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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 wellbeing 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 3month 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 followup.

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, homehelp 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 chisquared 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 ± 7.9	80.8 ± 7.7	79.1 ± 7.1	0.004
Basic ADL (range: 0-20)	11.5 ± 6.8	12.1 ± 6.5	12.6 ± 6.6	0.076
CCla	2.1 ± 1.6	2.0 ± 1.6	2.1 ± 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 ± 1.2	2.3 ± 1.2	2.5 ± 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 ± 11.7	63.8 ± 13.0	65.3 ± 15.2	0.477
Spouse caregiver (%)	39.7	40.8	45.7	< 0.001
ZBI score (range: 0–88) ^b	$\textbf{27.9} \pm \textbf{16.7}$	30.3 ± 17.2	29.5 ± 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.

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.

^a Charlson comorbidity index.

^b The Zarit Burden Interview, n = 1253.

Table 2Logistic regression analysis to identify the factors associated with insufficient informal care levels (vs. sufficient).

Variables	Multivariate*	
	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 wit	th 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. excel	llent)	
Moderate	0.77	0.44-1.37
Poor	10.31	5.53-19.21

 $^{^{\}star}$ 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).

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

Variables [*]	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

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

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

Table 4Associations between various types of events and levels of informal care—Cox proportional hazard models.

	Informal care level (vs. su	Informal care level (vs. sufficient)			
	Moderate	Moderate			
	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.

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

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

^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.

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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FACTORS ASSOCIATED WITH NONADHERENCE TO MEDICATION IN COMMUNITY-DWELLING DISABLED OLDER ADULTS IN JAPAN

To the Editor: Nonadherence to drug therapy is a serious problem for older people, because adherence to medication is essential for obtaining the optimal therapeutic effects of medication. ^{1–4} Although numerous studies have identified the factors related to nonadherence to drug therapy, only limited studies have taken a wider perspective, focusing on adherence in older community-dwelling disabled adults and on factors affecting adherence. ^{5,6} The aim of this study was to identify the factors associated with nonadherence to drug therapy in older community-dwelling disabled adults.

The present study used baseline data on participants in the Nagoya Longitudinal Study for Frail Elderly. 4,7,8 The study population consisted of 1,722 older communitydwelling disabled adults (611 men, 1,161 women; mean age 80.3 ± 7.6 , range 65–104) and 1,502 caregivers (375 men, 1127 women; mean age 64.1 ± 12.6 , range 31–93). The baseline data included the recipients' demographic characteristics, activities of daily living (ADLs), depressive symptoms as assessed using the short version of the Geriatric Depression Scale (GDS-15), physician-diagnosed chronic conditions, living arrangement, number of prescribed medications, and self-reported difficulty with self-medication management, which was assessed as previously described.⁴ The participants or family were also asked whether they were receiving any assistance for taking medication or medication management from others. The participants were divided into two groups: no difficulty with self-medication management, and difficulty with self-medication management. Data were also obtained from caregivers concerning their own personal demographic characteristics, their subjective health status, and burden as assessed according to the Zarit Burden Interview. The adherence rate to the prescribed medication was defined as the total number of pills taken divided by the total number of prescribed pills as assessed by the self-reported average medication adherence during 1 month. It was decided to use self-reporting rather than other forms of adherence measurements because they are prohibitively expensive and cumbersome, and there is little evidence that they are superior to selfreport instruments.^{1,9} Nonadherence was defined as less than 80% of the adherence rate. Univariate and multivariate logistic regression were used to determine which characteristics of the disabled older adult or caregiver predicted nonadherence to prescribed medication.

Of 1,772 participants, 223 (12.6%) were categorized as nonadherent. Univariate logistic analysis demonstrated that participants living alone (vs living with someone, odds ratio (OR) = 1.43, 95% confidence interval (CI) = 1.04-1.96), with depression (GDS-15 \geq 11 vs <5, OR = 1.61, 95% CI = 1.03-2.53), and with dementia (vs its absence, OR = 1.47,95% CI = 1.10-1.96) and participants who had difficulty with self-medication management (vs no difficulty with self-medication, OR = 1.69, 95% CI = 1.24-2.30) were more likely to be nonadherent. Multivariate analysis (Table 1, Model 1) showed that medication nonadherence was associated with participants living alone, having depression, and having difficulty with self-medication. When participants who had difficulty with self-medication were divided as to the absence or presence of assistance (Model 2), nonadherence was associated with participants living alone, participants with depression, the presence of dementia, participants who had difficulty with self-medication but had no assistance, and participants with assistance. For participants who had difficulty with self-medication and had assistance, none of the variables of care recipients were associated with nonadherence in univariate analysis. Multivariate analysis revealed that a male caregiver and poor subjective health status of the caregiver were likely to result in nonadherence in participants having assistance.

In the present study, it was observed that participants who had difficulty with self-medication management had a high risk of nonadherence to medication. In particular, participants needing support but who did not have any, had a OR of nonadherence 3.2 times as high as those who had no difficulty with self-medication management, suggesting that medication management assessment is needed to determine which older people are at risk of medication management problems and to minimize adverse events attributable to poor medication adherence. Participants receiving medication management assistance had an OR of medication nonadherence 1.64 times as high as participants who had no difficulty with self-medication management. These results may imply that families or relatives living with disabled older patients may not always give appropriate assistance for medication management. A male caregiver and subjective poor health status of the caregiver were associated with recipient nonadherence to prescribed medication, suggesting that caregivers with those characteristics may tend to provide inadequate levels of assistance for medication or that neglectful behavior by caregivers may be involved in this association.

