

Table 5
Staff education concerning end-of-life care ($N = 1689$)

Variables	GHS number	%
Staff education	683	40.4
Item topics		
Physical care	503	29.8
Etiology/symptom	497	29.4
Mental support for dying patients	473	28.0
Communication skill	436	25.8
Mental support for family	422	25.0
Living will	340	20.1
Technical terms	165	9.8
Legal systems	127	7.5
Domestic and foreign affairs	115	6.8
Social problems	78	4.6
Others	33	2.0
Methodology		
Lecture	478	28.3
Small learning group	338	20.0
Case study	282	16.7
Video/film	113	6.7
Visit to hospice	60	3.6
Others	72	4.3

support if necessary. The two groups were found to have equally established such arrangements with hospitals. End-of-life care, including outside and grief support for family members, was more frequent in Group 1. GHs in this group were more likely to have actual experience with end-of-life care, and were more confident that they could provide on-site end-of-life care and grief support. Staff training and discussions about available end-of-life care options at the GH were found to be more frequent in Group 1.

4. Discussion

Because the response rate was not satisfactory, we should take it to mean that some GHs having regressive policies for end-of-life care did not respond to the present survey. Also, it is possible that our results did not accurately reflect the current status of end-of-life care at GHs, because the number of GHs has nearly doubled after the study was conducted, as mentioned above.

4.1. Current status of end-of-life care at GHs

Although the law stipulates that the maximum number of users per unit should be 9 (Natsume, 2004), our GH subjects reported accommodating about 13 users. This is because several subjects had two units (data not shown). Most GHs in Japan were established after 2000, which coincides with the introduction of the public long-term care insurance system,

Table 6
Differences between two policy groups

Variables	Group 1, N = 1175		Group 2, N = 464		P value
	Average/GHs Number	%	Average/GHs Number	%	
Quota (average)	12.67		12.81		n.s.
Establishment					
2000–	1091	92.9	413	89.0	0.001
Staff occupation					
Certificated care worker/helper	1153	98.1	458	98.7	n.s.
Nurse	584	49.7	193	41.6	0.003
Physician	80	6.8	29	6.3	n.s.
Nurses' night shift	324	27.6	101	21.8	0.016
Organization					
Non-profit organization					<0.001
Incorporated medical institution	243	20.7	122	26.3	
Incorporated social welfare institution	280	23.8	199	42.9	
Others	96	8.2	6	1.3	
Profit-making organization	531	45.2	126	27.2	
Affiliated institution/in-home care services					
Day service/care	536	45.6	280	60.3	<0.001
In-home service center	492	41.9	305	65.7	<0.001
Home help	262	22.3	143	30.8	<0.001
Short stay	236	20.1	168	36.2	<0.001
Nursing home	193	16.4	137	29.5	<0.001
Geriatric intermediate care facility	120	10.2	99	21.3	<0.001
Home-visit nursing care	126	10.7	63	13.6	n.s.
Hospital	95	8.1	66	14.2	<0.001
Clinic	111	9.4	34	7.3	n.s.
Others	149	12.7	55	11.9	n.s.
None	353	30.0	115	24.8	0.034
Single-type structure	763	64.9	208	44.8	<0.001
First-aid manual	1061	90.3	429	92.5	n.s.
Admission to hospital possible	1080	91.9	419	90.3	n.s.
Within 24 h	965	82.1	369	79.5	n.s.
Medical end-of-life care support	962	81.9	249	53.7	<0.001
At GH when user dies	785	66.8	162	34.9	<0.001
Overall end-of-life care	1068	90.9	194	41.8	<0.001
Support from the outside	378	32.2	59	12.7	<0.001
Grief care for the bereaved family	874	74.4	268	57.8	<0.001
End-of-life care experience	268	22.8	13	2.8	<0.001
Staff education	532	45.3	135	29.1	<0.001

Notes: A Chi square test was conducted between Group 1 and Group 2 on the total number of GHs. Group 1, GHs with progressive policies for end-of-life care; Group 2, GHs with regressive policies for end-of-life care.

and national data show that the number of GHs has been steadily increasing every year since (Tokyo Dementia Care Research and Training Center, 2004b). The system has made it possible for profit-making organizations, including GHs, to provide in-home care services. Our results seem to reflect this proliferation of GHs. The overall number of full-time and part-time staff, on average, was 12.1, approximately one for every user. One out of ten GHs had a physician, and slightly fewer than half had a nurse. In the case of physicians, our guess is that they were sometimes also head managers but never staff members. Most of the GHs in our study were run by either nonprofit or profit-making organizations, and the ratio between nonprofit and profit-making GHs was consistent with national data (Tokyo Dementia Care Research and Training Center, 2004b).

A small number of GHs were affiliated with a hospital or with a geriatric intermediate-care facility at which limited medical services were available. Also, many GHs were self-contained physical plants. These results suggest that most GHs were not at a disadvantage in applying for medical support or for admission to hospital or geriatric intermediate care facilities.

This study found that many GHs had established arrangements with a hospital where urgent hospitalization is possible, and that many were equipped with first-aid manuals. All GH users suffer from dementia and illnesses related to aging (Morrison, 2000). Therefore, staff should be prepared to take emergency measures in life-threatening situations (Tokyo Dementia Care Research and Training Center, 2004b).

Many GHs responded that they could receive medical end-of-life care support from outside. A number of studies have suggested that home medical assistance by the medical profession in Japan is poor (Hashimoto, 2001; Iwasaki, 2003). Our results did not support this claim with regard to GHs. Further research is needed to examine to what extent home medical assistance is available at GHs.

A discussion of the typical patterns of dementia and its symptoms over time is needed to promote the quality of life of patients and their families. In Japan, a user must be diagnosed with dementia in order to get admitted to a GH (Nakaguma, 2004a). This may help promote discussions on such a sensitive issue as end-of-life care, which are usually difficult to initiate. Our study results confirmed that general information about various issues related to advanced dementia was in fact being provided to users and their families.

However, our results also suggested that GH subjects do not provide enough information to users and their families about the end-of-life care available at their own GHs. Due to the controversy about whether or not GHs are sufficiently competent to provide end-of-life care, staff may be reluctant to broach issues related to care options. Providing information to users about the type of care they can receive in the end-of-life stage and warning them about treatment limitations may help them and their families to make sound end-of-life care decisions. Further discussions are needed to define the role of GHs in end-of-life care for Japanese elderly with dementia.

