

The current trend toward a community-based healthcare system means that when older people require care, much of it is provided at home. Thus, family members are providing care for ill or disabled older relatives. Family caregiving has been intensively studied in the past decade, particularly the impact on caregivers of providing home care to a family member. Caregiver burden has been defined as a negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles.¹⁻³ It is well documented that informal care for the disabled elderly places heavy burdens on family caregivers.¹⁻³ Previous studies demonstrated that caregiver burden is associated with the substantial care needs of seriously ill patients, which are in turn associated with the presence of dementia, behavioral problems, poorer physical functioning, and factors that are not readily modifiable.⁴⁻⁷ Caregiver burden can lead to a chronic stress response that can worsen caregiver health, contribute to psychiatric morbidity in the form of increased depression,⁸ contribute to the risk of health problems such as wound healing impairment, elevated blood pressure, and coronary heart disease risk and immune function impairment,⁹⁻¹¹ and is an independent risk factor for mortality.¹²

Thus, most of the previous studies on caregiver burden have focused on examining its cause(s) and extensively examining caregiver health. However, conversely, much less attention has been paid to the impact of caregiver burden or distress on the health of the partner, the care recipient. In fact, it remains uncertain whether caregiver burden or distress has any influence on the health-related outcomes of care recipients, although the association of caregiver burden with long-term care placement has been well demonstrated.^{13,14} In this study, we investigated whether caregiver burden is associated with adverse health outcomes of the care recipients, including all-cause mortality and hospitalization for acute illness, during a 3-year study period. In addition, we examined the effect of community-based respite care services, including day-care, home-help, and nursing-home respite stay services on the adverse outcomes of care recipients.

METHODS

Study Setting and Cohort Participants

In this study, we employed baseline data on the care recipient and caregiver pairs in the Nagoya Longitudinal Study for Frail Elderly (NLS-FE) and data on the mortality and hospitalization of the care recipients during the 3-year follow-up period. Japan introduced a universal-coverage long-term care insurance (LTCI) program in 2000. Under the LTCI program, each applicant's care levels are determined according to eligibility criteria. Eligibility status is classified into six levels ("needs support" and care levels 1-5) by the estimation of care needs based on an assessment of the current physical and mental status of the patient and their use of medical procedures.¹⁵ The NLS-FE was designed to compare the outcomes of different uses of community-based care services provided by the LTCI program.^{16,17} The study sample consisted of 1,875 community-dwelling elderly (632 men and 1,243 women, age 65 years or older) with some degree of physical or mental disability. They were eligible for the LTCI program, lived in Nagoya City, Japan, and received various kinds of community-based services from the Nagoya City Health Care Service Foundation for Older People, which has 17 visiting nursing stations associated with care-managing centers. These 1,875 NLS-FE participants and 1,502 caregivers (373 of the 1,875 participants lacked a primary caregiver), who were enrolled between December 1, 2003, and January 31, 2004, were scheduled to undergo comprehensive in-home assessments by trained nurses at the baseline and at 6, 12, and 24 months. At 3-month intervals, data were collected about any important events in the lives of the participants, including mortality and admission to the hospital for acute illness during the 3-year follow-up. Written informed consent for participation was obtained from the participants, care recipients, and caregivers, or, for those with substantial cognitive impairment, from a surrogate (usually the closest relative or legal guardian), according to procedures approved by the Institutional Review Board of Nagoya University Graduate School of Medicine.

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Data Collection

The data were collected at the clients' homes through structured interviews with care recipients or surrogates and caregivers and from care-managing center records taken by trained nurses. The data included each participant's demographic characteristics, general socioeconomic status, living arrangements, subjective economic status, use of medical services, and the utilization of a total of seven community-based services available under LTCI programs, including the day-care service, visiting nurse service, home-help service, visiting bathing service, visiting rehabilitation, assistive device leasing, and nursing-home respite stay (overnight respite, temporary stays at nursing facilities). The data also included depressive symptoms as assessed by the 15-item Geriatric Depression Scale (GDS-15) (range: 0–15, with higher values indicating more depressive symptoms)¹⁸ and a rating for eight basic activities of daily living (bADL) using summary scores ranging from 0 (total disability) to 20 (no disability). The information on the following physician-diagnosed chronic conditions was obtained from care-managing center records: ischemic heart disease, congestive heart failure, cerebrovascular disease, diabetes mellitus, dementia, chronic obstructive pulmonary disease, cancer, hypertension, and other diseases comprising the Charlson Comorbidity Index,¹⁹ which represents a sum of weighted indexes that takes into account the number and seriousness of preexisting comorbid conditions (range: 0–19, with a higher value indicating higher comorbidity).

Data were also obtained from caregivers concerning their own personal demographic characteristics including caregiver relationship to care recipient (spouse or not), and the presence of behavioral disturbance of the care recipient according to the primary assessment dataset of the public LTCI, including wandering, hallucinations, physically aggressive behaviors, verbal aggression, delusions, altered sleep-wake cycles, sexually disinhibited behaviors, aberrant behaviors, abnormal eating behaviors, and resistance to care. Depressive symptoms were assessed by the GDS-15, and the caregiver's subjective burden was assessed by the Japanese version of the Zarit Burden Interview (ZBI), which is a 22-item self-report inventory that examines the burden associated with functional behavioral impairments in the home care situation (range: 0–88, with higher values

indicating a greater burden). The primary caregivers were also asked to rate their current overall health in three categories of subjective health status (poor, fair, and good to excellent).

Subjects for the Analysis

Among the original 1,502 pairs at baseline, 276 caregivers could not complete or refused to assess the ZBI, and the data on comorbidity condition or sociodemographic characteristics were lacking for 159 participants. The study sample, therefore, consisted of 1,067 community-dwelling disabled elderly (387 men, 680 women, age range: 65–104 years) and paired caregivers (256 men, 811 women, age range: 31–90 years). There were no statistical differences in mortality and hospitalization rates during the follow-up period between participants with and without caregiver ZBI measurements among the 1,502 participants. Of these 1,067 pairs, 259 care recipients could not complete the GDS-15 because of severe cognitive impairment or communication impairment, and 101 caregivers because of refusal to do the assessment.

Statistical Analysis

The ZBI score was categorized into quartiles (quartile 1: score, 0–15, N = 284; quartile 2: 16–26, N = 253; quartile 3: 27–39, N = 269; quartile 4: 40–84, N = 261). Baseline characteristics of the study participants, including both care recipients and caregivers, were examined using the Jonckheere–Terpstra test or the General Linear Models for trends across the quartiles of the ZBI score. Analysis of variance for multiple comparisons was used to determine differences among the quartiles of the ZBI score for continuous variables, and the Pearson χ^2 test was used to test categorical variables. The end point of this study was defined as the time to all-cause death or hospitalization because of acute illness, whichever occurred first, during follow-up. Cox proportional hazard models and the Kaplan–Meier method (differences between strata of the ZBI score levels determined using log-rank tests) were used to assess the association of quartiles of the ZBI score with those adverse outcomes after enrollment during a 3-year period (3-month intervals). To create an ideal model for a multivariate Cox proportional hazards model, we first evaluated the association between

each covariate and all-cause death or hospitalization, using the univariate Cox proportional hazards model. Covariates included, for the recipient, sociodemographic characteristics, the presence or absence of regular medical checkups, the number of community-based services, economic status, bADL score, the Charlson comorbidity index, and the presence or absence of selected major comorbidities and behavioral problems. Covariates also included, for the caregiver, sociodemographic characteristics, subjective health status, and categorized ZBI score. In the multivariate analysis, the covariates included were variables associated with each event with $p < 0.05$ in univariate analysis. In models considering the quartiles of the caregiver ZBI score, we compared hazard ratios (HRs) with a corresponding 95% confidence interval (CI) in the second, third, and fourth quartiles with those in the first quartile (referent).

Additional analyses stratified by the use or nonuse of community-based respite care services including day-care, home-help, and nursing-home respite stay services were also performed using a consistent set of covariates to examine the data for possible interactions of these variables with the adverse health outcomes of care recipients. Student's *t*-test and analysis of covariance (ANCOVA) were used to compare the caregiver ZBI score according to the service use and nonuse groups. Covariates of ANCOVA included recipient gender, age, bADL score, the Charlson comorbidity index, the presence or absence of dementia and behavior problems, caregiver gender, and caregiver age.

The data were analyzed using the SAS, Release 9.13. Probability value of < 0.05 was considered significant.

RESULTS

The baseline distribution of the sociodemographic characteristics of the care recipients and caregivers according to the quartiles of the ZBI score is shown in Table 1. We used analysis of variance or Pearson χ^2 test to evaluate differences among the quartiles of the ZBI score. The bADL score decreased, and the number of community-based services used, the Charlson comorbidity index, and recipient GDS-15 score increased as the level of the ZBI quartile increased. The care recipients whose caregivers' ZBI

scores were in higher quartiles were more likely to show a higher prevalence of dementia (χ^2 test: $\chi^2 = 61.09$, degrees of freedom [*df*] = 3, $p < 0.001$; Jonckheere-Terpstra test: *z* statistics, *Z* value = 7.51, $N = 1,067$, $p < 0.001$), behavioral problems ($\chi^2 = 14.75$, $df = 3$, $p = 0.002$; Jonckheere-Terpstra test, *Z* value = 8.58, $N = 1,067$, $p < 0.001$) and a history of cerebrovascular disease ($\chi^2 = 10.31$, $df = 3$, $p = 0.016$; Jonckheere-Terpstra test, *Z* value = 2.37, $N = 1,067$, $p = 0.018$). The caregiver's GDS-15 score increased (General Linear Model, *F* value = 313.48, $df = 1,964$, $p < 0.001$), and the prevalence of good to excellent subjective health status of the caregiver decreased with increasing quartiles of the ZBI score (Jonckheere-Terpstra test, *Z* value = 5.37, $N = 1,067$, $p < 0.001$). There were no differences in the rate of regular medical checkups (χ^2 test, $\chi^2 = 5.66$, $df = 3$, $p = 0.130$), living arrangements (living alone or with one person versus living with two or more, $\chi^2 = 1.46$, $df = 3$, $p = 0.692$), and three categories of economic status ($\chi^2 = 6.70$, $df = 3$, $p = 0.349$) among the quartiles of the ZBI score.

