health was significantly related to feelings of burden in caregivers. Moreover, the results of bivariate analysis and multiple regression analysis indicated that physical health of caregivers was weakly associated with caregivers' burden. Furthermore, satisfaction with verbal communication with the family was also related to feelings of burden among the caregivers. These two factors accounted for nearly 53% of the variance of J-ZBI\_8 scores that indicated caregiver burden. In our previous study conducted among healthy elderly individuals, a close relationship was detected among satisfaction with verbal communication, general health status, and social activity.<sup>12</sup> Hence, satisfactory verbal communication plays an important role in maintaining relationships with other family members, and reduced opportunities for verbal communication sometimes lead to increased feelings of burden in family caregivers. In addition, previous studies have indicated a stronger relationship between caregiving and depression, stress, and social

interaction than between caregiving and physical health outcome.<sup>7,15</sup> Taken together with the results of the present study, these findings suggest that caregivers' burden has little significant association to physical health.

Some studies have reported that the caregivers of dementia patients can exhibit severe psychological problems, <sup>16,17</sup> a finding that is supported by the present results. On examining the relationship between caregiver burden and attributes of the impaired elderly including ADL and cognitive function, bivariate analysis indicated that cognitive status of the impaired elderly as evaluated by HDS-R was significantly related to family caregiver burden. However, multiple stepwise regression analysis indicated no significant relationship between these two variables. Previous studies have also detected no significant relationship between caregiver burden and cognitive status.<sup>4,5</sup>

Type of disease (such as stroke and Alzheimer's disease) has been found to affect the association between elderly individuals' ADL and their caregivers' burden. The present results indicated no significant relationship between ADL of the impaired elderly and caregivers' burden. However, subjects in the present study had a variety of diseases, and it was therefore difficult to control for type and severity of illness. From these findings, it is therefore impossible to elucidate the relationship between ADL of the impaired elderly and the burden experienced by family caregivers.

Neither the family relationship between the elderly person and the caregiver nor caregiver age had a significant influence on caregiver burden. While bivariate analysis indicated that caregivers' gender was significantly related to the burden, multiple regression analysis did not show such a significant relationship. It has previously been reported that caring for a first-degree relative can strongly affect burden and stress among family caregivers. However, this was not supported by the present findings. Our previous studies have demonstrated that the notion of caregiving as a family duty strongly remains in northern rural areas of Japan. However, concepts of caregiving differ greatly according to local customs and in the future it will be necessary to repeat this survey in a variety of regions.

The present study has several methodological limitations. First, sample size was relatively small and little detailed information regarding disease history was gathered. Nevertheless, the present results suggest that family caregivers experiencing high burden have significantly lower mental health and satisfaction with verbal communication. This might be attributable to the objective demands of caregiving causing symptoms of depression and decreasing both the energy available for engaging in verbal communication and the oppor-

tunities to do so. Second, as the study design was cross-sectional, we cannot rule out a bidirectional relation-ship between family caregivers' burden and mental health and satisfaction with verbal communication. While the present findings provide important basic information, longitudinal studies are needed to obtain stronger scientific evidence, and to evaluate causality between family caregivers' burden and QOL in the future.

Maintaining QOL of family caregivers is essential in order to preserve the quality and sustainability of home care. A decline of mental health and satisfaction with verbal communication is likely to result in increased caregivers' burden. Conversely, improving these factors would lead to a reduction in caregiver burden. In addition to the public service system, informal services also play an important role in improving mental health and satisfaction with verbal communication among caregivers. We advocate that, in future, family caregivers receive counseling by trained professionals.

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#### REVIEW ARTICLE

# Family caregiver burden and quality of home care in the context of the Long-Term Care insurance scheme: an overview

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Key words: burden, caregiver, home care, Japan, long-term care, quality.

