

## RESEARCH ARTICLE

# Burdens, Needs and Satisfaction of Terminal Cancer Patients and their Caregivers

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### Abstract

**Objectives:** Terminal cancer patients and their caregivers often experience traumatic stress and need many types of assistance. In the present study we interviewed terminally ill cancer patients and caregivers to determine how much burden they experienced and to find out what factors are most important for satisfaction. **Design:** We constructed a questionnaire including overall care burden and needs experienced, and administered it to 659 terminal cancer patients and 659 important caregivers at 11 university hospitals and 1 national cancer center in Korea. **Results:** Finally, 481 terminal cancer patients and 381 caregivers completed the questionnaire. Care burden was not insubstantial in both and the caregiver group felt more burden than the patient group ( $P < 0.001$ ). While the patient group needed financial support most (39.0%), the caregiver group placed greatest emphasis on discussion about further treatment plans (44.8%). Stepwise multiple logistic regression analyses showed that in the patient group, patient's health status (OR, 2.03; 95% CI, 1.16-3.56) and burden (OR, 2.82; 95% CI, 1.76-4.50) influenced satisfaction about overall care, while in the caregiver group, high education level (OR, 1.84; 95% CI, 1.76-4.50), burden (OR, 2.94; 95% CI, 1.75-4.93) and good family function (OR, 1.94; 95% CI, 1.24-3.04) were important. **Conclusions:** Our study showed that burden was great in both terminal cancer patients and their caregivers and was perceived to be more severe by caregivers. Our study also showed that burden was the factor most predicting satisfaction about overall care in both groups.

**Key words:** Burden of terminal illness - caregivers - cancer patients - financial support - treatment plans

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### Introduction

Serious illness has an adverse effect on patients, family, and friends (Cora et al., 2012). Terminal cancer patients suffer from multidimensional experience related to physical symptoms, psychological distress, existential concerns, and social-relational worries (Snowdon et al., 2010; Ugur and Fadiloglu, 2010). They require assistance, including home nursing care, help with transportation, homemaking services, and personal care; that the families of terminal cancer patients take on substantial burdens in caring for them (Yang et al., 2004; Dy et al., 2011; Kimman et al., 2012). In one study, 5% of caregivers had quit their job or declined advancement, and a large proportion lost work hours or used special

leave or holidays to fulfill their caregiving responsibilities (Xian et al., 2011). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) reported that families of seriously ill patients experienced substantial economic losses. In 20% of families, a family member had to stop working; 31% of families lost most of their savings (Abernethy et al., 2011).

Terminal cancer patients need various support about symptom control, occupational functioning, emotional support, information, financial support, and so on (Smith and Hillner, 2010; Wang and Guo, 2012). And caregivers of terminal cancer patients need higher levels of available support for the patient, too (McLaughlin et al., 2011). However, there are few studies which compared

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supports terminal cancer patients and their caregivers respectively needed. And there are few studies which compared burden the two groups had, too. In this study, we investigated burden and need of terminal cancer patients and their caregivers and those differences, which is important for caregivers have critical role in palliative care (Bekelman et al., 2011).

It appears that there is still a considerable way to go before all patients dying of cancer receive the best quality of palliative care, according to their needs (Kallen et al., 2012). Satisfaction with services provided for people in their last year of life is useful to examine quality of palliative care, and clarifying factors influencing satisfaction is useful for increasing quality of palliative care.

The primary purpose of this study was to describe how much burden terminal cancer patients and their caregivers had experienced and what support they most needed and those differences. Burden in this study was defined as the situation in which an individual or his/her family member experiences trouble from medical care, nursing, finance, and psychological stress. We also sought to identify the correlates with the satisfaction of terminal cancer patients and their caregivers.

## Materials and Methods

### *Participants and procedures*

The Study to Understand Risks, Priority and Issues at End-of-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. Details of the study design have been published previously.

In the SURPRISE, patients were eligible to participate if they were aged 18 years or older, diagnosed as terminal at an outpatient clinic, or inpatient room, capable of filling out questionnaires or communicating with an interviewer, and 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 the physicians' judgment, was refractory to conventional anticancer therapy (surgery, radiotherapy, chemotherapy, or hormone therapy) and who was likely to die within months. The patients were asked to identify their primary family caregiver, defined as the relative who provided them with the most assistance. The family caregivers were invited to participate in the study but were ineligible if they were not well enough to fill out questionnaires, not able to communicate with an interviewer, or not able to understand the intent of this study well enough to provide informed consent. They were given information explaining the study and asked to participate. All patients and caregivers provided informed consent to participate in this study, and our institutional review boards approved

the protocol.