During the 3-year period, 268 care recipients died and 455 were admitted to hospitals (Table 2). The participants whose caregivers' ZBI scores were in the higher quartiles were more likely to die and be hospitalized during the follow-up period than those whose caregivers' scores were in the lower quartile categories (χ^2 test, $\chi^2 = 9.78$, $df = 3$, $p = 0.020$; $\chi^2 = 11.09$, $df = 3$, $p = 0.007$, respectively).

Kaplan-Meier curves of survival and the cumulative incidence of hospitalization during the 3-year period among care recipients according to the quartile of the caregivers' ZBI scores demonstrated that all-cause mortality and hospitalization increased with higher quartiles of caregiver ZBI at baseline (log-rank χ^2 test, mortality: $\chi^2 = 17.29$, $df = 3$, $p < 0.001$; hospitalization: $\chi^2 = 23.61$, $df = 3$, $p < 0.001$; Fig. 1).

The univariate Cox proportional hazards model revealed that the recipients whose caregivers' ZBI scores were in the highest quartile were 1.93 times and 1.86 times more likely to suffer all-cause mortality and hospitalization, respectively, during the 3-year period than those in the lowest quartile (95% CI: 1.38–2.71, Wald χ^2 test, $\chi^2 = 14.80$, $df = 1$, $p < 0.001$; 95% CI: 1.43–2.42, Wald $\chi^2 = 21.16$, $df = 1$, $p < 0.001$). The GDS-15 score of the care recipients and caregivers was not associated with mortality and hospitalization in univariate analysis (mortality: HR: 1.03; 95% CI: 0.98–1.07, Wald χ^2

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TABLE 1. Baseline Characteristics of Study Participants According to ZBI Score Quartile of Caregivers

	Quartile Group of Caregiver ZBI Score				F	p
	1st, Score: 0-15, n = 284	2nd, Score: 16-26, n = 253	3rd, Score: 27-39, n = 269	4th, Score: 40-84, n = 261		
Care recipients (n = 1067)						
Men/women, N (% of men)	89/195 (31.3)	88/165 (34.8)	100/169 (37.2)	110/151 (42.1)		0.065
Age, M (SD), year ^a	81.0 (7.1)	81.1 (7.7)	81.2 (7.8)	80.8 (8.5)	0.10	0.962
Basic ADL (range: 0-20), M (SD) ^a	14.2 (6.1)	12.5 (6.2)	11.0 (6.5)	10.4 (6.3)	20.07	<0.001
Charlson comorbidity index, M (SD) ^a	1.8 (1.5)	2.2 (1.5)	2.3 (1.5)	2.4 (1.7)	7.06	<0.001
GDS-15 (range: 0-15), M (SD) ^{a,b}	5.4 (3.4)	6.2 (3.2)	6.6 (3.4)	8.1 (3.7)	21.19	<0.001
No. of service uses (range: 0-7), M (SD) ^a	2.0 (1.1)	2.2 (1.2)	2.4 (1.3)	2.5 (1.3)	8.97	<0.001
Presence of chronic disease, no. (%)						
Ischemic heart disease	36 (12.7)	31 (12.3)	36 (13.4)	29 (11.1)		0.882
Congestive heart failure	17 (6.0)	20 (7.9)	22 (8.2)	27 (10.3)		0.321
Cerebrovascular disease	93 (32.7)	110 (43.5)	120 (44.6)	111 (42.5)		0.016
COPD	11 (3.9)	11 (4.3)	14 (5.2)	18 (6.9)		0.400
Dementia	66 (23.2)	92 (36.4)	135 (50.2)	135 (51.7)		<0.001
Cancer	29 (10.2)	22 (8.7)	14 (5.2)	28 (10.7)		0.098
Presence of behavioral problems, no. (%)	8 (2.8)	11 (4.3)	21 (7.8)	26 (10.0)		0.002
Caregiver variables (n = 1067)						
Men/women, no. (% of men)	71/213 (25.0)	69/184 (27.3)	56/213 (20.3)	60/201 (23.0)		0.350
Age, M (SD), year ^a	64.1 (13.0)	65.4 (12.2)	63.5 (12.6)	65.8 (11.3)	2.05	0.106
GDS-15 (range: 0-15), M (SD) ^{a,c}	3.4 (3.0)	4.7 (3.2)	5.8 (3.5)	8.5 (3.4)	107.98	<0.001
Relationship to care recipient, no. (%)						
Spouse	115 (40.5)	119 (47.0)	106 (39.4)	128 (49.0)		0.061
Nonspouse	169 (59.5)	134 (53.0)	163 (60.6)	133 (51.0)		
Health status, no. (%)						
Good to excellent	150 (52.8)	101 (39.9)	98 (36.4)	80 (26.2)		<0.001
Fair	103 (36.3)	127 (50.2)	148 (55.0)	169 (55.4)		
Poor	31 (10.9)	25 (9.9)	23 (8.6)	56 (18.4)		
ZBI score (range: 0-88), M (SD) ^a	9.4 (4.7)	21.0 (3.1)	32.6 (4.0)	52.5 (9.8)	2553.05	<0.001

Notes: M: mean; SD: standard deviation; COPD: chronic obstructive pulmonary disease.

^aAnalysis of variance for multiple comparisons was used to determine differences among the quartiles of the ZBI score for continuous variables ($df = 3, 1063$ except for recipient GDS-15 [$df = 3, 804$] and caregiver GDS-15 [$df = 3, 962$]), and the Pearson χ^2 test was used to test categorical variables ($df = 3$).

^bn = 808.

^cn = 966.

TABLE 2. Adverse Events During 3-year Period According to the Quartile Group of ZBI Score

	Quartile Group of ZBI Score				Total, n = 1,067	p ^a
	1st, n = 284	2nd, n = 253	3rd, n = 269	4th, n = 261		
Adverse outcomes, no. (% of each quartile)						
All-cause death	58 (20.4)	63 (24.9)	64 (23.8)	83 (31.8)	268 (25.1)	0.020
Hospitalization	98 (34.5)	111 (43.9)	119 (44.2)	127 (48.7)	455 (42.6)	0.007

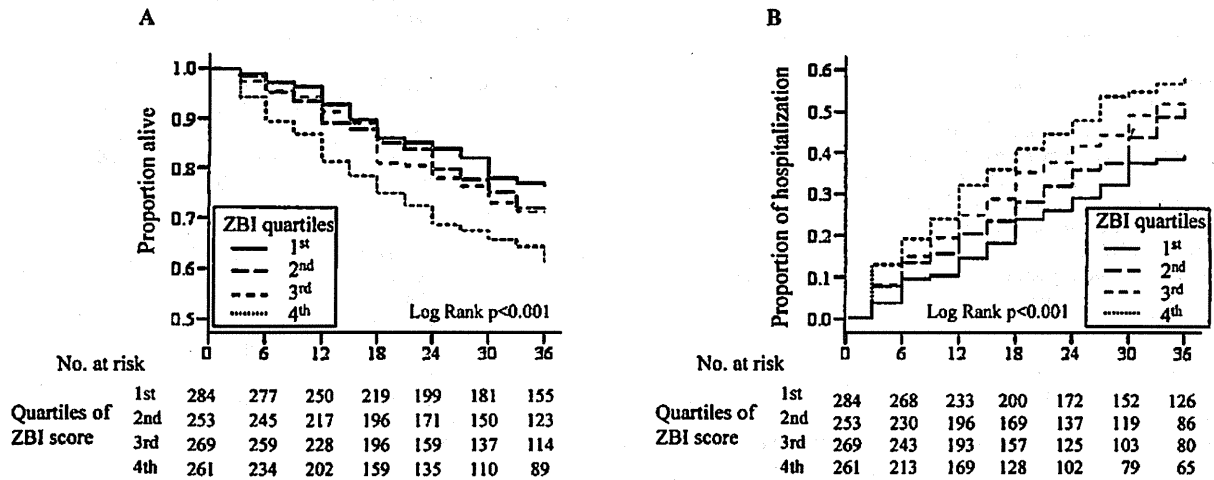
^aPearson χ^2 test. Degree of freedom is equal to 3.

test, $\chi^2 = 1.52$, $df = 1$, $p = 0.218$, and HR: 1.02; 95% CI: 0.98-1.05, Wald $\chi^2 = 1.072$, $df = 1$, $p = 0.301$, respectively; hospitalization: HR: 1.02; 95% CI: 0.99-1.05; Wald χ^2 test, $\chi^2 = 1.54$, $df = 1$, $p = 0.215$, and HR: 1.01; 95% CI: 0.99-1.04; Wald $\chi^2 = 0.81$, $df = 1$, $p = 0.369$, respectively).

