RESEARCH ARTICLE

Employment Status and Work-Related Difficulties among Family Members of Terminally Ill Patients Compared with the General Population

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Abstract

Background: Although caregiving to patients with terminal illness is known to be a stressful burden to family members, little attention has been focused on work-related problems. We aimed to investigate employment status and work-related difficulties of family caregivers of terminal cancer patients, comparing with the general population. Methods: Using structured questionnaires, we assessed family caregivers of 481 cancer patients determined by physicians to be terminally ill, from 11 university hospitals and the National Cancer Center in Korea. Results: Among 381 family caregivers of terminal cancer patients (response rate, 87.6%), 169 (43.9%) were not working before cancer diagnosis, but currently 233 (63.7%) were not working. Compared with the general population (36.5%), the percentage of not working among the family caregivers was higher (OR=2.39; 95% CI= 1.73-3.29). A major reason for not working was to provide assistance to the patients (71.6%). 40.6% of those who continued working and 32.3% of those who not working family members reported extreme fatigue. Caregivers of old age, those who were female, those with a lower household income, and those caring for patients with a low performance status were not working at a more significant rate. Conclusion: Family caregivers of terminal cancer patients suffer job loss and severe work-related difficulties, probably due to caregiving itself and to fatigue. We need to develop supportive programs to overcome the burden of caregivers of the terminally ill.

Key words: Terminal cancer patient - caregiver - employment status - work-related difficulty

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Introduction

Although caregiving to patients with terminal illness is known to be a stressful burden to family members (Chochinov et al., 2011; Fairfield et al., 2012; Kimman et al., 2012; Tordoff et al., 2012), little attention has been focused on the impact of caregiving on employment status and work-related difficulties among family members of patients with terminal illness. Caregiver burden is closely connected to patient demands, and it might be related to the overall outcomes of the caregiving process (Dybicz et al., 2011). For example, several studies have documented typically high levels of dailyliving assistance, including help with transportation, shopping, homemaking, emotional support, nutritional care, nursing care, and personal care (Shahmoradi et al., 2009; O'Connor and Kumar, 2012; Stiel et al., 2012). As a result of daily-living assistance, many studies focused on family caregiver burdens such as high levels of stress, poor physical condition, emotional health, and family savings losses (Bukki et al., 2011; Duclos et al., 2012; Gomes et al., 2012; von Gunten, 2012).

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As many caregivers reported spending over 40 hr per week providing care, it is not surprising that caregiving frequently interferes with employment (Pantilat et al., 2012). Employment status among family caregivers has especially important implications for society, the labor market, and family economics (Unroe et al., 2012). Although previous studies have focused on the return to work of cancer survivors (Knapp et al., 2011; Phipps et al., 2011; Flannelly et al., 2012; Unroe et al., 2012) and employment status among caregivers of cancer patients (Gomes et al., 2012; Pantilat et al., 2012), unfortunately, it is not fully understood how many family caregivers of terminal cancer patients maintain their employment status with caregiving. We aimed to evaluate employment status and work-related difficulties of family caregivers with terminal cancer patients, comparing with the general population.

Materials and Methods

Study sample

Family caregivers of terminal cancer patients. The Study to Understand Risks, Priority, and Issues at Endof-Life (SURPRISE), a multicenter study designed to identify important ethical issues, care burden, and quality of care at the end of life in Korea, recruited terminal cancer patients for this prospective cohort study from 11 university hospitals and the National Cancer Center, Korea; none had a stated policy about the disclosure of terminal illness. In SURPRISE, patients were eligible to participate if they were (1) aged 18 year or older, (2) diagnosed as terminal at an outpatient or inpatient facility, (3) capable of filling out questionnaires or communicating with an interviewer, and (4) competent enough to understand the intent of the study and provide informed consent. We defined a terminal cancer patient as someone with progressive advanced disease that, in a physician's judgment, was refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy, or hormone therapy) and who was likely to die within

Participants were given information explaining the study and were asked to participate. All patients and caregivers provided informed consent to participate in this study, and our institutional review boards approved the protocol.

Physicians identified 702 consecutive terminal cancer patients. Of those, 83 were excluded (11 continued conventional anticancer treatment after enrollment, 14 were of non-evaluable disease status in follow-up, 15 were lost to follow-up in front of treatment plan, and 43 had become physically or mentally incapacitated). Of the 619 remaining eligible participants, 481 (77.7%) gave written informed consent and completed the questionnaire.