Because relatively few studies have been carried out concerning end-of-life care at GHs, interviews with several head officers of GHs in Aichi prefecture, in central Japan, were conducted to define the following possible conditions for a GH to provide end-of-life care: (1) no medical intervention, (2) an understanding, on the part of users and their families, of the limits and abilities of the GH, (3) an understanding, on the part of staff, of the limits and

abilities of the GH and (4) no complaint of pain. Our results suggest that some GHs met all four conditions.

The use of medical intervention, including pain control, prevents GHs from providing end-of-life care, as they are not obligated to arrange for a physician or nurse (Tokyo Dementia Care Research and Training Center, 2004a,b). Therefore, medical assistance should be provided from the outside (Tokyo Dementia Care Research and Training Center, 2004a). Still, 24 h at-home medical assistance, which is necessary for some patients, has not been readily available in Japan. Furthermore, our results suggest that the end-of-life care options available at GHs are not always easy for users, families, and GH staff to understand. Since the criteria for admission to GHs are not defined, many people in Japan believe that a GH is a small institution for the elderly who are in the early stages of dementia and can live with other users (Suisyu, 2001; Nakaguma, 2004a; Tokyo Dementia Care Research and Training Center, 2004a,b). GH managers may have misgivings about the ability of users, families, and their staff to understand end-of-life care provision policies. As mentioned above, whether or not end-of-life care at GHs is even desirable requires further consideration.

Nonmedical end-of-life care could be available in many GHs should they decide to provide it. This includes different types of care, from physically demanding care to mental support. Meanwhile, care that includes outside assistance, including advice about law and property management, was available in a very limited number of GHs. Regardless of end-of-life care settings, an interdisciplinary team in the community should be available to care for patients and their families (Berry and Kuebler, 2002). Given the small size of GH facilities, further outside support is needed to provide successful end-of-life care.

Providing grief support at a hospital is challenging work (Suzuki, 2001). However, our results suggest that many GHs plan to offer grief support in the future. This may be because end-of-life care at GHs emphasizes life care support over medical support.

Only a few GHs provided education or training to their staff about end-of-life care. Due to a shift in the place of death from home to hospitals over the past several decades, very few people now die at home (Iwasaki, 2003). Without training, GH staff, especially inexperienced nonmedical staff, may be terribly shocked to face the death of a user. Staff education about end-of-life care does not always necessitate that GHs have progressive policies. Still, at the very least, death education not only improves the quality of care provided by the staff but also supports the staff's mental health. A broader perspective concerning death education for staff is also necessary for GHs with regressive policies toward end-of-life care.

4.2. Policy differences in GH backgrounds

Factors such as year of establishment, profit or nonprofit basis, and type of physical structure appeared to have a significant impact on end-of-life care policies. In the year 2000, the public long-term care insurance system was introduced, which promoted the participation of profit-making organizations in operating GHs (Nishizawa, 2001). Because institutional care provided by profit-making organizations was restricted (Nishizawa, 2001), most of them opted to build a self-contained physical plant. GHs do not receive preferential treatment for providing end-of-life care (Iwasaki, 2003; Nakaguma, 2004a;

Tokyo Dementia Care Research and Training Center, 2004b), so it is highly unlikely that profit-making organizations would be willing to provide such care for profit. There is also no advantage for GHs established after 2000 to provide end-of-life care compared with GHs established prior to 2000 (Iwasaki, 2003; Nakaguma, 2004a; Tokyo Dementia Care Research and Training Center, 2004b).

Self-contained physical plants seemed to be strongly correlated to the other three factors mentioned above. GHs with no affiliate, similar to self-contained physical plants, were also found to be more likely to have progressive policies regarding end-of-life care. Since nursing homes and geriatric intermediate-care facilities have legal obligations to arrange for the services of medical staff, affiliated facilities and hospitals may be more likely than not to make preparations to receive GH users who need end-of-life care. In addition, there is the possibility that affiliated in-home care services work in closer cooperation with GHs to promote end-of-life care at users' homes. In this study, we also examined cases where users were transferred halfway through end-of-life care initiated at their own GHs. However, we were unable to obtain sufficient data to analyze the results. Additional study is needed to prove our hypothesis.

The presence of nurses had a significant impact on end-of-life care policies. Since nurses are not reluctant to provide medical care, GH patients were likely to receive medical interventions in the end stage. In addition, the existence of outside medical end-of-life care support was significantly correlated to a GH's policies. In agreement with studies indicating that home visits by a physician or a nurse promoted death at home (Iki et al., 1991; Hitomi et al., 2000), our results suggested that outside medical assistance promotes end-of-life care at GHs. However, we can also assume that the decision to provide end-of-life care prompted GH managers to implement procedures to receive outside medical assistance. It is difficult to determine from this study precisely what the best means are for building closer connections with outside medical assistance for quality end-of-life care at GHs. We need to perform a narrative study to gather more in-depth data.

Predictably, the ease of providing end-of-life care at a GH was found to be significantly related to the GH's policies. As expected also, GHs with progressive policies were likely to have more experience in end-of-life care than GHs with regressive policies. We can therefore argue that such experience has a positive effect on the policies. However, issues related to the satisfaction of managers and staff should be examined by performing additional research.

We also see a relationship between staff education and GH policies. GHs should be encouraged to provide staff with education and training about end-of-life care. However, even in GHs with progressive policies, we found that such education was insufficient. Previous studies have called attention to the lack of end-of-life care education for medical professionals (Shiraishi et al., 1998; Itatani and Shoji, 1999; Sullivan et al., 2003; Uemura, 2004). We also need to develop effective educational programs for nonmedical professionals, such as GH staff, to promote essential knowledge and information regarding end-of-life care.

5. Conclusions

Many GHs have implemented progressive policies for end-of-life care, and the number of GHs with such policies is expected to increase in Japan. This study showed that GHs

with progressive policies for end-of-life care have different backgrounds than those with regressive policies. Our results suggested that the availability of medical interventions within or outside of GHs, self-contained physical plant, and staff education are associated with progressive policies for end-of-life care at GHs. Further research is needed to determine what the most effective end-of-life care systems are for GHs.