As shown in Table 3, multivariate adjustment for confounders, including recipient gender and age,

badL score, number of community-based services used, the Charlson comorbidity index, caregiver gender and age, presence or absence of behavioral problems (only for all-cause mortality analysis), and the subjective health status of the caregiver (only for hospitalization analysis), showed that the highest quartile of caregivers' ZBI scores (compared with the lowest quartile) was associated with a 1.54-fold risk

FIGURE 1. Kaplan–Meier Plot for Probability of Event-Free Survival (A) and Probability of Hospital Admission (B) According to Increasing Quintiles of the Zarit Burden Interview Score



Log-rank χ^2 test, mortality (A): $\chi^2 = 17.29$, $df = 3$, $p < 0.001$; hospitalization (B): $\chi^2 = 23.61$, $df = 3$, $p < 0.001$.

of all-cause death and a 1.51-fold risk of recipient hospitalization. When the analyses were conducted using the ZBI score as a continuous variable, the recipients who had caregivers with higher ZBI scores were associated with higher risk of mortality and hospitalization (HR: 1.01, 95% CI: 1.00–1.02, Wald χ^2 test, $\chi^2 = 6.92$, $df = 1$, $p = 0.009$, and HR: 1.01, 95% CI: 1.00–1.01, Wald $\chi^2 = 8.86$, $df = 1$, $p = 0.003$, respectively). The HRs of the top quartile were similar when the comorbidity index score was replaced with the presence or absence of chronic diseases that were identified as risk factors by univariate analysis in each event (Table 3).

Based on ANCOVA adjusted for recipient gender, age, BADL score, the Charlson comorbidity index, the presence or absence of dementia and behavior problems, caregiver gender, and caregiver age, no differences in the adjusted average ZBI scores were detected between users and nonusers of these services (ANCOVA, adjusted mean ZBI score (standard deviation): day-care service, nonuse, 27.9 (16.4) versus use, 29.3 (16.5), F value = 1.92, $df = 1, 1057$, $p = 0.166$; home-help service: nonuse, 29.0 (16.4) versus use, 27.9 (16.4), F value = 1.06, $df = 1, 1057$, $p = 0.304$) except for the nursing-home respite service, for which users showed higher ZBI scores than nonusers (nonuse, 28.1 [16.4], versus use, 32.1 [16.8], F value = 5.26, $df = 1, 1057$, $p = 0.022$).

In Table 4, using the multivariate Cox proportional hazards model, we examined the association between higher versus lowest quartile of the ZBI score and care recipient all-cause mortality and hospitalization within subgroups of various community-based respite service use status. Overall, within nonusers of these respite care services, the highest quartile of caregiver burden was associated with all-cause mortality and hospitalization. No apparent association was observed within users of these services except for users of the day-care service, who showed a statistically significant association between the highest quartile and the risk of hospitalization (HR: 1.56, 95% CI: 1.03–2.36, Wald χ^2 test, $\chi^2 = 4.50$, $df = 1$, $p = 0.034$).

DISCUSSION

In the present study, we observed that the recipients with caregivers with a baseline ZBI score in the highest quartile were 1.54 and 1.51 times more likely to show increased risk of all-cause mortality and hospitalization during a 3-year follow-up period, respectively, in comparison with those with caregivers in the lowest. These relationships existed independently of various other risk factors for mortality and hospitalization, including gender, age, number of community-based services used, ADL status, and

TABLE 3. Multivariate Cox Proportional Hazards Models and Association Between Baseline Characteristics and Risk of Mortality and Hospitalization During 3-year Follow-up

	All Death						Hospitalization					
	Model 1 ^a			Model 2 ^b			Model 1 ^c			Model 2 ^d		
	Wald χ^2	p	HR (95% CI)	Wald χ^2	p	HR (95% CI)	Wald χ^2	p	HR (95% CI)	Wald χ^2	p	HR (95% CI)
Care recipient variables												
Men (versus women)	22.41	<0.001	1.98 (1.49-2.63)	24.25	<0.001	2.06 (1.54-2.75)	3.39	0.065	1.23 (0.99-1.54)	3.05	0.081	1.22 (0.98-1.52)
Age ^e	66.21	<0.001	1.07 (1.05-1.09)	45.71	<0.001	1.06 (1.04-1.08)	6.08	0.014	1.02 (1.00-1.03)	3.24	0.072	1.01 (1.00-1.03)
Basic ADL score ^e	26.01	<0.001	0.94 (0.92-0.96)	32.04	<0.001	0.93 (0.91-0.96)	7.89	0.005	0.97 (0.96-0.99)	12.95	<0.001	0.97 (0.95-0.99)
No. of service uses ^e	0.84	0.360	0.94 (0.83-1.05)	0.90	0.343	0.93 (0.83-1.05)	2.28	0.131	1.07 (0.97-1.17)	1.75	0.186	1.06 (0.97-1.16)
Charlson comorbidity index ^e	8.84	0.003	1.12 (1.04-1.22)			—	2.13	0.145	1.05 (0.98-1.12)			—
Chronic disease (versus absence)												
Congestive heart failure		—		5.16	0.023	1.54 (1.06-2.23)		—			—	
COPD		—				—		—		3.090	0.079	1.40 (0.96-2.03)
Dementia		—		4.298	<0.001	1.33 (1.02-1.74)		—			—	
Cancer		—		14.64	<0.001	1.99 (1.40-2.82)		—		18.10	<0.001	1.84 (1.39-2.44)
Behavioral problems (versus absence)	0.20	0.657	1.11 (0.72 to 1.70)	0.23	0.629	1.12 (0.72-1.74)		—			—	
Caregiver's variables												
Men (versus women)	0.03	0.863	1.02 (0.74-1.42)	0.01	0.984	0.99 (0.71-1.38)	0.01	0.942	0.99 (0.77-1.27)	0.13	0.714	0.95 (0.74-1.22)
Age ^e	0.36	0.551	1.00 (0.99-1.02)	0.47	0.492	1.00 (0.99-1.02)	0.07	0.788	1.00 (0.99-1.01)	0.04	0.847	1.00 (0.99-1.01)
Subjective caregiver health status (versus good to excellent)												
Fair		—				—	2.95	0.086	1.21 (0.97-1.50)	2.52	0.113	1.19 (0.96-1.48)
Poor		—				—	2.99	0.084	1.32 (0.96-1.82)	2.69	0.101	1.31 (0.95-1.80)
ZBI score (versus 1st quartile)												
2nd	0.13	0.717	1.07 (0.75-1.53)	0.23	0.629	1.09 (0.76-1.57)	2.06	0.151	1.22 (0.93-1.61)	2.51	0.113	1.25 (0.95-1.64)
3rd	0.01	0.942	1.01 (0.71-1.46)	0.06	0.809	1.05 (0.73-1.51)	2.93	0.087	1.27 (0.97-1.68)	3.95	0.047	1.32 (1.00-1.75)
4th	5.80	0.016	1.54 (1.09-2.17)	4.44	0.035	1.45 (1.03-2.05)	8.62	0.003	1.51 (1.15-1.98)	8.29	0.004	1.50 (1.14-1.97)

Notes: Degree of freedom is equal to 1. COPD: chronic obstructive pulmonary disease.

^aModel 1 included gender, age, bADL score, number of community-based services used, regular medical checkups, Charlson comorbidity index, behavioral problems, caregiver's age and gender, the Zarit categories that are associated with mortality in univariate analysis.

^bModel 2 for analysis of all-death, which included variables used in Model 1 plus presence or absence of heart failure, dementia, and cancer, which are associated with all-death in univariate analysis, instead of Charlson comorbidity index.

^cModel 1 included gender, age, bADL score, number of community-based services used, regular medical checkups, Charlson comorbidity index, caregiver's age and gender, subjective caregiver health status, and the Zarit categories that are associated with mortality in univariate analysis.

^dModel 2 for analysis of hospitalization, which included variables used in Model 1 plus presence or absence of cancer and COPD, which are associated with all-death in univariate analysis, instead of Charlson comorbidity index.

^eContinuous variables.

