

Caregiver burden, patients' self-perceived burden, and preference for palliative care among cancer patients and caregivers

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Abstract

Objective: Recently, caregiver burden (CB) has emerged as an important issue in the area of palliative medicine. However, patients' feelings related to being a burden to their families (i.e., self-perceived burden [SPB]) is also a significant issue. We evaluated the relation of CB and SPB as preference for palliative care.

Methods: A national, multicenter, cross-sectional survey of 326 patient–caregiver dyads was performed. A set of paired questionnaires evaluating CB and SPB (five domain items assessed on a four-point Likert scale) were independently administered to patients and their caregivers. Among the respondents, only the patients with distant stage cancer and their caregivers were included. Multivariate analyses were conducted to identify the associations between CB and SPB and preference for palliative care.

Results: Caregivers and patients who preferred palliative care to life sustaining treatment reported higher CB and SPB scores, respectively. Caregivers who felt more of a burden were more likely to prefer palliative care over life sustaining treatment for their patients (adjusted odds ratio [aOR] = 1.67, 95% CI: 1.21–2.31). In addition, patients who perceived their caregivers' burden as large tended to prefer palliative care (aOR = 1.61, 95% CI: 1.16–2.22).

Conclusions: Both CB and SPB increased preference for palliative care. This could be interpreted that high CB can lead to preference for palliative care in both patients and their caregivers, potentially threatening patient autonomy. Efforts to relieve CB and SPB are needed.

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Background

As the number of patients with chronic, life-limiting illnesses grows, family caregiver burden (CB) has emerged as an important issue in the area of palliative medicine [1,2]. A patient who has a disease such as cancer, stroke, or dementia, which all demand caregiver support, relies on family caregivers to assume the burdens for physical care, monitoring symptoms, and managing illness-related finances [3]. According to previous studies, caregivers experience increased strain, impaired mental and physical health, and a deteriorated quality of life because of CB [4]. Furthermore, these studies have suggested that the CB affects medical decisions, including the choice of

placement for end-of life (EOL) care [5] or patient institutionalization [6].

At the same time, patients also feel like they are a burden to their families [7], which is referred to as 'self-perceived burden' (SPB). SPB is 'a multidimensional construct arising from the care-recipient's feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt at being responsible for the caregiver's hardship' [8]. According to previous studies, SPB is a common and troubling concern for people who are nearing the end of their lives that impacts their quality of life and their medical choices [9,10], such as preference for the type of EOL care [11].

However, there are limited studies on CB and SPB and their association with medical decisions. Our study objective is to evaluate the association of CB and SPB with preference for palliative care over life-sustaining treatment (LST) using a patient–caregiver dyad survey.

Methods

Study population and data collection procedure

This study was a part of the Cancer Patient Experience study, which is an annual, nationwide survey of cancer patient experience in South Korea. In 2011, the study was conducted with patient–caregiver dyads in order to explore the disparate views of cancer patients and their family caregivers. The study, which was conducted at the National Cancer Center and all government-designated Regional Cancer Centers ($n=9$) in Korea, aimed to provide a large and representative sample.

Patients and their family caregivers were recruited by trained interviewers at outpatient clinic waiting areas or inpatient wards, and the interviewer explained the purpose and procedure of the survey. The inclusion criteria were patients: (1) older than 18 years, (2) that had a cancer diagnosis, (3) who were currently receiving cancer treatment or follow-up, and (4) who were in proper physical and mental condition to complete a questionnaire. Caregivers needed to be family members of the patients and older than 18 years to be included in the study.

We counted a patient–caregiver dyad when both the patient and the family member agreed to participate, and they provided informed consent separately. We approached 1,299 dyads, and 990 dyads (participation rate = 76.2%) agreed to participate. Among the respondents, we included only patients with distant stage cancer and their caregivers in the analyses because this condition is more relevant to the EOL care issue ($n=383$). If there were any unanswered items on the questionnaire, we excluded the dyad from the analyses ($n=57$). Most of the missing response occurred in the patients' response to the EOL decision ($n=32$), probably because of the patients' reluctance to hypothesize about such conditions. Consequently, 326 patient–caregiver dyads were included in the final analyses. This study was approved by the Institutional Review Board of the National Cancer Center, Korea.

