

that dyspnea was worse in men than in women. Significant differences between the two groups may have been detected had this study investigated the severity of dyspnea.

Sputum experience was more common in male than in female decedents. Since sputum often leads to dyspnea, it might have been possible to relieve dyspnea symptoms in male decedents by treating for sputum. However, very little is known regarding sputum experience in the last days of life. Further studies are needed to shed light on this issue.

The present study demonstrates that nausea and vomiting experience was higher among female than male decedents. Although no significant differences were observed before adjustment, significant gender difference appeared after adjustment for age and other baseline characteristics. Thus, our findings are consistent with previous literature^{1,8,16-18} in suggesting that female gender is an independent predictor of gastrointestinal symptoms such as nausea and vomiting.

Our data shows that there were no significant gender differences in pain experience. The fact that there was no significant gender difference in the use of opioids is strongly indicative of gender similarity in symptom experience. A number of studies have suggested that pain experience is more common in women than men. Because it is generally believed that pain is less common in elderly patients rather than younger cancer patients,^{6,19} the absence of gender differences in pain experience in our study may have been due to the fact that our study sample was limited to elderly patients aged 65 and over. Also, it is difficult to interpret this finding, because in this study we did not assess the severity of pain. In future studies, a complete pain assessment should be included for a more comprehensive result.³

Also, in this population, acute confusion occurred equally in female and male decedents. According to Cobb et al.,² men are at higher risk of showing acute confusion. To our knowledge, no study has been conducted to investigate differences between female and male patients with

regard to the presence of acute confusion at end-of-life. Additional studies are needed to confirm gender differences in this respect.

Our study has a number of limitations. Because female decedents were significantly older than their male counterparts, it is likely that their disease was at a more advanced stage since disease progression is related to age. This may have had an impact on symptom experience in this group.

Also, the small number of patients and limited study settings may account for the lack of gender differences in symptom experience. In addition, the Japanese Society of Hospice and Home-care is interested in hospice and home-care, and selection bias is thereby also possible. Larger studies may reveal statistically significant differences between women and men in Japan.

Finally, our database does not systematically capture the full extent of the study subjects' characteristics that could affect symptom experience, especially the ability to convey symptoms.

Conclusions

The purpose of this secondary analytic study was to evaluate the gender differences in symptom experience of elderly cancer patients at home during the last two days of life.

Patients' records indicate gender differences in the experience of symptoms such as nausea, vomiting, and sputum; in care receipt, however, no gender differences were noted. This study suggests that consideration should be given to gender differences in symptom experience and management at end-of-life. Additional studies should be conducted to supplement our knowledge on the subject and improve care.

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End-of-life care at group homes for patients with dementia in Japan Findings from an analysis of policy-related differences

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Abstract

In Japan, the number of group homes for patients with dementia (GHs) has been increasing in recent years. A growing number of elderly people now prefer to spend their final years in group homes or other long-term care facilities, a choice that their families support. The aim of this nationwide study is to clarify the current end-of-life care policies and practices of GHs. The subjects were 3701 managing directors of GHs. Data were collected through mailed, anonymous, self-reported questionnaires in 2003. The content of the questionnaires included: (1) general characteristics of the GH, (2) end-of-life care policies and experiences, (3) available end-of-life care services at the GH, (4) staff education concerning end-of-life care, and (5) types of information provided to users and families. The response rate was 45.6%. Many GHs had implemented progressive policies for end-of-life care. GHs with progressive policies for end-of-life care were found to have different backgrounds than those with regressive policies. Only a few GHs provided end-of-life care education for their staff. GHs with progressive policies for end-of-life care tended to have the following characteristics: availability of medical intervention within and outside of the GH, self-contained physical plant and staff education about end-of-life care. Further research is needed to determine the most effective end-of-life care systems for GHs. © 2005 Elsevier Ireland Ltd. All rights reserved.

Keywords: End-of-life care; Group homes; Death education; Dementia; Grief care

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1. Introduction

Due to the aging of the population and longer life spans, end-of-life care for the elderly has become a major national problem in Japan (Hiroi, 1998; Hashimoto, 2001; Hirakawa et al., 2004; Suzuki and Iguchi, 2004). Although most deaths reportedly occur in hospitals, it is generally believed that elderly people wish to die either in a long-term care facility or at home, where they have spent many years (Sauvaget et al., 1996; Hashimoto, 2001; Iwasaki, 2003; Tilden et al., 2004).

However, due to rising health care costs in Japan (Hiroi, 1998) and the growing demand for institutional or home care rather than hospital care, institutional care has received much attention within the long-term care insurance system (Hashimoto, 2001). As a result, we expect a gradual shift in the place where people spend their last years, from hospitals to long-term care facilities or group homes.

