

**Caregiver burden for impaired elderly Japanese with prevalent stroke and dementia
under long-term care insurance system**

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1 **ABSTRACT**

2 **BACKGROUND:** Limited data are available on caregiver burden for stroke and
3 dementia patients. We examined the associations of prevalent stroke and dementia with
4 family caregiver burden in Japanese general populations.

5 **METHODS:** A total of 916 Japanese home caregivers, whose family members were
6 covered by long-term care insurance, responded to the caregiver burden questionnaire.
7 The questionnaire included caregiver's age, sex, employment status, patient-caregiver
8 relationship, patient's history of stroke, symptoms of dementia, care levels under
9 long-term care insurance and the Zarit Caregiver Burden Interview.

10 **RESULTS:** Mean total score from the Zarit Caregiver Burden Interview was 12%
11 higher in patients with stroke, than in those without it ($p=0.02$), and 40% higher in
12 those with dementia, than in those without it ($p<0.001$). Compared with non- stroke
13 patients without dementia, mean total score was 21% higher in stroke patients without
14 dementia ($p=0.01$), 49% higher in non-stroke patients with dementia ($p<0.001$) and
15 55% higher in stroke patients with dementia ($p<0.001$). After adjustment for
16 caregiver's age, sex, employment status, patient-caregiver relationship, patient's care
17 level and community, the higher scores remained statistically significant for non-stroke

18 patients with dementia and for stroke patients with dementia, but not for stroke patients
19 without dementia.

20 **CONCLUSIONS:** Prevalent stroke and, more strongly, dementia were associated with
21 increased family caregiver burden. Among patients with dementia, the presence of
22 stroke did not enhance caregiver burden further.

23 **INTRODUCTION**

24

25 Aging of society is an important public health problem in Japan as well as western
26 countries, because of the increased need to care for the elderly. Recent studies [1-5]
27 indicated that caring for the elderly, especially for the demented elderly, is associated
28 with the caregiver's poor physical and mental health and low quality of life.

29 Stroke and dementia are two major causes of disabilities and abnormalities in
30 the elderly. Each causes physical disability, cognitive impairment and behavioral
31 disturbance, increasing caregiver burden [6-10]. Approximately 20 to 57% of stroke
32 patients have dementia [11-15] while 24 to 50% of dementia patients have a history of
33 stroke [15-19]. Therefore, caring for patients with stroke or dementia is also an
34 important public health problem. However, no study has examined caregiver burden
35 for patients with stroke, dementia or their combination, comprehensively.

36 We thus examined the association of family caregiver burden according to
37 patients' prevalent stroke, dementia or both among community-based samples of
38 Japanese. Our *a priori* hypothesis was that caregiver burden is the highest in stroke
39 patients with dementia, intermediate in non-stroke patients with dementia and stroke
40 patients without dementia compared with non-stroke patients without dementia.

41 **METHODS**

42

43 **Subjects**

44 Subjects were home caregivers living in eight communities across Japan; Honjo
45 (presently Yuri-Honjo), a north-eastern rural community, n=45,722 by 2000 census;
46 Ikawa, a north-eastern rural community, n=6,116; Kasama, a mid-eastern rural
47 community, n=30,076; Takato (presently Ina), a central rural community, n=7,040; Yao,
48 a mid-western urban community, n=274,777; Yawatahama, a western rural community,
49 n=33,285; Kagami (presently Konan), a western rural community, n=6,363; and Noichi
50 (presently Konan), a western rural community, n=16,595. We recruited the patients
51 covered by the long-term care insurance (LTCI) ranging from care levels 1 to 5. From
52 2002 to 2003, the caregiver burden questionnaire was mailed to the family for all 1,361
53 patients with care level 1 or more, living with their family in the seven communities
54 other than Yao City and in Yao city, to 38 volunteers belonging to Family Caregiver
55 Society. A total of 916 caregivers of the family member replied to the questionnaire.
56 The response rate was 65%. Informed consent was obtained from them when they
57 completed the questionnaire.