#### Abstract

This review outlines the findings of 22 studies conducted between 1997 and 2005 by Arai and 19 collaborators regarding caregiver burden and assessment of quality of home care for the elderly. The published research covers the following: cross-sectional studies on caregiver burden; changes in caregiver burden; appropriateness of the Long-Term Care insurance assessment scheme; attitudes towards caregiving among caregivers; the development of the short Japanese version of the Zarit Caregiver Burden Interview (J-ZBI\_8); and the effectiveness of service use in reducing caregiver burden and development of a Home Care Quality Assessment Index (HCQAI).

#### 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 also in many developed countries. In Japan for example, in a survey conducted by Arai et al. targeting a general population of 2224 people, 70% gave as the second reason for not wanting to live long their wish not to be a burden to their own family members. And when asked what they would feel if diagnosed with dementia, approximately 70% stated they would feel embarrassed to become a burden to their family. And when their family.

It was Professor Steven Zarit of Pennsylvania State University who 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).<sup>4,5</sup> 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.

Arai et al. developed a Japanese version of this assessment scheme, called J-ZBI, 6 which is currently the most widely used assessment tool for caregiver burden in Japan.

This review outlines the findings of 22 studies conducted between 1997 and 2005 by Arai and 19 collaborators regarding caregiver burden and assessments of the quality of home care for the elderly.

#### Cross-sectional studies on caregiver burden

A study was conducted using the J-ZBI in Japan prior to the implementation of the Long-Term Care (LTC) insurance scheme 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 behavioral and psychological symptoms of dementia (BPSD) and behavioral disturbances of the disabled elderly were strongly correlated to feelings of caregiver burden (odds

ratio = 4.75, 95% confidence interval = 1.45–15.54, P = 0.01). The above findings did not differ after the LTC insurance scheme was implemented; BPSD 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). We also found that the subscore of health-related quality of life (HRQOL) with respect to mental health and satisfaction with verbal communication was a factor influencing caregiver burden. 9

Subsequently, Schreiner *et al.* found that a cutoff score ranging from 24 to 26 has significant predictive validity for identifying caregivers at risk for depression. <sup>10</sup> A J-ZBI cutoff of 24 correctly identified 72% of caregivers with probable depression. <sup>10</sup>

In addition, a qualitative study was conducted in order to elucidate the caregiver burden and problems associated with the care of patients with frontotemporal dementia (FTD) in home-care settings. Behavioral symptoms peculiar to FTD were found to pose huge problems and a heavy burden to the family caregiver. The conclusion was that more resources should be allocated to meet the specific needs of FTD patients and their families.<sup>11</sup>

#### Changes in caregiver burden

Arai *et al.* 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 has been described in detail elsewhere. 12,13

As a part of the study, a longitudinal analysis was conducted between October 1998 and October 2000 in an attempt to determine how caregiver burden may have changed before and after the implementation of the LTC insurance scheme. It was found that the

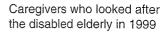
number of services used in 2000 was significantly greater than in 1998. However, caregiver burden itself did not change from 1998 to 2000, the first year in which the new system was in place. A similar analysis was then undertaken to compare caregiver burden between 1999 and 2001; there was no significant difference between the mean J-ZBI scores in 1999 and 2001. Overall, these longitudinal studies showed that the degree of caregiver burden did not change among the caregivers who had been continuously providing care prior to the launch of the LTC insurance scheme.

Comparisons were also made 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 1, 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 scheme.<sup>15</sup>

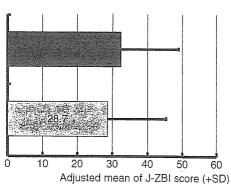
### Appropriateness of the Long-Term Care insurance assessment scheme

In the LTC insurance scheme, services are allocated based on the Government-certified Disability Index (GCDI) (Yokaigodo). <sup>16</sup> We were concerned at the time whether the LTC insurance scheme in Japan had indeed developed a fair and appropriate way of allocating resources to the nation's disabled elderly population, especially those with dementia. Specifically, we investigated whether the GCDI scores under the LTC insurance scheme adequately reflected the needs of people with dementia of Alzheimer's type (DAT) and vascular-type dementia (VD). <sup>17</sup> In fact, the GCDI score among DAT patients proved to be lower

**Figure 1** 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 (months), number of family members, ADL score (Barthel Index), score of behavioral disturbances (TBS).