The SURPRISE collected demographic data for the patients and the caregivers and clinical information [primary cancer site, date of diagnosis, presence of metastases, basis of terminal status, and Eastern Cooperative Oncology Group performance status (ECOG PS)] for the patients. We administered the questionnaires in person at an outpatient clinic or inpatient room, to both group at the same time within days of diagnosis of terminal cancer. Both groups were followed for 2 months by mail, and the family caregivers were interviewed by telephone about 3 months after the patient died.

### *Materials*

The SURPRISE constructed one questionnaire for both groups to examine their emotional responses to, and attitudes toward, disclosure of the terminal diagnosis. Questions covered the following topics: awareness that the illness was terminal, how the awareness was acquired, feelings upon learning the diagnosis, and attitudes toward disclosure of the terminal status. The questionnaire of the SURPRISE also (1) gathered demographic information (age, sex, relationship of caregiver to patient, level of education, income, and religiousness), (2) included the Quality Care Questionnaire-End of Life (QCQ-EOL) (3) evaluated care burden and care needs, and (5) overall satisfaction with care. The patient and family caregiver questionnaires were similar. We administered the questionnaires to both group at the same time within days of diagnosis of terminal cancer, one month, and two months after the diagnosis of terminal cancer, and we followed-up patients' death through the procedure. We interviewed caregivers by telephone about 3 months post-bereavement.

### *Data analysis*

The primary outcome was burden of terminal cancer patients and their caregivers when the satisfaction about overall care was the dependent variable. We used chi-square test to determine significant differences in dependent and independent variables between the patient and family groups. To evaluate the strength of agreement of burden, need, and satisfaction between the two groups, we used the Spearman correlation coefficient. We used univariate logistic regression analysis to estimate the odds ratio (OR) for each independent variable (The OR is the extent to which being a member of a specific group increased or decreased the probability of agreeing with the model of satisfaction about overall care).

We dichotomized the score distributions of all the SURPRISE questionnaire items based on distribution of each items. We used indicator variables for independent variables that were categorical. In addition, for factors significantly associated in univariate analysis, we performed multivariable logistic regression analysis with stepwise selection for each dependent variable to assess which of the independent variables best predicted satisfaction about overall care of terminal cancer. We

set the significance level at  $P < 0.05$  and used the SAS statistical package, version 9.1.

## Results

### Sample characteristics

481 of the patients and 381 of the caregivers completed the questionnaire with informed consent. The most common reasons given for non-participation were a lack of time and poor eye-sight. Table 1 gives the subject characteristics. The patient group consisted of more men ( $P < 0.001$ ), was older ( $P < 0.001$ ), had a lower education level ( $P < 0.001$ ), and had fewer present job ( $P < 0.001$ ) than the caregiver group.

### Difference in burden felt between terminal cancer

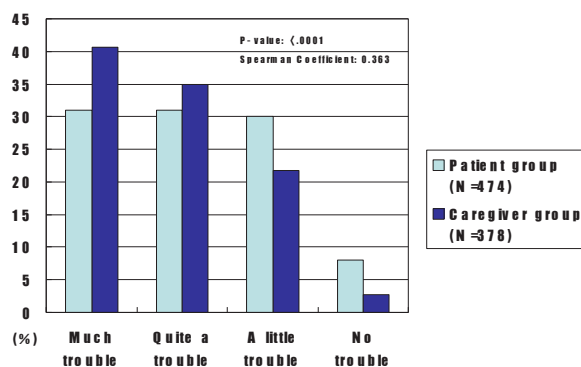
**Patients and Their Caregivers** The caregiver group felt more burden than the patient group ( $P < 0.001$ ). (Figure 1) The questionnaire of burden was composed of 4 point scale (much trouble, quite a trouble, a little trouble, and no trouble) and the caregiver group was more than the patient group to choose much trouble (40.7% vs. 31.0%) and quite a trouble (34.9% vs. 31.0%). Response pattern of the two groups were not strongly correlative (Spearman Coefficient: 0.363) and corresponding (Kappa Coefficient: 0.282).