In conclusion, the results suggest that, in older community-dwelling disabled adults, the lack of medication assistance for those needing medication support was associated with a higher risk of nonadherence, although even those receiving assistance had a higher risk of nonadherence than those with no difficulty with self-medication management.

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Table 1. Logistic Regression Analysis for Nonadherence

		Odds Ratio (95% Confidence Interval)			
	Multiv	ariate*			
Characteristic	Model 1 [†]	Model 2 [‡]	Multivariate for Those Having Assistance [§]		
Care recipient characteristics					
Men (vs women)	0.86 (0.61-1.23)	0.89 (0.62-1.28)	_		
Age (continuous variable)	0.99 (0.97-1.02)	0.99 (0.97-1.02)			
Living alone (vs living with someone)	2.00 (1.35-2.95)	1.94 (1.31-2.86)	1.38 (0.59–3.25)		
GDS-15 (range 0-15) (vs score 0-5)					
6–10	1.22 (0.85-1.77)	1.25 (0.86-1.81)			
≥ 11	1.61 (1.02-2.53)	1.68 (1.06-2.66)			
Presence of dementia (vs absence)	1.34 (0.91-1.97)	1.56 (1.04-2.36)	_		
Medication management (vs self medication	n)				
Difficulty with self-medication	2.04 (1.37-3.05)	_			
Absence of assistance		3.20 (1.92-5.34)			
Presence of assistance		1.64 (1.05-2.54)	_		
Caregiver characteristics					
Men (vs women)		-	1.90 (1.18–3.06)		
Age (continuous variable)	<u> </u>		1.00 (0.98–1.02)		
Subjective health status (vs good to excelle	nt)				
Fair			0.90 (0.54–1.49)		
Poor	CONTRACTOR MARKET CONTRACTOR STORY MARKET CONTRACTOR STORY CONTRACTOR STORY CONTRACTOR STORY CONTRACTOR STORY CO		2.09 (1.11-3.94)		

^{*}The covariates included in the multivariate analysis were variables associated with nonadherence with *P*<.05 in univariate analysis. Activity of daily living score, presence of comorbid diseases (ischemic heart disease, congestive heart failure, cerebrovascular disease, diabetes mellitus, cancer, or hypertension), number of medication, and regular medical examination were not associated with nonadherence in univariate analysis. All analyses were performed using SPSS version 17.0 (SPSS, Inc., Chicago, IL).

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Author Contributions: Masafumi Kuzuya: study concept, design, conduct of study, interpretation of data, study supervision, and preparation of manuscript. Hiromi Enok: and Sachiko Izawa: analysis and interpretation of data. Jun Hasegawa and Yusuke Suzuki: conduct of study and interpretation of data. Akihisa Iguchi: study supervision.

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[†]Model 1 includes sex, age, living alone (vs living with someone), 15-item Geriatric Depression Scale (GDS-15) categories, presence of dementia (vs absence), and difficulty with self-medication (vs no difficulty).

[‡]Model 2 includes sex, age, living alone (vs living with someone), GDS-15 categories, presence of dementia (vs absence), and absence or presence of medication assistance (vs no difficulty).

[§]Logistic regression analysis was conducted to identify the predictor of the risk of nonadherence in 929 participants who had difficulty with self-medication and had assistance. The covariates included in the multivariate analysis were variables associated with nonadherence with P<.05 in univariate analysis. None of the variables of care recipients, including sex, age, comorbidity, depressive status, and number of prescribed medications, were associated with nonadherence in univariate analysis. The relationship to care recipient (spouse vs nonspouse) and the Zarit Burden Interview score were not associated with nonadherence in univariate analysis.

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ORIGINAL ARTICLE: EPIDEMIOLOGY, CLINICAL PRACTICE AND HEALTH

Factors influencing death at home in terminally ill cancer patients

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Aim: The purpose of this study is to investigate factors affecting terminally ill cancer patients dying at home.

Material: Ninety-two terminally ill cancer patients who were receiving home medical care services and died between April 2005 and December 2006 were included in the study. The data included patients' and caregivers' demographic characteristics, disease-related information, place of death, and status of home care support. To identify the factors predicting the place of death, multivariate logistic regression analyses were performed.

Results: Patients of families who had no preference regarding the place of death or a preference for death at home were more likely to die at home (vs preference for hospital death, odds ratio = 5.87, 95% confidence interval = 1.02–36.53; odds ratio = 90.35, 95% confidence interval = 8.15–1001.51, respectively) after adjusting for potential confounders. Meanwhile, if the patient's family preferred that the patient not die at home, the patient's place of death was not at his/her home irrespective of his/her preference.

Conclusion: The results suggested the stronger involvement of families' preferences regarding the patients' place of death over patients' own preferences. Therefore, factors affecting families' preferences need to be clarified for the dissemination of death at home for terminally ill cancer patients. **Geriatr Gerontol Int 2010; 10: 154–160.**

Keywords: death at home, factors, home medical care services, Japan, place of death, terminally ill cancer.

