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ORIGINAL ARTICLE

Effect of advanced cancer patients' awareness of disease status on treatment decisional conflicts and satisfaction during palliative chemotherapy: a Korean prospective cohort study

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Abstract
Purpose Our purpose was to evaluate the effect of cancer patients' awareness of their incurable disease status on decisional conflict and satisfaction with treatment choice.
Methods In this prospective cohort study, advanced cancer patients who were offered palliative chemotherapy completed questionnaires on their knowledge of their condition, their treatment decision conflicts, and their satisfaction with their treatment decisions.
Results We enrolled 98 patients; 94 reported that they were aware of their advanced status and 50 were not. Decisional conflicts for all patients showed a significant decrease after treatment, but aware patients were significantly more satisfied with their decision ($P = 0.02$).
Conclusion Patients' awareness of their incurable status was associated with greater satisfaction with their decision to receive palliative chemotherapy.

Keywords Decision making · Palliative chemotherapy · Patients' awareness of incurable status · Decisional conflicts and satisfaction

Introduction

Palliative chemotherapy can improve survival and quality of life. It is associated, however, with several adverse effects, including nausea, hair loss, and fatigue [1]. Advanced cancer patients who are candidates for palliative chemotherapy may have difficulty deciding on whether to undergo unpleasant treatments during the time they have left to live [2–4]. Although most physicians [5–8] and patients [9–15] in the West now accept as ethical that patients are entitled to know of their terminal status, that is commonly not the case in Korea [16]. It is a common practice among Korean physicians to inform only family members when a patient's condition becomes incurable so that family and physicians, rather than the patient, often make the final treatment decisions. The truth is withheld in the belief that its disclosure causes patients to feel hopeless and to suffer emotional distress [17].

To the best of our knowledge, no studies have been published on whether patients' awareness of their incurable status has an impact on conflicts and satisfaction with their treatment decision. Here, using a deci-

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sional conflict scale (DCS) [18], we evaluated the effect of cancer patients' awareness of their incurable status on decisional conflicts and satisfaction with decision making for palliative chemotherapy.

Participants and methods

Participants

From August 2007 through December 2008, patients at Kyung Hee University Hospital, Seoul National University Hospital, and the Korea National Cancer Center for whom palliative chemotherapy for histologically confirmed metastatic or recurrent cancer was planned within several days were given information explaining the study and asked to participate. To be enrolled, they had to be at least 18 years old, have a life expectancy of greater than 6 months, be capable of understanding the intent of the study, and be able to complete questionnaires without help. Patients were ineligible if they had participated in a clinical trial, received immunotherapy or palliative chemotherapy for treatment of cancer, or received concomitant radio- or immunologic therapy (to permit proper evaluation of the effect of chemotherapy). The study was approved by the institutional review boards of the two university hospitals, and all patients provided informed consent.

Methods

We obtained demographic data from questionnaires and clinical data from hospital data repositories. We personally administered the questionnaires on demographic information and awareness of disease status and DCS at an outpatient or inpatient facility within days before patients received palliative chemotherapy. We assessed responses before the third or fourth cycle using Response Evaluation Criteria in Solid Tumors. Two to 3 months after the start of therapy, patients were followed up at an outpatient or inpatient facility and given the DCS questionnaire. The questionnaire was designed to gather demographic information (age, sex, education level, marital status, monthly household income, employment status at diagnosis, who paid the medical expenses, drinking and smoking status, and whether or not they had a religious affiliation, private insurance, or comorbidities). Another questionnaire asked if patients had been told about their disease, its stage, and the treatment goal. Because all enrolled patients would be receiving chemotherapy, they were aware that they had cancer but might not have known that their disease had reached an advanced stage.

The DCS was composed of 16 items. The total score consisted of five subscores (for uncertainty regarding their treatment decision, being uninformed regarding their condition, lacking value clarity, lacking support, and lacking satisfaction with their treatment decision) and could range from 0 to 100. A high score represented a high level

Table 1 General characteristics of study subjects (n=98)