Caregivers who started to look after the disabled elderly in 2001



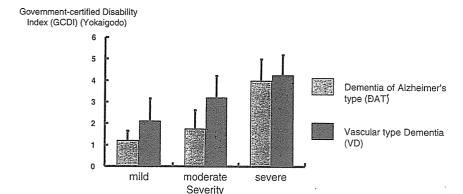


Figure 2 Government-certified Disability Index (GCDI) (Yokaigodo) and severity in dementia of Alzheimer's type (DAT) and vascular-type dementia (VD) patients.

Table 1 The short Japanese version of the Zarit Caregiver Burden Interview (J-ZBI\_8)20-22

- ⊚ 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
- $\Delta$  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
- Δ 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
- - 0. Never 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

Notes: ⊚ J-ZBI\_8 Personal Strain; △ J-ZBI\_8 Role Strain.

than among VD patients (Fig. 2), indicating that DAT patients were classified as 'less disabled' on their GCDI than VD patients. Since the amount of care services patients were allowed to use under the existing LTC insurance plan was determined solely by the GCDI score, it appeared 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 VD patients.

#### Caregivers' attitudes towards caregiving

The LTC scheme has demonstrably changed the attitudes of caregivers. More caregivers came to believe that society must look after the elderly after only one year under the new program. 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. In

### Development of short Japanese version of Zarit Caregiver Burden Interview: its reliability and validity

Under the new LTC insurance system, it became even more important to monitor the wellbeing of not only the impaired elderly but also the family caregivers. To facilitate the assessment of family caregiver burden in clinical settings, Arai et al. proposed a short version of the J-ZBI, consisting of the following two factors: personal strain (five items) and role strain (three items).20 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. Subsequently, Kumamoto et al. conducted a cross validation study. 21,22 Overall, the J-ZBI\_8 produced results comparable to those of the full version, i.e., the J-ZBI. The shorter vet no less reliable and valid eight-item version would thus mean easier administration of the instrument for assessing family caregiver burden in clinical settings.

## Effectiveness of service use on reducing caregiver burden

Since relatively few observational studies had been conducted on the impact of home-care services on burden or other aspects of the caregiver's experience, a new study by Kumamoto et al.23 then sought to examine whether the use of care services reduces the feelings of burden among family caregivers in Japan. The specific aims were to test three hypotheses: (i) that severity of impairment and dementia among the disabled elderly increases the feelings of burden among family caregivers and that support from family members decreases burden; (ii) that the amount of services used by older people and their caregivers is affected by the severity of dementia and ADL deficiencies among the disabled elderly and the amount of support from family members; and (iii) that controlling for severity, the use of care services under the LTC insurance program serves to reduce feelings of burden among family caregivers.

A structural equation model was developed using the data obtained from 82 pairs of community-dwelling disabled elderly and their principal family caregivers. The model included the following variables: age of the disabled elderly; the severity of ADL deficiency and behavioral disturbances; use of formal (public) care services; support from family members; and feelings of burden among family caregivers.<sup>23</sup> The structural equation model revealed that, after controlling for the effects of severity on service use, homecare services effectively reduce feelings of burden among family caregivers.

These findings suggested that care services provided under the LTC insurance scheme had been successfully reducing burden among family caregivers. The next issue was whether the quality of home care is related to caregiver burden. However, there was no objective tool for assessing quality of home care. Thus, Arai *et al.* launched a study with the specific aim to develop an assessment tool for home care. <sup>24,25</sup>

# Development of a Home Care Quality Assessment Index (HCQAI)

The aim of this study was to develop a Home Care Quality Assessment Index (HCQAI) that may be used for overall assessment of home care in three areas: (i) conditions of the impaired elderly (outcome); (ii) car-

egiver and caregiving situation (process); and (iii) the home care environment (input).