TABLE 4. Subgroup Cox Hazard Analysis According to Quartiles of the ZBI Score

Use or Nonuse	No. of Case Total	Quartile Group of ZBI Score (1st: Reference)								
		2nd			3rd			4th		
		Wald χ^2	p	HR (95% CI)	Wald χ^2	p	HR (95% CI)	Wald χ^2	p	HR (95% CI)
All death^a										
Day-care service										
Nonuse	165/573	1.03	0.310	1.26 (0.81-1.96)	0.07	0.791	0.95 (0.58-1.54)	5.06	0.024	1.66 (1.07-2.59)
Use	103/494	0.31	0.579	0.84 (0.45-1.58)	0.15	0.695	1.12 (0.64-1.97)	0.75	0.387	1.29 (0.72-2.31)
Home-help service										
Nonuse	155/618	0.76	0.382	1.25 (0.76-2.05)	0.16	0.688	1.11 (0.67-1.85)	12.7	<0.001	2.32 (1.46-3.69)
Use	113/449	0.10	0.757	0.92 (0.54-1.57)	0.23	0.633	0.88 (0.52-1.49)	0.63	0.426	0.80 (0.46-1.39)
Nursing-home respite stay service										
Nonuse	237/959	0.34	0.558	1.12 (0.76-1.65)	0.09	0.768	1.06 (0.72-1.56)	9.75	0.002	1.79 (1.24-2.58)
Use	31/108	0.42	0.517	0.70 (0.24-1.79)	0.77	0.381	0.63 (0.23-1.76)	1.86	0.173	0.46 (0.15-1.41)
Hospitalization^b										
Day-care service										
Nonuse	250/573	1.72	0.189	1.27 (0.89-1.82)	3.46	0.063	1.43 (0.98-2.10)	5.07	0.024	1.54 (1.06-2.24)
Use	205/494	0.86	0.353	1.23 (0.80-1.88)	0.93	0.334	1.22 (0.81-1.84)	4.50	0.034	1.56 (1.03-2.36)
Home-help service										
Nonuse	260/618	3.56	0.059	1.45 (0.99-2.14)	4.88	0.027	1.54 (1.05-2.25)	18.00	<0.001	2.25 (1.55-3.27)
Use	195/449	0.01	0.945	1.01 (0.68-1.51)	0.01	0.930	1.02 (0.67-1.54)	0.40	0.528	0.87 (0.57-1.33)
Nursing-home respite stay service										
Nonuse	400/959	2.30	0.130	1.25 (0.94-1.67)	2.09	0.148	1.24 (0.93-1.67)	9.32	0.002	1.57 (1.18-2.10)
Use	55/108	0.21	0.646	1.26 (0.47-3.34)	0.65	0.419	1.43 (0.60-3.41)	0.02	0.891	1.06 (0.44-2.56)

Notes: Multivariate Cox proportional hazard models. Degree of freedom for all variables is equal to 1.

^aModel included gender, age, basic activities of daily living (BADL) score, number of community-based services used, Charlson comorbidity index, behavioral problems, caregiver's age and gender, and the Zarit categories.

^bModel included gender, age, BADL score, number of community-based services used, Charlson comorbidity index, caregiver's age and gender, subjective caregiver health status, and the Zarit categories.

comorbidity. To our knowledge, this is the first report addressing the relationships between caregiver burden and mortality or hospitalization for dependent older care recipients living in the community.

In addition, subgroup analysis revealed that the association between a high caregiver burden and adverse health outcomes of care recipients was mainly observed in nonusers of community-based respite services, including day-care, home help, or nursing-home respite stay services. No association was found between high caregiver burden and adverse health outcomes of care recipients among users of these services except for users of day-care services with a hospitalization risk.

There are a number of possible mechanisms for these associations. Previous research has found caregiver burden to be a factor in determining the quality of care given and, specifically, a negative indicator of the willingness of caregivers to continue in the caregiving role.^{2,20} The caregiver burden may lead to a lower quality of care, leading over time to abuse or neglect and, ultimately, to negative health outcomes for the care recipient.^{21,22} In fact, it has been demon-

strated that a lack of needed care for disabled older individuals or a decreased quality of family caregiving results in poor outcomes for care recipients.²³⁻²⁵ Thus, caregiver burden and emotional distress can be a detriment to the health and well-being of care recipients through inadequate provision of care.

In this study, we demonstrated that the GDS-15 score of the caregiver as well as the care recipient increased as the level of the ZBI quartile increased. These results may indicate that caregiver burden is associated with depressive symptoms in the care recipients and that there may be interrelationships between the emotional distress of the caregiver and depressive symptoms in care recipients. A number of reports have suggested that depressive symptoms have been shown to be an important risk factor for mortality and to increase the risk of physical disability through poorer adherence to healthy life styles.²⁶⁻²⁸ However, the GDS-15 scores of care recipients were not associated with all-cause mortality and hospitalization in this cohort. There are several possible reasons for this difference between our cohort and others. The subjects of the current

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investigation had multiple medical problems and functional limitations and were probably at higher mortality and hospitalization risk than those in these prior studies.²⁶⁻²⁸

It has been demonstrated that the death or serious illness of a spouse increases the risk of death or affects the health of a partner.^{29,30} A possible mechanism of this association is that spousal illness or death may deprive a partner of social, emotional, or other practical support.^{29,30} In the present study, subjective poor health status of the caregiver was associated with risk of hospitalization for the care recipient but not with mortality in this cohort. The highest level of caregiver burden was associated with hospitalization for dependent elderly care recipients, even after adjustment for the subjective health status of the caregivers, making it unlikely that our findings were confounded by the poor health status of the caregiver, at least at baseline.

Community-based long-term care services are believed to relieve stress on family caregivers and enable older people with disabilities to remain at home for a longer period of time.³¹ However, the usefulness of these services for reducing caregiver burden is still controversial. Some studies have demonstrated a positive effect of respite service on caregiver burden, but others have shown no effect or a negative relationship between respite service use and caregiver burden.³²⁻³⁶ In our cohort, no difference in the caregiver ZBI score was observed between users and nonusers of day-care services and home-help services, and a rather higher average ZBI score in users of nursing-home respite stay services compared with nonusers was observed, although cross-sectional determination of respite care service use and the ZBI measurement do not allow evaluation of the causal and consequent relationships between service use and caregiver burden. However, the present study found that the adverse outcome for care recipients with caregivers with the highest burden is more evident in nonusers of respite services than in service users. It is possible that the use of these long-term care services decreased the adverse health outcomes of care recipients through other factors beyond caregiver burden.

Our study has several strengths, including the relatively large number of paired participants and outcome events, a prospective design, and a well-defined population. Our analyses took into account potential confounders including age, gender, BADL,

comorbidity, and subjective health status of the caregiver. We also adjusted for the number of community-based services used and conducted an analysis stratified by the use or nonuse of community-based respite care services.

This study has potential limitations. Subjects with acute illness at enrollment were excluded from participating in the NLS-FE, and the present study used statistical control of potential confounding variables to rule out third factors that might produce an association between caregiver burden and care recipient adverse health outcomes during the follow-up period. However, because of the observational design of the present study, differences in unmeasured factors, including social circumstances, caregiver's competence in caring for a disabled recipient, the health condition of the caregivers during the study period not at baseline, and the length of caregiving may in part account for the findings. We used only the presence or absence of selected major comorbidities and behavioral problems as covariates in the analyses. The lack of assessment of the severity of the recipient's medical illness or significant behavioral problems, both of which would require more time for care providing, may have influenced the results in the present study. The present findings may not be generalizable to other populations, given that health practices, a variety of social and economic factors, ethnic attitudes about caring for very old people, and the cost of healthcare may have influenced these results. It should be noted that multiple analyses in the present study increased the chances of making high likelihood of Type I errors.

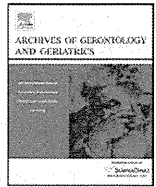
We demonstrated high caregiver burden as an important risk of the adverse health outcomes of care recipients, including all-cause mortality and hospitalization. This risk of care recipient adverse health outcomes associated with a heavy caregiver burden was attenuated in community-based respite care service users. In the community setting, interventions directed toward the reduction of caregiver burden and improving caregiver well-being may not only delay long-term care placement and prevent the deterioration of caregiver health but also reduce care recipient adverse health outcomes. A community-based service may thus yield benefits for care recipients and may favorably affect the complex and interrelated variables of the caregiver and the recipient. These efforts may facilitate the continuation of home care of the disabled elderly.

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Impact of informal care levels on discontinuation of living at home in community-dwelling dependent elderly using various community-based services

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ABSTRACT

The aim of the study was to examine the effect of informal care levels on overall discontinuation of living at home, all-cause death, hospital admission, and long-term care placement for community-dwelling older people using various community-based services during a 3-year period. Prospective cohort study of 1582 community-dwelling disabled elderly and paired informal caregivers was conducted. Baseline data included the recipients and caregivers' demographic characteristics, comorbidities, informal care levels (sufficient, moderate, and insufficient care), which were evaluated by trained visiting nurses, and the level of formal community-based service use. Among 1582 participants, 97 died at home, 692 were admitted to hospitals, 318 died during their hospital stay, and 117 were institutionalized in long-term care facilities during 3 years of follow-up. A multivariate Cox hazard model demonstrated that when compared with a sufficient informal care level, an insufficient informal care level was associated with overall discontinuation of living at home, all-cause mortality, hospitalization, and institutionalization during 3 years of follow-up (hazard ratio: 1.65, 95% confidence interval: 1.15–2.36; 1.98, 1.17–3.34; 1.56, 1.04–2.35; 2.93, 1.25–6.86, respectively). The results suggested that informal caregiving is an important factor in the prevention of overall discontinuation of living at home in a population of disabled older people.

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1. Introduction

The proportion of older people and long-term care use are increasing in developed countries. There is a projected trend toward reduced institutional care that will increase the number of severely disabled people living in the community. There is a great deal of public policy and clinical interest in effective and efficient ways to help disabled elderly individuals to continue to live in community settings. A number of previous reports demonstrated the risk factors for each type of event by which stable living at home is discontinued, including all-cause death, hospital admission, and long-term care placement (Shugarman et al., 2002; Ishizaki et al., 2006; Muramatsu et al., 2007; Beswick et al., 2008). However, only limited data are available regarding the risk factors for all-inclusive discontinuation of living at home (Beswick et al., 2008).

A number of studies have demonstrated the association between the inadequate provision of care (unmet care needs) and adverse health outcomes for the community-dwelling elderly

(Gaugler et al., 2005; Sands et al., 2006). In most prior studies, unmet needs have been defined as the absence of informal assistance, formal services, or some combination of both accompanied by ADL needs (Gaugler et al., 2005; Sands et al., 2006). However, the care needs of older disabled people living in the community are not only related to ADL tasks but also various other domains including psychological, behavioral, and social domains (Georges et al., 2008). No study has investigated the effect of the overall informal care levels provided by family on adverse outcomes for care recipients in terms of continuation of living at home.