Characteristic		No. (%)
Age, years	24–40	4 (4.0)
	41–60	50 (50)
	61–78	44 (44)
Mean (SD)	57.3 (10.9)	
Sex	Male	67 (68)
	Female	31 (32)
Marital status	With spouse	76 (81)
	Without spouse	18 (19)
Educational level	≤ middle school	39 (42)
	≥ high school	54 (58)
Employed	Yes	48 (50)
	No	47 (50)
Practices a religion	Yes	60 (63)
	No	35 (37)
Monthly household income (USD)	≤ 2,000	43 (46)
	> 2,000	51 (54)
Comorbidity	Yes	42 (44)
	No	53 (56)
Drinking status	Yes	34 (42)
	No	48 (58)
Smoking status	Ever	56 (66)
	Never	29 (34)
ECOG PS	0	40 (41)
	1–2	58 (59)
Recurrence	Yes	25 (26)
	No	73 (74)
Metastasis	Yes	87(92)
	No	8(8)
Type of cancer	Stomach	44 (45)
	Lung	32 (33)
	Esophageal	4 (4)
	Colorectal	3 (3)
	Other	15 (15)
Responsibility for medical expenses	Patient	42 (44)
	Family member	53 (56)
Private insurance	Yes	42 (46)
	No	50 (54)

ECOG PS Eastern Cooperative Oncology Group performance status, *0* fully active, able to carry out all pre-disease performance without restriction, *1* restricted in physically strenuous activity, but ambulatory and able to perform work of a light or sedentary nature, e.g., light house work and office work, *2* ambulatory and capable of self-care, but unable to perform work activities, up and about more than 50% of waking hours

Table 2 Predictors of patient’s awareness of incurable status

Potential predictor	Aware of terminal status (n=98)		P^{a}
	Yes No. (%)	No No. (%)	
Age, years			
24–40	3 (75)	1 (25)	
41–70	28 (56)	22 (44)	
61–78	18 (41)	26 (59)	0.21
Sex			
Male	31 (46)	36 (54)	
Female	18 (58)	13 (42)	0.28
Marital status			
With spouse	42 (55)	34 (45)	
Without spouse	7 (39)	11 (61)	0.21
Educational level			
Middle school or less	18 (46)	21 (54)	
High school or more	30 (56)	24 (44)	0.37
Employment status			
Yes	27 (56)	21 (44)	
No	22 (47)	25 (53)	0.36
Religious affiliation			
Yes	31 (52)	29 (48)	
No	18 (51)	7 (49)	0.98
Monthly household income, USD			
≤2,000	24 (56)	19 (44)	
>2,000	25 (49)	26 (51)	0.51
Comorbidity			
Yes	20 (48)	22 (52)	
No	27 (51)	26 (49)	0.75
Drinking status			
Yes	18 (53)	16 (47)	
No	25 (52)	23 (48)	0.94
Smoking status			
Current, ever	26 (59)	30 (41)	
Never	17 (46)	12 (54)	0.29
ECOG			
0	17 (45)	21 (55)	
1–2	31 (53)	27 (47)	0.40
Recurrence			
Yes	10 (42)	14 (58)	
No	38 (53)	34 (47)	0.35
Metastases			
Yes	47 (54)	40 (46)	
No	1 (12)	7 (88)	0.03
Person paying medical expenses			
Patient	20 (48)	22 (52)	
Family member	29 (55)	24 (45)	0.49
Private insurance			
Yes	25 (60)	17 (40)	
No	22 (44)	28 (56)	0.14
Having a neighbor with cancer			
Yes	32 (51)	31 (49)	
No	15 (48)	16 (52)	0.83
Patient’s expectation of palliative chemotherapy			
Complete cure	19 (46)	22 (54)	
Other (disease control, prolonged survival, symptom control, disease progression)	30 (53)	27 (47)	0.54
No. of doctors consulted			
1	27 (49)	28 (51)	
≥2	18 (46)	21 (54)	0.78
Informed of terminal status pre-treatment			
Yes	37 (52)	34 (48)	
No	11 (44)	14 (56)	0.49
Preferred role in treatment decision making			
Active	7 (70)	3 (30)	
Collaborative	6 (33)	12 (67)	
Passive	15 (52)	14 (48)	0.17
Hesitant about receiving chemotherapy			
Yes	34 (70)	14 (30)	
No	14 (30)	33 (70)	0.01

[a] Chi-square test

of each of the negative attributes. We calculated transformed DCS scores and their change from baseline to follow-up. We collected clinical data that included primary cancer site, presence of metastases, recurrence, response to chemotherapy, and Eastern Cooperative Oncology Group (ECOG) performance status.