Acknowledgments

We are grateful to all the participants of this study. We also thank Koji Tamakoshi, MD, Ph.D., for his statistical consultations. Financial support for this project was provided by the Sasagawa Health Science Foundation, Tokyo.

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ORIGINAL ARTICLE

Evaluation of gender differences in caregiver burden in home care: Nagoya Longitudinal Study of the Frail Elderly (NLS-FE)

Yoshihisa HIRAKAWA, Masafumi KUZUYA, Yuichiro MASUDA, Hiromi ENOKI, Mitsunaga IWATA, Jun HASEGAWA and Akihisa IGUCHI

Department of Geriatrics, Nagoya University Graduate School of Medicine, Nagoya, Aichi, Japan

Correspondence: Yoshihisa Hirakawa MD PhD, 65 Tsuruma-cho, Showa-ku, Nagoya, Aichi 466-8550, Japan. Email: y.hirakawa@k8.dion.ne.jp

Received 5 December 2005; accepted 13 April 2006.

Abstract

Background: Japan is presently experiencing a growth in the number of male caregivers and this situation has given rise to some concerns over gender differences. Previous studies have suggested that there are gender differences in caregiver burden in home care, however, it is still unclear whether or not gender differences exist. We therefore conducted this study to attain a better understanding of the Japanese male caregiver burden in home care, using data from the Nagoya Longitudinal Study of Frail Elderly (NLS-FE).

Methods: NLS-FE is a large prospective study of community-dwelling elderly persons eligible for public long-term care insurance who live in Nagoya city and use the services of the Nagoya City Health Care Service Foundation for Older People, which comprises 17 visiting nursing stations and corresponding care-managing centers, from November to December 2003. Data used in this study included the Japanese version of the Zarit Caregiver Burden Interview, caregivers' and dependents' characteristics, and the caregiving situation. The differences in dependent and caregiver characteristics between male and female caregiver groups were assessed using the χ^2 -test for categorical variables or the unpaired *t*-test for continuous variables. Multiple logistic regression was used to examine the association between dependent and caregiver characteristics and caregiver burden.

Results: A total of 399 male caregivers and 1193 female caregivers were included in our analysis. Before and after controlling baseline variables, we did not detect a difference between male and female caregivers with respect to caregiver burden.

Conclusion: Our study suggests that differences in caregiver burden may not necessarily exist between male and female caregivers in Japan.

Key words: care management, caregiver burden, gender, home-visit nursing, long-term care insurance.

INTRODUCTION

In Japan, the proportion of elderly persons in the population has steadily increased in recent years.¹ The growth of the aging population has triggered an increase in the demand for services and a rise in costs which, in turn, have brought about social and economic burdens to the society.^{2,3} Thus, in recent years, there has been growing interest in home care in

Japan,⁴ especially after the introduction of the public long-term care insurance system in April 2000.¹

Meanwhile, the structure of families has changed significantly and consequently young family members now tend to live apart from their aging parents and are thus unable to care for them personally.^{3–5} While daughters and daughters-in-law have traditionally played a significant role in caring for disabled elderly

persons in Japan, male caregivers are now growing in number, as the frequency of spouse care-giving rapidly increases.^{3,5}

In Western countries, a number of studies have suggested that there are gender differences in caregiver burden in home care.⁶⁻¹⁰ In Japan, however, it is still unclear whether or not gender differences exist because very few studies have so far been conducted on the topic.^{3,5,11}

In order to expand our knowledge of the Japanese male caregiver burden in home care, we conducted a subanalysis study of the Nagoya Longitudinal Study of Frail Elderly (NLS-FE), which is a large prospective study of community-dwelling elderly.

METHOD

Study design and subjects of NLS-FE

The NLS-FE consisted of a cross-sectional analysis of a total of 1875 subjects (632 men, 1243 women). The study subjects were community-dwelling elderly (aged 65 years or older) eligible for the public long-term care insurance who lived in Nagoya city (central Japan), and were provided with various home care services from the Nagoya City Health Care Service Foundation for Older People, which comprises 17 visiting nursing stations and corresponding care-managing centers. During the registration period (1 November 2003–31 December 2003), 1875 out of 3630 elderly users agreed to take part in this study. Informed consent for participation was obtained verbally from the patients or, for those with substantial cognitive impairment, from a surrogate, and from the caregivers according to procedures approved by the institutional review board of the Nagoya University Graduate School of Medicine.

Data collection and instruments

A total of 56 nurses and 48 care-managers visited the users' homes and collected data from standardized interviews with patients or surrogates and caregivers, as well as from medical and visiting nursing station records. The abstractors were blinded to the study hypothesis or anticipated study results. Data we used in this analysis included the following items about the caregiver and the dependent.

Caregiver

Age, kinship of caregiver, use of care service, nurse's judgment of use of care service, family care provision,

caregiver's state of health, use of care services in detail, family care sufficiency, caregiver burden (Japanese version of the Zarit Burden Interview (J-ZBI), nurse's assessment of caregiver burden), and depression (Geriatric Depression Scale (GDS-15)).

Dependent

Age, sex, spouse, number of family members, family relationship, ease of access to the house, financial state, nutrition, degree of care needed, sight, hearing, communication with family, dementia, activities of daily living (ADL) scale of demented elderly, behavioral disorder, depression (GDS-15), ADL scale of disabled elderly, ADL (mobility on bed, transfer, walking inside, walking outside, dressing the upper half of the body, dressing the lower half of the body, feeding, toilet use, grooming, bathing, use of stairs), instrumental ADL (IADL) (preparing meals, housework, washing, money management, medication, telephone use, shopping, transportation use), illness, pressure ulcer, person in charge of medication.

Depressive mood was assessed by the Japanese short version of the GDS-15,¹² in which high scores are characteristic of subjects who are in a greater depressive mood. Subjective caregiver burden was assessed by the Japanese version of the J-ZBI,¹³ which is a 22-item self-report inventory that examines the burden associated with functional behavioral impairments in the home care situation.