To develop the HCQAI, a list of items for assessment was drawn up, and the reliability of each item was verified using (a) test-retest reliability; and (b) inter-rater reliability. Impaired elderly and their family caregivers who used the visiting nurse station of the Okazaki Medical Association were surveyed. A  $\kappa$  coefficient of 0.4 or greater generally served as the inclusion criteria for test-retest and inter-rater reliability of each item. A factor analysis was then conducted for items satisfying the above criteria, using 10 scales.

As a result, Cronbach's α showing internal consistency (reliability) for these scales was 0.6-0.9. Two scales corresponded to care within the home: the 'barrier-free' and 'improvement of water facilities'; three to the caregiver situation: 'dressing appropriately for the season', 'mistreatment towards the elderly' and 'hygiene and assistance'; and five involved conditions of the impaired elderly: 'cognition', 'paralysis', 'vision and hearing', 'ADL' and 'gross motor.' The HCQAI developed in the study, consisted of 41 items, and could assess the quality of home care both objectively and comprehensively, based on professional staff observation (Fig. 3).24,25 Few indexes of this kind exist worldwide to scientifically assess input, process and outcome in the delivery of quality home care for the impaired elderly.

It is hoped that this review briefly outlining recent studies relating to family care burden and home care quality under the LTC insurance scheme will familiarize the reader with some of the present and past issues in this fast-changing field.

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#### Quality of Home Care Input **Process** Outcome Cognition Dressing appropriate for the season Barrier-free Paralysis Mistreatment Improvement of Vision and hearing by the caregiver water facilities ADL Hygiene and assistance Gross motor

Figure 3 Subscales of Home Care Quality Assessment Index (HCQAI).

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### Use of home care services effectively reduces feelings of burden among family caregivers of disabled elderly in Japan: preliminary results

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#### **SUMMARY**

**Background** Relatively few observational studies have been conducted on the impact of home care services on burden or other aspects of the caregiver's experience.

Objectives To examine whether the use of care services reduces the feelings of burden among family caregivers in Japan. Specifically, the study was aimed at testing the following three hypotheses: (1) The severity of impairment and the dementia among the disabled elderly increases the feelings of burden among family caregivers and the support from family members decreases burden: (2) the amount of services used by older people and their caregivers is affected by the severity of dementia and ADL deficiencies among the disabled elderly and the amount of support from family members: and (3) controlling for severity, the use of care services under the LTC insurance program serves to reduce the feelings of burden among family caregivers.

**Methods** A structural equation model using the data obtained from 82 pairs of community-dwelling disabled elderly and their principal family caregivers. The model included the following variables: age of the disabled elderly; the severity of ADL deficiency and behavioral disturbances; use of formal (public) care services; support from family members; and feelings of burden among family caregivers.

**Results** The structural equation model revealed that, after controlling for the effects of severity on service use, home care services effectively reduce feelings of burden among family caregivers.

Conclusions The findings suggest that care services provided under the LTC insurance have been successfully reducing burden among family caregivers in the study area. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS - caregiving: long term care; service use: caregiver burden; community setting

#### INTRODUCTION

It is well-documented that informal care for the disabled elderly is a heavy burden for family caregivers

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(Montgomery et al., 1985; Zarit et al., 1986; Vitaliano et al., 1991; Arai et al., 2002) and that informal instrumental support is effective in alleviating caregiver burden (Pearlin et al., 1995; Miller et al., 2001).

A variety of formal supports and interventions have been found to have an impact on feelings of burden. Psycho-educational interventions can reduce the feelings of burden among family caregivers (Schulz *et al.*, 2002; Sörensen *et al.*, 2002), and use of respite care can delay institutionalization of the disabled elderly (Lawton *et al.*, 1989; Kosloski and Montgomery, 1995). However, these are experimental interventions in which the elderly and family use only one or a few kinds of services and/or specialized interventions such as counseling.