Introduction

For many years, various attempts have been made worldwide to provide optimal home care for terminally ill cancer patients who prefer to die at home. However, according to the report on palliative care issued by the World Health Organization (WHO) in 2004, many of the patients who expressed their wishes of dying at home actually died in hospitals in Britain, the USA,

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Germany, Switzerland and France.^{2–8} In Britain in particular, the proportion of patients who died at home has decreased from 27% in 1994 to 22% in 2003.^{9,10}

An opinion poll clarified that approximately two-thirds of Japanese patients diagnosed with the final stage of cancer preferred to receive medical treatments at home. A similar trend is also observed in other countries. A similar trend is also observed in other countries. Health, Labor and Welfare initiated a Long-Term Care Insurance (LTCI) program in 2000, In which people requiring health care can receive home care services. In 2006, the services offered in this program were extended to terminally ill cancer patients. Moreover, with an aim to enhance home medical care, the designation of clinics supporting home care, which are required to provide round the clock home visiting medical care in

cooperation with local home nursing stations was commenced. These series of movements toward the promotion of home care led to an emergence of group practice that only provides home visiting medical care without outpatient-based services. Despite an overt policy of the government to shift from institutional care to home care, the proportion of patients who died at home in Japan still remained approximately 12% in 2005, which is lower than that in Western countries, 15,18,19 and even has a trend of gradual decline in recent years.

It is very natural for terminally ill cancer patients to wish to spend the last period of life in their own homes, where they can be themselves rather than being patients to receive care. However, many patients who wish to die at home are in fact hospitalized during the terminal stages and end up dying at the hospital. Other than patients' wishes of dying at home, there are other factors that may influence decisions as to whether or not patients can go home. Among the possible factors, conditions related to the patient's family or caregivers, by which patients' wishes themselves could be influenced, might be of particular significance. Also, environmental factors such as locations, accessibility to nearby home care clinics or hospitals if necessary, quality of the services provided and so on might have some influences on dying at home. Although several studies have investigated whether the places where patients die are the same as those where they wish to die, few studies have addressed the question of which factors can be requisites for terminally ill cancer patients to be able die at home if they wish. 20,21 The purpose of this study is to investigate factors affecting terminally ill cancer patients to die at home, thereby to suggest possible rooms for improvement under the existing home care system in order to meet the needs of the patients.

Methods

Study design and subjects

This study consisted of a retrospective analysis of a total of 92 patients with a diagnosis of terminal stage cancer, who resided in Nagoya, an urban area of Japan with a population over 2 million, and had died between April 2005 and December 2006. All patients living at home were receiving various home care services through Mitsuba Home Care Clinic and from home visit nursing stations. The Mitsuba Home Care Clinic is a private clinic running a group practice of four full-time doctors specializing in offering home medical care on a roundthe-clock basis within the city of Nagoya. All patients are assigned to one of the four doctors as an attending physician, who performs regular home visits. In case of emergency or upon patients' request, the clinic is prepared to offer irregular home visits by one of the four doctors on a shift. Informed consent for the

participation in this survey was obtained verbally from the patients and caregivers.

Data collection

The four doctors visited patients' homes and collected data from standardized interviews with patients or their surrogates, from caregivers and from visiting nurse records. The data, which were recorded on an electronic chart, included patients' and caregivers' demographic characteristics, the period between the doctor's first visit and the patient's death, living arrangements, the presence or absence of notification about diagnosis/ prognosis of advanced malignancy to the patient, patient's or family's preference for the place of death, the primary caregiver's relationship to the patient, the presence or absence of other family caregivers to assist the primary family caregiver, administration of morphine, oxycodone or fentanyl, i.v. hyperalimentation, and number of home visits per week by the family physician or the home care nurse.

Analytical methods

To examine the differences between patients who died at home and at hospitals, the χ^2 -test or Student's *t*-test was used for independent variables or continuous variables, respectively. To identify the predictors for death at home, a logistic regression analysis was performed. Multivariate analysis was performed when a significant difference was observed in the univariate analysis. In the multivariate analysis, the following three models were employed: (i) model 1 that was designed based on patient characteristics; (ii) model 2 that was designed based on family characteristics; and (iii) model 3 that was designed based on the integration of models 1 and 2. The risk of a variable was expressed as an odds ratio (OR) with a corresponding 95% confidence interval (CI). The analysis was performed using the statistical software SPSS ver. 11.0.22 Probability values of 0.05 or less were considered statistically significant.

Results

Table 1 lists the characteristics of terminally ill cancer patients who died at home and at hospitals. Results of the χ^2 -test and Student's t-test revealed a significant difference in the following items: (i) whether the patient preferred to die at home; (ii) whether the patient's family preferred the patient to die at home; (iii) the frequency of home visits by the family physician; and (iv) the frequency of home visits by the home care nurse.