58

59 **Long-term care insurance system in Japan**

60 The LTCI system was launched as the national insurance in April 2000[20, 21]. Every
61 Japanese aged ≥ 40 pays premium on the LTCI, but this system is relied 50% on
62 subsidies from general revenues from national, prefectures and municipalities. Japanese
63 aged 40 to 64 years who was diagnosed aging-related diseases (e.g. alzheimer's disease
64 and stroke), and Japanese aged ≥ 65 years who was certified having the need to be
65 cared is eligible for benefits based on the care level under the LTCI. To receive the care,
66 the eligible persons and their caregivers apply for the insurance. The care level was
67 determined according to the questionnaire on current physical and mental status and
68 use of medical procedures and the primary care physician's statements. That care level
69 had a good correlation with the Barthel index (Spearman's coefficient = -0.86) and the
70 Mini-Mental State Examination (Spearman's coefficient = -0.42) [10]. Table 1 shows
71 the summary of the care levels.

72

73 **Survey questionnaire**

74 The caregiver burden questionnaire included several caregiver burden factors,
75 including age, sex, employment status, and patient-caregiver relationship (husband,
76 wife, biological father, biological mother, father-in-law, mother-in-law or others),

77 patient's care level under LTCI (care level 1, 2, 3, 4 or 5), patient's history of stroke
78 and symptoms of dementia. The patient-caregiver relationship was classified into three
79 categories; spouse (husband or wife), biological parents (biological father or mother)
80 and others (father- or mother-in-law or others). Patient's history of stroke was asked
81 "which of these diseases (stroke, cerebral infarction, cerebral thrombosis, cerebral
82 embolism, intraparenchymal hemorrhage or subarachnoid hemorrhage) have you ever
83 been diagnosed by doctor?" Prevalent stroke was defined as one or more history of
84 stroke. Patient's symptoms of dementia were asked with respect to the presence or
85 absence of, 1) terribly forgetful, 2) inability for significant conversation, and 3)
86 wandering or hyperactivity at night. We selected these symptoms since our preliminary
87 study showed that they were easily identified and frequent by observed among the
88 physician-diagnosed dementia patients in Japan; 93% among the dementia patients vs
89 22% among the non-dementia patients for forgetfulness, 68% vs 6% for problems of
90 conversation and 25% vs 2% for hyperactivity at night. Prevalent dementia was
91 defined as one or more symptoms.

92 Caregiver burden was measured with the Zarit Caregiver Burden Interview
93 (ZBI) [22]. The original version was translated into Japanese with successful validation
94 [23]. As the original version defined, the 22 items in ZBI were scored on a standard

95 5-point scale (0 to 4) for each item. ZBI included two factors; personal strain (PS)
96 factors such as personal stress from care, consisting of 12 items, and role strain (RS)
97 factors, including social role limitation from care giving, consisting of 6 items. The
98 total score, PS score, and RS score potentially ranged from 0 to 88, 0 to 48 and 0 to 24,
99 respectively [24, 25]. Higher scores indicate higher burden.

100

101 **Statistical analysis**

102 Mean values of each ZBI item and score were tested by the analysis of variance
103 according to age, sex, employment status, patient-caregiver relationship, prevalent
104 stroke and dementia and care levels under LTCI. We used the multiple linear regression
105 analysis to evaluate caregiver's and patient's factors associated with caregiver burden.
106 Among combined categories of prevalent stroke and dementia, crude and
107 multivariate-adjusted mean values of ZBI scores were tested by Tukey test. The Tukey
108 test compared all pairs by using the studentized range distribution to consider the
109 multiple comparison. Since ZBI scores were significantly associated with age, sex,
110 employment status, patient-caregiver relationship and care levels under LTCI in the
111 univariate analysis, we included these factors as well as community into the
112 multivariate models as potential confounders. All analyses were conducted using the

113 SAS statistical package version 8.02 (SAS Institute Inc., Cary, NC). All *P*-values for
114 statistical testes were two-tailed and $P < 0.10$ to 0.05 and $P < 0.05$ was regarded as
115 borderline significance and statistical significance, respectively.