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By contrast, in a typical community setting the disabled elderly use various kinds of care services provided in their community, taking account of the degree of their own disability, the capacity of available informal care, and their financial status. These types of services are widely available in Western countries and Japan, yet have rarely been evaluated for their effects on caregivers. One problem is that a true experimental design is usually not possible for practical and political reasons—namely that services are widely available and so control groups cannot be restricted in their access. One alternative is to conduct a controlled observational study that allows for estimation of benefits associated with community-based services such as respite care (e.g. Shadish et al., 2001). Although not providing the same type of control as an experimental design, these quasi-experimental approaches may actually improve internal validity compared to a field experiment and allow for adequate examination of the impact of the intervention on participants (Zarit et al., 2003). Given the central role of community-based respite services in the care of elders and their families, there is considerable need for evaluations of effectiveness, yet relatively few observational studies have been conducted on the impact of these services on burden or other aspects of the caregiver's experience (Bass et al., 1996; Arai et al., 1998).

The paucity of observational (cross-sectional) studies derives from the methodological difficulties in elucidating the relationship between the use of care services by the disabled elderly and the feelings of burden among family caregivers in a real setting. First, in a community setting, the degree of impairment of the elderly will be positively correlated with the amount of services they use (Arai et al., 2000). In other words, people use more services when their relative has more impairment. Indeed, under most public care systems, including the LTC insurance system in Japan, the severity of one's impairment determines the amount of care services which the elderly are eligible to use (Arai, 2001; Arai et al., 2003). Second, the feelings of burden among family caregivers are known to be positively correlated with the degree of impairment of the elderly, in particular the degree of behavioral disturbances (Zarit et al., 1986; Harper and Lund, 1990; Draper et al., 1992; Donaldson et al., 1997). Taken together, these findings suggest that service users would be caring for people with greater impairment and would feel more burdened as a result than non-users. A comparison of users and non-users that did not take into account the effects of severity on burden might mistakenly

conclude that service use was associated with increased burden. Overall, it is difficult to show whether the use of such care services is effective in reducing caregiver burden because of the complex relationship between use of care services and caregiver burden (Pot *et al.*, 2005).

The aim of the present study was to examine whether the use of care services reduces the feelings of burden among family caregivers. Using a crosssectional (observational) design, we tested the following three hypotheses: (1) The severity of impairment, including ADL deficiencies and severity of dementia among the disabled elderly, increases feelings of burden among family caregivers and the support from family members decreases burden: (2) the amount of services used among the elderly and caregivers is affected by the severity of impairment (ADL deficiencies and severity of dementia) among the disabled elderly and the amount of support from family members, and (3) once severity is taken into account, the use of care services under the LTC insurance program is associated with lower feelings of burden among family caregivers.

#### **METHODS**

Subjects

The design of the Matsuyama Caregiver Study was described in detail elsewhere (Arai et al., 2000; Arai et al., 2002). Briefly, Subjects in the present study were drawn from a list of 143 community-dwelling 'registered disabled elderly' from Matsuyama Town (population: 7,239) in northern Japan; all of these 'registered disabled elderly' had applied for services under the LTC insurance system. Moreover, those 143 elderly and their caregivers were invited to participate by a letter explaining the study, which has also been fully endorsed by the ethical committees of both Matsuyama Town and the National Institute of Longevity Sciences. Consequently, 95 elderly agreed to take part in the present study. These 95 elderly were comprised of seven elderly residing in their home alone, and 88 residing with caregivers. Thus, these 88 elderly persons residing with caregivers and their respective caregivers were identified as the eligible subjects. Among them, 82 (93%) elderly and their caregivers returned the completed questionnaire.

#### **MEASURES**

Each caregiver was asked to complete a self-report questionnaire, which included: (1) the Japanese

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