Patients were asked about their primary family caregivers who provided them with the most assistance. We enrolled one caregiver per patient. The family caregivers were invited to participate in the study but were ineligible if they were (1) not aged 18 year or older, (2) not well enough to fill out questionnaires, (3) not able to communicate with an interviewer, (4) not able to understand the intent of the study well enough to provide informed consent, or (5) a patient with a history of cancer.

Of the 481 eligible patients, 30 had no caregivers, 13 had caregivers who were not competent enough to participate in the study, and 3 had caregivers who were not able to read the questionnaire. Of the 435 eligible caregivers, 58 declined to participate; the most common reasons given were inconvenience and lack of time. The remaining 381 caregivers completed the questionnaire (response rate, 86.7%). Details of the study population and data collection methods have been previously described elsewhere (Knapp et al., 2011).

General population

The survey was conducted in age and sex strata according to the guidelines of the 2000 Korean Census in 15 geographic districts. Probability proportional to size technique considers the size of individual groups and corrects for differences in the probability of larger and smaller groups being sampled. Criteria of eligibility included (1) being physically and mentally fit to fill out the questionnaire or communicate with the interviewer and (2) aged more than 18 year. The interviewers visited each person at home or in the workplace, evaluated eligibility, and explained the purpose of the study to the eligible person.

Of 2447 potentially eligible persons, 1447 refused to participate or did not complete the survey. The most frequent reasons people gave for refusing to participate were that they felt too busy to complete the questionnaire (N=734), the survey was inconvenient (N=356), they did not want to provide personal information (N=156), or other reasons (N = 201). Of those who completed the survey, 6 had a history of cancer and were excluded. The final sample comprised 994 participants (response rate, 41%). The study population and data collection methods have been previously described elsewhere (Phipps et al., 2011).

Study variables

SURPRISE collected demographic data for the patients and the caregivers and clinical information for the patients. We administered the questionnaires by faceto-face interviews at an outpatient or inpatient facility to both groups at the same time within days of the baseline time point of the study, which was when the physician judged that the cancer was refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy, or hormone therapy) and the patient was likely to die within months. The patient and family caregiver questionnaires were similar and took about 20 minutes to complete. We used a questionnaire to collect information on the employment status, work-related difficulties, and sociodemographic characteristics of family caregivers of terminal cancer patients and the general population. Independent variables included gender, age, marital status, monthly household income, education, religion, health cost financing, family APGAR (a validated scale of family function, based on adaptability, partnership, growth, affection, and resolution), medical cost bearer, living together with family, Eastern Cooperative Oncology Group performance status (ECOG PS), relationship of patient, health status of patient, and terminal state recognized. Employment was delineated as either employed or not employed, where not employed included caregivers who were homemakers or retired.

If participants were currently working, they were asked what kind of work-related difficulties they were having. The question included the following five multiple-choice items for work: (1) reduced working hours, (2) lessened work-related ability than before cancer diagnosis, (3) easily fatigued and exhausted, (4) reduced opportunity for promotion, and (5) decreased wages. The question included the following multiplechoice items for not working: (1) physically limited, (2) easily fatigued and exhausted but not physically limited, (3) emotionally distressed (such as feeling depressed or anxious), and (4) for caregiving. If they were currently not working, they were asked why they were not working. The question included the same multiple-choice items used for homemakers. If the choice items were not applicable, participants were asked to write in the reason for not working. The design of this study has been used previously (Phipps et al., 2011; Flannelly et al., 2012)

Statistical analysis

We used propensity score to adjust for differences in characteristics between family caregivers of terminal cancer patients and the general population. Selected variables for propensity score included age, gender, education, marital status, religion, health cost financing, and monthly household income. Score adjustment did not correct for differences between family caregivers of terminal cancer patients and controls in unobserved characteristics. The propensity score is the estimated logistic regression model.

The primary outcome was the percentage of not working among 381 family caregivers of terminal cancer patients. We used a t-test for continuous variables and a chi-square test in univariate analysis to estimate the odds ratio (OR) for each independent categorical variable. For variables significantly associated in univariate analysis, we performed the multivariate logistic regression analysis with a stepwise selection method for each dependent variable to assess which of the independent variables best predicted not working because of caregiving. We set the significance level at P<0.05 and used SAS software, version 9 (SAS Institute, Cary, NC), for all analysis.