In order to identify the factors influencing the place of death of the patients, a logistic regression analysis was performed. As shown in Table 2, the unadjusted univariate analysis suggested that a higher probability of

Table 1 Characteristics of terminally ill cancer patients who died at home and hospital

Variable	No. of patients		
	Death at home	Death at Hospital	<i>P</i> -value
Patient demographics and clinical variables			
Age (mean \pm SD)	74.8 ± 10.3	72.9 ± 10.6	0.42
Sex (male/female)	29/31	18/14	0.68
Period between the doctor's first visit and the patient's death (days) (mean \pm SD)	49.5 ± 52.5	69.7 ± 82.7	0.26
Period (<27 days/≥27 days between the first visit and death)	28/32	18/14	0.38
Type of cancer (gastrointestinal tract/lung/liver/gallbladder/pancreas/others)	25/10/9/16	11/8/6/7	0.71
Living with family (yes/no)	58/2	28/4	0.09
Notification of actual diagnosis/prognosis of advanced malignancy to the patient (yes/no)	39/21	14/18	0.50
Patient's preference for the place of death (hospital/neither of them/home)	5/22/33	13/15/4	<0.0001
Family caregiver's status and role			
Family's preference for the place of death (hospital/neither of them/ home)	6/17/36	21/7/1	< 0.0001
Primary caregiver's relationship to the patient (spouse/children/others)	26/27/6	14/12/3	0.75
Primary caregiver's sex (male/female)	9/50	10/19	0.04
Other family caregivers who assist the primary family caregiver (yes/no)	32/27	7/22	0.03
Health care system and support			
Administration of morphine, oxycodone or fentanyl (yes/no)	29/31	16/16	0.88
Administration of i.v. hyperalimentation (yes/no)	12/48	22/10	0.23
No. of home visits per week by the family physician (mean \pm SD)	3.4 ± 1.8	2.6 ± 2.2	0.64
No. of home visits per week by the home care nurse (mean \pm SD)	3.4 ± 4.5	1.9 ± 2.0	0.07
No. of home visits by the family physician (<2.6 times per week/≥2.6 times)	24/36	22/10	0.01
No. of home visits by the home care nurse (<2.3 times per week/≥2.3 times)	25/35	21/11	0.03

The Student's *t*-test was employed for continuous variables and the χ^2 -test was employed for independent variables. SD, standard deviation.

home death was associated with no preference regarding the place of death (vs preference for hospital death, OR = 5.72, 95% CI = 1.73-18.97), strong preference for home death (vs preference for hospital death, OR = 14.30, 95% CI = 3.25-62.93), no family preference regarding the patient's place of death (vs family preference for hospital death, OR = 8.50, 95% CI = 2.40-30.09), family preference for home death (vs family preference for hospital death, OR = 125.90, 95% CI = 14.18-1119.04), female caregivers (vs male caregivers, OR = 2.92, 95% CI = 1.03-8.31), presence of other family caregivers (vs absence of other family caregivers, OR = 3.73, 95% CI = 1.38-10.05), frequent home visits (average ≥2.7/week by the family physician vs <2.7, OR = 3.30, 95% CI = 1.33-8.19), and frequent home visits (average ≥2.4/week) by the home care nurse (vs <2.4, OR = 2.67, 95% CI = 1.10-6.53).

In the logistic regression analysis, when a significant difference was observed in the univariate analysis, a multivariate analysis was performed using the three above-mentioned models. Using model 1, which was composed of patient characteristics, the following results were obtained. Patients with no preference regarding the place of death or a preference for home death were more likely to die at home (vs preference for hospital death, OR = 5.12, 95% CI = 1.37-19.14, OR = 16.53, 95% CI = 3.30-82.73, respectively). Using model 2, which focused on the characteristics of the family, we found that patients of families with no preference regarding the place of death or a preference for home death were more likely to die at home (vs family preference for hospital death, OR = 8.04, 95% CI = 2.08-31.08, OR = 136.57, 95% CI = 18.84-1347.51, respectively). The analysis of model 3, which was a combination of model 1 and model 2, found that the preference of the family was strongly associated with the place of death; patients of families with no preference regarding the place of death or a preference

Cancer patients and home death

Table 2 Logistic regression analysis of terminally ill cancer patients in connection with the place of death

Variable	Univariate	Multivariate		
	OR (95% CI)	Model 1 (patient) OR (95% CI)	Model 2 (family) OR (95% CI)	Model 3 (integration) OR (95% CI)
Patient's age (years)	1.00 (0.36-2.77)	1.02 (0.97-1.07)		1.00 (0.93–1.07)
Patient's sex (female, male = reference)	0.83 (0.35–1.97)	0.99 (0.35–2.84)		1.30 (0.24–6.93)
Period (≥27 days, <27 days = reference) [†]	1.47 (0.62–3.48)			
Type of cancer (gastroint				
Lung	0.55 (0.17–1.77)			
Liver/gallbladder/ pancreas	0.66 (0.19–2.31)			
Others	1.01 (0.32-3.13)			
Stay with family (yes, no = reference)	4.14 (0.72–23.99)			
Notification to the patient (yes, no = reference) [‡]	0.73 (0.29–1.85)			
Patient's preference (hosp	oital = reference)§			
Neither of them	5.72 (1.73–18.97)	5.12 (1.37-19.14)		2.18 (0.26-18.10)
Home	14.30 (3.25–62.93)	16.53 (3.30–82.73)		6.52 (0.79–53.66)
Family's preference (hosp		,		,
Neither of them	8.50 (2.40–30.09)		8.04 (2.08-31.08)	5.87 (1.02-36.53)
Home	125.9 (14.2–1119.0)		136.6 (13.8–1347.5)	90.4 (8.2–1001.5)
Primary caregiver's sex (female, male = reference)	2.92 (1.03–8.31)		2.40 (0.47–12.27)	2.64 (0.34–20.21)
Caregiver's relationship (spouse = reference)			
children**	1.21 (0.47–3.10)		0.61 (0.15-2.54)	0.76 (0.12-4.81)
Others	1.08 (0.23-4.98)		1.50 (0.20–11.07)	1.44 (0.16–12.97)
Other family caregiver (presence, absence = reference)	3.73 (1.38–10.05)		3.03 (0.79–11.68)	2.87 (0.66–12.47)
Narcotic drugs (yes, no = reference) ^{††}	0.94 (0.39–2.21)			
Intravenous hyperalimentation (yes, no = reference)##	0.55 (0.21–1.46)			
Family physician visit (≥2.6 times, <2.6 = reference) ^{§§}	3.30 (1.33–8.19)	2.23 (0.79–6.26)		1.36 (0.33–5.61)
Home care nurse visit (≥2.3 times, <2.3 = reference) ^{¶¶}	2.67 (1.10–6.53)	2.78 (0.97–7.91)		1.19 (0.26–5.57)