Successful end-of-life care requires proper guidance for the elderly and their families in making decisions about the available treatment frameworks and about where to die (Hiroi, 1998; Morrison, 2000; Hashimoto, 2001; Pekmezaris et al., 2004). It seems reasonable to assume that the range of end-of-life care options at long-term care facilities or homes is greater than that in hospitals (Hiroi, 1998; Hashimoto, 2001). The elderly and their families should be well informed about the various end-of-life care alternatives available to them.

A number of studies have been devoted to end-of-life care at hospitals. However, so far, very little research has dealt with long-term care facilities for the elderly. In Japan, the number of group homes for patients with dementia (GHs) has been on the rise, especially after the introduction of the public long-term care insurance plan in 2000 (Nakaguma, 2004b). The number reached 6645 by the end of April 2005, according to the WAM NET nationwide online database (<http://www.wam.go.jp/>). A GH is a small, home-style facility covered by public insurance. The law stipulates that each GH must provide specialized, in-home care services with mutual support for the elderly with dementia. Thus, it assumes the roles of both institution and home (Nakaguma, 2004a). Similarly, the number of elderly people choosing to spend their remaining years in GHs has been increasing. GHs should therefore be able to adequately respond to the often demanding needs and complex wishes of individual users (Uchiide, 2004).

The aim of this study is to clarify current end-of-life care policies and practices of GHs for patients with dementia in Japan, and related policy considerations. This study employs primary sources to assist GHs in designing quality end-of-life care programs based on their own particular policies.

2. Methods

2.1. Sample

The subjects in this study were managing directors of GHs. To obtain an up-to-date address list, we utilized WAM NET, a nationwide online database managed by the Independent Administrative Agency for Welfare Medical Treatment (Dokuritsu Gyousei Houjin Fukushi Iryou Kikan), which offers the latest information about GHs from sources

all over the country. The subjects were 3701 GH managing directors registered with WAM NET (<http://www.wam.go.jp/>) as of September 2003.

2.2. Research content

Data were collected through mailed, anonymous, self-reported questionnaires. The questionnaires covered the following: (1) general characteristics of the GH, (2) end-of-life care policies and experiences, (3) available end-of-life care services at the GH, (4) staff education concerning end-of-life care, and (5) kinds of information provided to users and families.

2.3. Data analysis

We first examined the overall results to understand the trends regarding end-of-life care at GHs in Japan. Then, to evaluate the factors correlated with end-of-life care policies at GHs, we compared the characteristics of GHs that had progressive policies toward end-of-life care (Group 1) with those that had regressive policies (Group 2). A GH was assigned to Group 1 when its reply was “will offer” or “will offer on certain conditions” regarding whether or not it provides end-of-life care. If a reply was “will not offer”, the GH was assigned to Group 2.

The data were analyzed using Statview-J5.0. Group differences were compared using the Mann–Whitney test and the chi square test. *P* values < 0.05 were considered significant.

3. Results

3.1. General description of subjects

Of the 3701 subjects contacted, 1689 responded, for a response rate of 45.6%. Table 1 shows the general characteristics of the respondents. The mean number of residents per GH was 13.1, and nearly two-thirds of GHs were established after the year 2000.

In approximately one-fourth of the GHs, nursing services were provided 24 h a day. The GHs had a mean of 12.1 staff members, with few attending physicians. More GHs were run by nonprofit organizations (57.8%) than profit-making organizations (39.8%). Moreover, the services that GHs were most affiliated with were day service/care (49.7%) and in-home service centers (48.9%). Nearly 30% of the GHs were not affiliated with any institution or in-home service. Slightly less than 60% were self-contained physical plants. Most GHs (90.6%) had a first-aid manual for medical emergencies. More than 90% of GHs had an ongoing arrangement with a hospital to which their users could be admitted, and approximately 80% responded that hospital admissions could be arranged around the clock. Additionally, 72.9% responded that the designated hospital could administer end-of-life care support if necessary, and 57% stated that such care was available at the GH during the impending death of a user.

Table 2 outlines the information that the GHs provide to users and their families. Over 70% of GHs responded that they provide users and families with information on the

Table 1
General characteristics of group homes (*N* = 1689)

Variables	Average/GHs number	%
Quota (average)	13.1	
Establish		
2003–(September)	470	27.8
2002	337	20.0
2001	214	12.7
2000	61	3.6
–1999	49	2.9
Number of staff (average)		
Overall	12.1	
Certificated care worker/helper	4.6	
Nurse	0.4	
Physician	0.1	
Nurse's night work	436	25.8
Organization		
Nonprofit organization	976	57.8
Incorporated social welfare institution	498	29.5
Incorporated medical institution	373	22.1
Others	105	6.2
Profit making organization	673	39.8
Others	32	1.9
Affiliated institution/in-home care services		
Day service/care	840	49.7
In-home service center	826	48.9
Home help	418	24.7
Short stay	414	24.5
Nursing home	344	20.4
Geriatric intermediate care facility	226	13.4
Home-visit nursing care	197	11.7
Hospital	166	9.8
Clinic	147	8.7
Others	207	12.3
Nothing	480	28.4
Building		
Single	995	58.9
Attached	668	39.6
First-aid manual	1530	90.6
Admission to hospital available	1537	91.0
In 24 h	1366	80.9
Medical support from outside available	1232	72.9
At GH when the user dies	962	57.0

progressive clinical course of dementia, the symptoms accompanying advanced dementia, and the required care for advanced dementia. However, only 37.2% responded that they supply users and families with information on the type of end-of-life care available at the GH.