In developed countries, varying community-based formal services are available to help the disabled elderly living in the community to continue living in the community. Although these services intend to reduce hospital and nursing-home admission, and mortality, a substantial number of studies have examined the effects of these programs on older people living in the community; the findings have been inconsistent. Recent meta-analysis has revealed the limited effect of complex intervention packages targeting disabled elderly individuals living in the community on mortality, hospital and nursing-home admissions (Beswick et al., 2008).

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In contrast, much less attention has been paid to the impact of the level of informal care mainly provided by relatives to allow the continuation of living at home. Concern that formal services might substitute for informal care is not borne out by the available evidence (Greene, 1983; Denton, 1997; Penning, 2002).

Japan introduced a universal-coverage long-term care insurance (LTCI) program in 2000 (Tsutsui and Muramatsu, 2005). This program induced a radical change from traditional family-based care toward the socialization of elderly care and the integration of medical care and welfare services. The aims of the LTCI home care programs are not only to reduce the care burden of caregivers but also to maintain and improve the functional abilities and well-being of elderly people, to reduce the use of institutional care services, and to reduce mortality. Under the LTCI program, older people who are eligible for the LTCI program can choose any community-based service with a 10% co-payment for services received.

The goal of this research was to examine the effect of informal care levels on overall discontinuation of living at home and on each event leading to the discontinuation of living at home, including all-cause death, hospital admission, and long-term care placement, during a 3-year period for community-dwelling older people using various community-based services under the LTCI program.

2. Subjects and methods

In the present study we employed baseline data on the participants in the Nagoya Longitudinal Study for Frail Elderly (NLS-FE) and data on the mortality, hospitalization, institutionalization, and any events which blocked the continuation of living at home of these participants during the 3-year follow-up period. Details of the participants ($n = 1875$, age range: 65–104) and the NLS-FE have been published elsewhere (Kuzuya et al., 2006a,b). The participants were eligible for the LTCI program, lived in Nagoya City, and were provided various kinds of community-based services by the Nagoya City Health Care Service Foundation for Older People, which has 17 visiting nursing stations associated with care-managing centers. These NLS-FE participants, who were enrolled between 1 December 2003 and 31 January 2004, were scheduled to undergo comprehensive in-home assessments by trained nurses at the baseline and at 6, 12, and 24 months. At 3-month intervals, data were collected regarding any important events in the lives of the participants, including admission to the hospital for acute illness and mortality during the 3-year follow-up.

Written informed consent for participation was obtained from the participants, care recipients and caregivers, or, for those with substantial cognitive impairment, from a surrogate (usually the closest relative or legal guardian) according to procedures approved by the institutional review board of Nagoya University Graduate School of Medicine. Since the 293 participants who had no caregivers at baseline were excluded, the study population consisted of 1582 community-dwelling disabled elderly (562 men and 1022 women, age 65 years or older).

2.1. Data collection

The data were collected at the clients' homes from standardized interviews with patients or surrogates and caregivers, and from care-managing center records taken by trained nurses. The data included clients' demographic characteristics, depressive symptoms as assessed by the short version of the Geriatric Depression Scale (GDS-15) (Yesavage, 1988), and a rating for ten basic activities of daily living (bADL) (feeding, mobility on bed, bathing, grooming, dressing, using the toilet, walking inside and outside, transferring, and using stairs) using a summary score ranging from

0 (total disability) to 20 (no disability). The interview with participants also included questions about the utilization of a total of seven community-based services available under LTCI programs, including the day-care service, visiting nurse service, home-help service, visiting bathing service, visiting rehabilitation, assistive device leasing, and nursing-home respite stay (overnight respite, temporary stays at nursing facilities).

Information on the following physician-diagnosed chronic conditions was obtained from care-managing center records: ischemic heart disease, congestive heart failure, cerebrovascular disease, diabetes mellitus, dementia, chronic obstructive pulmonary disease, cancer, hypertension, and other diseases comprising the Charlson comorbidity index (CCI) (Charlson et al., 1987), which represents a sum of weighted indexes, taking into account the number and seriousness of preexisting comorbid conditions (range: 0–19, with a higher value indicating higher comorbidity). It should be noted that clients eligible for LTCI have their own primary care physicians, since the physician needs to submit a report on their clinical status every 6 months. The economic status of care recipients, divided into three categories (enough: enough financial resources; moderate: no need for financial support from relatives; poor: need for financial support from relatives), was also obtained from care recipients or their surrogates.

Data were also obtained from caregivers concerning their own personal demographic characteristics, the relationship to the patient, the degree of help from other relatives (divided into three categories), preference for care at home, and their subjective burden as assessed by the Japanese version of the Zarit Burden Interview (ZBI) (Arai et al., 1997), which is a 22-item self-reported inventory that examines the burden associated with functional behavioral impairments in the home care situation. Information on the living arrangement and economic status category of the care recipients was recorded based on interviews with caregivers. The primary caregivers were also asked to rate their current overall health using three categories of subjective health status (poor, fair, good to excellent).

2.2. Informal and formal care levels

Quality of care is multidimensional and determining the need for care is a complex process. In the present study, to assess the informal care levels, trained visiting nurses subjectively evaluated the informal care levels for the care recipients provided by family caregivers and categorized them into three groups: sufficient care, moderate care, and insufficient care. This subjective evaluation was a matter of determining the assistance levels of caregivers for care recipients who live in need of physical, mental, and social assistance at home. The level of formal community-based service use under the LTCI program does not matter. The formal care levels were evaluated by two methods: the number of regular uses of the three major community-based care services, namely the visiting nurse service, day-care service, and home-help service, per month at the baseline and the number of uses of community-based service at the baseline among the seven services provided under the LTCI program described above.

2.3. Statistical analysis

Analysis of variance with a Bonferroni correction and the chi-squared test were used to compare differences among participants receiving sufficient, moderate, or insufficient informal care levels at baseline.

Univariate and multivariate logistic regression models were used to assess the association between insufficient informal care levels (vs. sufficient levels) and the characteristics of care recipients and caregivers at baseline. The following baseline data

Table 1
Baseline characteristics of participants according to informal care levels, mean \pm S.D.

Variables	Informal care level			p
	Sufficient	Moderate	Insufficient	
Care recipients (n = 1582)	815	627	140	
Men/women, n	315/500	199/428	46/94	0.020
(% of men)	38.7	31.7	32.9	
Age (years)	81.4 \pm 7.9	80.8 \pm 7.7	79.1 \pm 7.1	0.004
Basic ADL (range: 0–20)	11.5 \pm 6.8	12.1 \pm 6.5	12.6 \pm 6.6	0.076
CCI ^a	2.1 \pm 1.6	2.0 \pm 1.6	2.1 \pm 1.6	0.626
Chronic diseases (% of total)				
Congestive heart failure	8.4	7.9	10.6	0.621
Cerebrovascular disease	39.9	35.7	35.8	0.268
Dementia	43.0	38.1	31.4	0.016
Cancer	8.6	8.6	9.8	0.904
Number of regular uses of seven services,	2.3 \pm 1.2	2.3 \pm 1.2	2.5 \pm 1.2	0.240
Regular medical checkups (%)	58.2	62.0	66.4	0.109
Living alone (%)	7.2	12.2	19.3	<0.001
Economic status (%)				
Enough	29.1	19.7	15.0	
Moderate	68.0	74.1	63.6	<0.001
Poor	2.8	6.1	21.4	
Caregiver (n = 1582)				
Men/women, n	165/650	184/443	50/90	<0.001
(% of men)	20.2	29.3	35.7	<0.001
Age (years)	64.0 \pm 11.7	63.8 \pm 13.0	65.3 \pm 15.2	0.477
Spouse caregiver (%)	39.7	40.8	45.7	<0.001
ZBI score (range: 0–88) ^b	27.9 \pm 16.7	30.3 \pm 17.2	29.5 \pm 18.5	0.064
Subjective health status (%)				
Good to excellent	44.1	40.0	34.1	
Moderate	48.8	45.9	24.0	<0.001
Poor	7.2	14.1	41.9	

Notes: ANOVA, others were analyzed by χ^2 test.

^a Charlson comorbidity index.

^b The Zarit Burden Interview, n = 1253.

were used in univariate analysis: the gender, age, ADL status, CCI, living arrangement, and economic status of the care recipient; the number of uses of community-based service at the baseline among the seven services provided under the LTCI program; and the caregiver's gender, age, relationship to the recipient, subjective health status, and ZBI score. The covariates included in the multivariate analysis were variables to be associated with insufficient informal care levels with $p < 0.05$ in univariate analysis.

Cox proportional hazard models were also used to determine the association of informal care levels at baseline with the discontinuation of living at home or any event which blocked the continuation of living at home, including 3-year all-cause mortality, hospitalization, and institutionalization. To create an ideal model for multivariate models, we first evaluated the association between each covariate and each adverse outcome during the 3-year period using the univariate Cox proportional hazard model. The covariates included in the multivariate analysis were variables to be associated with each adverse outcome with $p < 0.05$ in univariate analysis. The risk of a variable was expressed as an odds ratio (OR) and a hazard ratio (HR) with a corresponding 95% confidence interval (CI). All analyses were performed using the Statistical Package for the Social Sciences (SPSS) Version 15.0. A probability value of <0.05 was considered significant.