[†]The period between the doctor's first visit and the patient's death (days). [‡]Notification of actual diagnosis/prognosis of advanced malignancy to the patient. [§]Patient's preference for the place of death. [§]Family's preference for the place of death. [‡]*Other family caregivers who assist the primary family caregiver. ^{‡†}Administration of morphine, oxycodone, or fentanyl. ^{‡‡}Administration of i.v. hyperalimentation. ^{§§}No. of home visits per week by the family physician. ^{§§}No. of home visits per week by the home care nurse. CI, confidence interval; OR, odds ratio.

for home death were more likely to die at home (vs preference for hospital death, OR = 5.87, 95% CI = 1.02-36.53, OR = 90.35, 95% CI = 8.15-1001.51, respectively) after adjusting for potential confounders.

Next, logistic regression analyses were performed after excluding the variables that were strongly associated with home death, patient and family preference for place of death. As shown in Table 3, model 1 and model

Table 3 Logistic regression analysis of terminally ill cancer patients in connection with the place of death

Variable	Multivariate Model 1 (patient) OR (95% CI)	Model 2 (family) OR (95% CI)	Model 3 (integration) OR (95% CI)
Patient age (years)	1.01 (0.96–1.06)		0.97 (0.94–1.06)
Patient sex (female, male = reference)	0.96 (0.37-2.47)		1.24 (0.35-4.34)
Primary caregiver's sex (female, male = reference)	2.03 (0.67-6.11)	1.82 (0.50-6.61)	
Caregiver's relationship to the patient (spouse = referen	nce)		
Children [†]		1.28 (0.43-3.87)	1.26 (0.33-4.83)
Others		0.80 (0.24-2.67)	0.74 (0.18-3.04)
Other family caregiver (presence, absence = reference)	3.72 (1.15-9.29)	3.09 (1.02-9.32)	
Family physician (≥ 2.6 times, $< 2.6 = \text{reference}$) [‡]	2.83 (1.09–7.31)		2.70 (0.95-7.70)
Home care nurse (≥2.3 times, <2.3 = reference)§	2.25 (0.88-5.74)		2.13 (0.74–6.12)

[†]Other family caregivers who assist the primary family caregiver. [‡]No. of home visits per week by the family physician. [§]No. of home visits per week by the home care nurse. CI, confidence interval; OR, odds ratio.

2 identified frequent home visits by the family physician and the presence of other family caregivers as the variables associated with home death. The full adjustment in model 3 demonstrated that patients who had other family caregivers were more likely to die at home (OR = 3.09, 95% CI = 1.02-9.32).

Discussion

Analysis of the results

The ratio of deaths at home obtained in this study was 65% higher than that obtained in a previous study.²⁹ The higher rate of death at home in the present study may be due to the fact that the data was collected in a practice that only provides home care. In this study, various factors that affect the place of death were clarified by analyzing the data collected from a single home care clinic located in an urban area. We observed that among the patients who died at home, those who lived with family caregivers and had very frequent home visits by the family physician were greater in number than those who lived without family caregivers and had fewer visits by the family physician. This suggests that the place of death is not simply determined by the patient's and/or family's wishes but can be determined by other factors such as social background or service provisions for home care. Regarding the influence of preference on the place of death, our results suggest stronger influence of the family's preferences over the patient's own preferences. However, there is a possibility that the patient's own preferences themselves might be influenced by the family's preferences if the priority of the patient's wish is thought not to cause any nuisance to his/her family. Although the factors associated with the patient's and the family's wish regarding the place of death were so influential that they may relatively weaken the influences of other factors, their wish might also be determined by many other confounding factors as suggested. Therefore, we performed a logistic regression analysis, excluding the patients' and families' preferences regarding the place of death. The result of the logistic regression analysis demonstrated that frequent visits by family physicians and the existence of other family caregivers appear to be significantly associated with patients' death at home relative to frequent visits by home care nurses. What this result implies is that more patients may be able to fulfill their wishes of dying at home if frequent on-demand visits by family physicians with support from complementary family caregivers are available. Whilst almost all home care nursing services are provided by a group, which enables them to provide roundthe-clock visiting services, the majority of family practitioners in Japan maintain solo practices, which makes it difficult for them to provide such seamless home medical care and meet patients' needs. Although many home care medical services are provided in cooperation with home care nursing services, most of which are able to receive calls anytime or visit patients' homes whenever necessary, there still exists obstacles for the implementation of seamless cooperation partly because they are in many cases operated by different running bodies. In order to respond well to patients' needs as suggested from the present results, much improvement in the quality of service provisions is urgently required.