After obtaining consent, the patients and family members were instructed to answer the survey in separate locations so that information was not shared and responses by one would not be influenced by the presence of the other. Clinical information, such as primary cancer diagnosis, epidemiology, and end results (SEER) stage, was retrieved from the hospital information systems of the participating centers.

Measures

For this study, we developed a set of paired questionnaires that examined preferences for either type of EOL care—palliative care or LST. Caregivers were asked to provide

their preference for the type of EOL care that should be provided for their patients. Similarly, patients were asked about their preference on this issue.

To examine CB and SPB, a paired set of questions were administered to the dyads. The caregivers were asked how much they had suffered from each of the five burden domains over the previous month: physical, emotional, social, financial, and daily life. We quoted burden domains from the Caregiver Burden Inventory developed by Novak [12,13], but changed the 'developmental' domain to a 'financial problem' domain in order to investigate a more practical situation for this population. The patients were also asked to score how much they thought their caregivers had suffered in the area of each domain during the previous month. Each domain was composed of a single-item question, and the respondents scored the level of burden in each domain using a four-point Likert scale (responses were 'not at all', 'a little', 'moderate', and 'much'). Details regarding each questionnaire and response choices are provided in Appendix 1. A pilot study was conducted with 30 cancer patients and their caregivers. We constructed scale scores for CB and SPB by calculating the mean of the five domains, as the domain scores of each scale were highly correlated. Cronbach's alphas for the CB and SPB scales were 0.88 and 0.90, respectively. Therefore, the scale scores could be regarded as overall burden perception.

Also, the survey questionnaire included EORTC QLQ-C30. It incorporates nine multi-item scales: five scales for physical, role, cognitive, emotional, and social functioning, three symptom scales and a scale for quality of life. Among the items, we included scales for physical functioning and overall quality of life in this study. The questionnaire also included questions assessing socio-demographic and medical information and how many years the caregiver had cared the patient.

Statistical analyses

We calculated the mean CB and SPB scores for each burden domain by EOL care preference, adjusted for patients' and caregivers' age, sex, education, income, years of caring, caregiver's relationship to patients, patients' physical functioning, and quality of life. The association between CB and SPB scores and preference for palliative care was examined by a series of multivariate logistic regression models adjusting for the same confounders. STATA software (ver. 13.0; STATA Corp., Houston, TX, USA) was used for all statistical analyses. The p -values of <0.05 were considered statistically significant.

Results

Study population characteristics

A total of 326 patient–caregiver dyads were included (Table 1). The mean age of the patients and caregivers was 58.9 and 50.3 years, respectively. Half of the patients

Caregiver burden and preference for palliative care

Table 1. Characteristics of the 326 patient–caregiver dyads.

	Patients (n = 326)		Caregivers (n = 326)	
	n	%	n	%
Age, mean (SD)	58.9 (12.6)		50.3 (14.7)	
Sex				
Male	166	50.9	104	31.9
Female	160	49.1	222	68.1
Education level				
Less than high school (<9 years)	147	45.1	101	31.0
High school and above (≥9 years)	179	54.9	225	69.0
Monthly income				
<two million KRW	205	62.9	181	55.5
≥two million KRW	121	37.1	145	44.5
End-of-life preference				
Palliative care	253	77.6	207	63.5
Life-sustaining treatment	73	22.4	119	36.5
Cancer type				
Gastric	40	12.3		
Lung	50	15.3		
Liver	12	3.7		
Colorectal	54	16.6		
Breast	43	13.2		
Uterine	21	6.4		
Others	106	32.5		
Patient–caregiver relation				
Spouse			186	57.1
Children			62	19.0
Daughter/son-in-law			12	3.7
Parent			48	14.7
Sibling			14	4.3
Others			4	1.2

Note. 'KRW' refers to Korean Won (1 USD = approximately 1,100 KRW as of the year 2011).

were women (49.1%), and caregivers were primarily women (68.1%). Caregivers had higher education (high school and above: 69.0% vs. 54.9%, respectively) and monthly income levels (≥two million KRW: 44.5% vs. 37.1%, respectively) than patients. Regarding preference for type of EOL care, 63.5% of caregivers and 77.6% of patients preferred palliative care to LST.