The study protocol was approved by the Institutional Review Board of the National Cancer Center and by the institutional review boards of all participating hospitals.

Table 1. Sociodemographic Characteristics of Caregivers of Terminal Cancer Patients and the General Population Before and After Propensity **Score Adjustment**

		Caregivers	General	P :	P Value
		N=381	Population**		Adj. for
			N=994		ropensity
		N (%)	N (%)		Score*
Sex	Male	127 (33.3)	` ` `	<u></u>	1 0.69
Sex	Female	254 (66.7)			1 0.09
Age	≤49	213 (56.3)	, ,		1 0.57
(N=378)	50-64	125 (33.1)			0.57
(11-370)	≥65	40 (10.6)			
Education	203	40 (10.0)	11 (1.5)		
	e School	91 (23.9)	161 (16.2)	0.0008	3 0.95
	school -	290 (76.1)			
Marital sta		230 (7011)	(0010)		
Marrie		306 (80.5)	706 (71.0)	0.0004	4 0.70
	wed/divorced				. 01/0
	ated/single	071 (13.5)	200 (23.0)		
Have a reli	_				
Yes	D-0	252 (67.4)	532 (53.5)	<0.0001	0.76
No		122 (32.6)			
Health cost	financino	122 (32.0)	102 (40.2)		
	i insurance	292 (77.4)	959 (96.6)	<0.0001	0.72
Medic		85 (22.5)			0.72
	ousehold inco	` /	54 (5.4)		
<2000		218 (59.1)	243 (24.5)	<0.0001	1 0.74
≥2000		151 (40.9)			0.74
Employme		151 (40.5)	150 (15.5)		
		68 (18.0)	264 (26.6)	0.0021	1 0.08
Self-employed Employed		144 (38.1)			1 0.00
1	orking/retired				
	maker	118 (32.2)			
Other	illakci	27 (7.1)			
	20	3 (0.07)			
Missi	_	- (()		
Yes	ether as a fam		NA		
		283 (75.5)			
No Cumant and	larimant	92 (24.5)	NA		
Current em		42 (11.7)	NT A		
	mployed	43 (11.7)			
Emplo		90 (24.6)			
	ployed /retire				
	maker	133 (36.3)			
Other		26 (7.1)			
Missin		15 (0.4)	NA NA		
Family AP	GAR	47 (12.1)	NTA		
<3		47 (13.1)			
4-7		154 (42.8)			
>7		159 (44.2)	NA NA		
	ip of patient	104 (70.0)	37.4		
Spous	e	194 (50.9)			
Other	2	187 (49.1)			
ECOG PS ⁹	≤3	206 (69.6)			
** 1.	4	90 (30.4)			
Health stat		73 (20.0)			
	Bad	286 (79.9)	NA NA		
Terminal st	ate recognize				
	Yes	158 (42.2)	NA		
	No	216 (57.7)	NA		
*The proper	nsity score su	mmarizes the	collection of	different	observable

*The propensity score summarizes the collection of different observable characteristics between caregivers of terminal cancer patients and the general population, including age, sex, education, marital status, religion, monthly household income, and health cost financing; **Lee MK, Lee KM, Bae JM, et al., (2008) Employment status and work-related difficulties in stomach cancer survivors compared with the general population. Bri J Cancer, 98, 708-15; †US\$1=1,000won; ‡Employment status is the caregiver of a terminal cancer patient's working status at the patient's diagnosis compared to the general population's current employment status. Family APGAR is a validated scale of family function based on adaptability, partnership, growth, affection, and resolution. Sastern Cooperative Oncology Group performance status

Results

Sample characteristics

Family caregivers of terminal cancer patients differed significantly from the general population in several sociodemographic characteristics before adjustment for propensity score, but not after adjustment for propensity score (Table 1).