Comparison with other studies

In a previous systematic review, 17 factors were identified as influencing the place of death in terminally ill cancer patients.²³ The following factors were associated with a lesser probability of death at home: (i) non-solid cancers such as leukemia and myeloma; (ii) being of an ethnic minority; (iii) availability of beds in hospitals; (iv) residence in an area with easy accessibility to medical treatment; and (v) previous hospitalization. On the

contrary, the following factors were associated with a higher probability of death at home: (i) a long clinical history; (ii) a decrease in physical function; (iii) excellent social circumstances; (iv) a patient's preference to die at home; (v) a family's strong preference that the patient die at home; (vi) use of visiting care services; (vii) use of visiting care services available 24 h in case of emergency; (viii) residence in rural areas; (ix) staying with relatives; (x) receiving family support; (xi) being married; and (xii) a tradition of home being the place of death. Another study suggested the importance of caregivers' satisfaction with home medical care for patients to be able to die at home.²⁴

Many of the patients who participated in this study died at home despite the fact that they were urban residents who had relatively easier access to hospitals in case of emergency. Likewise, the convenience of what the patients and their families had benefited from by easy access to home medical care services provided by an urban-based group practice may lie behind the higher rate of death at home observed in the present study. Among the patients who died at home, none of them had non-solid cancer such as leukemia and myeloma, which is in keeping with a previous report. 25-28 In the present study, the following factors were associated with a higher probability of death at home^{23,25}: (i) patient's wish; (ii) family's wish; (iii) use of visiting care services; (iv) use of visiting care services available 24 h in case of emergency; and (v) staying with relatives. However, unlike previous studies, 23,26-28 the association of these factors with death at home did not persist except for the family's wish in the multivariate analysis.

Limitations of study and future directions

The data used in this study were collected from a single clinic with a group practice providing only home care. Although such a type of practice is recently emerging due to increased demand, particularly in urban areas, it is not yet a common type of medical practice overall. Therefore, the results obtained cannot necessarily be generalized in other clinical settings given the uniqueness of services this clinic was able to offer. Because the information obtained in this study relied largely upon the interviews of patients or their family caregivers made by the physicians who were directly engaged in the care provided, data related to the responses of the interviewees can be biased, given possible considerations of the respondents to not offend their attending physicians. Also, the low rate of notification of diagnosis/ prognosis to the patients can raise a question about the validity regarding what the patients had expressed as their true preferences. Other than the variables we adopted in this study, there was a lot of other information that we did not collect such as patients' activities of daily living, physical symptoms, mental status, competence to express themselves, relationship to nurses/doctors, social environment and caregivers' age and health condition^{23,26,28} which might have influenced the results. In the present study, the possible change in the family's preference regarding the place of the patient's death from the first visit until the patient's death was not addressed.

It is desirable for a patient to die at a place of his/her preference. However, the present situation surrounding home care service provisions does not necessarily fulfill patients' wishes of dying at home if they do not exist. The results of the present study suggest a strong involvement of family preference in the very important decision-making process related to patient's autonomy. Under the current family environment where only a limited source of informal care can be expected, the significance of improving home care services in order for patients to be able to die at home was confirmed in this study. Further investigations to clarify factors that would determine or influence family preference in choosing place of death for the patient are strongly desired.

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在宅療養要介護高齢者の介護環境ならびに生命予後,入院, 介護施設入所リスクの性差

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要 約 目的:要介護認定を受けた在宅療養中の高齢者の性別による身体機能,疾病背景,介護環境(生活 環境、介護者の有無ならびに続柄、サービス使用状況)、さらに3年間の生命予後、入院、施設入所の相異 を明らかにする. 方法:名古屋市在住で要介護認定を受け在宅療養中の高齢者1,875名, さらにその主介護 者 1,568 名を対象にした縦断調査(the Nagoya Longitudinal Study for Frail Elderly)の登録時のデータなら びに3年間の死亡、入院、介護施設への入所に関する縦断的データを使用した、結果:登録された要介護者 の性別構成は女性(66.3%)が男性(33.7%)の約2倍存在していた. 男性に比較して女性要介護高齢者の 平均年齢は高く(女性: 81.5 ± 7.5 (SD) 歳, 男性: 78.8 ± 7.6 (SD) 歳, p<0.001), 独居が多く(女性: 26.2%, 男性:14.6%, p<0.001), 主介護者が配偶者である割合が男性要介護高齢者に比較して低かった(女性: 22.1%, 男性:73.6%, p<0.001). 女性要介護高齢者は訪問介護サービスの利用率が高く(女性:48.8%, 男性: 43.2%, p=0.021), また重篤な併存症の有病率は男性に比較して低く(男性 vs 女性, 脳血管疾患: 46.6% vs 28.3%, <0.001;慢性閉塞性肺疾患:9.9% vs 5.9%, p=0.003;悪性腫瘍:12.9% vs 7.3%, p< 0.001), 骨折の罹患率 (過去 5 年間) が高かったが (27.4% vs 14.7%, p<0.001), 3 年間の死亡率, 入院率 は男性要介護高齢者よりも女性で低かった (男性 vs 女性%, 死亡率:31.3% vs 20.6%, p<0.001;入院率: 48.6% vs 39.9%, p<0.001). 介護施設への入所は男性よりも高かった (5.2% vs 8.4%, p=0.011). Cox 比 例ハザード解析では男性と比較した女性要介護者の死亡、入院、施設入所のハザード・リスク(95% 信頼 区間) は単変量解析でそれぞれ 0.61 (0.51~0.74), 0.76 (0.66~0.88), 1.48 (1.00~2.19) で, 多変量解析で はそれぞれ0.51 (0.39~0.66), 0.83 (0.69~0.99), 1.19 (0.73~1.93) であった. 結論: 在宅療養中の要介護 高齢者は女性が多く,主介護者の続柄など介護環境に性差が存在する.さらに女性要介護高齢者では男性よ りも3年間の死亡率は低いものの、介護施設へ入所する率が多いことが明らかとなった.