The Japanese long-term care system is a public and mandatory long-term care insurance for the frail and elderly. The insurance system is financed by premiums from everyone aged 40 years and older and a government subsidy. Everyone aged 65 years and older is eligible for benefits based strictly on physical and mental disability, in six levels of need ranging from 'not applicable' to '5' (completely dependent in ADL).¹ Also, Japan's Ministry of Welfare identifies four ranks of ADL of disabled elderly ranging from J (independent in ADL) to C (bed-ridden).¹⁴

Statistical analysis

We excluded from our analysis those caregivers whose sex had not been specified and divided the study caregivers into two gender groups. Consequently, a total of 399 male caregivers and 1193 female caregivers were included in the analysis. The differences in dependent and caregiver characteristics between male and female caregiver groups were

assessed using the χ^2 -test for categorical variables or the unpaired *t*-test for continuous variables. Multiple logistic regression was used to examine the association between dependent and caregiver characteristics and the caregiver burden, adjusting for age, sex and other factors associated with $P < 0.05$ on bivariate analyses between female and male caregivers. Data was analyzed using Statview-J5.0.

RESULTS

Caregivers' gender differences in characteristics of dependents

The distribution of dependent characteristics is shown in Table 1. Significantly more dependents of male caregivers were female or married, and fewer of their dependents had residents compared to female caregivers. Dependents of male caregivers were less likely to have close relations with other family members. No significant differences were found between male and female caregivers in the ease of access to their houses, financial hardship, nutrition, or intravenous hyperalimentation. Dependents of male caregivers had better hearing ability than those among female caregivers. In cognitive function, behavioral disorder or ADL, no statistical differences were found between male and female caregivers (Table 2). In IADL, no statistical differences were found except in food preparation, home maintenance and laundry, with which men are less accustomed. In illness, dependents of female caregivers were more likely to have congestive heart failure, ulcer disease, peripheral vascular disease, or cerebrovascular disease. Among the male caregivers, dependents were more likely to be independent in taking medication.

Caregivers' gender differences in characteristics of caregivers and caregivers' burden

The distribution of caregiver characteristics is shown in Table 3. Male caregivers were more likely to be older and generally the spouse of the dependent. About one-quarter (26.1%) of female caregivers were daughters-in-law, while a few male caregivers were sons-in-law. In formal care services, female caregivers were more likely to use a day care/service, while male caregivers were more likely to use home help or home-visit nursing care. No significant differences were noted between them in depressive mood according to the GDS-15. According to the nurse's subjective assessment, male caregivers were less likely

to use sufficient formal or informal support or to have good health. No differences were found between male and female caregivers in levels of burden according to the J-ZBI or nurse's subjective assessment.

Multivariable analyses

A multiple regression analysis was carried out to more systemically examine the relations between sex and J-ZBI while adjusting for differences in baseline variables, in which statistically significant differences were detected between the male and female caregiver groups. The multivariable-adjusted results of the J-ZBI are shown in Table 4. Even after adjusting for these baseline variables, there were no significant differences between the two groups in the J-ZBI.

DISCUSSION

Characteristics of the study population

The findings of the present study were similar to a few previous studies,^{3,5} namely that the dependents of female caregivers were more likely to be men and older. In addition, they had more residents than the male caregivers' dependents. In the caregivers' characteristics, daughters-in-law constituted 26.1% of the female caregiver group, while spouses constituted the majority of the male caregiver group. It is possible that the kinship difference was related to the differences between the two groups in dependents' age, sex or number of residents.

Cognitive function is a major predictor of caregiver burden.¹⁵⁻¹⁸ A few studies have suggested that male caregivers are less competent at providing care for elderly people with dementia and are more likely to reject the idea of doing it at home.^{15,19} Thus, we estimated that male caregivers cared for fewer cognitively impaired elderly with problematic behaviors than female caregivers.³ However, in our study, there was no significant difference between the two caregiver groups in terms of dependents' cognitive impairment and behavioral disorders.

In addition, some studies have suggested that there is a strong relation between depression and sex.^{20,21} However, no significant differences were found in the dependents. The dependents in the female caregiver group had graver illnesses and greater difficulty in taking medicine by themselves, but this may be due to the fact that they were generally older than the dependents under the care of male caregivers.

Table 1 Differences between male and female caregivers in dependents' characteristics

Variable	Category	Male caregiver N %, mean \pm SD (range)	<i>n</i> = 399	Female caregiver N %, mean \pm SD (range)	<i>n</i> = 1193	<i>P</i> -value	
Age (years)		78.2 \pm 7.8 (53–97)		81.6 \pm 8.0 (56–104)		<0.001	
Sex (females)		322	80.7	701	58.8	<0.001	
Marital status	Married	252	63.2	553	46.4	<0.001	
	Bereaved	137	34.3	611	51.2		
	Divorced	3	0.8	12	1.0		
	Not married	5	1.3	17	1.4		
Number of residents		1.7 \pm 1.5 (0–12)		2.1 \pm 1.5 (0–10)		<0.001	
Quality of family relationship	Close	103	25.8	374	31.3	<0.001	
	Average	270	67.7	786	65.9		
	Estranged	23	5.8	30	2.5		
	Not at all	3	0.8	0	0.0		
Suffering from financial hardship	Not at all	84	21.1	300	25.1	NS	
	Low	288	72.2	828	69.4		
	Rather frequently	14	3.5	48	4.0		
Nutrition	Very frequently	11	2.8	16	1.3		
	Per oral	380	95.2	1123	94.1	NS	
	Parenteral	18	4.5	66	5.5		
Degree of care required	Intravenous hyperalimentation	2	0.5	2	0.2	NS	
	Not applicable	1	0.3	1	0.1	NS	
	Assistance required	22	5.5	56	4.7		
	Degree 1	108	27.1	297	24.9		
	Degree 2	78	19.5	255	21.4		
	Degree 3	64	16.0	204	17.1		
	Degree 4	47	11.8	167	14.0		
Dementia	Degree 5	76	19.0	210	17.6		
	Present	127	31.8	426	35.7	NS	
Behavioral disorder	Present	72	18.0	240	20.1	NS	
Depression							
GDS-15		5.7 \pm 4.1 (0–15)		5.7 \pm 4.0 (0–15)		NS	
ADL scale of disabled elderly	Independent	16	4.0	41	3.4	NS	
	J1	28	7.0	82	6.9		
	J2	55	13.8	143	12.0		
	A1	75	18.8	211	17.7		
	A2	70	17.5	254	21.3		
	B1	47	11.8	155	13.0		
	B2	35	8.8	118	9.9		
	C1	25	6.3	57	4.8		
	C2	43	10.8	126	10.6		
Illness	Ischemic heart disease	38	9.5	147	12.3	NS	
	Congestive heart failure	23	5.8	110	9.2	0.030	
	Ulcer disease	2	0.5	24	2.0	0.039	
	Peripheral vascular disease	4	1.0	36	3.0	0.026	
	Liver disease	13	3.3	34	2.8	NS	
	Cerebrovascular disease	134	33.6	497	41.7	0.004	
	Connective tissue disease	20	5.0	53	4.4	NS	
	Diabetes	54	13.5	138	11.6	NS	
	Dementia	128	32.1	441	37.0	NS	
	Chronic pulmonary disease	21	5.3	85	7.1	NS	
	Hemiplegia	115	28.8	334	28.0	NS	
	Renal failure	12	3.0	54	4.5	NS	
	Neoplasia	28	7.0	107	9.0	NS	
	Leukemia/lymphoma	1	0.3	0	0.0	NS	
	Metastatic solid tumor	2	0.5	4	0.3	NS	
	Hypertension	100	25.1	271	22.7	NS	
	Pressure ulcer	26	6.5	91	7.6	NS	
	Person in charge of medication	Oneself	176	44.1	403	33.8	<0.001
		Family	185	46.4	716	60.0	
Others		19	4.8	28	2.3		