### Difference of needs in between terminal cancer patients and their caregivers

The patient group needed financial support most (39.0%) and the caregiver group needed discussion about further treatment plan most (44.8%) (Figure 2). The patient group needed financial support to a greater extent than the caregiver group (39.0% vs. 36.2%), and the caregiver group needed discussion about further treatment more than did the patient group (44.8% vs. 38.3%). Response patterns of the two groups weakly corresponded with one another (Kappa Coefficient: 0.328).

### Difference of satisfaction that terminal cancer patients and their caregivers felt toward overall care

The patient group and the caregiver group were satisfactory with overall treatment not differently



**Figure 1. The Percentage of Subjects that Answered: How much Trouble Are You Experiencing Now?**

( $P = 0.816$ ) (Figure 3). The questionnaire of satisfaction was composed of 6 point scale (much satisfactory, satisfactory, so so, unsatisfactory on the whole, unsatisfactory, and much unsatisfactory) and each distribution of response of the two groups were nearly similar. Response pattern of the two groups were intermediately correlative (Spearman Coefficient: 0.417) and corresponding (Kappa Coefficient: 0.433).

### Univariate logistic regression analyses of factors related to satisfaction about overall care

In the patient group, patient's health status, burden, family apgar were likely to influence satisfaction about overall care, while in caregiver group, marital status, education level, present job, burden, family apgar were likely to influence satisfaction about overall care.

**Table 1. Characteristics of Study Subjects**

Characteristic	Patient Group (n=481)		Caregiver Group (n=381)	
	No.	%	No.	%
Sex				
Male	273	56.9	127	33.3
Female	207	43.1	254	66.7 <sup>†</sup>
Mean Age (yr)±SD	57.2±11.7		46.8±13.5*	
Education				
Did not complete college	396	82.3	351	73
Completed college	85	17.7	130	27.0 <sup>†</sup>
Religiousness				
Religious	334	69.4	252	67.4
Nonreligious	147	30.6	122	32.6
Marriage status				
Married	360	75.8	306	80.5
Unmarried	115	24.2	74	19.5
Job before cancer diagnosis				
Employed	263	56.1	212	56.1
Not employed	206	43.9	166	43.9
Present job				
Employed	46	10.2	133	36.3
Not employed	404	89.8	233	63.7 <sup>†</sup>
ECOG PS				
0~2	286	59.5		
3~4	195	40.5		
Primary cancer				
GI cancer	188	39.2		
Others	291	60.8		
Metastasis				
Yes	428	90.1		
No	47	9.9		
Cause to be determined as terminal				
Unresponse to chemotherapy	269	56		
General prostration	142	29.6		
Side effect of chemotherapy	3	0.6		
Denial of further chemotherapy	65	13.5		
Others	1	0.2		
Relationship to patient				
Spouse			194	50.9
Child or daughter in law			136	35.7
Others			51	13.4

SD, Standard Deviation; ECOG PS, Eastern Cooperative Oncology Group performance status; \*Comparison between patient group and caregiver group (using t-test for mean or  $\chi^2$  test for other variables); P was derived by the chi-square test ( $\dagger < 0.001$ )

**Table 2. Odds Ratios and 95% CIs from Univariate Logistic Regression Analysis Predicting Satisfaction about Overall Care**