As a potential predictor of disease awareness and DCS change, we used the original control preference scale developed by Degner and colleagues [19]. Patients’ preferences regarding palliative chemotherapy were collected

Statistical analysis

Over the course of the study period, we used a *t* test or chi-square test to compare the characteristics of all subjects at follow-up with those lost to follow-up, the Mann–Whitney or Kruskal–Wallis test to evaluate differences in baseline DCS according to demographic and clinical information and patients’ disease awareness, and the paired *t* test to compare DCS scores. We compared DCS scores between those who were aware of their advanced status and those who were not at the two time points on the basis of multivariate-adjusted mean DCS subscale scores by analysis of covariance. We entered plausible variables, such as reports on patients' expected progress, variables that were significant in univariate analysis, and patients' awareness of their disease status. We then selected a stepwise multivariate regression model for prediction of change in DCS score. We calculated two-sided *P* values and considered $P<.05$ as statistically significant. All statistical test were performed by using SAS version 9.0 (SAS institute, Cary, NC).

Results

Sample characteristics

A total of 122 incurable cancer patients who satisfied the inclusion criteria were asked to participate in the study. Of those, 100 (80%) agreed to participate and provided informed consent. The most common (54%) reasons for refusing to participate were inconvenience and time constraints. Two patients failed to complete the full questionnaire, leaving 98 participants. Of those, 62 completed the questionnaires and 36 dropped out prior to completion of the study (follow-up rate 63.3%). Of those who dropped out, 28 withdrew consent, seven were lost to follow-up, one experienced severe chemotherapeutic toxicity, and two died.

The mean age of the group was 57.3 years, and it contained a much higher proportion of men (68%), married people (81%), patients with metastasized cancer (92%), and patients without disease recurrence (75.0%). The most common diagnoses were stomach cancer (45%) and lung cancer (32%). Table 1 summarizes the characteristics of all of the patients at baseline.

Awareness of incurable status

Of the 98 enrolled patients, 94 (96%) reported knowing that they had cancer; 50 (51%) reported not being aware that their disease had reached an incurable status, and 25 (26%) stated that they had not been informed in advance of the therapy. In response to a question on the purpose of chemotherapy, 42 (43%) patients reported that it was to completely cure them, 28 (28%) that it was to control the disease, 18 (18%) that it was to prolong life, and 10 (10%) that it was to control symptoms.

Table 2 shows predictors of patients' awareness of their incurable status according to potentially associated patient characteristics. Neither demographics nor financial status were predictive, but patients with metastases were more likely than those without metastases to be aware of their end-of-life situation ($P=0.02$), and aware patients were more likely than unaware patients to be hesitant about wanting chemotherapy ($P=0.01$). On average, patients consulted two to three doctors before deciding whether to receive treatment, and 16 (17%) patients consulted more than four doctors. A total of 78 (80%) patients reported that doctors influenced their decision regarding receipt of chemotherapy the most, while 20 (20%) reported that their families influenced them most. Almost half of the patients (49%) reported that they were hesitant to receive chemotherapy because of its possible side effects.

Patients' preference for involvement in treatment decision making

Fifty (51%) of the patients expressed a preference for a passive role in treatment decision making, while 17 (17%) preferred an active role and 31 (32%) preferred a collaborative role.

Changes in decisional conflict score

Total decisional conflict scores showed a significant decrease after treatment ($P=0.045$), as did the informed ($P=0.026$) and value clarity ($P=0.009$) subscores (Table 3). In univariate analysis, being female, having a religious affiliation, having

Table 3 Decisional conflict score before and after palliative chemotherapy

	Mean (SD)		P^a
	Pre-treatment	Post-treatment	
Total score	35.7 (5.8)	30.9 (10.9)	0.045
Uncertainty subscore	36.7 (20.8)	32.5 (14.3)	0.11
Informed subscore	37.6 (19.7)	29.7 (13.2)	0.026
Values clarity subscore	41.8 (22.6)	33.7 (16.2)	0.009
Support subscore	33.2 (15.9)	30.2 (12.6)	0.21
Effective decision subscore (decisional satisfaction)	30.3 (17.3)	28.4 (12.2)	0.80

[a] Paired *t* test

medical expenses paid by the family, and being or having been a smoker were associated with a significant decrease in post-treatment total decisional conflict score (Table 4). In satisfaction with decision making after palliative treatment, being younger, female, unemployed at the time of diagnosis, a non-drinker, a smoker, and awareness of advanced disease status were positively associated (Table 4).