The χ^2 -test for categorical variables or the unpaired *t*-test for continuous variables was conducted between male and female caregiver groups. ADL, activity of daily living; GDS, geriatric depression scale.

Table 2 Differences in dependents' ADL and IADL between male and female caregivers

Variable	Category	Male caregiver		Female caregiver		P-value
		n	%	n	%	
ADL						
Mobility on bed	Independent	260	65.2	781	65.5	NS
	Partly dependent	75	18.8	231	19.4	
	Dependent	64	16.0	179	15.0	
Transfer	Independent	214	53.6	600	50.3	NS
	Partly dependent	104	26.1	355	29.8	
	Dependent	81	20.3	238	19.9	
Walking inside	Independent	225	56.4	672	56.3	NS
	Partly dependent	84	21.1	262	22.0	
	Dependent	90	22.6	259	21.7	
Walking outside	Independent	86	21.6	241	20.2	NS
	Partly dependent	163	40.9	499	41.8	
	Dependent	149	37.3	453	38.0	
Dressing the upper half of the body	Independent	193	48.4	548	45.9	NS
	Partly dependent	113	28.3	367	30.8	
	Dependent	93	23.3	278	23.3	
Dressing the lower half of the body	Independent	184	46.1	501	42.0	NS
	Partly dependent	105	26.3	349	29.3	
	Dependent	110	27.6	343	28.8	
Feeding	Independent	265	66.4	797	66.8	NS
	Partly dependent	89	22.3	238	19.9	
	Dependent	45	11.3	158	13.2	
Toilet	Independent	223	55.9	619	51.9	NS
	Partly dependent	86	21.6	288	24.1	
	Dependent	89	22.3	286	24.0	
Grooming	Independent	164	41.1	477	40.0	NS
	Partly dependent	140	35.1	414	34.7	
	Dependent	95	23.8	302	25.3	
Bathing	Independent	91	22.8	259	21.7	NS
	Partly dependent	168	42.1	501	42.0	
	Dependent	140	35.1	433	36.3	
Using stairs	Independent	86	21.6	272	22.8	NS
	Partly dependent	146	36.6	416	34.9	
	Dependent	166	41.6	504	42.2	
Visual acuity	Adequate	278	69.7	825	69.2	NS
	Difficulty reading small characters	96	24.1	289	24.2	
	Blind	11	2.8	23	1.9	
	Unknown	14	3.5	56	4.7	
Auditory capacity	Adequate	313	78.4	763	64.0	<0.001
	Difficulty hearing a low voice	80	20.1	395	33.1	
	Completely impaired	2	0.5	11	0.9	
	Unknown	4	1.0	23	1.9	
Communication with family	Possible	356	89.2	1065	89.3	NS
	Impossible	43	10.8	128	10.7	
IADL						
Food preparation	Independent	27	6.8	93	7.8	<0.001
	Mostly independent	85	21.3	168	14.1	
	Fairly dependent	91	22.8	208	17.4	
	Completely dependent	196	49.1	724	60.7	
Home maintenance	Independent	14	3.5	29	2.4	0.003
	Mostly independent	88	22.1	216	18.1	
	Fairly dependent	93	23.3	213	17.9	
	Completely dependent	204	51.1	735	61.6	
Laundry	Independent	35	8.8	107	9.0	<0.001
	Partly dependent	78	19.5	153	12.8	
	Fairly dependent	78	19.5	174	14.6	
	Completely dependent	208	52.1	758	63.5	

Table 2 *Continued*

Variable	Category	Male caregiver		Female caregiver		P-value
		n %	n = 399	n %	n = 1193	
Money management	Independent	107	26.8	310	26.0	NS
	Mostly independent	75	18.8	194	16.3	
	Fairly dependent	58	14.5	171	14.3	
	Completely dependent	158	39.6	518	43.4	
Medication	Independent	149	37.3	389	32.6	NS
	Mostly independent	47	11.8	148	12.4	
	Fairly dependent	65	16.3	208	17.4	
	Completely dependent	137	34.3	447	37.5	
Telephone	Independent	138	34.6	409	34.3	NS
	Mostly independent	70	17.5	180	15.1	
	Fairly dependent	50	12.5	156	13.1	
	Completely dependent	141	35.3	448	37.6	
Shopping	Independent	30	7.5	84	7.0	NS
	Mostly independent	56	14.0	162	13.6	
	Fairly dependent	94	23.6	241	20.2	
	Completely dependent	219	54.9	706	59.2	
Transportation use	Independent	28	7.0	84	7.0	NS
	Mostly independent	48	12.0	163	13.7	
	Fairly dependent	99	24.8	237	19.9	
	Completely dependent	224	56.1	709	59.4	

The χ^2 -test was conducted between male and female caregiver groups. ADL, activity of daily living; IADL, instrumental activity of daily living; NS, not significant.