116 RESULTS

117

118 Table 2 shows the distribution of care levels under LTCI and crude mean ZBI scores,
119 according to age, sex, employment status of caregiver, patient-caregiver relationship,
120 patient's prevalent stroke and dementia. The proportions of care levels were 33.3% for
121 care level 1, 26.5% (care level 2), 15.5% (care level 3), 13.0% (care level 4) and 11.7%
122 (care level 5). Care levels were positively associated with caregiver's age, spousal
123 caregiver, and prevalent stroke and dementia among patients, and inversely with
124 caregiver's status of being employed. Mean values (standard deviation) of total, PS and
125 RS scores of ZBI were 33.7 (17.8), 18.6 (9.5) and 8.5 (6.0), respectively. Total, PS and
126 RS scores of ZBI were higher in caregivers aged ≥ 65 years than in those aged < 65
127 years, and higher in females than in males, and in non-workers than in workers. Mean
128 total, PS and RS scores of ZBI were higher when the caregiver was a spouse, and for
129 patients with prevalent stroke and dementia. According to multiple regression analysis,
130 we found significant associations of total score with female, prevalent stroke and
131 dementia, of PS score with spousal relationship, prevalent stroke and dementia, and of
132 RS score with female and prevalent dementia (shown in Table 3).

133 To examine the relation between caregiver burden and care levels under LTCI,
134 we presented the crude mean values of each ZBI item according to care levels in Table
135 4. Most of the mean values of ZBI items and total, PS and RS scores increased linearly
136 according to care levels from 1 to 4, and reached a plateau at care level 5. The mean
137 values of ZBI items 2, 6, 10, 11, 12, 16, 17, 19, 20, 22 and RS score did not differ
138 between care levels 4 and 5; the mean values of ZBI items 8 and 14 were higher or
139 tended to be higher for care level 5 than for care level 4 ($p=0.08$ for item 8 and $p=0.04$
140 for item 14), whereas the mean values of ZBI items 1, 3, 4, 5, 7, 9, 13, 15, 18, total
141 score and PS score were lower or tended to be lower for care level 5 than care level 4
142 ($p=0.01$ for item 5, $p=0.01$ for item 9, $p=0.08$ for item 18 and the other items were not
143 significant).

144 The distributions of care levels and the crude and multivariate-adjusted mean
145 ZBI scores according to the combination of prevalent stroke and dementia are shown
146 in Table 5. Compared with non-stroke patients without dementia, caregiver burden was
147 higher in stroke patients without dementia, in non-stroke patients with dementia and in
148 stroke patients with dementia. Among patients without dementia, ZBI total, PS and RS
149 scores were significantly higher in those with, than in those without stroke. However,
150 among patients with dementia, ZBI total, PS and RS scores were similar between those

151 with and those without stroke. These associations did not alter substantially for
152 non-stroke patients with dementia and stroke patients with dementia after adjustment
153 for potential confounding factors. The interaction between dementia and stroke for ZBI
154 score was of borderline significance for PS score ($p=0.07$), but not significant for total
155 or RS score ($p=0.25$ and 0.39 , respectively).

156 **DISCUSSION**

157

158 The present study confirmed that both prevalent stroke and dementia were associated
159 with increased family caregiver burden, and prevalent stroke was not associated with
160 further increase in caregiver burden for the demented elderly. Stroke and dementia
161 cause disability in ADL, cognitive impairment and behavioral disturbance, all of which
162 increase caregiver burden [8, 11, 13, 14]. Furthermore, caregiver burden was not
163 associated with type of dementia, that is, vascular or Alzheimer's types [10, 26]. These
164 findings, together with our present results, suggest that although both stroke and
165 dementia increase caregiver burden, the presence of stroke for the demented elderly
166 does not affect the caregiver burden.