Employment status of family caregivers of terminal cancer patients and the general population

Among 381 family caregivers of terminal cancer patients, 169 (43.9%) were not working at cancer

Table 2. Changed Working Status of Caregivers and the General Population*

Working,	Not	aOR,	aOR,	^a OR, Change in	
	Working,	Not Working	Currently	y Employment	
		at Diagnosis	Not Worki	ng Status	
N (%)	N (%)	(95%CI)†	(95%CI)	(95%CI)‡	
General Popula	ation (N=99	94)**:			
Current work	king situatio	n			
631 (63.5)	363 (36.5)	1 (Ref.)		1 (Ref.)	
Caregivers of Terminal Cancer Patients (N=381):					
Employment status at patient's diagnosis (N=378)					
212 (56.1)	166 (43.9)	0.95 (0.69-1.30)	1(Ref.)		
Current emp	loyment sta	tus (N=366)			
133 (36.3)	233 (63.7)	1.4	19 (1.10-2.0	1) 2.39 (1.73-3.29)	

^aOR, adjusted odds ratio; CI, confidence interval. Working status is classified into working and not working. "Working" stands for the subjects who are self-employed or employed, and "not working" stands for the subjects who are unemployed, retired, or homemakers. **Lee MK, Lee KM, Bae JM, et al., (2008) Employment status and work-related difficulties in stomach cancer survivors compared with the general population. Br J Cancer, 98, 708-15. †Odds ratio of not having worked at the time of diagnosis for caregivers of terminal cancer patients compared with the general population's current working situation, adjusted for age, sex, education, marital status, religion, monthly household income, health cost financing, and propensity score; ‡Odds ratio of currently not working for caregivers of terminal cancer patients compared with the general population's current employment status, adjusted for age, sex, education, marital status, religion, monthly household income, health cost financing, and propensity score. Odds ratio of currently not working for caregivers of terminal cancer patients compared with employment status at the time of diagnosis, adjusted for age

Table 3. Reasons for Work-Related Difficulties among Caregivers of Terminal Cancer Patients

	N=381 %
Reasons for not working (N=74)	
For caregiving	53 (71.6)
Retied	10 (13.5)
Limited in physical functioning	2 (2.7)
Other	6 (8.1)
Work-related difficulties experienced by worker* (N=13	3)
Easily fatigued and exhausted	54 (40.6)
Decreased wages	44 (33.1)
Less work-related ability than before cancer diagnosis	32 (24.1)
Reduced working hours	27 (20.3)
Missed an opportunity for promotion	4 (3.0)
Other	21 (15.8)
Housework-related difficulties experienced by homemak (N=133)	ter*
For caregiving	75 (56.4)
Easily fatigued and exhausted but not limited in	
physical functioning	43 (32.3)
Emotional distress (depression and anxiety)	21 (15.8)
Limited in physical functioning	11 (8.3)
Other	12 (9.0)

^{*}Items answered by multiple choices

diagnosis, but currently 233 (63.7%) were not working. Compared with the general population (36.5%), the percentage of not working among the family caregivers (63.7%) was higher (adjusted OR (aOR)=2.39; 95% confidence interval (CI)=1.73-3.29; Table 2).

Table 4. Univariate Result of the Relationship to Employment Status among Caregivers of Terminal Cancer Patients