The ADL of the dependents in the male and female caregiver groups were matched, except for auditory capacity. Dependents in the female caregiver group were more dependent in IADL. A good explanation for this is that the male dependents were generally unskilled²² and more female caregivers cared for a male dependent than male caregivers.

As for the characteristics of the caregivers, consistent with previous studies,³⁻⁵ male caregivers were more likely to be older than their female counterparts. Also, as mentioned earlier, there was a kinship difference between the male and female caregiver groups. According to previous studies,^{17,23} the differences in age and kinship should be taken into account in analyzing our results.

In items of care services, consistent with previous studies, the male caregiver group was more likely to use home help.^{3,19} It is generally believed that men are less experienced with housework^{3,7} and our results probably reflect this situation. In addition, female caregivers were more likely to use a day care/service in our study. Sugiura *et al.* and Colline *et al.* previously explained that women tended to prefer respite care.^{3,6,22} Our results seem to support their suggestions. Contrary to what might be expected, more frequent use of home-visit nursing care by male caregivers was observed in this study. Male caregivers

were less likely than female caregivers to help an older person with different types of illnesses who may need more nursing care. However, to our knowledge, few studies have so far dealt with this issue.⁷ Additional studies are needed to obtain a more accurate appraisal of the gender differences in the use of in-home care.

Inconsistent with earlier studies,^{3,24} which found that female caregivers showed a higher depression rate than male caregivers, we detected no significant difference in GDS-15 in this study. In addition, the nurses' subjective assessment in this study showed that male caregivers used less formal or informal care, and that male caregivers were in worse health. It is possible that this had a negative effect on the male caregivers, resulting in a higher depressive mood, because there is a strong relation between caregiver burden and depression.^{20,21,25} However, the GDS-15 was developed to assess the depressive mood of the elderly²⁶ and not that of a younger population. We should think of this result only as a suggestion.

Gender differences in caregiver burden

This study focused on differences in caregiver burden according to gender. Our results, regardless of adjusting, did not reveal any difference between male and female caregivers with respect to caregiver burden.

Table 3 Gender differences in main caregiver characteristics

Variable	Categories	Male caregiver N %, mean \pm SD (range)	n = 399	Female caregiver N %, mean \pm SD (range)	n = 1193	P-value
Age (years)		68.3 \pm 12.7 (31–91)		62.5 \pm 12.1 (31–93)		<0.001
Kinship	Spouse	234	58.6	417	35.0	<0.001
	Child	143	35.8	419	35.1	
	Daughter/son-in-law	5	1.3	311	26.1	
	Sibling	8	2.0	27	2.3	
	Other	9	2.3	18	1.5	
	Unknown	0	0.0	1	0.1	
Types of care service use	Day care/service	166	41.6	586	49.1	0.009
	Home-visit rehabilitation	31	7.8	90	7.5	NS
	Home-visit bathing	46	11.5	165	13.8	NS
	Short stay	37	9.3	142	11.9	NS
	Home help	211	52.9	451	37.8	<0.001
	Family physician home-visit	256	64.2	707	59.3	NS
	Home-visit nursing care	232	58.1	609	51.0	0.014
	Housing adjustments	93	23.3	297	24.9	NS
Care implements rental	237	59.4	770	64.5	NS	
Depressive mood GDS-15		5.5 \pm 4.0 (0–15)		5.1 \pm 3.9 (0–15)		NS
Nurse's assessment Use of care service by caregiver	Sufficient	157	39.3	531	44.5	NS
	Average	189	47.4	545	45.7	
	Insufficient	53	13.3	115	9.6	
	Unknown	0	0.0	0	0.0	
Caregiving by family	Sufficient	167	41.9	656	55.0	<0.001
	Average	183	45.9	446	37.4	
	Insufficient	47	11.8	85	7.1	
	Unknown	2	0.5	0	0.0	
Caregiver's health	Excellent	141	35.3	522	43.8	<0.001
	Normal	193	48.4	529	44.3	
	Below standard	63	15.8	135	11.3	
	Unknown	2	0.5	0	0.0	

The χ^2 -test for categorical variables or the unpaired *t*-test for continuous variables was conducted between male and female caregiver groups. GDS, geriatric depression scale; NS, not significant.

This finding supports the result of Aoki *et al.*'s study⁵ and differs from various other studies which suggested that female caregivers showed more caregiver burden than their male counterparts.^{3,6–11} Our results suggest that further studies are needed to prove the gender difference in caregiver burden, at least in Japan. In Japan, the public long-term care insurance system which was implemented in 2000 provides a care-management system by professional care managers.^{27,28} Care management facilitates the selection of appropriate care services for elderly people among available care services provided in the community based on a care need assessment.²⁸ A care manager needs to monitor a dependent's physical and mental condition to assess the latest care need as occasion demands.^{27,28} Therefore, the system provides for a high level of care and helps caregivers cope with

stress, giving them relief from caregiver burden.²⁹ It is possible that the care management system lessened the female caregiver burden and narrowed the gender gap in caregiver burden. Moreover, female caregivers reportedly tend to seek informal support from family and neighbors.^{3,5} We did not investigate the use of informal care, except family care, and therefore we were unable to determine the extent to which caregivers were given informal support by care providers except family.

Study limitation

The current study has several limitations. Although the NLS-FE is a large-scale observational study, it does not include the complete spectrum of elderly patients in the Nagoya area. In addition, the selection of subjects was somewhat biased because the par-

Table 4 Gender differences in caregiver burden and depressive mood

Variable	Category	Male caregiver n %, mean ± SD (range)	n = 399	Female caregiver n %, mean ± SD (range)	n = 1193	P	Odds ratio unadjusted	95% CI	Odds ratio adjusted for age	95% CI	Odds ratio adjusted for age and other variables†	95% CI
Caregiver burden												
J-ZBI		26.0 ± 18.5(0-81)		27.3 ± 17.6(0-84)		NS	1.004	0.997-1.011	1.005	0.998-1.012	1.004	0.995-1.012
Nurse's assessment												
	Severe	113	28.3	274	23.0	NS						
	Moderate	215	53.9	715	59.9							
	Light	69	17.3	196	16.4							

†Controlling for dependent's age, marital status, number of residents, quality of family relationship, cognitive heart failure, ulcer disease, peripheral vascular disease, cerebrovascular disease person in charge of medication, auditory capacity, food preparation, home maintenance, laundry, caregiver's age, kinship, use of daycare/service, use of home help, use of home-visit nursing care, caregiving by family, and caregiver's health status. The χ^2 -test for categorical variables or the unpaired t-test for continuous variables was conducted between male and female caregiver groups. Multiple logistic regression was used to examine the association between dependent and caregiver characteristics and the Japanese version of the Zarit Burden Interview (J-ZBI). CI, confidence interval; NS, not significant.

ticipants were groups of users of home nursing stations using home visiting nurses or care planning services.