Key words: 介護保険, 要介護高齢者, 在宅療養, 介護保険サービス, 性差

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緒 言

平成21年版 高齢社会白書によると、日本における 高齢化はとどまることを知らず、平成20年度には65歳 以上の高齢者人口は、過去最高の2,822万人となり、総 人口に占める割合(高齢化率)も22.1%(前年21.5%) となり、22%を超える結果となった¹⁾、要介護高齢者の

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これらより高齢者人口のかなりの数が要介護高齢者であり、さらにそのうち 2/3 以上を女性が占めていることがわかる。このように高齢者人口、要介護者集団においては数の上で明らかに性差があることが報告されている。しかし、その要介護高齢者の性別による背景(疾病構成、日常生活動作、精神心理的状態)、介護環境(独居状態、主介護者の有無、主介護者の背景、介護保険サービスの使用状況)の相違、さらには性別による予後、病院への入院、介護施設への入所に対するリスクの相違などは明らかではない。今回 1,875 名の在宅療養中に要介護者、ならびにその主介護者たちを対象にしたコホート調査を基に上記の疑問を明らかにする。

対象と方法

1. 対象者

名古屋市で行われた the Nagoya Longitudinal Study for Frail Elderly (NLS-FE) の登録時 65 歳以上であっ た高齢者のデータ(1.875名)を使用した. NLS-FE は 名古屋市の17訪問看護ステーション併設居宅介護支援 事業所を基盤とした訪問看護サービス利用者(65歳以 上の高齢者), 訪問看護未利用者に, 訪問看護師または 介護支援専門員から書面で研究内容に関する説明をし、 文書での同意を得られた要介護高齢者(1,875名), さら にはその主介護者(1,568名)を調査対象(登録者)と する縦断的調査である.(登録は平成16年1月に終 了)2-5. 登録者に関し、登録時に行った基本調査は1年 ごとに行われ、経過中3年間、3カ月ごとにイベントの 有無を調査した. イベントとは1)病院への入院(処置, 検査入院を含む), 2) 介護施設(老人保健施設, 特別養 護老人ホーム, グループ・ホームなど) への入所, 3) 死 亡, 4) 脱落(訪問看護サービスの中止)を示す. なお, 本研究は平成19年1月に終了している.

2. 基本調査内容

基本調査内容は a) 患者の属性 b) 社会的背景 c) 介護状態の把握 d) 看護サービス内容 e) 疾病背景 f) 既往歴 (特に転倒, 骨折) g) 身体機能ならびに精神心理機能 (基本的 ADL: Barthel index (range: 0~20)⁶, 認知症の有無,うつの有無: Geriatric depression scale short version (GDS-15, range: 0~15)⁷) h) 栄養状態 (身体計測, 摂取状況を含む i) 併存症の評価: Charlson index (range: 0~9)⁸ j) 薬剤調査 k) 主介護者の状態(健康状態,介護負担感(日本語版 the Zarit Burden Interview: ZBI)),看護師の主観的調査 (サービス利用状況,患者の健康状況,家族の介護状況,主介護者の健康状況ならびに負担)などである。慢性疾患(冠

動脈疾患,心不全,脳血管障害,認知症,慢性閉塞性肺疾患,糖尿病,高血圧,悪性腫瘍)の有無はかかりつけ医からの情報を基に聴取された.さらに過去半年間の転倒歴,過去5年間の骨折歴を聴取した.これらの情報は本人または介護者,かかりつけ医からの情報を基にした.なお,GDS-15は認知症,またコミュニケーション不能者には実施しなかった.

3. 縦断調査

登録から3年間の経過中、イベント発生に関する報告書を看護師または介護支援専門員は記載し、3カ月ごとに名古屋大学に郵送した。イベントとは1)病院への入院(処置、検査入院を含む)、2)介護施設(老人保健施設、特別養護老人ホーム、グループ・ホームなど)への入所 3)死亡 4)脱落を示す。

4. 解析

登録時基本調査内容の男性・女性の相違,ならびに3年間の観察中に起こったイベント(死亡,入院,介護施設への入所)の性差を検討した.使用する解析法はstudent-t test,カイ二乗検定,Kaplan-Meier 検定,Cox比例ハザード検定などを使用した.女性要介護者の男性要介護者と比較した死亡,入院,介護施設入所のリスクをCox比例ハザード検定で解析した.多変量解析では単変量解析で統計的有意(p<0.05)な因子をモデルに投入した.