Characteristics		Working	Not Working P Value	
		N (%)	N (%)	
Age	≤49	92 (44.4)	115 (55.6)	< 0.0001
	50-64	35 (29.9)	82 (70.1)	
	≥65	4 (10.3)	35 (89.7)	
Sex	Male	70 (56.9)	53 (43.1)	< 0.0001
	Female	63 (25.9)	180 (74.1)	
Education	< High school	58 (29.0)	142 (71.0)	< 0.0001
	> High school	67 (53.2)	59 (46.8)	
Marital status	Married	104 (35.0)	193 (65.0)	0.3403
	Widowed/divorc	` /	40 (58.8)	
	/separated/singl	e		
Health cost fire				
	Health insurance	(/	173 (61.3)	0.1374
	Medical aid	24 (29.6)	57 (70.4)	
Have a religion		79 (32.0)	168 (68.0)	0.0159
	No	51 (45.1)	62 (54.9)	
Monthly hous	ehold income (US			
	<2000	54 (25.7)	156 (74.3)	< 0.0001
	≥2000	76 (52.4)	69 (47.6)	
Living togeth	er as a family			
	Yes	46 (52.3)	42 (47.7)	0.0003
	No	85 (31.1)	188 (68.9)	
Family APGA		19 (41.3)	27 (58.7)	0.6769
	4-7	52 (34.7)	98 (65.3)	
	>7	57 (37.1)	93 (62.9)	
Relationship of				
	Spouse	55 (29.3)	133 (70.7)	0.0038
	Other	78 (43.8)	100 (56.2)	
Age	≤49	34 (42.5)	46 (57.5)	0.2598
	50-64	55 (32.2)	116 (67.8)	
C	≥65	43 (37.7)	71 (62.3)	0.0006
Sex	Male	60 (28.8)	148 (71.1)	0.0006
E1	Female	73 (46.2)	85 (53.8)	0.6047
Education	< High school	66 (38.4)	106 (61.6)	0.6047
Mr. S. L. a.	> High school	65 (35.7)	117 (64.3)	0.6101
Marital status		105 (37.2)	177 (62.8)	0.6181
	Widowed/divorc	ed/ 27 (34.2)	52 (65.8)	
Hava a maliaia	separated/single	05 (27.0)	162 (62 0)	0.9152
Have a religion		95 (37.0)	162 (63.0)	0.8153
E1	No	36 (37.5)	65 (28.6)	
Employment	status at patient's		122 (67.2)	0.1202
	Working	64 (32.6)	132 (67.3)	0.1382
Cumant amail	Not working	64 (40.2)	95 (59.7)	
Current emplo	•	12 (44.4)	15 (55 6)	0.2215
	Working		15 (55.6)	0.3213
ECOC DS+	Not working ≤3	110 (34.9) 81 (40.9)	205 (65.1) 117 (59.1)	0.0318
ECOG PS‡	4	24 (27.6)	63 (72.4)	0.0316
Diagnosis	Stomach cancer	20 (29.0)	49 (71.0)	0.369
Diagnosis				0.309
	Lung cancer Colon cancer	17 (36.2) 24 (44.4)	30 (63.8) 30 (55.6)	
	Other	71 (36.4)	124 (63.6)	
Health status	Good	30 (41.0)	43 (58.9)	0.2769
ricaiui status		. ,		0.2768
Tarminal state	Bad	98 (27.3)	188 (52.4)	
Terminal state	Yes	57 (27 2)	06 (62.7)	0.6077
		57 (37.2)	96 (62.7)	0.6977
	No	73 (35.3)	134 (64.7)	
*US\$1=1,000 v	von; †Family APGA	R is a validate	d scale of fam	ily function.

^{*}US\$1=1,000 won; †Family APGAR is a validated scale of family function, based on adaptability, partnership, growth, affection, and resolution; ‡Eastern Cooperative Oncology Group performance status

Table 5. Model-Based Adjusted Odds Ratio of Not Working by the Stepwise Method in Separate Logistic Regression Analyses in Caregivers of **Terminal Cancer Patients**

Characteristic		Caregiver (N=381) P		
		OR* of	Not Working (95%)	CI)
Caregiver†: Age		≤49	1 (Ref)	
	C	50-64	1.47 (0.75-2.91)	0.1511
		≥65	7.32 (2.13-25.22)	0.0039
	Sex	Male	1 (Ref)	
		Female	4.92 (2.62-9.22)	< 0.0001
Monthly household income (US\$)			income (US\$)	
		≥2000	1 (Ref)	
		< 2000	0.46 (0.25-0.85)	0.0126
Patient†:	ECOG PS	≤3	1 (Ref)	
		4	1.96 (1.01-3.82)	0.047

*Odds ratio estimates of not working vs. working, where "working" stands for the subjects who are self-employed or employed and "not working" stands for the subjects who are unemployed, retired, or homemakers; †Model-based odds ratios are from a series of logistic regression models with the stepwise method whose covariates were caregiver factors (age, sex, education, marital status, having a religion, relationship of patient, household monthly income, and living together with family) and the patient factor (sex, ECOG PS) that were significant (P < 0.05) in univariate analysis (Table 4)

Work- and housework-related difficulties among family caregivers of terminal cancer patients

A major reason for not working was to provide assistance with care to the patients (53, 71.6%). Those who continued working reported easier fatigability (54, 40.6%), decreased wages (44, 33.1%), less work-related ability (32, 24.1%), and reduce working hours (27, 20.3%). For those doing housework, caregiving itself (75, 56.4%) was identified to be the most common difficulty, followed by easy fatigability (43, 32.3%) and emotional distress (21, 15.8%; Table 3).

Associated factors of the work situations of family caregivers of terminal cancer patients

Among family caregivers, age, gender, educational level, having a religion, monthly household income, living together with family, and relationship of patient were associated with employment. Among terminal cancer patients, gender and ECOG PS were associated with employment (Table 4).