Table 2
 Provided information for user and family (*N* = 1689)

Content of information	GHs number	%
Dementia may be progressive	1313	77.7
About symptoms accompanying advanced dementia	1298	76.9
About required care accompanying advanced dementia	1228	72.7
About available end-of-life care in GH	628	37.2
About others	83	4.9

Table 3 shows the end-of-life care policies and experiences of the GHs. Concerning whether or not they offered end-of-life care at their facilities, 22.3% of GHs responded that they do, whereas 47.2% explained that they will under certain conditions. Of the subjects who responded that they would offer end-of-life care under specific conditions, more than half were found to meet all four conditions we thought necessary for end-of-life care at GHs: (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. However, only a small proportion of GHs (16.9%) had experience in providing end-of-life care. This percentage increased between 2000 and 2002.

Table 4 lists the available end-of-life care services offered by the various GHs. Overall, 76.4% of subjects deemed it possible to provide end-of-life care at their GHs if necessary. Regarding end-of-life care items, providing families and users with the option to express their wishes was possible at most GHs, whereas outside support, religious healing, and advice about law and property management were less often available. Sixty-nine percent of GHs deemed it possible to provide grief support for the bereaved family. Grief support items are shown in Table 4.

Table 3
 End-of-life care policies and experiences (*N* = 1689)

Variables	GHs number	%	Users number
End-of-life care policy will offer	377	22.3	
Will offer on certain conditions	798	47.2	
Item of condition			
Unnecessity of medical intervention	551	32.6	
Understanding of user and family	532	31.5	
Understanding of staff	462	27.4	
No complaint of pain	417	24.7	
Will not offer	464	27.5	
End-of-life care experience	285	16.9	
Year			
2002	189	11.2	333
2001	78	4.6	115
2000	33	2.0	60

Users number is the number of users received end-of-life care at GHs.

Table 4
Available end-of-life care services in group homes (N = 1689)

Variables	GHs number	%
Item of available care in their own group homes		
Overall	1291	76.4
Ask family's wish	1148	68.0
Ask user's wish	1107	65.5
Provide family with information	1052	62.3
Support a comfortable posture	1039	61.5
Get close	1029	60.9
Support family participation	1002	59.3
Touch	998	59.1
Listen with great interest	862	51.0
Provide a good environment	818	48.4
Massage	668	39.6
Heal religiously	151	8.9
Advice about law and property management	103	6.1
Others	41	2.4
Get support from the outside	445	26.3
Communities and voluntary organizations	215	12.7
Municipalities	117	6.9
Others	139	8.2
Item of available grief care for the bereaved family		
Overall	1166	69.0
Telephone	692	41.0
Letter	611	36.2
Others	355	21.0

Table 5 details the types of end-of-life care training and education that staff members receive. Such training was provided by 40.4% of GHs, and lectures were the most frequent training method.

3.2. Factors associated with end-of-life care policies

To examine the factors associated with end-of-life care policies, we analyzed the data from the end-of-life care policy items obtained from 1639 GHs. Table 6 shows the results of a comparative analysis of the general characteristics of GHs having progressive (Group 1) or regressive (Group 2) policies for end-of-life care. No significant differences were found between the two groups in the number of residents per GH. Relative to Group 2, significantly more GHs in Group 1 were established after the introduction of the public long-term care insurance, had nurses, and were run by a profit-making organization.

GHs in Group 1 were less likely to have affiliations with other institutions or in-home services, and were more likely to be affiliated with long-term care facilities, including nursing homes and geriatric intermediate-care facilities, as well as in-home care services or hospitals. Significantly, more GHs in Group 1 were self-contained physical plants and had established arrangements with hospitals from which they could obtain end-of-life care

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.

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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)

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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)	n = 399	Female caregiver N %, mean \pm SD (range)	n = 1193	P-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		
	Very frequently	11	2.8	16	1.3		
Nutrition	Per oral	380	95.2	1123	94.1	NS	
	Parenteral	18	4.5	66	5.5		
	Intravenous hyperalimentation	2	0.5	2	0.2		
Degree of care required	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		
	Degree 5	76	19.0	210	17.6		
Dementia	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
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	