3. Results

3.1. Baseline characteristics of participants

Out of 1582 care recipients and matched caregivers, a sufficient informal care level was found in 815 pairs, while moderate and insufficient informal care levels were found in 627 and 140 pairs,

respectively. There were differences among these three groups in the recipients' gender distribution, age, living arrangement, and economic status, and in the caregivers' gender and subjective health status and the rate at which the caregiver was the recipient's spouse (Table 1). It should be noted that 10.3% of caregivers did not live in the same household as the recipient. The highest rate of living alone was observed among care recipients with insufficient informal care levels (19.3%).

3.2. Factors associated with insufficient care levels

When insufficient care levels with sufficient levels were compared, multivariate logistic regression analysis revealed that recipients receiving insufficient informal care were less likely to be male, more likely to be living alone, more likely to have a poor economic status, and more likely to have a male caregiver and a caregiver with poor subjective health status (Table 2). The higher ZBI score was not associated with insufficient informal care levels in univariate analysis OR (95%CI) = 1.01 (0.99–1.02).

3.3. Cox proportional hazard analysis for discontinuation of living at home

Among the 1582 participants, 906 experienced at least one event which led to the discontinuation of living at home during the 3-year study period. Among these 906 participants, 97 died at home, 692 were admitted to an acute-treatment hospital, and 117 were institutionalized in long-term care facilities as the first event causing a disturbance of stable living at home during the 3-year follow-up. Of 692 participants who were admitted to a hospital, 318 died during their hospital stay.

Table 2

Logistic regression analysis to identify the factors associated with insufficient informal care levels (vs. sufficient).

Variables	Multivariate ^a	
	OR	95%CI
Care recipients		
Men (vs. women)	0.55	0.31–0.96
Age (years) (continuous)	0.96	0.93–0.99
Living arrangement (vs. living with two or more)		
Living alone	2.88	1.39–5.96
Living with one person	1.03	0.61–1.75
Economic status (vs. enough)		
Moderate	1.40	0.78–2.53
Poor	7.80	3.32–18.30
Caregiver		
Men (vs. women)	1.99	1.15–3.42
Age (years) (continuous)	1.00	0.98–1.02
Subjective health status (vs. excellent)		
Moderate	0.77	0.44–1.37
Poor	10.31	5.53–19.21

^a All the listed variables which were $p < 0.05$ in univariate analysis were entered into the analysis.

To identify the factors associated with the discontinuation of living at home over the 3-year follow-up, Cox proportional hazard models were conducted. Multivariate analysis using covariates which were associated with the discontinuation of living at home in univariate analysis revealed that the following characteristics were associated with overall discontinuation of living at home: male, older, lower ADL status, presence of cancer, higher ZBI score, and moderate to insufficient informal care level (Table 3).

Table 3

Cox proportional hazard analysis for discontinuation of living at home during 3-year follow-up.

Variables ^a	Univariate		Multivariate ^a	
	Hazard ratio	95%CI	Hazard ratio	95%CI
Care recipients				
Men (vs. women)	1.21	1.05–1.38	1.26	1.04–1.53
Age (years) (continuous)	1.02	1.01–1.03	1.03	1.02–1.04
Basic ADL (continuous)	0.86	0.84–0.88	0.97	0.96–0.99
Presence of chronic diseases (vs. absence)				
Congestive heart failure	1.29	1.03–1.63	1.05	0.79–1.40
Dementia	1.45	1.28–1.66	1.12	0.94–1.33
Cancer	1.66	1.33–2.06	1.72	1.34–2.22
Regular medical checkups (vs. absence)	1.34	1.17–1.54	1.11	0.93–1.32
Living arrangement (vs. living alone)				
Living with one person	1.25	0.97–1.60	0.75	0.51–1.12
Living with two or more	1.40	1.10–1.78	0.89	0.62–1.29
Number of regular uses of seven services (continuous)	1.24	1.18–1.30	1.08	0.99–1.17
Caregiver				
Men (vs. women)	0.92	0.79–1.07	1.04	0.84–1.29
Age (years) (continuous)	1.01	1.00–1.02	1.00	0.99–1.01
ZBI score (continuous)	1.01	1.01–1.02	1.01	1.01–1.02
Informal care level (vs. sufficient)				
Moderate	1.06	0.93–1.22	1.19	1.01–1.42
Insufficient	1.32	1.05–1.67	1.65	1.15–2.36
Subjective health status (vs. excellent)				
Moderate	1.39	1.21–1.61	1.19	0.98–1.43
Poor	1.57	1.28–1.93	1.12	0.84–1.50

^a Listed are caregiver's gender and variables with $p < 0.05$ in univariate analysis.

^a All the listed variables were entered in the analysis.

3.4. Association between various types of events and levels of informal care

To examine the associations between various types of events which blocked the continuation of living at home during the 3-year follow-up and the levels of informal care, Cox proportional hazard models were used (Table 4). In crude models, compared with a sufficient informal care level, insufficient informal care level was associated with hospital admission, but not with institutionalization and all-cause death during the 3-year follow-up. In the full-adjusted models, insufficient informal care levels were strongly associated with all-cause mortality, hospital admission, and institutionalization in long-term care facilities during the 3-year follow-up.

4. Discussion

In the present study we identified the factors associated with events leading to the discontinuation of living at home, including all-cause death, hospital admission, and long-term care placement, for a 3-year period in community-dwelling disabled older people using LTCI programs. The results suggested that the following factors were identified as predictors of the discontinuation of living at home in a multivariate model: for the care recipients, male gender, lower ADL status, and the presence of cancer at baseline; and for the caregivers, higher caregiver burden and an insufficient level of informal care. The HR of insufficient informal care levels for the discontinuation of living at home was comparable to that of the presence of cancer.

In most of the prior studies, insufficient care levels (unmet care needs) were defined as the absence or insufficiency of informal (usually family caregiver) or formal (paid caregiver) assistance in combination with ADL needs (Gaugler et al., 2005; Sands et al., 2006). However, needs for personal assistance services are not only for older people with difficulty in performing ADL tasks but also for

Table 4

Associations between various types of events and levels of informal care—Cox proportional hazard models.

	Informal care level (vs. sufficient)			
	Moderate		Insufficient	
	Hazard ratio	95%CI	Hazard ratio	95%CI
All death				
Unadjusted	0.85	0.69–1.04	1.10	0.78–1.54
Full-adjusted ^a	1.06	0.81–1.37	1.98	1.17–3.34
Hospital admission				
Unadjusted	1.07	0.92–1.26	1.38	1.07–1.79
Full-adjusted ^b	1.18	0.97–1.44	1.56	1.04–2.35
Institutionalization				
Unadjusted	1.40	0.96–2.04	1.35	0.69–2.65
Full-adjusted ^c	1.46	0.94–2.27	2.93	1.25–6.86

^a Adjusted for care recipient's gender, age, bADL score, the presence or absence of heart failure, dementia, and cancer, regular medical checkups, living arrangement, number of service uses, and caregiver's gender, age, the ZBI score, and subjective health status.

^b Adjusted for care recipient's gender, age, bADL score, the presence or absence of cancer, regular medical checkups, living arrangement, number of service uses, caregiver relationship, and caregiver's gender, age, the ZBI score, and subjective health status.

^c Adjusted for care recipient's gender, age, bADL score, the presence or absence of dementia, number of service uses, and the caregiver's gender, age, ZBI score, and subjective health status.

those with hearing or visual problems, cognitive impairment, incontinence, falls, and behavioral symptoms with dementia (Georges et al., 2008). Therefore, due to the difficulty of objectively evaluating informal care levels provided by relatives, in this study we used the subjective evaluation of informal care levels by visiting nurses who often visited the clients' homes, contacted the recipients and their caregivers at home, and knew their care environment well.

Although the accuracy and reliability of the subjective evaluation was not evaluated in this study, there were more family members living with care recipients, a lower rate of dissatisfaction with the help provided by other relatives (data not shown), and more caregivers who preferred to care for the patient at home (data not shown) in the group with a sufficient informal care level compared with those in the insufficient group. Previously, using the same cohort, we reported that a lack of medication assistance for community-dwelling disabled older people among those needing medication support was associated with a higher risk of hospitalization (Kuzuya et al., 2008). Among participants who reported difficulty with self-medication ($n = 1085$), 497 (84.1%) of 591 participants with sufficient informal care levels received medication assistance from caregivers. On the other hand, 328 (79.0%) of 415 participants with moderate informal care levels, and 45 (57.0%) of 79 with insufficient informal care levels received medication assistance from caregivers ($p < 0.001$, the chi-squared test). These results indicate that this subjective evaluation by visiting nurses seems to be closely related to the actual informal care level. It should be noted that higher ZBI scores were not associated with insufficient informal care levels in the present study, suggesting that caregiver burden does not contribute to the care levels provided by the caregivers.

We observed that poor levels of informal care were associated with poor economic status. However, when economic status was included in the multivariate model, poor informal care levels were still a strong risk factor for the discontinuation of living at home for community-dwelling elderly (data not shown). In addition, we demonstrated that poor informal care levels were associated with all-cause death, hospital admission, and long-term care placement after adjusting for confounders. These associations persisted even after adjusting for the number of uses of formal care under the LTCI program.