Table 2. Association between caregiver burden and caregivers' preference for palliative care.

	Caregivers' end-of-life care preference			Odds ratios of choosing palliative care per one point increase in burden scores
	Palliative care (n = 207)	Life-sustaining treatment (n = 119)	p-value	
	Adjusted mean* (SE)	Adjusted mean* (SE)		
Scale score	2.44 (0.05)	2.16 (0.07)	0.002	1.67 (1.21–2.31)
Domain score				
Physical burden	2.35 (0.06)	2.23 (0.08)	0.272	1.16 (0.90–1.51)
Emotional burden	2.36 (0.06)	2.10 (0.09)	0.016	1.39 (1.07–1.81)
Social burden	2.42 (0.07)	2.03 (0.09)	0.001	1.57 (1.21–2.04)
Financial burden	2.55 (0.07)	2.27 (0.10)	0.025	1.31 (1.04–1.65)
Daily life burden	2.53 (0.07)	2.19 (0.09)	0.002	1.50 (1.16–1.94)

Note. 'SE' refers to standard error and 'CI' refers to confidence interval.

*Each analysis was adjusted for caregivers' age, sex, education, income, years of caring, relationship to patients, and the patients' age and sex, overall quality of life, and physical functioning.

The association between caregiver burden and end-of-life care preference

For caregivers, the adjusted mean scale scores for each domain were significantly higher for those who preferred palliative care than for those who preferred LST, except for the physical burden domain. The likelihood of a caregiver preferring palliative care increased as the CB score increased (aOR 1.67, 95% CI: 1.21–2.31 for the scale score). This tendency was present in all burden domains except for the physical burden domain (Table 2).

The association between self-perceived burden and end-of-life care preference

Similar to the caregivers, for patients, the adjusted mean scores of scale and each domain were higher in palliative care preference group than in LST preference group. The likelihood of a patient preferring palliative care increased as the SPB score increased (adjusted odds ratio [aOR]: 1.61, 95% CI: 1.16–2.22 for the scale score). This tendency was present for each burden domain except for the financial burden domain (Table 3).

Discussion

To our knowledge, this is the first study to investigate the potential impact of CB and patients' SPB on preference for the type of EOL care with a dyadic approach. By investigating the patient–caregiver dyad at the same time, we were able to compare the patients' and caregivers' perspectives on EOL preference within their relationships. In addition, strengths of this study include use of nationwide representative data and a large sample size.

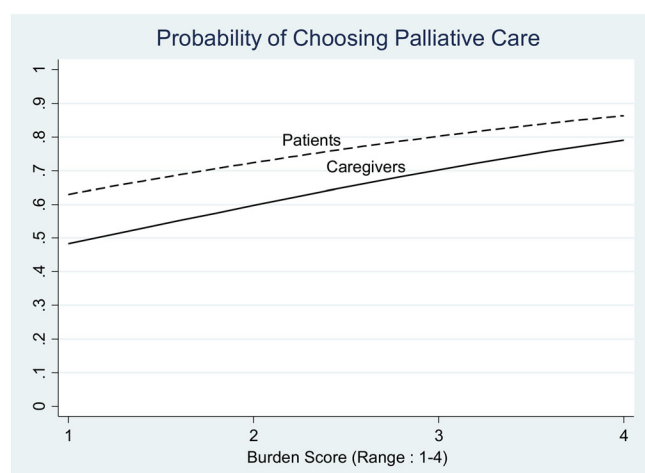
The present study showed that patients and caregivers who preferred palliative care to LST reported higher CB and SPB scores. In addition, as the CB and SPB scores increased, the likelihood of preferring palliative care to LST also increased (Figure 1).