Predictors of change in DCS score

Table 5 presents the results of multiple linear regression analysis exploring predictors of change in DCS score in our sample. Being female and having a religious affiliation showed a significant association with total score. Notably, having a religious affiliation was significantly associated

Table 4 Univariate association of patients' characteristics with change of decisional conflict

	Score change[a] (0–100) of decisional conflict from pre-treatment to post-treatment[b]					
	Uncertainty subscore *n*=57	Informed subscore *n*=58	Values clarity subscore *n*=58	Support subscore *n*=57	Decisional satisfaction *n*=57	Total score *n*=58
Age, years						
24–64	34.97 to 31.63	35.82 to 28.40	41.80 to 31.97	31.83 to 29.16	28.14 to 26.40	34.13 to 29.56
65–78	39.20 to 36.11	40.77 to 33.33	40.74 to 38.89	35.80 to 32.99	34.49 to 36.29	38.26 to 35.57
P value	0.271	0.291	0.081	0.773	0.022	0.195
Sex						
Male	35.62 to 35.09	36.77 to 29.61	40.05 to 34.65	33.06 to 32.57	28.89 to 30.54	34.74 to 32.51
Female	37.82 to 28.26	38.73 to 28.99	44.87 to 31.16	33.02 to 25.54	32.79 to 24.73	37.00 to 27.82
P value	0.115	0.324	0.153	0.016	0.015	0.029
Employment status						
Yes	36.93 to 33.62	35.46 to 30.46	42.99 to 33.05	32.39 to 30.60	29.36 TO 29.09	35.11 to 31.36
No	36.43 to 30.91	39.58 to 28.49	40.89 to 33.87	34.50 to 28.90	31.54 TO 27.76	36.42 to 30.10
P value	0.180	0.324	0.612	0.130	0.021	0.074
Religious affiliation						
Yes	39.70 to 31.53	40.33 to 27.48	45.61 to 32.89	35.30 to 29.05	31.93 to 27.36	38.35 to 29.79
No	31.51 to 33.33	32.70 to 32.61	35.68 to 34.42	30.21 30.80	27.86 to 30.07	31.37 to 32.18
P value	0.008	0.324	0.039	0.085	0.069	0.007
A person to pay medical expenses						
Patient him(her)self	35.04 to 35.51	32.22 to 30.43	38.82 to 35.14	30.98 to 32.43	27.35 to 31.25	32.96 to 32.99
Other members of family	38.02 to 30.18	42.015 to 28.83	44.75 to 32.43	35.42 to 28.04	32.94 to 26.63	38.15 to 29.29
P value	0.283	0.032	0.143	0.150	0.227	0.047
Informed at pre-treatment						
Yes	35.98 to 30.93	36.00 to 27.96	42.34 to 30.74	32.68 to 27.87	28.29 to 26.90	34.50 to 28.91
No	38.043 to 36.11	42.01 to 33.89	40.62 to 40.00	34.85 to 35.56	35.80 to 32.08	38.71 to 35.63
P value	0.191	0.591	0.0130	0.057	0.551	0.092
Patients report of expected progress						
Complete cure	35.87 to 33.02	38.62 to 31.48	43.05 to 34.56	35.41 to 28.85	26.50 to 28.24	35.35 to 31.11
Others (disease control, prolonged survival, symptom control, disease progression)	36.53 to 32.10	36.47 to 27.69	40.38 to 32.35	31.41 to 30.76	32.57 to 28.43	35.45 to 30.44
P value	0.527	0.542	0.811	0.077	0.542	0.991
Awareness of disease status						
Yes	36.23 to 31.45	39.67 to 29.84	43.15 to 36.83	33.15 to 28.76	31.39 to 25.20	36.49 to 30.14
No	36.31 to 33.61	34.94 to 28.89	39.73 to 29.72	32.95 to 31.11	28.73 to 31.60	34.29 to 31.37
P value	0.749	0.355	0.918	0.645	0.022	0.247

[a] Mean difference indicates score at post-treatment minus score at pre-treatment

[b] Higher score indicates increasing uncertainty, uninformed, unclear, unsupported, dissatisfied, and decisional conflict