			N	%*	OR	95% CI	N	%*	OR	95% CI
Characteristics	Gender	Male	260	50.4	1.33	0.92 1.93	125	39.2	1.00	
		Female	199	43.2	1.00		249	49	1.49	0.96 2.31
	Age groups (yrs)	20-59	243	47.7	1.04	0.72 1.5	299	43.5	1.00	
		60-79	216	46.8	1.00		75	54.7	1.57	0.94 2.61
	Marital status	Married	344	46.5	1.00		299	48.8	1.99	1.16 3.4
		Unmarried	112	49.1	1.11	0.72 1.7	74	32.4	1.00	
	Education	Did not completed college	378	45.2	1.00		245	50.6	1.79	1.15 2.77
		Completed college	81	56.8	1.59	0.98 2.58	129	36.4	1.00	
	Job before cancer diagnosis	Employed	261	50.6	1.36	0.94 1.97	212	45.3	1.00	
		Not employed	198	42.9	1.00		162	46.3	1.04	0.69 1.57
	Present job	Employed	70	37.1	1.00		148	36.5	1	
		Not employed	389	49.1	1.63	0.97 2.76	226	51.8	1.87	1.22 2.86
	Religion	Religious	318	49.4	1.32	0.88 1.96	254	46.9	1.15	0.75 1.79
		Nonreligious	141	42.6	1.00		120	43.3	1.00	
	Family's total income	Below \$2,000	208	49	1.28	0.83 1.96	215	44.7	1.00	0.66 1.53
		Above \$2,000	142	43	1.00		148	44.6	1.00	
	Who pay the cost for treatment	Patient	101	46.5	1.02	0.64 1.62	104	45.2	1.00	
		Others	256	46.1	1.00		266	45.9	1.03	0.65 1.62
	Insurance type	Medical insurance	277	45.9	1.00		286	45.5	1.00	
		Sort of medicaid	81	46.9	1.04	0.64 1.72	85	45.9	1.02	0.63 1.65
	ECOG PS	0~2	268	45.5	1.18	0.82 1.72	214	44.4	1.00	
		3~4	191	49.7	1.00		160	47.5	1.13	0.75 1.71
	Primary cancer	GI cancer	180	47.8	1.04	0.72 1.52	146	43.8	1.00	
		Others	278	46.8	1		227	47.1	1.14	0.75 1.74
	Metastasis	Yes	408	46.3	1		338	45.6	1	
		No	46	58.7	1.65	0.89 3.06	32	50	1.2	0.58 2.47
	Cause to be determined as terminal	Unresponse to chemotherapy	256	44.9	1		210	42.9	1	
		Others	203	50.3	1.38	0.89 2.15	163	49.7	1.32	0.87 1.99
Health	Patient's health status	Good	97	61.9	2.09	1.32 3.31	75	49.3	1.16	0.7 1.93
		Poor	357	43.7	1		292	45.6	1	
	Awareness of patient's present status	Aware	267	44.9	1		312	46.2	1.11	0.64 1.92
		Not aware	190	51.1	1.28	0.88 1.86	62	43.6	1	
Burden	Burden	Experience much trouble	286	40.2	1		280	38.9	1	
		Not experience much trouble	168	60.1	2.24	1.52 3.31	92	66.3	3.09	1.88 5.06
Need	Discussion about treatment plan	Yes	170	45.9	1		166	43.4	1	
		No	277	48.7	1.12	0.77 1.64	198	48.5	1.23	0.81 1.86
	Financial support	Yes	173	48.6	1.06	0.73 1.55	130	46.2	1	0.65 1.54
		No	274	47.1	1		234	46.2	1	
	Psychological support	Yes	58	44.8	1		46	52.2	1.32	0.71 2.45
		No	389	48.1	1.14	0.65 1.98	318	45.3	1	
	Religious support	Yes	13	38.5	1		12	50	1.17	0.37 3.71
		No	434	47.9	1.47	0.47 4.57	352	46	1	
Family Function	Family APGAR†	Good	151	53.6	1.7	1.1 2.61	156	55.1	2.03	1.33 3.11
		Poor	190	40.5	1		199	37.7	1	

ECOG PS, Eastern Cooperative Oncology Group performance status; OR, Odds Ratio; CI, Confidential Interval; Burden in this study was defined as the situation in which an individual or his/her family member experiences trouble from medical care, attendance, economics, and psychological stress; \*%: percentage of people who replied they are satisfactory with overall treatment and 'so so' was regarded as unsatisfactory; †Family APGAR is a validated scale of family function based on adaptability, partnership, growth, affection, and resolution