Table 5 shows the results of multivariable logistic regression. Among caregivers, the factors of older age (aOR=7.32; 95%CI=2.13-25.22), female sex (aOR=4.92; 95%CI=2.62-9.22), lower household income (aOR=0.46; 95%CI=0.25-0.85), and low performance status of the patient (aOR=1.96; 95%CI=1.01-3.82) were significantly associated with not working.

Discussion

This study focused on the determinants of one consequence of caregiving itself: reduced caregiver employment. This is, to our knowledge, the first study to examine caregivers' work- and housework-related difficulties and the correlates of employment status in family caregivers of terminal cancer patients, as

compared with the general population.

We found that not working was higher among caregivers of terminal cancer patients (63.7%) than among the general populations (36.5%). A major reason for not working was to provide assistance with care to the patients (71.6%), and in addition, caregiving itself (56.4%) was identified to be the most common difficulty for those doing housework. 40.6% of those who continually working and 32.3% of those who not working family members reported fatigability.

Our results were similar to the findings of previous studies of caregivers of cancer patients; that is, previous studies showed that 20% of caregivers provided fulltime or constant care (Bukki et al., 2011), 5-20% of caregivers had quit their jobs or declined advancement as a result of caregiving (Dybicz et al., 2011; Fairfield et al., 2012; Pantilat et al., 2012). Fatigability was also a major reason for not working among cancer survivors in previous studies (Phipps et al., 2011; Flannelly et al., 2012). However, our findings were specific to caregivers of terminal cancer patients because we focused on comparing caregivers of terminal cancer patients with the general population.

This study also discovered factors significantly associated with not working: old age, female, and low household income were significantly associated with not working. This is a natural result, according to previous studies, which showed that almost three quarters of all care for dying patients was provided by women (Duclos et al., 2012; Fairfield et al., 2012; Gomes et al., 2012; O'Connor and Kumar, 2012; Stiel et al., 2012). Caregivers with old age or who were female provided the majority of assistance with informal care of patients and commonly reported higher levels of personal burden than younger or male caregivers (Gomes et al., 2012; von Gunten, 2012). Our findings show that patient gender were significantly associated with not working in univariate analysis; however, it was insignificantly associated with not working in multivariate analysis. Therefore our findings confirm that caregiver gender is more significantly associated with not working than patient gender.

The low monthly household income is related to the lower employment status. Caregivers with low monthly household incomes cannot afford to buy high-cost assistive care (Herr et al., 2012; Pantilat et al., 2012). Providing care for terminal cancer patients instead of working worsens the economic conditions of family caregivers with lower monthly incomes. This study was limited by our data showing only the association between income and unemployment, which cannot assume direction or a causal nature. A prospective cohort study that includes a follow-up of family income and change of employment status is needed.

We found that specific clinical characteristics can identify patients whose caregivers are more prone to reduced employment. ECOG PS was highly correlated with physical function (Smith et al., 2012) and is the main correlate of not working (Phipps et al., 2011; Gomes et al., 2012; Pantilat et al., 2012). Poor ECOG PS of a patient would become a greater stressor for the caregiver (Tordoff et al., 2012) and family caregivers of terminal cancer patients who had poor ECOG PS scores were likely to need more assistance with patients dependent on care for activities of daily living or IADL including help with transportation, shopping, homemaking, emotional support, nutritional care, nursing care, and personal care (Baker et al., 2011; Chochinov et al., 2011; Cohen et al., 2012; Fairfield et al., 2012; Gomes et al., 2012; Pantilat et al., 2012; Tordoff et al., 2012).

This study had several limitations. First was possible selection bias. However, we could verify that there seemed to be no systematic differences between participants and subjects who did not participate. Because the study sample was drawn from 11 hospitals and the National Cancer Center, Korea, while the control sample was drawn from 15 geographic districts, the health care market might be different for each group (Phipps et al., 2011). We corrected for the different distributions of sociodemographic characteristics between the two groups by propensity score adjustment. We found no differences in variables between the two groups after adjustment. That allowed for better control than was evident in studies that matched groups one-to-one for only a few characteristics such as age and gender (Dybicz et al., 2011). Second, we do not investigate caregiving time, caregiving duration, and reduced working hours. Thus we were unable to confirm that changed employment status was because of the time required for caregiving. However, caregiving time might be closely related to the relationship with the patient, living together as a family, and patient health status. We included these variables in our study. Third, this study analyzed employment status with baseline characteristics. Therefore our results did not explain the causal relationship between variables in our study and employment status. A future study will need to make these consequences clear.