167 The present study showed that female sex, prevalent stroke and dementia were
168 positively associated with caregiver burden. The relation of caregiver burden with
169 prevalent stroke and dementia was similar with the previous studies [1, 6, 8, 9, 27].
170 However, most of previous studies [1, 6, 9, 27] showed that caregiver burden did not
171 vary according to sex. This discrepancy may be explained in several ways. First, the
172 number of subjects was much larger in the present study than in the previous studies,
173 thus we could detect the sex difference. Second, the present and previous studies

174 surveyed in different countries, and differences in culture and welfare system may lead
175 to the different result.

176 Increased caregiver burden according to care level was expected because care
177 levels are constructed based on disability with ADL and the severity of cognitive
178 impairment [14]. The plateau in caregiver burden from care levels 4 to 5 may reflect
179 the different characteristics of patients between the two care levels. Patients at care
180 level 4 consisted of severely impaired mobile elderly with special needs while those at
181 care level 5 were non-mobile elderly. Immobility of patients diminished behavioral
182 disturbance, leading to the attenuation of caregiver burden [28]. In the present study,
183 the restriction of caregiver's time did not differ between care levels 4 and 5. The
184 feeling of dependency from patients tended to be higher at care level 5 than at care
185 level 4; the excessive psychological stress from patients tended to be lower at care
186 level 5 than at care level 4. Non-mobile elderly, mainly assigned as level 5, may need
187 to be helped more because of lower levels of ADL, which may increase dependency,
188 but they may show fewer behavioral disturbances, leading to less psychological stress
189 for caregivers. In contrast, the severely impaired mobile elderly, mainly assigned as
190 level 4, may have fewer problems with ADL, but may show various behavioral
191 disturbances compared with non-mobile elderly.

192 Limitations of the present study warrant discussion. First, the study subjects
193 may include less severely impaired patients than the national representative sample
194 because care levels 4 and 5 comprised 25% of this study, compared with 29% in the
195 national report [29]. This may be interpreted as meaning that caregivers with higher
196 burden are less likely to response to the study than those with lower burden. This may
197 lead to the underestimation of the associations. Second, we used the self-administered
198 questionnaire on caregiver burden and histories of stroke and dementia. This may
199 cause some misclassification, but the large sample size contributed to detect the
200 associations.

201 The strength of the present study is that we used community-based samples
202 with the largest sample size among the previous studies. Most of the previous studies
203 [7-10, 26-28] sampled from hospital or nursing home patients, which overrepresented
204 severely impaired patients, and thus these studies may overestimate caregiver burden.
205 Even in the community-based study [6], the sample size was not large enough to
206 estimate after adjustment for the potential confounders. The present study enabled us to
207 make reliable analyses of caregiver burden for prevalent stroke and dementia without a
208 serious selection bias.

209 In conclusion, the present study showed that family caregiver burden was high
210 for patients with stroke, and even higher for patients with dementia in the general
211 population. Among patients with dementia, the presence of stroke was not associated
212 with the further increase of caregiver burden. To reduce family caregiver burden, the
213 prevention of stroke and dementia, and sufficient social support for caregiver would be
214 important.

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Table 1. Care levels under long-term care insurance and benefits for home care.

Care level	Severity of impairment (Example)	Maximum coverage of home- and community-based service US \$/month [‡]
Care level 0	Slight impairment (Eating, toileting and dressing are almost self-supported but occasionally need slight support)	513
Care level 1	Light impairment (Eating, toileting and dressing are almost self-supported but sometimes need partial support)	1,382
Care level 2	Moderate impairment (Eating and dressing are almost self-supported but toileting needs partial support)	1,623
Care level 3	Severe impairment (Eating and dressing need partial support and toileting needs full support)	2,229
Care level 4	Severe impairment with special needs (Eating, toileting and dressing need full support, but not being bedridden)	2,550
Care level 5	Bedridden (Eating, toileting and dressing need full support, and being bedridden)	2,986

[‡] 1 US \$=120 yen

Table 2. Proportions of care levels under long-term care insurance and mean Zarit Caregiver Burden Interview scores according to characteristics of caregivers and patients.