Another limitation is that we requested that each station perform its own evaluation due to a shortage of staff and the large quantity of settings. This may have biased the assessors' evaluation and limited the validity of the results, including the nurses' subjective assessment.

Finally, this study is an analysis of data from a large-scale study. Therefore, our database does not always capture the full extent of the dependents' and caregivers' characteristics needed to obtain a precise analysis. A lack of data concerning caregiving period, caregiving hours per day or details of required care weakened the impact of our findings.^{23,30}

CONCLUSION

We conducted a subanalysis of a large scale observational study in Japan. Our results indicated that there were no differences in caregiver burden between male and female caregivers. Further studies are needed to confirm whether or not gender differences do in fact exist.

ACKNOWLEDGMENTS

We are grateful to all participants in this study. We also thank Ms. N. Sano for her editorial work.

Conflict of interest declaration

The authors declare that they have no competing interests.

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Gender Differences in Symptom Experience at End-of-Life among Elderly Patients Dying at Home with Advanced Cancer in Japan

JMAJ 49(11•12): 351–357, 2006

Yoshihisa Hirakawa,*¹ Yuichiro Masuda,*¹ Masafumi Kuzuya,*¹
Akihisa Iguchi,*¹ Kazumasa Uemura*²

Abstract

Background It is unclear whether gender differences exist among elderly patients dying at home with advanced cancer in terms of symptom experience and care receipt at end-of-life. The aim of the present study is to determine the gender-specific features in symptom experience in the last days of life with distinction of age (65 and over).

Methods We conducted a sub-analysis study of the Dying Elderly at Home (DEATH) project, a multicenter study of 240 elderly patients dying at home. We assessed the frequency of symptoms and end-of-life care receipt in elderly patients dying at home during the last two days of their lives in order to evaluate the differences observed between the two gender groups. A total of 52 female and 65 male decedents were included in the analysis.

Results Female decedents experienced coma more frequently than male decedents, but the opposite was true of sputum. There were no significant differences in all care options between the two groups. After controlling for age, ADLs, cognitive impairment, and cause of death, gender was determined to be a significant independent predictor of nausea/vomiting and sputum.

Conclusions This study suggests that consideration should be given to gender differences in symptom experience and management at end-of-life.

Key words Opioid, Terminal care, Death, Pain, QOL

Introduction

The growth of the aging population in Japan has triggered an increase in the demand for end-of-life care for the elderly dying with cancer.¹ In advanced cancer, when cure is impossible, symptom management should be the focus of attention. A better understanding of symptom experience of such patients would be useful for counseling patients and families and better designing programs, such as home benefits, to care for patients at the end of life.

A number of studies have suggested that there may be differences in symptom experience among men and women cancer patients.^{2–4} Thus, the application of gender-specific information on elderly symptom experience at end-of-life may improve the quality of life of all elderly cancer patients.

However, it remains unclear whether gender differences exist because this topic has not yet been widely investigated. A few studies have reported no gender differences in symptom experience,^{5,6} while other studies have suggested the existence of age-related differences in symptom experi-

*1 Department of Geriatrics, Nagoya University Graduate School of Medicine, Nagoya

*2 Center of Medical Education, Nagoya University School of Medicine, Nagoya

Correspondence to: Yoshihisa Hirakawa MD, PhD, Department of Geriatrics, Nagoya University Graduate School of Medicine, 65 Tsuruma-cho, Showa-ku, Nagoya, Aichi 466-8550, Japan. Tel: 81-52-744-2364, Fax: 81-52-744-2371, E-mail: y.hirakawa@k8.dion.ne.jp

ence.^{3,5,7-9} In order to investigate the gender-specific features in symptom experience of elderly cancer patients in the last days of life with distinction of age (65 and over), we conducted a sub-analysis study of the Dying Elderly at Home (DEATH) project. This is a prospective observational study of two hundred and forty community-dwelling elderly dying at home in Japan. Because in recent years a growing number of elderly people chose to spend the last years of their lives at home,¹⁰⁻¹² home death has been the focus of increasing attention.¹³

Our results motivated us to make a recommendation for the development of appropriate end-of-life care plans for male and female elderly patients in community settings.

Methods

Study design and population

The present data was obtained from the Dying Elderly at Home (DEATH) project, a multicenter observational study. The DEATH project was conducted in collaboration with the Japanese Society of Hospice and Home-care. The society is a non-profit organization consisting of general physicians and other medical and social professionals interested in hospice and home-care. Two hundred and forty decedents aged 65 or older who were using 16 study clinics belonging to the society with diagnoses of all illnesses including advanced cancer and who died at home from October 2002 to September 2004 were included in the study. Decedents were excluded if they were transferred to a hospital at death. The following information was collected: sociodemographics, ADLs (Japan's Ministry of Welfare identifies four ranks of ADL of disabled elderly as follows¹⁴: Rank J (independent in ADLs), Rank A (house-bound), Rank B (chair-bound), and Rank C (bed-ridden), cognitive impairment, observed symptoms and provided end-of-life care during the last 48 hours of their lives. Symptom experience was assessed based on our original questionnaire focusing on the following twenty symptoms, which represent common symptoms among elderly patients at the end of life. Thus, we did not hypothesize that there are gender differences in experience of the symptoms. With the approval of the Japanese Society of Hospice and Home-care, we used a questionnaire that included a list of common symptoms and treatments at the

end-of-life as follows:

Symptoms

Dyspnea, uncontrolled pain, controlled pain, coma, acute confusion, anxiety, dizziness, nausea and vomiting, anorexia, diarrhea, constipation, fever, urinary and fecal incontinence, hematemesis, hemoptysis, bottom blood, other types of hemorrhage, cough, sputum, and others.