Table 3. Association between patients' self-perceived burden and preference for palliative care.

	Patients' end-of-life care preference		P-value	Odds ratios of choosing palliative care per one point increase in burden scores
	Palliative care (n = 253)	Life sustaining treatment (n = 73)		
	Adjusted mean* (SE)	Adjusted mean* (SE)		
Scale score	2.78 (0.05)	2.44 (0.10)	0.004	1.61 (1.16–2.22)
Domain score				
Physical burden	2.90 (0.06)	2.54 (0.12)	0.007	1.46 (1.11–1.94)
Emotional burden	2.79 (0.07)	2.29 (0.13)	0.001	1.58 (1.22–2.06)
Social burden	2.63 (0.07)	2.25 (0.13)	0.011	1.40 (1.08–1.82)
Financial burden	2.76 (0.07)	2.59 (0.13)	0.237	1.17 (0.91–1.52)
Daily life burden	2.83 (0.06)	2.54 (0.12)	0.032	1.35 (1.02–1.78)

Note. 'SE' refers to standard error and 'CI' refers to confidence interval.

*Each analysis was adjusted for patients' age, sex, education, income, years under care, overall quality of life, physical functioning, and caregiver relationship to patients.

**Figure 1.** Probability of choosing palliative care.

The caregivers who reported a higher sense of burden were more likely to prefer palliative care over LST. Generally, in palliative care, relief of physical symptoms and emotional support is provided for patients by a multidisciplinary team that includes nurses, social workers, and volunteers, thereby reducing the need for direct support from the family caregivers [14]. This is in contrast to the situation of maintaining LST, in which health care professionals generally focus only on medical treatment and all other care is placed on the family caregivers. Moreover, the cost of palliative care is generally lower than receiving LST [15]. Specifically, in Korea, palliative care programs are largely based on inpatient services [16]. Korean traditional value has been that families take total responsibility for elderly members [17]. In this situation, the lower cost and multidisciplinary support provided by inpatient palliative care services may be expected by caregivers to relieve their burden.

Similar findings were noted in some previous studies. Higher CB has been identified as one of the predictors of institutionalization of dementia patients [18] and nursing home admission [19]. While choice of palliative care can be advocated from social perspectives [20], one

concern illustrated by our findings is that a referral to palliative care may become a means of abandoning the patients. In Korea, where National Health Insurance exists, the patients with the lowest incomes are covered by a government-funded Medicaid program; these patients tend to be referred to palliative care facilities sooner than usual patients who are covered by the National Health Insurance [21]. Another study found that many of the Korean general public believe that EOL decisions should be made by family caregivers if there is a socioeconomic burden [22]. If the palliative-care-referral decision is made on the basis of the caregiver's expectation of a lowered burden, and not on the basis of the patient's dignity, there is a threat to patient autonomy and the decision can be considered as a sort of abandonment.

Therefore, efforts to relieve CB are needed in order to prevent palliative care referrals that are not wanted by the patients themselves. The efforts might include financial and psychological supporting programs. To reduce socioeconomic burden, supportive policies such as no-payment loans [23] or expanded coverage of cancer insurance programs [24] could be considered. Also, some interventional studies showed that educational programs providing information about the natural course and treatment process of the patient's disease and building support groups of caregivers to discuss caregiving problems lowered CB [25]. Such policies and support programs would help to relieve CB.

In our study, SPB affected patients' preferences for the type of EOL care in a similar fashion. For many patients, not being a burden to others is regarded as an important component for dignity [26] and good death [27,28]. In this regard, SPB may affect patients' medical decisions, including decisions for treatment, advance directives, and place to receive care, especially at their EOL [10,11,29]. Burdening others was ranked among the important reasons cited by patients for not wanting LST [11]. Especially in Asian cultures, which are widely influenced by Confucianism, bothering others ('Meiwaku' in Japanese [30]) is considered discourteous. In a qualitative study in Korea, the patients regarded palliative care referral as giving

up treatment for the caregivers [31]. In this context, patients who have higher SPB would choose palliative care to avoid further burdening their caregivers.