A number of studies have demonstrated the association between the following characteristics of caregivers and recipient long-term care placement: higher burden (Yaffe et al., 2002),

nonspouse caregiver (Kesselring et al., 2001), and poor relationship between caregiver and recipient (Spruytte et al., 2001). However, only limited data are available on the effect of caregiver characteristics and living arrangement on the adverse health outcomes of care recipients, including hospital admission and mortality. It has been demonstrated that care recipients whose caregiver is a spouse have a significantly lower risk of mortality (Temkin-Greener et al., 2004), and that living arrangement affects the mortality of community-dwelling older people (Kandler et al., 2007). It is possible that these factors may affect the association between informal care levels and long-term care placement as well as adverse health outcomes including all-cause death and hospitalization in the present study. However, these associations persisted even after adjusting for these parameters in our multivariate models, suggesting that these confounders are not a major reason for this association.

What makes our results particularly interesting is that the participants used various community-based services under the LTCI program to maintain stable living at home. The association between caregiver care levels and poor outcomes with regard to continuous living at home persisted even after adjustment for the number of formal services used. In addition, the present study did not reveal a beneficial effect of the number of regular uses of seven community-based services or the number of uses of three major services per month (data not shown) on stable living at home, suggesting that informal community-based services were not able to substitute for informal care.

This study has various limitations. The subjective evaluation of informal care levels by visiting nurses may not be accurate or reflect precise care levels. Because of the observational design of the present study, differences in unmeasured factors, including the severity of chronic diseases suffered by the recipients, the health conditions of the caregivers during the study period not at baseline, and the length of caregiving may account in part for the findings. In addition, these findings may not be generalizable to other populations, given that they may have been influenced by health practices, a variety of social and economic factors, ethnic attitudes about caring for very old people, and cost.

5. Conclusions

The results suggest that informal caregiving is an important factor not only in the prevention of long-term care placement but also in the prevention of adverse health outcomes including hospital admission and all-cause death in a population of disabled

older people using various community-based services under the LTCI program. Family members and friends provided care for the majority of older patients in need, even providing nursing and personal care, which require skills on the part of the caregiver. Informal caregiving has an incremental positive effect on the health of care recipients. Although there is some evidence that caregiver training intervention appeared to be effective in improving the psychological health and quality of life of caregivers (Hepburn et al., 2001; Belle et al., 2006), it is not apparent that the caregiver training intervention has any positive effect on stable living at home for disabled community-dwelling older people. Future interventions for family caregivers should focus not only on caregiver health but also on stable living at home for disabled community-dwelling older people by providing adequate help to meet care recipients' needs.

Conflict of interest statement

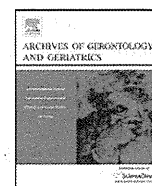
The authors have no conflicts of interest with the manufacturers of any drug evaluated in this paper.

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Association between the caregiver's burden and physical activity in community-dwelling caregivers of dementia patients

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ABSTRACT

Physical activity in the elderly has a significant influence on their health status. Studies have shown that elderly caregivers have fewer physical activities relative to non-caregivers. The present study aimed to identify factors associated with lower physical activity in elderly caregivers of demented patients. A cross-sectional survey of 50 elderly caregivers living with patients diagnosed with Alzheimer's-type dementia showed that the Zarit caregiver burden interview (ZBI) scores were significant predictors of physical activity measured by the questionnaire score (QS) of physical activities. Among the three subscales of the QS, it was only leisure time activity scores (LS) that the ZBI scores significantly predicted. The numbers of chronic diseases were associated with lower household activity scores (HS) and sport activities scores (SS). Physical activities, in particular leisure activities, were found to be inversely associated with care burden assessed by the ZBI. Interventions to increase the physical activity levels of older caregivers may improve their health status and quality of life.

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1. Introduction

It has been reported that lower levels of physical activity increase the risk of cardiovascular events (Blair et al., 1989) and higher mortality (Lee et al., 1995; Barengo et al., 2004) and that increased physical activity levels can help to maintain physical functions (Chu et al., 2004), contribute to the prevention of the cardiovascular disease (Dubbart, 2002), and decrease mortality (Davis et al., 2001). In addition, habitual physical exercise has been reported to be beneficial in terms of maintaining psychological health in the elderly (Bowen et al., 2006; Gautam et al., 2007).

In Japan aging of the population is occurring at an unprecedented rate, and the ratio of older adults aged 65 and above is estimated to reach 25% in 2015 (Health and Welfare Statistics Association, 2003). Under the urgent pressure of expected increases in the social burden related to care of the older population, Japanese government commenced an initiative to promote health called Healthy Japan 21 (Japan Health Promotion and Fitness Foundation, 2000). In this program, regular physical activities with an intensity of moderate degree (such as doing simple gymnastics and walking) is recommended for health promotion of older adults.

Despite such encouragement to exercise regularly for physical fitness, in general it had been shown that elderly caregivers have few physical activities (Burton et al., 1997; Wilcox et al., 2000; Fredman et al., 2006). As such, the physical health of elderly caregivers of demented patients might be at risk due to their reduced opportunities for regular exercise. The psychological burden of care in caregivers of demented patients has been suggested to be greater than that in caregivers of non-demented patients, presumably due to the psychological and behavioral symptoms present in demented patients (Onishi et al., 2005). Moreover, a possibility that the physical health of those caring for patients with dementia might also be at stake has been suggested by previous findings, showing a higher prevalence of hypertension (Shaw et al., 1999), a higher mortality rate in these individuals (Schulz and Beach, 1999), and reduced lymphocyte sensitivity (Bauer et al., 2000).

As mentioned above, caregivers have smaller amount of physical activities and higher care burden, and both conditions are associated with deteriorated health and higher mortality. Indeed, several studies reported that psychological distress is a factor associated with lower physical activity (Kaplan et al., 2001; Lim and Taylor, 2005). However, there has been a dearth of study thus far to investigate the association of reduced physical activities and care burden in this "high-risk" population.

In the current study we tried to find the associated factors with reduced physical activities in the caregivers of the demented, in

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particular focused on the association between the types of physical activities and the care burden.

2. Methods

2.1. Sample and study design

The study participants were 50 caregivers aged 65 and older who were living with elderly patients diagnosed with Alzheimer's-type dementia according to DSM-IV (American Psychiatric Association, 1994) diagnostic criteria. Diagnoses were made by a group of experienced geriatricians.

The study was approved by the ethics committee of the Nagoya University Graduate School of Medicine, and all participants gave written consent after being given a detailed description of the study.

2.2. Assessment of caregivers

Caregivers were assessed using three assessment tools. Firstly, the Japanese version of the ZBI (Zarit et al., 1980) is a questionnaire that includes 22 items. The caregiver's burden, assessed based on physical, psychological, and economical factors, was scored (0–88). Higher score indicated increased burden. Secondly, physical activity was assessed by the physical activity QS for the elderly (Voorrips et al., 1991). The QS comprises three subscales: household activity scores (HS), sport activity scores (SS), and leisure time activity scores (LS). Items related to the household activity scores were questions with 4–5 possible ratings, ranging from very active to inactive. The SS is an assessment of activity in all types of sports (e.g., walking, golf, gymnastics, and so on). The LS assesses leisure activity (e.g., gardening, ceramic art, and so on). The SS and LS are assessed by the hours per week spent on each type of activity, and by the period of the year during which the activity is normally performed. All activities are graded their intensity, hours and period of the year. Thirdly, the visual analogue scale (VAS) (Carlsson, 1983), a simple and commonly used self-rating scale originally developed for the subjective assessment of pain (0–100), was used to assess the mood of caregivers.

2.3. Assessment of care recipients

Care recipients were assessed using two assessment tools. Firstly, the Japanese version of the neuropsychiatric inventory (NPI; Hirono et al., 1997) was used to evaluate the psychobehavioral symptoms of care recipients. Secondly, the cognitive function and severity of dementia were assessed using the mini-mental state examination (MMSE; Folstein et al., 1975) (0–30).

2.4. Statistical analysis

Quantitative data analyses were carried out using SPSS (version 17.0) statistical software. Results were considered statistically significant at the level of $p < 0.05$. Multiple linear regression was used to estimate unique variance in QS or inferior scores (HS, SS, LS). The independent variables were ZBI, age, gender, VAS for depression, number of chronic diseases, and number of persons living together. Additionally, Pearson's correlation coefficient was computed to estimate the association between the time spent for caregiving and the QS.

3. Results

Table 1 shows demographic data and various health parameters of the participating caregivers and their care recipients. Hyperten-

Table 1

Health factors for caregivers and care recipients, mean \pm S.D. or n (%).

Caregiver	
Male/female	18/32
Age (years)	73.3 \pm 4.2
Systolic blood pressure (mmHg)	128.3 \pm 22.4
Diastolic pressure (mmHg)	77.5 \pm 9.5
HbA _{1c} (%)	5.6 \pm 0.8
HDL-C (mg/dl)	59.6 \pm 16.5
LDL-C (mg/dl)	112.6 \pm 32.0
Triglyceride (mg/dl)	144.0 \pm 66.2
Body mass index (kg/m ²)	22.6 \pm 3.3
Having no other family members	28 (56)
Comorbidity of chronic disease	
Hypertension	45 (90)
Diabetes	28 (56)
Hypercholesterolemia	12 (24)
Cancer	17 (34)
Others	2 (4)
Others	4 (8)
Care recipient	
Male/female	31/19
Age (years)	76.6 \pm 6.4
MMSE score	18.0 \pm 7.5
NPI	14.0 \pm 11.3

sion was the most prevalent condition of caregivers (56%), followed by hypercholesterolemia (34%) and diabetes (24%). More than half of the participants lived with other family members (56%). Care recipients showed various degrees of psychobehavioral symptoms assessed by NPI (14.0 \pm 11.03).