	Total	Caregivers						Patients						
		Age		Sex		Employment status		Patient-Caregiver relationship			Stroke		Dementia	
		<65 years‡	≥65 years	Male‡	Female	Unemployed‡	Employed	Spouse	Biological parents‡	Others	No‡	Yes	No‡	Yes
No.	916	473	433	171	733	567	332	328	231	338	414	390	403	436
Care levels under long-term care insurance														
Care level 1, %	33.3	36.6	29.3*	32.0	33.5	27.2	43.0***	28.3†	35.4	36.1	39.0	26.8***	42.4	25.4***
Care level 2, %	26.5	27.5	25.6	26.2	26.7	25.1	29.4	25.8	29.1	25.5	28.0	24.5	27.9	25.4
Care level 3, %	15.5	14.4	16.9	16.9	15.1	18.4	11.0**	18.5†	13.1	14.4	15.2	15.3	12.3	18.8**
Care level 4, %	13.0	11.2	14.8	11.1	13.5	14.4	10.4†	14.0	11.4	13.2	10.7	16.6*	10.3	15.4*
Care level 5, %	11.7	10.4	14.4	14.0	11.2	14.9	6.2***	13.4	11.0	10.9	7.1	16.8***	7.1	15.0***
Zarit Caregiver Burden Interview score														
Total score	33.7	32.1	35.9**	30.8	34.4*	35.0	31.6*	35.2*	31.3	34.1†	31.5	35.2**	27.8	38.9***
PS score	18.6	17.8	19.6**	17.3	18.9†	19.1	17.7*	19.4*	17.3	18.8†	17.6	19.3*	15.7	21.3***
RS score	8.5	8.0	9.0*	7.1	8.8**	8.8	7.9*	8.8†	7.8	8.7†	8.0	8.8†	6.9	10.0***

† p<0.10, * p<0.05, ** p<0.01, *** p<0.001

‡ Reference group for statistical testing.

Table 3. Predictors of caregiver burden (multiple linear regression analysis).

Variable	Total score			PS score			RS score		
	β	(SE)	<i>p</i>	β	(SE)	<i>p</i>	β	(SE)	<i>p</i>
Caregiver characteristics									
Age (5 years increment)	0.4	(0.4)	0.27	0.2	(0.2)	0.29	0.2	(0.1)	0.20
Female	-3.1	(1.7)	0.08	-1.4	(0.9)	0.13	-1.5	(0.5)	0.005
Patient-caregiver relationship [‡]									
Spouse	3.1	(2.1)	0.13	1.8	(1.1)	0.09	0.6	(0.6)	0.35
Others	1.3	(1.7)	0.46	0.8	(0.9)	0.35	0.3	(0.5)	0.56
Worker	-1.6	(1.5)	0.27	-0.5	(0.8)	0.47	-0.6	(0.5)	0.20
Patient characteristics									
Stroke	3.0	(1.4)	0.03	1.4	(0.7)	0.06	0.6	(0.4)	0.17
Dementia	11.2	(1.4)	<0.0001	5.7	(0.7)	<0.0001	3.2	(0.4)	<0.0001

SE, standard error.

[‡] Compared with biological parents.

Table 4. Mean scores of each Zarit Caregiver Burden Interview items according to prevalent stroke, dementia and care levels under long-term care insurance.