5. 倫理面への配慮

本研究は名古屋大学倫理委員会の承認を得て実施した。十分なインフォームド・コンセントの後、必ず要介護者本人、主介護者の書面による同意書をもって登録とした。匿名化された情報は名古屋大学で厳重に管理し、全て集団的に分析し、個々のデータの提示などは行わず、個人のプライバシー保護に努めた。

結果

表1に男女別登録された要介護高齢者ならびに主介護者背景を示す、登録された要介護高齢者は女性が明らかに多く(66.3%)、男性(33.7%)のほぼ2倍であった、年齢は女性81.5歳と男性78.8歳に比較し有意に高齢であった(p<0.001)、登録者のうち、独居で在宅療養中の要介護高齢者は女性で26.2%であり、男性14.6%に比較し有意に多かった。8割以上の要介護高齢者には主介護者が存在していたが、配偶者が主介護者である割合は女性の要介護高齢者で22.1%、男性で73.6%であった。主介護者介護負担感(ZBI)は男性要介護者の主介護者で有意に高かった。

登録時の平均基本的 ADL ならびに GDS-15 得点は性

	男性	女性	
	n = 632, 33.7%	n = 1,243, 66.3%	p
年齢, mean (SD)*	78.8 (7.6)	81.5 (7.5)	< 0.001
独居, n (%)	92 (14.6)	326 (26.2)	< 0.001
主介護者有無(n = 1,568), n (%)			
有り	556 (88.0)	1,012 (81.4)	< 0.001
無し	76 (12.0)	231 (18.6)	
介護者女性,n(%)	482 (86.7)	697 (68.9)	< 0.001
介護者年齡,mean (SD)*	67.9 (11.2)	61.9 (12.7)	< 0.001
主介護者続柄,n(%)			
配偶者	409 (73.6)	224 (22.1)	< 0.001
嫁(孫嫁を含む)	44 (7.9)	274 (27.1)	
子供	92 (16.5)	467 (46.1)	
兄弟(姉妹)	4 (0.7)	30 (3.0)	
主介護者 ZBI, ** mean (SD)*	31.2 (17.2)	27.6 (16.8)	< 0.001
居宅サービス使用(%)			
デイ・ケア (サービス)	43.5	43.9	0.865
訪問看護サービス	56.2	48.0	0.001
訪問介護サービス	43.2	48.8	0.021
定期的受診	61.7	58.4	0.164
ショートステイサービス	8.5	9.7	0.402
訪問入浴サービス	11.7	11.2	0.734
訪問リハビリテーションサービス	9.3	5.3	0.001
福祉用具レンタルサービス	65.8	56.3	< 0.001

表 1 要介護者性別登録時の背景,居宅サービス使用状況ならびにその主介護者の背景

差を認めなかった(表 2). 併存症の重症度のスケールとして使用した Charlson comorbidity index の平均得点は男性で高得点であり、より生命予後に係る併存症の集積が男性に認められた。定期的なかかりつけ医への受診率は性差を認めなかったが、男性で多剤服用(6種類以上)が多かった(表 2). 慢性疾患の有病率では脳血管障害、慢性閉塞性肺疾患、悪性腫瘍は男性での有病率が有意に高かったが、認知症は逆に女性で有意に高かった、過去半年間の転倒経験率は男女間で差を認めなかったが、過去5年間の骨折の既往率は女性で有意に高かった(表 2).

図1に男女別、要介護度を示した、男女とも要介護1をピークとする分布を示し、ほぼ同様の分布であった、登録時の居宅サービスの使用率はデイケア(デイサービスを含む)、ショートステイ、訪問入浴サービスでは男女差を認めなかった(表1).一方、訪問看護サービス、訪問リハビリテーション、福祉用具レンタルサービスの使用は男性でより高率で使用されていた。逆に訪問介護サービスは女性の要介護高齢者でより高率に使用されていた(表1).

3年間の観察期間中に要介護者1.875名のうち、454

人死亡し、そのうち 107 名が在宅での看取りであった. 男性の死亡率は 3 年間で 31.3%、女性は 20.6% で有意に男性の死亡率が高かった (表 3). 在宅死の率は男女の差を認めなかった. 一方、3 年間で一度でも入院を経験した要介護高齢者は 1,875 名のうち 803 名あり、男女別では男性では 48.5% と女性(39.9%)に比較し有意に高かった. 介護施設への入所は逆に女性で高率(男性:5.2% vs 女性:8.4%)であった (表 3).

図2に男女別、累積生存率、累積入院率、累積入所率を示す(Kaplan-Meierのプロット)、死亡、入院に関しては有意に男性が女性に比較して高率であった。一方逆に女性の方が高い率で介護福祉施設に入所した。

性による3年間の観察期間における死亡、入院、介護施設入所に対するリスク差を明らかにするために、Cox比例ハザード検定を行った。男性要介護者に比較し女性の死亡、入院のハザード・リスク(HR)は単変量解析ではそれぞれ0.61(95%信頼区間(95%CI):0.51~0.74)、0.76(0.66~0.88)で、多変量解析ではそれぞれ0.51(0.39~0.66)、0.83(0.69~0.99)であった(表4).一方、介護施設入所の女性要介護者のHR(95%CI)は単変量解析では1.48(1.00~2.19)と有意差を認めたが、多重

^{*:} student t-test, それ以外はカイ二乗検定

^{**:} 日本語版 the Zarit Burden Interview (range: 0~88, n = 1.257)