The average ZBI score was 32.1 \pm 19.8, with female caregivers having higher scores (36.0 \pm 21.6) than male caregivers (25.3 \pm 14.4). The HS and VAS for depression in female caregivers were significantly higher than those for male caregivers. Meanwhile, the QS (4.1 \pm 2.9), SS (1.3 \pm 2.7) and LS (1.0 \pm 2.0) were higher in male caregivers, none of these trends reached statistical significance (Table 2).

To compute the unique variance in the QS, the variables (ZBI scores, gender, age, VAS for depression) were forced into the regression equation as the first step, followed by the number of chronic diseases and the number of persons living together as second and third steps, respectively (model 1, 2). The analysis showed that the ZBI scores were significant predictors of the QS and LS (model 1, 2), but they did not predict the HS and SS (Table 3).

In order to compute the unique variance in each inferior score of the QS (HS, SS, LS), the variables for the ZBI, gender, age, the VAS for depression, and the number of chronic diseases were forced into the regression equation as the fourth and fifth steps. The number of chronic diseases emerged as a significant predictor of the HS and SS, while only the ZBI scores were significant predictors of the LS.

The significant negative association was estimated between the time spent for caregiving and the QS ($r = -0.312$, $p < 0.05$).

Table 2

Gender comparison of psychosocial and physical activity scales, mean \pm S.D.

	All	Male	Female	p
Number	50	18	32	
ZBI	32.1 \pm 19.8	25.3 \pm 14.4	36.0 \pm 21.6	0.067
QS	3.9 \pm 2.7	4.1 \pm 2.9	3.8 \pm 2.7	0.671
HS [*]	2.1 \pm 0.5	1.8 \pm 0.4	2.2 \pm 0.4	0.009
SS	1.2 \pm 2.4	1.3 \pm 2.7	1.2 \pm 2.3	0.882
LS	0.6 \pm 1.6	1.0 \pm 2.0	0.4 \pm 1.2	0.199
Depression [*]	29.4 \pm 25.7	18.6 \pm 22.2	35.5 \pm 25.9	0.024
No. of chronic diseases	1.5 \pm 0.9	1.6 \pm 0.9	1.4 \pm 0.8	0.562
No. of family members	3.0 \pm 1.7	2.9 \pm 1.5	3.1 \pm 1.7	0.633

^{*} $p < 0.05$.

^{**} $p < 0.01$.

Table 3
Multiple linear regression model for physical activity and ZBI.

	Variables	β	<i>T</i>	<i>p</i>
QS	(Model 1)			
	ZBI [*]	-0.340	-2.177	0.035
	Gender	0.109	0.777	0.441
	Age	-0.081	-0.602	0.550
	Depression	-0.194	-1.246	0.219
	No. of chronic diseases	0.150	1.131	0.264
QS	(Model 2)			
	ZBI [*]	-0.340	-2.102	0.041
	Gender	0.088	0.617	0.540
	Age	-0.066	-0.484	0.631
	Depression	-0.186	-1.178	0.245
	No. of family members	0.063	0.463	0.646
HS	ZBI	-0.039	-0.249	0.804
	Gender ^{**}	0.419	3.023	0.004
	Age	-0.035	-0.264	0.793
	Depression	-0.198	-1.284	0.206
	No. of chronic diseases [*]	-0.272	-2.067	0.045
	SS	ZBI	-0.070	-0.447
Gender		0.129	0.913	0.366
Age		-0.103	-0.756	0.454
Depression		-0.293	-1.863	0.069
No. of chronic diseases [*]		0.354	2.644	0.011
LS		ZBI ^{**}	-0.479	-3.046
	Gender	-0.135	-0.957	0.344
	Age	0.028	0.207	0.837
	Depression	0.175	1.114	0.271
	No. of chronic diseases	-0.209	-1.557	0.127

* $p < 0.05$.** $p < 0.01$.

4. Discussion

In the current study we examined factors associated with low physical activities of the caregivers who were taking care of older patients with dementia. Physical activities, especially leisure activities were inversely associated with care burden measured by the ZBI, and the observed association was independent of depressive mood.

Several reasons may be considered to explain the association between low physical activities and higher care burden. As supported by an inverse correlations observed between the time spent for caregiving and the QS, providing care has been described as a stressful experience that may erode psychological well-being and physical health of caregivers (Pinquart and Sorensen, 2003). Accordingly, caregivers with high care burden may have less temporal or psychological capacity to spare time for physical activities. Caregivers may also be prone to feel physically fatigued by a sense of burden. Care burden was reportedly associated with depressive mood (Adams, 2008), and depressive mood generally lowers the level of physical activity (Wise et al., 2006). The association between physical activity and ZBI scores observed in the current study, however, was independent of depressive mood measured by VAS. In other words, the care burden itself was associated with lower activity levels, but depressive mood did not intervene between these two factors. A more detailed analysis of depressive mood may be necessary to confirm these findings.

On the other hand, the ZBI scores had no significant relationship with the HS and the SS. Housekeeping works are the necessities of life in most households, thus routinely operated, and also some sport-related activities, such as playing golf, can be long-standing habit hard to give up. Therefore such activities may not easily be affected by a sense of burden.

The current investigation also revealed that many caregivers have chronic medical conditions. Subjects with chronic disease generally have low levels of physical activity (Arne et al., 2009),

and the impact of the disease was negatively correlated with the mental health status (Forbes et al., 2007). In the current study, the number of chronic diseases was associated with lower HS and SS, but not with QS and LS.

Higher mortality in caregivers has been reported (Schulz and Beach, 1999; Fredman et al., 2008), however, the underlying mechanism of higher mortality remains unknown. Many literatures indicated that low physical activities including leisure are closely associated with higher mortality (Lee et al., 1995; Barengo et al., 2004), and the effectiveness of exercise in maintaining physical health in the elderly has been demonstrated (Struck and Ross, 2006). Recently, Byberg et al. (2009) reported that increased leisure activities reduced the mortality. The current study suggested that care burden reduces the overall physical activities in the caregivers, and it particularly affects the time spent for leisure activities. Taken all these findings together, one can easily conceive that the reduced physical activities due to care burden may have some deteriorating effects on caregivers' health. To prevent caregivers from having their own health status at stake by caregiving, it may be appropriate to seek for external sources of care provision in view of reducing substantial burden by sharing it with professional care providers. In Japan the public long-term care insurance system was launched in 2000, aiming to provide sufficient support for disabled older adults and their caregivers. Various types of supports that the insured can benefit from the insurance policy include home aides, day care, and short-term stay in the facilities. However, it has been suggested that the care burden of caregivers has not necessarily decreased since the introduction of the insurance scheme (Okamoto and Harasawa, 2009), and several reports suggested that the health-related quality of life of caregivers (Morimoto et al., 2003; Takai et al., 2009) had in fact deteriorated. Improvement of service provisions would be warranted in order to meet substantial needs of informal caregivers as well as care recipients.

On the other hand, increasing physical activities of the caregivers may help to reduce care burden. It may be difficult for older adults to maintain or begin the habit of regular exercise (Conn et al., 2003), however, given the results of the current study that leisure score was most strongly associated with care burden, interventions attempting to increase leisure activities may reduce care burden.

Limitations of the current study are as follows. Firstly, assessments of the physical activity levels of caregivers relied on self-reported scoring of the three domains. Therefore the variances inherent in subjective assessments may have affected the results. Secondly, the sample size was relatively small and study design was cross-sectional. A longitudinal intervention involving more participants would be warranted to investigate the effects of increased physical activities on care burden.

In conclusion, we observed an association between lower physical activity levels in the caregivers of demented patients and a higher care burden. This association was particularly strong with regard to leisure activities.

Conflict of interest statement

None.

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ORIGINAL ARTICLE: BEHAVIORAL
AND SOCIAL SCIENCES

Physical and functional factors in activities of daily living that predict falls in community-dwelling older women

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Aim: In order to propose rehabilitation strategies for the reduction of falls risk, thereby preventing falls in older women, the present study was designed to explore the physical and functional factors related to actual incidence of falls.

Methods: Fifty-eight female patients aged 65 years and older (mean age \pm standard deviation, 80.5 ± 5.7), who were attending a geriatric outpatient clinic participated. All the participants were assessed with their activities of daily living, gait and balance using various scales. Their handgrip strength and muscle strength of lower extremities were also measured using dynamometers. Falls of the participants during the 6 months follow-up period were recorded.

Results: Correlation analysis investigating associations between the scores of assessment scales and actual measurement of muscle strength and balance showed that there were significant correlations between handgrip strength and Falls Efficacy Scale, Functional Reach test, Timed Up and Go test, Berg Balance Scale, Motor Fitness Scale, motor Functional Independence Measure in fallers and non-fallers. A binary logistic stepwise regression analysis incorporating all the possible variables into the model revealed that only inability to “being able to go up and down the staircase” in the Motor Fitness Scale remained a significant variable to predict falls during the period of observation.

Conclusion: The results confirmed that the sub-item in the Motor Fitness Scale has a possibility of being a significant predictor of falls in older women, and therefore might prove useful in considering specific rehabilitation program on falls prevention as well as screening this population at risk of falls. *Geriatr Gerontol Int* 2011; 11: 348–357.

Keywords: activities of daily living, incidence of falls, physical performances, preventing falls, risk assessment of falls.

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