*Stepwise multiple logistic regression analyses*

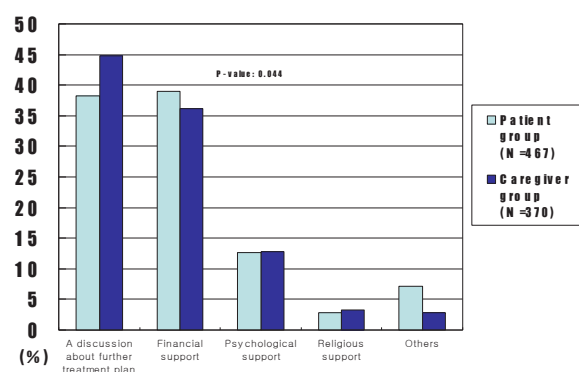
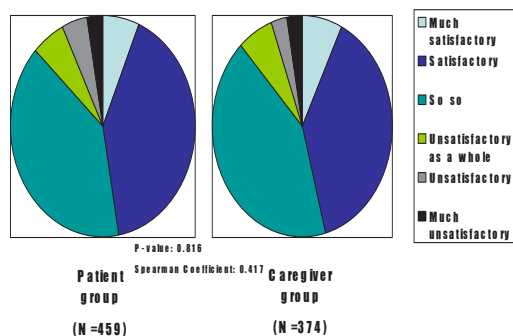
In stepwise multiple logistic regression analyses, we excluded factors that were not associated in univariate analysis with attitude satisfaction about overall care. In the patient group, burden was the strongest factor predicting satisfaction about overall care (OR, 2.82;

95%CI, 1.76-4.50) and patient's good health status was the next factor predicting satisfaction about overall care (OR, 2.03; 95%CI, 1.16-3.56). The patients who experienced much trouble were less satisfactory than the patients who did not experienced much trouble. In the caregiver group, burden was the factor most predicting

**Table 3. Stepwise Multiple Logistic Regression Analysis: Predicting Satisfaction about Overall Care**

Characteristics		Patient group			Caregiver group			
		OR	95% CI		OR	95% CI		
Marrige status	Married				NA			
	Unmarried				1.00			
	Education	Under completed college				1.84	1.14	2.95
		Completed college				1.00		
Present job	Employed				1.00			
	Not employed				NA			
Health	Patient's health status	Good	2.03	1.16	3.56			
		Poor	1.00					
Burden	Burden	Experience much trouble	1.00			1.00		
		Not experience much trouble	2.82	1.76	4.5	2.94	1.75	4.93
Family function	Family APGAR*	Good	1.00			1.94	1.24	3.04
		Poor	NA			1.00		

OR, Odds Ratio; CI, Confidential Interval; Burden in this study was defined as the situation in which an individual or his/her family member experiences trouble from medical care, attendance, economics, and psychological stress; \*Family APGAR is a validated scale of family function based on adaptability, partnership, growth, affection, and resolution

**Figure 2. The Percentage of Subjects that Answered: What Help Do You Need?****Figure 3. The Percentage of Subjects that Answered: How Much Are You Satisfied with Overall Care?**

satisfaction about overall care (OR, 2.94; 95%CI, 1.75-4.93). And good family relationship (OR, 1.94; 95%CI, 1.24-3.04), and low level of education (OR, 1.84; 95%CI, 1.14-2.95) were factors significantly predicting satisfaction about overall care, too.

## Discussion

There were two key findings in this study: 1) the caregiver group felt more burden than the patient group ( $P < 0.001$ ); 2) burden was the factor most predicting satisfaction about overall care in both the patient group

and the caregiver group.

There were some studies about burden of caregivers of terminally ill patients (Bekelman et al., 2011; Nelson et al., 2011; Rittenberger et al., 2011; Xian et al., 2011). However, to our knowledge, there had been few studies to compare burden of terminal cancer patients and their caregivers.

In our study, a number of terminal cancer patients and their caregivers replied that they experienced much trouble and the caregiver group felt burden more than the patient group (Figure 1). Because terminal cancer patients are on the verge of death and frequently suffer from various symptoms like pain or fatigue (physical), (Casadio et al., 2010; Minnock et al., 2010; Smith and Hillner, 2010) it might be natural that they feel burden more than their caregivers. However, in our study, the caregiver group experienced burden more than the patient group. This result suggests that care burden might be more serious than disease burden in palliative care. Our finding is consistent with a previous study in which caregiver's psychological morbidity was equal to or greater than the patient's (Xian et al., 2011). In another previous study, almost 40% of the spouse caregivers reported depressive symptoms in a range that was likely to be clinically significant, a prevalence that was almost two-fold than their ill partners (Rittenberger et al., 2011). Previous studies have demonstrated that caregivers of patients with cancer have increased health problems and psychosocial stress (Bergen-Jackson et al., 2009; Kiely et al., 2010; Zhou et al., 2010; Bell et al., 2011; Gilbertson-White et al., 2011; Legler et al., 2011; Stevens et al., 2011). Therefore, in palliative care, care burden could have a bad impact on caregivers.