Item	Care levels					<i>p</i> for difference between care level 4 and 5
	1 [‡]	2	3	4	5	
No. of subjects	305	243	142	119	107	
1. Excessive request of care from patient	1.1	1.3	1.6	1.7	1.4	0.15
2. Unavailability of enough private time	1.4	1.7	2.3	2.4	2.4	0.98
3. Feeling stress from doing housekeeping or work	1.6	1.9	2.1	2.3	2.1	0.26
4. Feeling trouble from patient's behavior	1.5	1.6	2.0	2.0	1.7	0.13
5. Anger when caregiver close by patient	1.3	1.4	1.5	1.5	1.1	0.01
6. Negative effect on relationship with other family or friends	1.0	1.2	1.4	1.6	1.5	0.73
7. Being afraid of patient's future	2.2	2.2	2.3	2.4	2.2	0.28
8. Feeling dependency from patient	2.6	2.7	3.0	2.9	3.2	0.08
9. Strain when being around patient	1.5	1.7	1.9	2.1	1.6	0.01
10. Suffering health for involving with patient	0.9	1.1	1.3	1.7	1.8	0.89
11. Having little privacy because of care	0.7	0.9	1.0	1.1	1.0	0.40
12. Suffering social life for care	1.1	1.5	1.6	1.9	1.9	0.93
13. Loss comfort about having friends over because of patient	1.0	1.1	1.3	1.4	1.2	0.39
14. Expectation of only your care from patient	1.9	2.3	2.5	2.5	2.9	0.04
15. Economic burden to care	1.2	1.4	1.6	1.8	1.6	0.42
16. Unavailability of taking much longer time to care	1.1	1.4	1.6	1.7	1.7	0.80
17. Loss control of life since patient's illness	1.4	1.9	2.2	2.3	2.3	1.00
18. Wish to leave the care to someone else	1.1	1.3	1.4	1.7	1.4	0.08
19. Uncertainty about what to do about patient	1.0	1.2	1.4	1.4	1.3	0.38
20. Feeling of duty to do more for patient	1.0	1.1	1.2	1.2	1.2	0.90
21. Possibility of doing a better job in caring	0.7	0.7	0.9	0.8	0.7	0.51
22. Overall burden of care	1.8	2.2	2.3	2.5	2.5	0.94
Total score	28.9	32.4 [*]	37.7 ^{***}	40.8 ^{***}	37.6 ^{***}	0.22
PS score	16.2	18.0 [*]	20.7 ^{***}	21.8 ^{***}	20.5 ^{***}	0.35
RS score	6.8	8.2 ^{**}	9.6 ^{***}	10.5 ^{***}	10.1 ^{***}	0.59

† $p < 0.10$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

‡ Reference group for statistical testing.

Table 5. Distribution of care levels under long-term care insurance, and mean and multivariate adjusted mean values of Zarit Caregiver Burden Interview scores among combination of stroke and dementia.

Dementia Stroke	Combination of stroke and dementia			
	No [‡]	Yes	No	Yes
No.	193	167	200	193
Care levels under long-term care insurance				
Care level 1, %	49.5	34.5**	28.9***	20.1***
Care level 2, %	28.1	28.6	27.9	22.2
Care level 3, %	11.2	12.5	19.6 [†]	17.5
Care level 4, %	6.6	14.9 [†]	14.7*	18.0**
Care level 5, %	4.6	9.5	8.8	22.2***
Zarit Caregiver Burden Interview score				
Total score				
Mean	25.3	30.5*	37.8***	39.1***
Multivariate-adjusted mean [§]	26.5	30.0	38.1***	38.5***
PS score				
Mean	14.3	17.4**	20.9***	21.1***
Multivariate-adjusted mean [§]	14.9	17.1	21.1***	20.8***
RS score				
Mean	6.3	7.6	9.9***	10.1***
Multivariate-adjusted mean [§]	6.8	7.3	9.9***	9.7***

[†] p<0.10, * p<0.05, ** p<0.01, *** p<0.001

[‡] Reference group for statistical testing.

[§] Tested by Tukey test, adjusted for age, sex, employment status, patient-caregiver relationship, care levels of long-term care insurance and community.