End-of-life care

Heart massage, intubation, mechanical ventilation, oxygen inhalation, air-way placement, sputum suction, hyperalimentation, intravenous drip injection (except hyperalimentation), antibiotics, vasopressor, blood transfusion, opioids, urinary catheter placement, mental support, spiritual healing, others.

Data collection

Immediately after the death of study patients, general practitioners (GPs) were asked to fill out a questionnaire based on the patients' medical charts and their recollection of the clinical course followed. Family members or visiting nurses who witnessed the last 48 hours of the patients' lives were asked to provide additional information. The GPs and other information providers were blinded to the study hypothesis or anticipated study results. For ethical reasons, data on all eligible participants obtained from the Japanese Society of Hospice and Home-care remained anonymous. The research protocol was reviewed and approved by the Nagoya University Research Ethics Board.

Statistical analysis

We used the DEATH sample data of all decedents whose cause of death was any type of cancer, with or without metastasis. Decedents who were diagnosed with cancer but did not die of it were not included in the analysis. Thus, a total of 52 female and 65 male decedents were included in the analysis. To assess the differences in characteristics and symptom experience among female and male decedents, the survey data was divided into two gender groups. The data was analyzed using Statview-J5.0. Group differences were compared using the unpaired *t*-test and the chi square test. *P* values <0.05 were considered to be significant. We also performed a multivariable logistic regression analysis to identify any independent association between gender group and symptom, after adjusting for baseline

factors. As predictors of symptoms, age, ADLs, cognitive impairment, and cause of death were allowed to enter the model. We present the results as odds ratios and 95% confidence intervals.

Results

The distribution of female and male cancer decedent characteristics is shown in Table 1. Most female decedents were significantly older than their male counterparts. Furthermore, cognitive impairment was more common among female

decedents. There were no significant differences in ADLs, cause of death, or complicated illness between female and male decedents.

Female and male cancer decedents' symptom experience in the last two days of life is shown in Table 2. Coma was more frequent among female decedents, while sputum was more common among male decedents. Although nausea and vomiting tended to be frequent among female decedents, we detected no significant difference in nausea and vomiting between the two groups. There were no significant differences in the fre-

Table 1 Characteristics of male vs female elderly cancer decedents

Variable	Women (n=52)		Men (n=65)		P			
	n/average	%/SD	n/average	%/SD				
Age	76.42	1.32	73.17	1.05	0.05			
ADL scale of disabled elderly	J= independent	1	1.92	1	1.54	0.76		
	A= house-bound	4	7.69	7	10.77			
	B= chair-bound	10	19.23	16	24.62			
	C= bed-bound	30	57.69	29	44.62			
	Unknown	7	13.46	12	18.46			
Cognitive impairment	Present	17	32.69	10	15.38	0.03		
Cause of death (primary sites)	Gastric	9	17.31	19	29.23	0.47		
	Lung	12	23.08	15	23.08			
	Liver	3	5.77	5	7.69			
	Colorectal	6	11.54	8	12.31			
	Pancreas	3	5.77	4	6.15			
	Prostate	0	0.00	6	9.23			
	Breast	2	3.85	0	0.00			
	Kidney	1	1.92	2	3.08			
	Uterine	3	5.77	0	0.00			
	Blood	0	0.00	0	0.00			
	Brain	0	0.00	0	0.00			
	Others	8	15.38	5	7.69			
	Unknown	5	9.62	1	1.54			
	Complication (noncancer illness)	Pulmonary	3	5.77	5		7.69	0.68
		Cardiovascular	3	5.77	1		1.54	0.23
Cerebrovascular		2	3.85	2	3.08	0.82		
Kidney		1	1.92	0	0.00	0.26		
Liver		5	9.62	6	9.23	0.94		
Gastrointestinal		2	3.85	0	0.00	0.11		
Others		10	19.23	3	4.62	0.01		
Unknown	1	1.92	1	1.54	0.87			

ADL: activity of daily living

Table 2 Symptom experience of male vs female elderly cancer decedents in last two days of life

Symptom	Women (n=52)		Men (n=65)		P
	n	%	n	%	
Dyspnea	22	42.31	34	52.31	0.28
Pain (uncontrolled)	13	25.00	12	18.46	0.39
Pain (controlled)	23	44.23	35	53.85	0.30
Coma	31	59.62	20	30.77	<0.01
Acute confusion	14	26.92	12	18.46	0.27
Anxiety	5	9.62	9	13.85	0.48
Dizziness	1	1.92	1	1.54	0.87
Nausea and Vomiting	19	36.54	14	21.54	0.07
Anorexia	29	55.77	42	64.62	0.33
Diarrhea	3	5.77	4	6.15	0.93
Constipation	5	9.62	4	6.15	0.49
Fever	12	23.08	18	27.69	0.84
Incontinence	9	17.31	9	13.85	0.60
Hematemesis	1	1.92	3	4.62	0.43
Hemoptysis	0	0.00	1	1.54	0.37
Bottom blood	2	3.85	5	7.69	0.38
Other hemorrhage	2	3.85	7	10.77	0.16
Cough	6	11.54	9	13.85	0.71
Sputum	10	19.23	25	38.46	0.02
Other symptom	12	23.08	17	26.15	0.70

Table 3 Care receipt of male vs female elderly cancer decedents in last two days of life

Care	Women (n=52)		Men (n=65)		P
	n	%	n	%	
Heart massage	0	0.00	1	1.54	0.37
Intubation	0	0.00	0	0.00	—
Mechanical ventilation	0	0.00	0	0.00	—
Oxygen inhalation	21	40.38	24	36.92	0.70
Airway placement	1	1.92	2	3.08	0.69
Sputum suction	11	21.15	18	27.69	0.42
Hyperalimentionation	5	9.62	9	13.85	0.48
Antibiotics	3	5.77	8	12.31	0.23
Vasopressor	0	0.00	0	0.00	—
Blood transfusion	0	0.00	0	0.00	—
Intravenous drip injection	16	30.77	22	33.85	0.72
Opioids	24	46.15	37	56.92	0.25
Urinary catheter placement	13	25.00	10	15.38	0.19
Mental support	0	0.00	3	4.62	0.12
Religious healing	1	1.92	1	1.54	0.87
Others	2	3.85	7	10.77	0.16