From a different standpoint, as terminal cancer patients usually feel themselves a burden to others (Konski et al., 2011; Chhabra et al., 2012), they might have underestimated their burden due to feeling sorry to their caregivers. In our study, terminal cancer patients needed financial support more than their caregivers and this suggests that patients might have felt sorry to their caregivers (Figure 2). In order to analyze the precise



reason that the caregiver group felt burden more than the patient group, further study will be needed.

In our study, the patient group needed financial support more than the caregiver group and the caregiver group needed discussion about further treatment plan more than the patient group. This result corresponded with a previous study, in which the caregiver required more detailed information than the patient about the dying process (Zeppetella et al., 2010).

In a previous study, unmet needs of patient and caregiver was the independent predictor of satisfaction (Rheims et al., 2011). However, in our study, need was not correlated with satisfaction in both the patient group and the caregiver group. It might be due to our classification of unmet need which was composed of just 4 items or due to interview method of our study that we requested participants to choose only 1 item which they thought most needed. Terminal cancer patients and their caregivers frequently need available support. In one study, caregivers and patients with advanced cancer consistently needed much available support for the patient but unmet needs were high, and this was associated with high level of caregiver burden (McLaughlin et al., 2011). Other study showed that nearly two-thirds of 614 cancer patients reported experiencing at least 1 unmet psychosocial need, particularly emotional, physical, and treatment-related needs (Sekeris et al., 2011).

In previous studies, patient perspectives on quality end-of-life care were influenced by physical and emotional symptoms, psychosocial elements, spiritual wellbeing, a sense of autonomy, and the strength of relationships (Capewell et al., 2010; Angelo et al., 2011; Loiselle and Sterling, 2012). In our study, patient's satisfaction on quality end-of-life care was influenced by physical symptoms (patient's health status), patient's burden, and the strength of relationship of family members. In multivariate analysis, burden was the strongest factor predicting attitude toward satisfaction about overall care in both the patient group and the caregiver group. In a previous study, caregiver burden was the most important predictor of both caregiver anxiety and depression (Xian et al., 2011). Economic burdens of terminal cancer patients could induce patient or caregiver to sell assets, take out a loan, or take an additional job and other burdens of terminal cancer patients induce them to consider euthanasia or physician-assisted suicide (Cora et al., 2012). Therefore, in order to increase well-being of terminal cancer patients and their caregiver, health care providers of palliative care unit should understand and be more concerned about burden of terminal cancer patients and their caregivers.

Our study has some limitations. First, the participants might not represent the general population of terminally ill patients and their family caregivers. Our study dealt with hospital outpatients and inpatients, but home-bound patients may be unaware of their prognosis or have different attitudes toward disclosure. And we can't exclude the possibility of selection bias introduced

by eliminating patients who elected to get more chemotherapy. Our large multicenter-based setting and high participation rate, however, should have minimized selection bias.

Second, because the questionnaire was not anonymous, we cannot exclude the possibility that patients answered according to family expectations, leading to an underestimation of the problems regarding disclosure of terminal illness. We minimized that risk, however, by not allowing patients and family caregivers to share information about their experiences or their attitudes about disclosure during completion of the questionnaire.

Third, we did not gather information about subscales of burden like finances, esteem, and schedules. Instead, we used a question 'How much trouble are you experiencing now?' for measuring burden of both terminal cancer patients and their caregivers. Because we intended to compare burden of terminal cancer patients and burden of their caregivers, we were not able to use previous developed instruments to measure burden of caregivers like 'The Caregiver Reaction Assessment' (Choi et al., 2012). Subscales of patient's burden and caregiver's may be different. So we chose the single question which was somewhat comprehensive in order to compare both of them. And the results of our study remind health care professionals of importance of a viewpoint that caregiver's burden is very serious in terminal cancer care and caregiver as well as terminal cancer patient should be cared in order to increase quality of terminal cancer care.

In summary, our study showed that burden was much in terminal cancer patients and their caregivers and burden of caregiver was especially important. And our study also showed that burden was the factor most predicting satisfaction about overall care of terminal cancer in both the patient group and the caregiver group.

Difference of burden and need in between terminal cancer patients and their caregivers shows that not only terminal cancer patients but also their caregivers are vulnerable and need concern from health care professionals. And additional studies including multiple aspects of burdens in terminal cancer patients and their caregivers, will be needed to strengthen our results.

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