Table 5 Model-based predictors of change of decisional conflict

	Beta coefficient (partial R^2)					
	Change of decisional conflict					
	Total score	Uncertainty subscore	Informed subscore	Values clarity subscore	Support subscore	Decisional satisfaction
Age (as higher)	NS	NS	13.52 (0.05)	NS	NS	NS
Female (ref. male)	−7.66 (0.05)	NS	NS	NS	−11.40 (0.10)	NS
Job, no (ref. yes)	NS	NS	NS	NS	NS	−12.19 (0.10)
Religious affiliation, yes (ref. no)	−9.93 (0.11)	−13.75 (0.11)	−14.14 (0.11)	−9.85 (0.04)	NS	Ns
Medical expenses paid by patient	NS	NS	13.57 (0.06)	NS	NS	NS
Informed at pre-treatment, yes (ref, no)	NS	NS	NS	−16.02 (0.11)	−10.34 (0.06)	NS
Awareness of disease status, yes (ref. no)	NS	NS	NS	NS	NS	−11.17 (0.09)
Model R^2	0.16	0.11	0.22	0.15	0.16	0.19

Positive change indicates higher decisional conflict, higher uncertainty, higher uninformed, higher values unclarity, higher unsupport, higher ineffective decision

with positive changes in uncertainty, informed, and value clarity subscores. Being unemployed and being aware of advanced disease status were significantly associated with decisional satisfaction.

Discussion

Paternalistic decision making that the physician makes the decision on behalf of the patient may lead to dissatisfaction in advanced cancer patients [11]. Western healthcare ideology supports communication between physicians and patients [20] and encourages patient participation in treatment decisions [21, 22]. Most patients who participate in decision making are informed about their health status [23, 24], and being informed is associated with age, degree of education, geographical area, ECOG performance status, tumor site, family composition, and the patient's perception of being supported in the disease experience [23].

In Korea, however, in our study sample, about half of the patients receiving palliative chemotherapy were not aware of the advanced status of their disease or of the purpose of the treatment. This probably reflects the Korean fear of letting patients know that they are dying. Due to the reduction in cancer death rates, decreased pessimism about the disease, and increased concern about patients' right to participate in their own care decisions, many Korean physicians have changed their attitude toward disclosure of terminal status [25, 26]. Family members, on the other hand, usually do not want patients to be informed of the exact status of their disease and sometimes do not even want patients to be told that they have cancer [16, 17]. When family members form a communication barrier between patients and doctors [16], patients cannot participate in treatment decisions and physicians have no choice but to discuss such decisions with family members alone. Regarding the patients' stance, half of the patients in this study expressed a preference for a passive role in treatment decision making, so paternalistic decision making may be appropriate for some Koreans.

Despite cultural barriers to informing patients of their bad prognosis and despite patient passivity, this study revealed satisfaction with treatment and little treatment decisional conflict. That is consistent with the report that patient satisfaction with information is more relevant than the level of information itself [27]. At the same time, patients' insight into their disease status is associated with increased satisfaction with the patient–physician relationship and decreasing levels of anxiety, mood disorder, and affective distress [27]. Geriatric cancer patients who are informed of their disease status report more positive expectations for the future than those who are not informed [23].

Advanced cancer patients who are informed about end-of-life care options are more likely than uninformed patients to not select intensive care [28], and end-of-life discussions enable patients to be more realistic about the benefits of aggressive therapies [29]. That is in agreement with our finding that among the terminally ill, informed patients were more likely than uninformed patients to question the value of chemotherapy. Clinical communication plays a crucial role in helping patients cope with the disease [30], and previous studies have found that the majority of cancer patients want general or detailed prognostic information [10, 13, 31]. Disclosure of advanced stage, however, can also give rise to psychological distress for both patients and their families [32]. Therefore, effective approaches that help informed patients make treatment decisions are needed [33]. Physicians can help patients cope with a terminal prognosis by exploring and fostering realistic forms of hope that are meaningful for particular patients and their families [34]. Based on work with Western populations, clinicians trained in shared decision making have developed patient decision aids, and allied health professionals can provide support for patient involvement in clinical decisions [35].

Our study had some limitations. Because those in very poor health and those who considered it too burdensome to talk about their disease could not be assessed, our patient sample was somewhat biased. Second, the study did not include a decisional regret scale, which would have strengthened the findings for disclosure of prognostic information. Third, the dropout rate was high, so a relatively small number of patients were involved in the final analyses.

Nevertheless, to the best of our knowledge, the current study is the first to demonstrate that patient awareness of terminal status results in psychological benefits in a country where it is still considered acceptable for physicians to not disclose disease status to patients and where half of the patients express a desire not to actively participate in decision making. Further study that validates this result is warranted.

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