In spite of the preceding limitations, we found that when compared to the general population, family caregivers of terminal cancer patients have work problems such as not working and severe work- and housework-related difficulty, probably due to easy fatigue and caregiving itself. We need to develop supportive programs for reducing the work-related burden of caregivers of terminal cancer patients.

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References

Baker JN, Harper J, Kane JR, et al (2011). Implementation and evaluation of an automated patient death notification policy at a tertiary pediatric oncology referral center. *J Pain Symptom Manage*, **42**, 652-6.

- Bukki J, Klein J, But L, et al (2011). Methicillin-resistant Staphylococcus aureus (MRSA) management in palliative care units and hospices in Germany: a nationwide survey on patient isolation policies and quality of life. *Palliat Med.*
- Chochinov HM, Kristjanson LJ, Breitbart W, et al (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*, 12, 753-62.
- Cohen LW, van der Steen JT, Reed D, et al (2012). Family perceptions of end-of-life care for long-term care residents with dementia: differences between the United States and the Netherlands. *J Am Geriatr Soc*, **60**, 316-22.
- Duclos A, Peix JL, Colin C, et al (2012). Influence of experience on performance of individual surgeons in thyearoid surgery: prospective cross sectional multicentre study. BMJ, 344, d8041.
- Dybicz SB, Thompson S, Molotsky S, et al (2011). Prevalence of diabetes and the burden of comorbid conditions among elderly nursing home residents. *Am J Geriatr Pharmacother*, **9**, 212-23.
- Fairfield KM, Murray KM, Wierman HR, et al (2012). Disparities in hospice care among older women dying with ovarian cancer. *Gynecol Oncol*, **125**, 14-8.
- Flannelly KJ, Emanuel LL, Handzo GF, et al (2012). A national study of chaplaincy services and end-of-life outcomes. BMC Palliat Care, 11, 10.
- Gomes B, Calanzani N, Higginson IJ (2012). Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliat Med*, 26, 102-7.
- Herr K, Titler M, Fine PG, et al (2012). The Effect of a Translating Research into Practice (TRIP)-Cancer Intervention on Cancer Pain Management in Older Adults in Hospice. *Pain Med*.
- Kimman M, Norman R, Jan S, et al (2012). The burden of cancer in member countries of the Association of Southeast Asian Nations (ASEAN). Asian Pac J Cancer Prev, 13, 411-20.
- Knapp C, Quinn G, Bower B, et al (2011). Posthumous reproduction and palliative care. J Palliat Med, 14, 895-8.
- Knapp CA, Madden V, Wang H, et al (2011). Pediatric nurses' attitudes toward hospice and pediatric palliative care. Pediatr Nurs, 37, 121-6.
- O'Connor NR, Kumar P (2012). Conservative management of end-stage renal disease without dialysis: a systematic review. *J Palliat Med*, **15**, 228-35.
- Pantilat SZ, Kerr KM, Billings JA, et al (2012). Characteristics of palliative care consultation services in California hospitals. *J Palliat Med*, **15**, 555-60.
- Phipps MS, Desai RA, Wira C, et al (2011). Epidemiology and outcomes of fever burden among patients with acute ischemic stroke. *Stroke*, **42**, 3357-62.
- Shahmoradi N, Kandiah M, Peng LS (2009). Impact of nutritional status on the quality of life of advanced cancer patients in hospice home care. Asian Pac J Cancer Prev, 10, 1003-09.
- Smith TA, Davidson PM, Lam LT, et al (2012). The use of non-invasive ventilation for the relief of dyspnoea in exacerbations of chronic obstructive pulmonary disease; a systematic review. *Respirology*, **17**, 300-7.
- Stiel S, Pastrana T, Balzer C, et al (2012). Outcome assessment instruments in palliative and hospice care-a review of the literature. *Support Care Cancer*.
- Tordoff J, Chang SY, Norris PT (2012). Community pharmacists' perceptions of services that benefit older

people in New Zealand. Int J Clin Pharm, 34, 342-50.

Unroe KT, Greiner MA, Johnson KS, et al (2012). Racial differences in hospice use and patterns of care after enrollment in hospice among Medicare beneficiaries with heart failure. Am Heart J, 163, 987-93 e3.

von Gunten CF (2012). Evolution and effectiveness of palliative care. Am J Geriatr Psychiatry, 20, 291-7.