Similar concerns can be raised regarding autonomous patient decisions in situations in which patients' fear of being a burden and attempts to minimize the families' burden prevent them from receiving the care they want [32]. Previous studies with patients on long-term dialysis who decided to stop receiving treatment revealed that not wanting to be a burden to others was a major factor in their decisions [33]. In the same vein, approximately half (47%) of the US public has identified fear of being a burden on family members as a possible reason for hastening their own death [34]. Patients often overestimate the amount of burden their illness causes and may have such feelings even when there are appropriate supports [11,32].

Therefore, healthcare professionals should be aware of this concern and be prepared to reduce this sense of burden. Participation of the patient in advance care planning is considered to help the patient avoid placing undue responsibilities for decision making on loved ones, and could relieve the sense of SPB [35]. Also, arranging an opportunity for patients to be able to talk frankly with their families about their sense of being a burden would be helpful [36].

This study has some limitations. First, it is cross-sectional and, thus, caution should be used when interpreting the results. While we interpreted the results as indicating that CB and SPB influence palliative care preferences, it is also possible that those who prefer palliative care have a tendency to overestimate their CB or SPB. Second, we did not measure objective burden, which, although related to subjective burden, is a distinct concept. However, subjective burden is generally a more important and relevant concept than objective burden in the framework of the patient-caregiver relationships [37]. Third, although the five burden domains that we used for this research were modified from the Caregiver Burden Inventory, the validity of the modified tool was not formally tested. However, high Cronbach's alphas showed the reliability of our domains. Fourth, because many respondents were recruited at outpatient clinics, their physical status tended to be relatively good. Thus, their considerations about EOL preference could be quite

different from actual decisions that would be made when death is an imminent possibility. To reduce this limitation, we included patient-caregiver dyads with distant stage cancer. Finally, our study was conducted in Korea, and our results may not be generalizable to other cultures. CB and SPB and their influence on medical decisions in EOL situations is largely shaped by the healthcare system and cultural differences [11].

Conclusions

In summary, the results of our study suggest that both CB and SPB influence palliative care preferences. Caregivers might want to refer patients to palliative care facilities because of their burdens rather than for patients' comfort. Further, patients may choose palliative care in order to avoid burdening caregivers even though they want LST. This raises concerns that the patients' autonomy could not be protected when the caregivers have a higher burden or the patients perceive themselves as being a greater burden to their families. Therefore, to ensure that palliative care referral decisions are consistent with the patients' wishes, there should be an effort to relieve CB and SPB, such as supportive fiscal policies and support programs for caregivers. Healthcare professionals might be able to suggest advance care planning and encourage communication to relieve SPB.

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Conflict of interest

No author has potential conflict of interest, including financial interests or relationships.

Appendix 1. Matched questionnaires used in this study

1. End-of-life choices

Despite the best treatments, some cancer patients experience deterioration of their condition with progression of the disease. Please imagine that such a situation has happened to your patient and the patient is in a condition where no effective treatment is available.

Patient preferences	Caregiver preferences
Which of the following care choices do you prefer in that situation? (1) Life-sustaining treatment, even though it can worsen my quality of life (2) Palliative care, even though it cannot prolong my lifespan	Which of the following care choices do you prefer for the patient in that situation? (1) Life-sustaining treatment, even though it can worsen the patient's quality of life (2) Palliative care, even though it cannot prolong the patient's lifespan

2. Perception of caregiver burden

Patients' self-perceived burden (SPB)	Caregiver burden (CB)
How much do you think your caregiver has suffered from each of following during the previous month?	How much have you suffered from each of following during the previous month?
(1) Physical burden (2) Emotional burden (such as anxiety and depression) (3) Social burden (personal relations and work life) (4) Financial burden (hospital cost) (5) Daily life burden (such as household living)	
Response options: 1 = 'not at all' 2 = 'a little' 3 = 'moderate,' 4 = 'much'	

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